# All Data

### E1- How did you become interested in PMS?

[Expert answers redacted- personally identifiable data]

### E2- How would you describe PMS to someone who didn’t know about it?

**Anne:** OK. So I would say that it's a very real condition, that I would describe it as a menstrual mental health condition… So the woman can feel very unwell (.) er a range of symptoms leading up to her period, but then goes back to 'normal' after the period. I would also, if I was describing it, say about the fi (.) around five percent of women who have very severe symptoms and these women may well be diagnosed as having another type of premenstrual disorder named premenstrual dysphoric disorder. And their psychological symptoms can be so severe that in about a third they can actually have suicidal ideation.

**Barbara:** The cyclic occurrence of mood symptoms just before menses.

**Fran:** Um, I would describe it as a constellation of emotional and physical symptoms (.) and behavioural symptoms that um (.) occur in er (.) most women, but lead to impaired functioning in only around 20% of those.

**Andrew:**  First, I would say that absolutely central to this concept is the timing of the symptoms that they should appear at some time in the pre-menstrual phase and they should disappear completely within a few days after the onset of menses. And that they should really disappear completely. If you have remaining symptoms in the follicular phase, it could be that you have some kind of premenstrual aggravation of something else; a depression, bipolar depression or generalized anxiety disorder or something like that, it should be (.) this timing is absolutely crucial. And then I would say that the (.) as already indicated by your initial comments, that (.) that the definition of PMS is poor and that er (.) um (.) many gynaecologists using the term PMS also referring to the ICD nomenclature of PMS, they regard any symptom as qualifying for this condition. And also they don't demand a certain severity degree, either. So if you have any of many different symptoms also to a mild extent, you by definition have PMS. I personally do not think that is a very suitable definition for the condition to study as a medical condition, because that would mean that the majority of women of a certain age have a diagnosis. And since most of these regard these (.) these complaints as very trivial and do not require treatment, there is no need to have a diagnosis for that. So I have in that regard been sceptical about the (.) the PMS definition in ICD. And I then personally prefer, though it's not perfect. I prefer the DSM definition of Premenstrual Dysphoric Syndrome. So that's how I would briefly discuss what this is all about.

**Debbie:** [00:05:01] Erm, for me, PMS is (.) is (.) is very mild [pause] symptoms in the two weeks before menses that could be physical or psychological or behavioural, emotional, cognitive, you know, could be anything really(.). Um, But I think the main criteria for me is it really can't interfere with your life at all. It's a (.) it's a (.) it's a nuisance (.) only (.) nothing more than mild nuisance. Premenstrual symptoms. That don't affect your life [pause]… Yes so I would say it affects a small percentage of the population. But I guess it's hard for me to answer that question without talking about PMDD because I think of them as a sort of continuum. But I really conceptualize anything that is impairing or significantly distressing at all. As a PMDD symptom. Whereas PMS, I would say, is not disordered. It's just sort of little mild changes that are not of any consequence and don't really bother you.

**Celia:** I would say it's a series of um (.) symptoms that can be psychological, that can behaviour (.) be behavioural. They can be physical symptoms that occur for up to two weeks prior to the onset of menstrual bleeding, with relief or almost complete relief by the end of the menstrual bleeding, or by about day four, and should not reappear again until sometime at around ovulation or just after, which in general is about two weeks before the menstrual period.

**Sarah:** I would say that it is cyclical changes in mood and with accompanying physical symptoms that affect some women over the menstrual cycle and usually occurs in the ten days prior to menses, and then it's alleviated by the onset of menses.

**Thomas:** Well (.) it's a (.) it's a number of symptoms which change with the different phases of the menstrual cycle. Usually they are (.) er at maximum during the five premenstrual days, the days just before the onset of the menstrual bleeding and they disappear when the menstruation proper has started. Then it's usually gone within three to four days and er (.) in a pure situation, the symptoms should be (.) away and not present during the rest of the menstrual cycle until the ovulatory period where there can be some symptoms and then they increase after the ovulation during the fifteen days from the ovulation to the onset of the bleeding, that's my way of describing it… Then there are, of course, menstrual exacerbation or premenstrual exacerbation, which means that there are other conditions which are also being (.) being changed in relation to the hormonal variations during the menstrual cycle. So (.) So that (.) or the different phases of the menstrual cycle. But they (.) they are not what we call the pure PMDD or PMS, pure PMS. In the olden days we called it pure PMS and later on the (.) the severity has been discussed as well. And this PMDD, diagnosis came up and it was mainly(.) Let's say the psychiatrists that actually took up the term, it was the American psychiatrists.

**Susan:** Well, what I would say is that many women experience change over the menstrual cycle. So I often talk about premenstrual change or premenstrual distress rather than PMS. It depends who I was talking to. If it was, somebody who said to me, what is PMS? If that's the question. Um, I say (.) what I would say is “Well, women expect change over the menstrual cycle. That's quite normal”. Um and that we don't understand why. And that we know that there are a small proportion(.) a smaller proportion of women who experience distress as part of that change and distress that might have a significant impact on their lives. And that that is often referred to as PMS; Premenstrual Syndrome. But PMS that (.) that's a label (.) social label that's put on to that experience. But what that distress is caused by, why women get that distress is to do with a complex interaction of factors which might include factors within the body, which might be hormonal changes, or changes in the neurotransmitters. And we don't understand fully what's happening there because not all women get that (.) or not or not all women get the distress interacting with what's happening in a woman's life. So if she's under pressure if she's under stress, er what she's doing in terms of diet and exercise and then what she thinks about those changes. So what meaning she makes of those changes in terms of her own psychology. And that is taking place in a particular cultural context. So if you live in a context where (.) and this is probably not something I'd say to a woman in the street 'cos it ends up getting a bit academic here. But if you live in a context where we have a concept of PMS, which we do in the West then, you might call those changes, 'PMS'. But if you live in a context where there isn't a cultural label for those changes, then you may not even take note of them and you certainly wouldn't call them PMS. So that's a bit of a long winded explanation.

**Marta:** Oh, I think I would say that PMDD is (.) um (.) severe mood (.) mood disorder that that strikes you once a month and it strikes you in the week or two weeks before (.) you have your (.) the onset of your menses.

**John:** I would say that it's a mixture of predominantly psychological but also physical symptoms that many women get premenstrually. But for some women, they're particularly extreme and those are the type of people that we are typically referring to when we say PMS, as you probably know, about 80 percent of women have some symptoms. It would be inappropriate to pathologize every woman in that group of 80 percent. But there are clearly some where that's disabling and in need of some help.

**Laura:** Er (.) I describe it as a sense of overwhelming tension with [pause] frequently accompanied by irritability and dysphoria, sort of a mixture of irritability, depression and anxiety occurring typically in the few days prior to the onset of menses and then continuing often into the menstrual period for a day or two.

**Zoe:** I'd describe PMS to someone who's never heard of it before, as that period, before a woman's period (.) or of that (.) that time (.) it can be a week sometimes. Generally it's a little bit longer than a week, but that week or so before um a woman's period where she is more sensitive and more vulnerable um to um (.) changes both within her body but also externally to stimuli and to environmental um stressors. So it's a period (.) I describe it as a period of increased sensitivity um (.) generally. That's how I describe it in lay terms. Yep.

**Geraldine:** So usually people think of PMS as a cluster of symptoms that appear before menstruation and er (.) disappear after the menses begins. So that's probably the closest definition, you know, that people would agree on. But even that is contested because you know what does 'before the menses' mean? Some people say it's like 3 to 5 or maybe 7 days before the menses. But you can read other sources that say any symptom after ovulation, but before the end of menstruation is PMS. So that's giving you like three weeks out of every four, which is crazy (.) uh for a definition. But that's what some sources do say.

**Chris**: Okay. It's a mood disorder which occurs only premenstrually. And the key thing is that the symptoms resolve after the period. And to be pure PMS, they have to be completely absent. The underlying cause of this is uncertain… And the symptoms can be a wide range and they can be so bad as to promote suicidal ideation or attempt.

**Jo:** So I would make the point that it's a cyclical problem. It's not there all the time. And that's really important. And also (.) Lots of women will have um (.) symptoms related to their menstrual cycle. But if it's not resulting in impairment, then that's not an issue. So impairment is a big part of the diagnosis… [Qu 10] Um (.) suicidality (.) premenstrually. Um (.) I think mood disorders (.) I think the psychological symptoms are the ones which tend to be most destructive; anxiety, depression. And then sort of physical symptoms, I think are less of an issue.

### P13- How would you describe PMS to someone who didn’t know about it?

**Alice:** I don’t really know about PMS, but I could describe like (.) what it's like before and during and after, because I think PMS is associated with (.) I think it's used maybe differently medically or with a layperson. I don't think people realize what it is? So I don't think I could describe that because I think people don't really know what it is. I could describe before, during and after (.) But that's what you want me to describe(.) I mean, all I can say in society, you might (.) people might say you’re experiencing PMS or you're about to have your period or you just had your period or on your period (.) and people will have a certain (.) preconception about it or experience themselves, and depending on who you're speaking to, one woman might not experience anything. One man might have a wife who experiences it and knows what it's like. So my partner didn't have a clue that a woman could go through it until he met me, in the way that I do (.) So I think you can describe it, but the problem is the association is so different for so many people that it's kind of got lost in translation?

**Beth:** [long pause] I'd say some girls and women find that (.) they can feel different and sometimes a bit unwell before they start their periods or over the first couple of days of their period. This is called PMS and it varies a lot from person to person and not everyone gets the same symptoms. It involves lots of symptoms like really common ones might be; feeling just tired or a bit down and you don't know why and you're more likely to cry at things, but it (.) it can also mean that you get a bit of an upset tummy or (.) well, you find it a bit hard to go for a poo. And, you know, there's a lot of variation between the symptoms and not everyone gets it. Some people don't get any PMS at all, but it's quite usual and common to get it as well. Although I don't think that's explaining it well, at all! [Laugh].

**Dani:** Erm [pause] I would just tell them that [pause] your hormones affect you in different ways, you have different (.) [Audible woooah] you have different hormones acting at different times of the month, and that at one point (.) they can just make you feel (.) either a bit more irritable or a bit more in pain. I actually don't know why we get PMS?! But yeah, I think that's how I would describe it, and it just at some point you just gonna feel a bit worse, but it always passes and it passes usually when you get your period or just after. But erm, yeah, it's just a sort change of mood and maybe change of (.) physical (.) how you feel physically.

**Emma:** [long pause] So, PM(.) I would probably say PMS relates to symptoms that people can get before their period, as a result of the change in hormones. For most women, symptoms are manageable, (.) erm but for a few women they can be severe to the point where they're debilitating.

**Faith:** Um, do you know (.) for me (.) I would highlight mental health? Cause mine is really bad. During (.) Like (.) so (.) I think I'd start lightly like things like your emotions may be (.) your emotions may be um a lot more um apparent than usual (.) Than you're used to (.) you might be a lot more reactive, but you might go through depression and anxiety and just feel really low. And not be able to put a finger on why. And even when you can get a finger on why, you can't get yourself out of that. And when you find it's happening regularly, it could be part of the symptoms (.) and then the more physical things like cravings and (.) dehydration and so on and so forth. And as for why I wouldn't know how to explain why [whispering] I've never actually been told why our bodies go through that?

**Gemma:** I would just (.) I would definitely just kind of bring it to a personal thing again. Like make it very general. And I'd say that during a period it's very, very common for you to experience a wide range of emotions and you don't have control over that. It will just happen. And sort of feel (.) don't feel bad for it. But know that it's happening. So know that if you're a bit more emotional, if you experience cravings, these things are all normal and you're gonna experience it differently to other people. So you're not gonna experience it how your friends experience it, so don't compare what you feel. And I would drag (.) I would tie it to mental health because I'd be like (.) because you have no control over your emotions. You can get elements of feeling really sad or be happy or crying a lot, but just know that it's because you're going through the cycle. [Last sentence whispered] That's why, I’d say.

**Helen:** Um, you know PMS (.) this is how I say it at work. You know, PMS is a collection of symptoms that vary from person to person with a period. You know, it could be anything from mild irritability. And weeping all the way to severe cramping, you know, exhaustion. It's just a wide variety of symptoms that kind of vary. But they. But the reason it's PMS is because it always happens right before your period starts in the premenstrual phase.

**Kathleen:** I'd just say it’s something (.) but again (.) that some women experience, but not all. Um, I would say (.) um that it's (.) sometimes there's a change in women's bodies and their hormones that might make them feel um particular emotions just before their period happens.

**Aisha:** Oh my god. I mean, I do kind of do that all the time [laugh] PMS (.) how do I describe it? I start off by asking questions. Or do you feel that this? Do you feel like that etc. and just compare it? And then I go into describing the (.) just yeah. You feel low and you feel a hormone imbalance, you feel like a different person. Yeah, just all the negative [laugh] aspects to it.

**Mala:** I would do it how my friend did it. So I would say this is the symptoms that you normally get. Do you (.) do you get them? It's a feeling or um (.) sometimes it's a physical thing that you might get prior to your period or sometimes you get after your period as well? So, it depends on the person, what they're going through.

**Noor:** I'd say it is just before you start your period and you're not your normal self.

**Ria:** But like looking at the normal curve and distribution, a lot of PMS quote unquote 'symptoms' are just things [laugh] that happen to us during that time, which are like beautiful and magical and also a huge struggle. Um, are(.) the way that I describe it to people is usually through the Four Seasons, though all like usually people can know what a period is. And I can talk about that. And then I say, OK, imagine that as winter. And then we go through. And then when I talk about PMS, I talk about how it's the autumn season. So it's a time to let things compost just like the trees are shedding their leaves. It's a time for us to let go of habits and things and people maybe that aren't working for us and we're ready to just like let fall away in our lives. It's a time to get ready for winter. So spending more time by ourselves, maybe doing a bit of reflection, snacking [laughter], saving up our stores for the winter. I always like to talk about how my food cravings are like here [indicates high up above head] [laugh]. In PMS, in terms of charting. So just making sure people are getting the nourishment that they need. Affirming the fact that it's total (.) like "go for the nachos, go for the cake! Do what you need to do to get through it" And then just being also like self-aware of the fact that we are going through a lot of changes because of the way our progesterone levels are changing, the way that um (.) in the modern world we(.) our food systems are so different. So we don't necessarily get the nutrients and all of the building blocks. Our body needs to have high progesterone levels. So I tend to start with like a metaphor and then I go into some of the emotional mental changes, some suggestions for rituals and ceremonies that people can do at that time. And then if they want to nerd out about like the physical, more like scientific Latin knowledge around like progesterone and hormones and um what the cervix is doing and all that stuff, then i'll (.) and then I'll go into it. Yeah.

### E3- Do/ did you (or close family member) identify as having PMS?

**Anne:** I would say (.) I mean, I'm now post menopause. Erm, I would say that er (.) when I was having periods, I couldn't tell where I was in my cycle. Get a little bit more irritable with the partner/husband. But I don't feel it ever significantly impacted on my quality of life. So, no, I've been lucky. I haven't had a personal experience, I would say where it (.) it interfered with things. Also, I'm sure you're aware that there tends to be that sort of triad of hormonal conditions; women with PMS tend to be more likely to suffer with perinatal depression and depression around the menopause again, all we think, hormonally related. And you know, luckily I'm just like a normal person. I have my ups and downs, but I wouldn't say that that hit me.

**Barbara:** Do/ did you identify as someone who gets PMS? NO

**Fran:** Did I have PMS? Is that what you’re asking? **Interviewer:** Yeah. **Fran:** No, I personally never had PMS.

**Andrew:** No, not the close (.) I wouldn't say that, but I, of course, know a lot of persons also personal contacts that have it (.) but, but not in the closest family no. Or (.) or that again, depends on the definition. If you have a very wide definition realizing that the menses are approaching, then I think the answer would be yes. But if you define it, that's a considerable (.) errr [pause] considerable discomfort. Then the answer will be no.

**Debbie:** [long pause] No [pause] I identify as someone who (.) I've always identified, as somebody who has [pause] um, menstrual depression. So more like my (.) well, I would say it's like a worsening of a chronic depression, right? So I would say it's like menstrual exacerbation [laugh]. But premenstrually I seem to be fine. So it's very different to what a lot of the patients describe.

**Celia:** Did I, do I have it or do I? **Interviewer:** Yeah. **Celia:** I personally don't have it. I never had it. No.

**Sarah:** Did I have PMS myself? No, I didn't actually. Which is pretty interesting. I also studied menstrual migraine and I didn't have that either, so (.)

**Thomas:** No, not really. It was this girl, which was (.) And she, of course, was a bit of a close friend, at least in our family, because she (.) we took her as more or less our, let's say, family member (.) she was quite a lot together with us. But she had a lot of problems. And unfortunately, actually, she made a suicide and um (.) well, it's now a long time ago. And this was also occurring during the premenstrual period. So that was a bit sad.

**Susan**: Did I? Yes. I (.) I have (.) I mean, I don't menstruate anymore, thankfully. From about a year ago. And that's a great relief in terms of not having those monthly changes. And so I have always had changes premenstrually and sometimes quite dramatically, um [pause] mainly psychological changes in terms of feeling quite irritable and angry. And sometimes feeling down, so feeling bad about myself. Um (.) But, yeah, I mean, I've never been suicidal around PMS. But I do (.) yes, I have had them, and I think they had (.) definitely having an impact on relationships. I didn't (.) I wasn't aware of it when I was younger and I actually was one of my friends that I lived with (.) I lived in a shared house at Uni. And it was one of my women friends who actually said it to me then. That she thought I had PMS. So I had no awareness of it at the time. But it's yes, I think I would identify as having had quite (.) you know (.) moderate to severe premenstrual change and something that felt wasn't a good thing. But I mostly learned how to cope with it in terms of psychological strategies. I've never taken anything medical (.) biomedical for it; pharmaceuticals for it.

**Marta:** Yes [long pause]. That was a very short answer, but I do actually.

**John**: No, not that I know of (.). **Interviewer:** Right. So again, in your understanding um (.) Oh sorry, I've missed one [question]. Can you remember how you first came to know about PMS? Was it before medical training or was it during your training? **John**: It would have been before medical training [pause] yeah. **Interviewer:** So as a teenager? **John:** Um [pause] I think probably in the context of a (.) oh I'm thinking about how personal to get now! [Quietly] I'll (.) I'll say it as I recall it. I recall my father telling me sometimes when my mother was a bit moody that it was her 'time of the month'. And that some women get moody at that time, and that's what's going on. So that would probably have occurred in the context of being snapped at or something. Um, having said that, I would not categorize my mother as having PMS of that severity. Just thinking about that is contradicting what I've just said about family members. But that's probably when (.) that would be my first recollection of that being mentioned.

**Laura:** I think when I was younger, I (.) I definitely (.) I certainly had bloating. And then I realized I was eating a lot of potato chips and salt when it was premenstrual. But I think I also (.) I think I would (.) I would get annoyed very easily. So I think I had a little bit of the irritability.

**Zoe:** Er, No. No. I know lots of people who (.) who do and my partner experiences um quite severe PMS. For me, I get clumsy and (.) but I'm clumsy (.) most of the time anyway. So [laugh] (.) but generally, no. I (.) I (.) I was quite fortunate not to experience um (.) PMS. I experienced a lot of menstrual pain and menstrual distress, but not PMS, no.

**Geraldine:** Er, No [laugh]. No, no. Of course, you know, that's not to say that I never had breast sensitivity. Or acne or something like that before my period. But I never had anything that I would categorize as PMS based on any definition or measure that I've ever seen.

**Chris:** I bet you my mother did. Except that we didn't know what PMS was and maybe my daughter, don't know? **Interviewer:** So is that just sort of with hindsight? **Chris:** With hindsight, with my mother, yes 'cos she varied in her [pause] mood and I'd be extremely surprised if it wasn't PMS.

**Jo:** Did I identify as someone? No. **Interviewer:** Or any members of your close family or friends? Was it something you had some experience with? **Jo**: Not at all. And I think in a way that sometimes um, has a negative influence on how you would accept that diagnosis. D'you know what I mean? I think sometimes people are very much like "because I don't have it and I'm a woman and I've got a cycle, then it doesn't exist". But (.) I think that this study was really (.) what has been really influential (.) because the patient population that we saw, were just (.) you know, they were incredible, really. And (.) um, we've probably seen the whole range of (.) probably severe end of the spectrum, but [inhale] not so much me but the study nurse spoke to (.) I think she spoke to a thousand women and she's spoken to every (.) every type of woman with PMS. And I think following on from that study, I have um had lots of contact with women. So, you know, again, I can see how catastrophic that can be on somebody's function. And it affects (.) affects family function as well, then… I did wonder whether [name of colleague] who was our research nurse had had it (.) because she was so amazing. I mean, well be (.) beyond anything you'd have expected (.) but, I didn't ask her [laugh]. I just didn't.

### P11- Do you identify as having PMS?

**Alice:** I don't say that I experience that or use that because my experience of that term is… I think it’s used really in a sexist way (.) I think people who just don't really know what PMS even is. In fact, our society doesn’t know what is. But it's been like stereotyped almost as ‘oh it’s just a woman who's moody because she's about to bleed or she's bleeding or she's on her period and she’s got PMS'. And I find that quite insulting. And I also think everybody is different and everyone experiences these things differently. You're interviewing me (.) but if you interview 10 women sitting at a bus stop who are or who are an age when they're having their periods, they will all have different experiences. And so no I don't say that I experience that (.) I'm just a woman who releases an egg every 28 days though I didn't even (.) I didn't even know it was every 28 days until we started trying for a baby. Another gap in my knowledge, people don't even talk about looking at that or tracking any of that, what any of that means or what secretions are (.) they don't know because they're only taught one thing, two things. So, no, I don't (.) I don't have experience because I feel that that's very negative.

**Beth:** Yes… Erm (.) because I wouldn't previously have identified (.) if you'd sort of talked to me, in my twenty's/ very early thirties, I would probably have said, no, I don't get PMS. I might get very, very slightly more irritable before a period, but not to the extent that it would have any effect on my life, but from my mid-thirties onwards, I would definitely say I've had PMS because I've noticed a definite pattern in several symptoms. Occurring in the week before my period. Every month consistently. Plus also some occurring around the time of ovulation. And I would put that down to my menstrual cycle. Yeah.

**Dani:** I mean. Yeah. [Pause] Definitely. Sorry [eating toast audibly] Hang on, let me take the mike down. Yeah, I definitely yeah, I definitely get PMS. [Other questions e.g. P3, P4, and P5 reveal mix of symptoms]

**Emma:** Yes. **Interviewer:** [Pause] and in your case. Well, we'll come to this later. But do you say to people 'you get PMS' or do you go straight for PMDD? How do you describe it when you're talking to people? **Emma:** So exactly as (.) as I brought it in earlier. Severe PMS slash PMDD and I usually have to (.) or I usually feel like I have to follow what PMDD is. Or 'Have you heard of that before?' or ‘you know what, that is?’ Yeah, but (.) but that can lead to a conversation of what it is and how it differs to PMS. [Other questions e.g. P3, P4 and P5 reveal mix of symptoms]

**Faith:** Yes, definitely… The cravings, the dehydration and the emotional aspects and (.) just the things that (.) I don't have patience for. I'm normally quite patient, but just not having the patience where (.) kind of (.) I'll reflect and I'll be like "Faith you really don't have to be angry like that" but it's after the fact and it really frustrates me 'cos it's like (.) I don't want to be so reactive to these sort of things, so knowing that I'm behaving in a way which isn't normal to me. [Other questions e.g. P3, P4, P5 reveal level of severity varies per symptom described]

**Gemma:** Yeah, definitely the emotions. Eatin' a lot (.) I put on weight (.) significant, which is so crazy, I've put on like 5, one period I've put on 7 pounds. Just going on. Yeah. And it would drop [clicks fingers] almost instantly thereafter. Which is so weird. Um, I think that's a big one. And I can see it it's so strange. As I have (.) I don't know what it is? Like I'm carrying something and when I go to toilet (.) don't know. And again, I know it's TMI I tell you, I go toilet like proper. It's crazy (.) like (.) for an hour, I'll just be on the toilet, so I think that that's (.) that's so weird [laugh] I find it so strange. And then after obviously that (.) I think that carries weight? And then I'll be fine. **Interviewer:** That's actually extremely common! **Gemma:** Is it really common? **Interviewer:** Yeah, so (.) so, constipation before then (.) diarrhoea when you start (.) **Gemma:** Yeahhh! **Interviewer:** bleeding (.) very very common! **Gemma:** Really? **Interviewer:** Maybe one of the most common (.) **Gemma:** Gosh! **Interviewer:** experiences (.) maybe the most common? **Gemma:** It makes me feel better that it's common! [laugh] Yeah. So (.) yeah.

**Helen:** Oh, yes, very much so. Because there wasn't like a diagnosis or term for PMDD. It was just 'you had PMS' Yeah. [Other questions reveal moderate-severe mood symptoms causing shame/ regret e.g. P3, P4, and P5]

**Kathleen:** Um [long pause] until quite recently, I would've said no. But as said, the last few years (.) basically, I feel like um my mood changes slightly. Yeah. [P16 reveals shame regarding emotional changes]

**Aisha:** Definitely, yeah [long pause]. [Other questions reveal mix of symptoms e.g. P3, P4 and P5]

**Mala:** I do… Because my mood (.) I'm normal throughout the week and one week before, my period is meant to start. My (.) I am a totally different person. Like I feel like everybody needs to walk on eggshells around me and I feel it (.) I feel it, too. And that's how I know that I'm going to start my period because my (.) my hormones are playing up. And when I do start my period, I'm normal again. So I know that I PMS prior to it… Before when (.) before (.) before I understood what PMS was (.) and I looked into it, I just thought, ‘Oh, I'm going to be starting my Period soon. That's probably why I'm acting like that’. And then I was curious as to why I was acting like that, because it wasn't normal for me to be just really angry. And next minute I'm happy. And I'm trying to make myself (.) make myself understand. I shouldn't be acting like that. It like a continuous battle in my brain. Um, and then when I did look into it, I realized that, OK, that's my PMS and now henceforth, when I'm when (.) I am when it's one week before and I'm feeling hungry all the time or cravings, or emotional I know I'm PMSing. So I think is a good way (.) it's good only because when I do (.) when I do feel it and I know that I'm PMSing I know how to regulate (.) I'm trying to regulate my emotions (.) Like "Mala, you're PMSing! So you need to calm down”. It's a good way of me regulating my emotions. [Other questions reveal level of severity as mild-moderate changes e.g. P3, P4, and P5]

**Noor:** I do… I think it's (.) so that because of the mood swings. I would put that under PMS, but I don't know if it actually is? …I think when you are not your normal self and it's just before your period and you know it's related to your period then. Personally, for me, that's PMS because that's something that's not in your usual behaviour. [Other questions reveal level of severity as mild-moderate changes e.g. P3, P4, and P5]

**Ria:** Definitely. Yeah. Based on the framework that I use; the Four Seasons, I believe that anybody who has a menstrual cycle experiences the season of autumn and what doctors call PMS. So yes [laugh] I do! For example, I'm in my PMS (.) so this is perfect. I'm literally in the PMS autumn season right now. Last night I had some friends over and it was like we were having dinner and so somebody brought up that (.) one of them is a lawyer and they work in H.R. and they were talking about how there is a sexual assault case that they were trying to basically package somebody out of (.) 'cos, they're just like a horrible human and they needed that person to exit. And even just like that small mention, I was just like crying and in tears. And in the (.) in like the patriarchal world that sometimes seen as like, "oh, you're being too sensitive or like, oh, you're like, are you PMSing?" Or even if I'm just like irritable, it's seen as a negative thing. However, I think that because PMS is autumn and it's a time when we can like do a lot of releasing as menstruators that it's important for us to acknowledge that it happens to everybody who menstruates and also try and see it in a more positive way rather than constructing it as like a pathology (.) that's a disease or a sickness in people, because it's (.) it's truly not. Like, of course, we need to support people through that. And it's a really, really hard time. And like hard (.) I (.) for me, it's the hardest season to get through for sure. However, and like acknowledging the more like low vibration, negative emotions and experiences that we probably go through and do go through at that time, however, we can still see it as like part of this natural important process, just like autumn and fall as a natural important process, then maybe we can shift the way that it's talked about or even experienced for people. Yeah. **Interviewer:** Yeah. I mean I've been in this (.) researching this subject for many years and I find that usually that weepiness, premenstrual weepiness, is quite often just empathy, I mean that should really be celebrated because I think that's a lovely human trait. **Ria:** Yeah! **Interviewer:** It's not quite the same as 'sad' tears, you're not kind of necessarily in pain, emotional pain. **Ria:** Yeah. **Interviewer:** It's more that something very moving has happened. **Ria:** Yeah. **Interviewer:** So it might be a bit sad, but it might also be very beautiful. **Ria:** Yeah. That's so true. It's so true. And I love that. And also I feel like trauma is processed through laughter and tears. And so, you know, we can (.) it's great to laugh. I think that's important. And then also, just like how you're saying, like, not all crying. Is because you're like sad or upset. It's because, you know, you're feeling! [Laughter] you're feeling for the world, you're feeling for humanity. We're in (.) we've always been in hard times but these are particularly hard times. From what I gather (.) around the world and what I gather from elders who are like, “what did y'all do?” [Laugh] Like, “what's going on here? This is not good”. So, yeah, and maybe even like as we cycle into the new decade. And think about reorganizing our societies in a way that is in right relation with each other and with the earth that. Can you imagine what it would be like if we used the Four Seasons as a way to like organize government or organize school? A lot of people talk about people missing school on their period and also during the PMS season. Like, what if we were just like, "that's OK. Like, take the time, go chill in your bed, take a nap, have your snacks" rather than being saying like, “oh, this person didn't show up for work or school or isn't being a productive part of our society and therefore leading to pathologize it and turn it into a disease and something that we can fix”. And you can tell just how I am. Like I'm just being very open. I don't usually. I have to be careful about who I obviously say stuff to because I think it's a really sensitive topic still and we're still maybe in the shifting phases, we're cycling into a new era of menstrual health activism and discourse. So, yeah. Not push it like not pushing people too far, but starting those conversations. So in our everyday life, how can we support PMS and see us (.) see it as this season? Then how could we even think about it for the long term and how we organize ourselves?

**Ria 2:** Yes, I think I mentioned this before, which is that everybody with a menstrual cycle [laugh] experiences the autumn season PMS. It's just a fact of the menstrual cycle. And I would say even I'd be curious to see that in people who don't identify as menstruators, because we seem to have this idea of sex being binary, like you either have a menstrual cycle or you don't. And I actually think that we're actually all like on a normal distribution. So there might even be people who identify as male because males also have oestrogen and progesterone, just like quote unquote, 'females' have testosterone, that they might experience it in relation to the lunar cycle. So during the (.) waning moon phase. So after full moon going into New Moon, I'd be curious to know if (.) if, you know, I magically got a bunch of funding to do a project to do a project about PMS in people who identify as male and see if they also experience similar accounts of what we as menstruators talk about when we say PMS and the autumn season.

### E4- How did you first come to know about PMS?

**Anne:** [Long pause] **Interviewer:** So was it in childhood? Was it when you were training? **Anne:** Yes, it was when I was training, so I cannot remember (.) I have no memories of being aware of it during my teenage years, you know, having started my periods. Obviously, friends, teenage friends, I have no memory of it then. Erm, or really during medical school, to be honest, I can't remember having any teaching about it. It was when I went to (.) was training as a GP and I can't remember a 'particular' patient who perhaps triggered my interest. It was more around the reading material, the things I was exposed to in terms of my training then, that (.) where I developed my interest. Yeah.

**Barbara**: Working in gynecology [sic] in an academic medical center [sic].

**Debbie:** I don't think I could say I do. I don't remember. It was young. You know, it was young. (.) Surely as a child? Yeah, yeah. But I don't remember. It wasn't talked about a lot. But (.) but I (.) you know (.).

**Celia:** [Long pause] **Interviewer:** Like maybe childhood, teenage years? Older? **Celia:** No, no, it was when I was a gynaecologist. I never heard of it before.

**Sarah:** No (.) It would have been when I was researching the area. I don't think I'd really come across it as a medical student, so I would have been in um, around my mid-20s.

**Thomas:** Yes, yes, 1972. **Interviewer:** And you were a medical student or had you finished? **Thomas:** Yes. Medical student.

**Susan:** Oh, I probably would be (.)Twenty? So I would have been in my second year at uni so I would have been twen (.) nineteen/twenty? Um, I don't know whether I had (.) I don't know if I had heard of it before (.) But I think when (.) it was my friend who actually said it. And I obviously had a knowledge of what (.) I must have had some notion of what PMS was, because I didn't say "what is that PMS you're telling me I've got?" so I must had awareness of it. It was something that was talked about. But it wasn't something I was particularly tuned in to. But she said it. And then I think, I though "yes, I have got it". But it wasn't something that I was then obsessed about or thought too (.) thought about. So it didn't become a kind of defining narrative in my life. It wasn't something that (.) but it was just. Then I had that moment when I read that paper that I thought, "oh, my God, yes! Someone said to me, I've got this, and yes, I do think I do have those changes. And yes, this is something I could study". So then I suppose it became more of a defining narrative in my life as an academic. And I think in my early writing. I didn't identify as a PMS sufferer (.) I didn't, you know 'out myself' as a PMS sufferer or take a particularly reflective stance around it, and certainly the PhD I did was very experimental. So there was no space for reflexivity in that. I didn't know what reflexivity was, so there even though I went on to study it. It wasn't. "I'm studying this and I experience this". That was (.) it was like they were completely separated because I was being a good, positive psychologist where all of that was outside of the framework. And um (.) I was really you know I was doing it because I was interested in it. But then I found a way of studying it, which completely objectified it.

**Marta:** Ahhh (.) It must have been during my (.) my (.) when I was a med student in the OBGYN course, I think pause] I don't think that it was [pause] maybe I had read about it in the media before going into med school, but um it wasn't something that was really discussed that much, at least not in (.) in the media?

**John:** It would have been before medical training [pause] yeah. **Interviewer:** So as a teenager? **John:** Um [pause] I think probably in the context of a (.) oh I'm thinking about how personal to get now! [Quietly] I'll (.) I'll say it as I recall it. I recall my father telling me sometimes when my mother was a bit moody that it was her 'time of the month'. And that some women get moody at that time, and that's what's going on. So that would probably have occurred in the context of being snapped at or something. Um, having said that, I would not categorize my mother as having PMS of that severity. Just thinking about that is contradicting what I've just said about family members. But that's probably when (.) that would be my first recollection of that being mentioned.

**Laura:** Yeah, I think it was when I was an adolescent and I was talking to a friend of mine and I was having a very difficult day, I was really upset about something. And she asked me when my period was and I said, I think I was about to get it. And she told me that was PMS.

**Zoe:** Oh [exhale] [pause] I'm not sure I had too much of a (.) It wasn't part of the vernacular um (.) and part of the discussions we had as adolescents. Um, so when there was still (.) there was and still is. But for my cohort or for my (.) my experience, um menstruation and just bleeding more generally were (.) were quite shameful and people didn't speak about it. Apart from the sort of [interference noise] the technical clinical description… Apart from the very clinical technical definitions you sort of got in you know, school sex education classes. Um and (.) and from my mother, there was not discussion of it. So it was not something that was widely discussed um within my peer group, within my family. Um not (.) not because of an overt shame. It just wasn't discussed. And so it was more of a silence than a, than a stigma or a shame? So I suppose. Um, I probably just became aware of it through popular culture, I can't remember when I became aware of it, but I do remember that in my um late um (.) in my late teens, my early 20s, when I was coming towards the end of my honours degree, I was already interested in women's reproductive health as a (.) as a topic area. So I was reading about it and (.) and coming across it both in terms of academic literature and popular culture at that time. But it was not something that was actually discussed amongst any of my peers or with my peers.

**Geraldine:** Just from reading about it. **Interviewer:** So what kind of age were you then? That was at university? **Geraldine:** Yeah, Graduate school. So, you know, in my 20s. [Pause] So now, you know, my mother did say when I was a child, occasionally my mother would be in a bad mood and she would say, "I got up on the wrong side of the bed today". And so, you know, decades later I thought, "Oh, I wonder if she was Premenstrual when she would tell me that I got up on the wrong side of the bed". That was her explanation for being in bed.

**Chris:** Hmmm I think (.) I think the resear (.) oh no, it was probably slightly in the undergraduate curriculum, but it wasn't very prominent. And then it was in the curriculum for the Royal College exams, but very low key (.)

**Jo:** Yeah. So I first got to know about PMS. Well, I might have known something about it before? But I went to a meeting I think was 2009 in Berlin, that [pharmaceutical company name] supported and [colleague's name] spoke at that. They had other speakers there. But everyone just, you know, it's obviously quite high level endocrinology and to be honest, at that stage in my career, I was a bit like, "wow, too much for me" kind of thing. But they were looking at potential treatments, which was good.

### P12- when did you first find out about PMS?

**Alice:** I mean, I have no idea. But when I think of that word or even the way I'm talking about it, you think of that phrase, I just see it as [sigh] a kind of way that society has categorized periods pre or during or post for women is very negative. And I would say that it's almost negative or used (.) like used as a joke, you know. 'Oh, well, don't speak to her today because she's probably on her period or she's about to have a period'. You know, I don't think that happens for men at all. And actually, I think that happens for women. Full stop. So some people will even say, 'don't speak to whoever today because she's going through the menopause'. I mean, for goodness sake, that's just so rude.

**Beth:** I guess. Erm, And I don't know if you mean how did I become aware of what PMS actually is, or how did I become aware that it was a thing? But it would have been (.) Like how did I first hear of it mentioned, but it would have been at school. And it would have been from boys. So I have a younger brother. I've got two brothers. My older brother's a lot older. And so my younger brother is the only one that I had to put up with this attitude about PMS from, because my older brother never lived with me as when we were kids. He was already grown up. And also, although I went to an all-girls school, there was a boy’s school next door and we (.) I travelled to the train every day (.) by train, every day from home to school and back. So there were a lot of boys on the train and we'd sort of all hang out together on the station platform and on the train home. And I remember (.) it would be a regular occurrence (.) if a girl was in an argument with a boy or seemed a bit moody. The boy would go 'ooh, ooh, P. M. T!' like that was the cause of the mood. So the first awareness I had of PMS or it wasn't sort of referred to as PMS back then, it was PMT (.) It was that it's a thing that girls and women get and it makes them stroppy and unreasonable. [Laugh] So yeah. **Interviewer:** And how old do you think you were? **Beth:** [00:27:22] Well, er, sort of eleven twelve when I first became aware of that. And the boys would use it as an insult, really, if they thought you were being moody.

**Dani:** God, it must have been from a magazine or something. Got a lot of my like sexual and reproductive education from girl’s magazines like shout and bliss and stuff. I'm sure they used to print all this kind of stuff. It must have been through there (.) **Interviewer:** So probably as a child? **Dani:** Yeah. I would have been like 10. I think I probably knew what it was, but just didn't really. In fact, the first memory I have of it is when I was in Florida on holiday and I remember being in a (.) in a big sort of pharmacy and there was a whole aisle that said PMS. [laugh] And I remember saying to my mom, "what is that?" But I don't know, but I (.) but then I have like a mixed memory. Of whether, she said, "oh, no, it's just the American version of PMT" or something like that? So I might have known, but I hadn't started my period then, so. Yeah, but I really can't remember. It's just I think it's always just been something that is just, you know, I've known about since I've known about periods maybe. I'm not sure. Sorry.

**Emma:** I think (.) I can't be certain, but I think probably through (.) through my mam, through conversations with her because she (.) she suffered with PMS. I don't think she ever had PMDD, but definitely she had PMS. And so I think she probably talked to me about it. **Interviewer:** So when you were a child, you think? **Emma:** Er (.) Yeah.

**Faith:** [Pause] It definitely wouldn't have been when I got my period first. I think it would have been down the line. I don't think we ever spoke about symptoms when we were (.) like in secondary school? **Gemma:** No, definitely not. **Faith:** So, I can't remember when but I know it was significantly after my period. **Interviewer:** So like maybe when you were a teenager? **Faith:** Yeah, I don't even know where (.) I guess it was (.) I think it would have even been something informal like through conversation? How did I find out about it? **Gemma:** For me, it was my brother. Yeah, he goes to me. You're acting that way cos you're on yer period (.) **Faith:** Oh, they always love that. **Gemma:** They love that! [loud] And he was the first person that said it to me and I was like 'What are you talking about? Like, he's like 'So you're on your period again'. which I think, by the way, that guys get periods, they just don't bleed cos living with a guy, they get (.) they have these three days in a month where they're unbearable but erm, that's definitely the thing. But he literally told me he was like, 'you're act (.) you're actin' different'. You're just (.) why (.) why d'yer actually keep gettin' upset about everything? So then I was like 'Hold on a minute' Then I actually thought about it and I spoke to my mum about it and she said yeah that's (.) she didn't say PMS though. She just said that when you go on the period your emotions are up and down. **Faith:** I think I know about that. Yeah. **Gemma:** Yeah. I didn't know the term (.) even the term now to me is kinda new, like I only heard about it like maybe two, three years ago. To be honest, like PMS like (.) **Faith:** That just reminded me (.) I had a friend (.) we have a friend [name] who we were really close to. He would always like when we were in school he'd come and say to me "Are you on your period?" [laugh]. And I would say "Why?" and he' like "Your hands are trembling". So apparently when I'm on my period my hands tremble (.)and I didn't know that (.) **Gemma:** Wooooow! **Interviewer:** Was he always right, though? **Faith:** Yeaaaah. Like [Overlapping] just picking up a pen, or picking up a cup or something like (.) my hands were trembling (.) **Gemma:** [Overlapping] That's so weird! It's weird what guys see, you know? It's really strange, but yeah (.) [brother's name] will always (.) he knows like that if I'm on my period. He's like “you’re on your period, aren't you?" and he doesn't just say it, he doesn't just say it to just be annoying. He's always right when he says it. **Interviewer:** I've never heard of hands trembling, but it makes some sense because your um (.) various hormones are doing different things, including like, adrenaline, and cortisol, and you know, adrenaline can make you (.) **Gemma:** Tremble, like shake? **Interviewer:** Yeah. Yeah. Like ready to fight or flight [laugh] but yeah. That's a very observant friend you have! He should be a doctor or a detective! [Laugh]. **Faith:** I'll tell him, yeah, he'll be happy! [Laugh]

**Helen:** Probably as an adolescent, you know, having my mom take me to the gynaecologist being like, she's so emotional, like PMS pretty much was, you know, a mainstay from the start.

**Kathleen:** [long pause] I don't remember when um (.) it would be a very long time ago. And it was (.) always it was always in a very negative way. Yeah. I don't think I've ever heard PMS spoken about in a positive way. It was always kind of "Oh, well. You know, you're about to get your period, it's PMS!" [in a teasing tone] that kind of thing. Yes. **Interviewer:** But do you think it was as a child or a teen or a bit later? **Kathleen:** I would probably say maybe in the late teens, young adults, yeah, definitely not before that.

**Aisha:** Um [exhale] I think it is because I must of tracked (.). I don't know. It was a Google search. Definitely. And. "Why do I feel anxiety? Why do I feel this, that" and PMS came to a (.) It was because I kept (.) my mood. I kept arguing with my mom and I get so angry suddenly and I was just googling it. And then I went to my doctor and I'd kind of calculated. Yeah, I do have PMS. At first it was like a week before I noticed it. But then when it came (.) a consequence of when it was 14 days before, and then I realized you can PMS for 14 days beforehand as well. That's (.) with me. As soon as it's 14 days, I start PMSing.

**Mala:** It wasn't (.) not so long ago. Actually it was probably (.) I can give you months (.) probably like six months ago? Yeah. **Interviewer:** OK and How did you find out? **Mala:** A friend told me that you are definitely PMSing [laughter]it's becoming a thing. You are acting so strange and that's not you normally. And then I was like, why am I acting like this? And she's like "when are you going to start your period?" and then I checked my Period calendar and it was in a week's time. So she was like "you are definitely PMSing". And then I went through the symptoms. That's me. That's me. That's me. That's me. [laugh]

**Noor:** It's only the (.) probably the last. Four (.) I'd say five years. Only because of my little sister. **Interviewer:** So through her experiences? **Noor:** Yeah (.) **Interviewer:** She'd been telling you about (.) **Noor:** PMS. Uhuh. **Interviewer:** So you never heard it at school or like anyone teasing anyone about PMS? **Noor:** Nowhere.

**Ria:** So yeah it was the t shirt, my gym, my cis male (.) gym teacher who had a t shirt about (.) that said PMS and something about Mad Cow, and I was (.) I'm like, I'm a second generation person. So my parents came here in the 80s. And so growing up, probably just like everybody, but for the most part, I feel like I was trying to catch up to cultural pop culture references where it's like, "OK, I need to know what this stuff is". And so I think I had heard of PMS. I wasn't menstruating at that point. So that was probably like, I don't know. Or maybe (.) I think I would have been actually because that would have been like when I was eleven or twelve, eleven, twelve, thirteen? So it's sort of in my early years. And then from then on, up until basically when I started doing my work which was two years ago, I think the main iteration of PMS that I heard was. "PMS equals negative comment. PMS negative comment. PMS negative comment". I'd never heard anybody talk about it positively. I don't think (.) yeah.

### E5- How common is PMS?

**Anne:** [Pause] Erm, I would put the prevalence of (.) pre (.) if we're talking about premenstrual disorders. So, you know, it just very simply the cyclical mood, er the cyclical symptom change with impact on quality of life. I would put that around the 20 percent mark? And then the very severe end of the spectrum, about 5 percent? I do have a (.) a slight confusion or difficulty around the diagnosis of premenstrual dysphoric disorder because that is based on (.) now. I'm just going to use a little bit [my notes]. So it is (.) that is based on the American Psychiatric Association's, the definition of where you need five out of eleven symptoms, one which must be from a list of the first four. And so that (.) that I think myself and the other trustees at NAPS come from a very clinical background where we do look at specific definitions. And I think that that definition, that diagnosis of premenstrual dysphoric disorder excludes some women that don't conform to those criteria, but still have very severe symptoms that impact on negative life and may make them feel suicidal. So I do have a slight issue. You know the (.) just the uncertainty around that. And I think that's why [names of colleagues] produced the comparison of a different definition (.) definitions, which is on the website. I can't (.) remember the original question now? Sorry. **Interviewer:** It was about prevalence (.)Well, with all prevalence, to be honest, it's a little bit with a pinch of salt, isn't it? It's a (.) **Anne:** It is, absolutely. Yeah. So to answer your question very simply. Twenty percent for PMS premenstrual disorders. Five percent for what we're saying is PMDD. But I think that five percent should also include the very severe end who don't conform to the criteria of the DSM 5.

**Barbara:** Most women may identify symptoms, but a moderate - severe problem with PMS may be around 20%. 3-6% meet the criteria for PMDD.

**Fran:** I thought I had just said? I think premenstrual symptoms occur in up to 80% of women, but the symptoms are problematic in interfering with their functioning and/or quality of life in 20%.

**Andrew:** Well , there has been a lot of epidemiological studies on this, and I would say that a majority of all women have got (.) perhaps 80 percent have got a condition that so that they can feel in some way from somatic complaints or maybe mood symptoms that the menses are approaching. And that is a majority. And for most of them, these symptoms are entirely trivial and they would not dream to ask for help for them, etc. Then if you look at a condition that is so severe that it's regarded by the women themselves to be a considerable problem, I would say around 5 to 7 percent or so of women of fertile age. If you use the DSM criteria and ask women to rate their symptoms daily for two prospective cycles and then use a definition in that that they should have a cyclicity in at least 5 symptoms, then you would be down to 2 percent or so I think. But (.) but that I think is fair to say that 5 to 7 percent have got symptoms that are sufficiently severe to be a major problem for them.

**Debbie:** It depends entirely on how you [pause] operationalize it. You know, how common is it for people to have mild changes that don't (.) like (.)? What I'm trying to think of is like, how common is it for people who have mild changes that don't interfere with your life? Probably like really common. Probably, you know, 80 percent or something like this. I wouldn't say all. I've known quite a few women who are like 'I've never had any symptom whatsoever' [laugh].

**Celia:** Well, I think probably it depends on the definition you have. If you're talking about disabling symptoms (.) certainly that would be under 7 percent if you're talking about bothersome symptoms. It could be up to 20 percent depending on whether you require one symptom or more than one or whether you require more than one day (.) premenstrually.

**Sarah:** Well, it depends if you're talking about. I mean, most women notice a little bit of a change in something (.) it might be a little bit of breast soreness. So they know from that that they're about to get a period. That's a good thing (.) they know when their period's due. They could be prepared. That is not a disorder. So if you're talking about a disorder that really it is debilitating. It's I think it's a small percentage of women it would probably be about 5% of menstruating women. If you're talking about how many women notice a change that causes them a little bit of distress, uh you know a little bit more than that (.) being a severe disorder? You know, it could be up to about 30 percent of women. But it's, you know, the intensity of symptoms vary a great deal.

**Thomas:** Well, it's very common, it's er (.) I can only refer to (.) I was part of a television program. And in the city of (.) of where I live, it's about 150K inhabitants. And (.) and during the two days after this program, the department had about 50 calls from patients who wanted to come and see us. So it was a very common (.) common way. But I mean, the severity varies a lot. And as a (.) as I would say that more (.) or more or less well over 50 percent perhaps, or up to 70 to 80 percent it has been recorded feel some changes in relation to the menstrual cycle. So it's (.) it's more uncommon not to feel changes than feel changes, although I mean, these are not to be considered to be pathological, I mean, to be considered as um 'disorders'. But these (.) these figures about three to five percent of the female population, in fertile ages (.) that have (.) have this a more severe condition. That's (.) that's also something which (.) which would need treatment and help in any way. And in (.) in (.) I would say that it's (.) it's more (.) more than the ones that actually fulfil the criteria of PMDD that need help. I would say about ten to fifteen percent or perhaps even more but, but at least in, in, in that range I would say. And the rest of course, I mean I think that they can manage themself by (.) by knowing what it's (.) what is happening. And also by (.) by changing their lifestyles, sometimes (.) many patients which I have met, they say that they keep a diary in advance so that they know the days when they are going to feel bad. And that helps them to, to at least feel (.). I mean, you're able to cope with the situation. But er, of course, I mean, 80 percent of the female population in fertile ages, are not being (.) have not a disorder. That's something which I have to say (.) Some lay press, it seems, has everyone more or less as having this disorder (.). and that's not true.

**Susan:** Well, I would say that (.) well, what the research shows us (.) it's not (.) that simple. So, there's a lot of studies that show that the majority of women say (.) so some studies say like 95 percent of women get some sort of premenstrual change, but that can be quite minor. It might not be noticeable. Women can cope with it and it certainly doesn't have any effect on women's daily lives. What, the research suggests is that between five and eighty (.)[correction] eight percent of women, depending on whatever study you're looking at, experience moderate to severe premenstrual changes which cause distress. Um, and there's some studies that say about 30 percent of women get moderate changes and then this 5 to 8 percent get severe changes. It depends on where you draw the line. In terms of what PMS is. So I would. That's why I kind of talk about it much more in terms of premenstrual distress and impact on lives, because you can have a change. Um, I don't know, I'll give you an example in terms of the menopause, which is I'm kind of in at the moment. So I get hot flushes and I'll probably have to get out my fan, actually (Oh, it's here in front of me!) so I'll probably get one while I'm talking to you. But that doesn't cause me distress (.) because I normalize my menopausal changes. The main change I have is hot flushes, which makes me feel hot. And then I'm getting a bit like that now. And I just get my fan out (.) and I'm not distressed by that. But there are many women who have that change that I'm having, and they're extremely distressed by it. And the idea of in the workplace or in an interaction with another person, someone knowing they were having a hot flush, causes them a lot of distress. And then they go and take drugs for it. So I suppose my (.) I would make a similar argument around premenstrual change in that many women experience premenstrual changes. And for some they're quite minor and they might know they're a bit more clumsy or they're a bit more irritable. Physical changes are an issue and I'm increasingly interested in issues around the body and embodiment And how women feel about their body's premenstrually which you know, I'm happy to talk about separately, if you want to talk about that? But we react to those changes differently as women. And so this thing about how many women get it is a hard number (.) I think lots of women get the changes, but it's how they then respond to it. And (.) that (.) that is whether they've actually got PMS.

**Marta:** [Audible exhale] Well, that's a good question. And if you're asking about my understanding, I would say I don't really know [laugh] I think the general estimates that are typically given (.) I mean, what I write myself when I when I write a paper, er (.) I would say it's it's found in three to five percent of women. I would definitely lean more towards 3 percent than the 5 percent. And (.) but (.) In all honesty, I think that even the 3 percent prevalence is probably a bit overrated [pause] I'm saying this because I'm currently working on a project on an endocrine disorder called Polycystic Ovary Syndrome, which is also common in women. And the typical prevalence rate reported in the literature is (.) if you take the low range around 6 percent. But when we look at the number of women who've been diagnosed in the Swedish registers, because in Sweden we have registers for everything. Every diagnosis made by a doctor. We can only see that about 1.5 percent of all women actually have been diagnosed with PCOS. And of course, you can suspect that some women go undiagnosed, but not (.) not seventy five percent that seems unlikely. And I think the same thing is going on with PMS. That it is common. I mean, anything that's above 1 percent is common in women, but maybe not as common as 3 percent… **Interviewer:** Do you have any theories or ideas about why the prevalence might be slightly exaggerated? **Marta:** I think that there's (.) I mean, the studies that have been done on (.) on the issue. I think the best study whatsoever is (.) is a prevalence study that was made in Reykjavik, where they actually asked women to perform daily symptom ratings for a number of months and they used very strict criteria to diagnose PMDD. Whereas I think that some of the higher estimates derive from (.) also population based studies, but more interview studies (.) er, where so that that probably means that (.) um we know that from (.) from just women reporting they have PMS. If you're actually try to verify prospectively quite a (.) almost 50 percent or something, actually don't have PMDD.

**John:** Well, it depends on the definition that's used. But premenstrual syndrome as defined, er (.) which is basically any symptom, physical or psychological, premenstrually that can be attributed to that (.) about 80% of women.

**Laura:** So PMS is about (.) PMS symptoms occur, but we don't have a good definition of PMS ACOG really hasn't (.) well, I guess the International Society for the Study of Premenstrual Disorders has a reasonable one. Um but [pause] about [pause] 20 percent of women probably experience at least an annoying set (.) set of symptoms, which would constitute a syndrome. Um, PMDD occurs in about 3 percent of women (.) at tops 5 percent.

**Zoe:** Um (.) I would say PMS is fairly common, like um if (.) if (.) it's impossible to put (.) It's not uncommon. I don't want to put percentages on it, but it's not an uncommon experience. Um, I think what is uncommon is um women who may have quite extreme experiences, but I think most women or many women um have a period of time before their period. And it may not be every cycle, but it can be um with (.) with many cycles where they experience an increased sense of just sensitivity and vulnerability to (.) to (.) to managing stressors.

**Geraldine:** Ha ha! [Laugh] Well [exhale] you know, the psychiatrist say that PMDD is about 2 to 3 percent of people in epidemiological studies. I don't know of any good estimates of how common PMS is (.) Uh, premenstrual symptoms. If you don't call it a 'syndrome', that's very common. Um (.) maybe 90 percent of women experience something? So it's a very slippery definition. But as I said before. Most women, anyway, seem to think they have it.

**Chris:** So we're talking PMS [pause] because it's difficult until you define it, so it probably occurs (.) premenstrual symptoms are almost certainly physiological and they probably occur in over 50 percent of the population. Severe PMS (.) depends how you're defining it. Because I sort of think severe PMS and PMDD are more or less the same thing. And so. So then you say it's 5 to 8 percent of the population, but of course you will find 25 percent of the population say as having severe symptoms.

**Jo:** It's a lot more common than I think we (.) we had previously thought. I mean, it might be 25 percent of women will have some element of PMS. I think it's (.) as time's gone on as well, because I have now [pause] as a result of this study attracted lots of women, who (.) who either are self-diagnosed or they've been diagnosed or (.) or they've struggled to be diagnosed. I think it's one of these things that's very difficult because the number of women with core PMDD is probably relatively small, but there are lots of women who've got other mental health issues or co-morbidities or whatever you like to call them. And so it's (.) it's a (.) I think some you know, lots of the women that I'm speaking to, now, are really very difficult to manage? **Interviewer:** Yeah. And you're seeing a lot of people because they're coming to you! **Jo:** And they're obviously coming because they're quite desperate. So I think it's good that there are um [pause] groups that put women in touch with other women because otherwise they'd be incredibly isolated, wouldn't they? But I mean, a lot of the patients that I'm dealing with are coming from far away. So a lot of it's being done by Skype or, you know, some sort of video conferencing; they might be in London. They could be in Hull or [inhale] wherever. But actually, for this particular problem, that doesn't matter as long as you can find somebody to co-manage them. So, you know, I have women in North Wales and I've just ended up finding out who the gynaecologists are who will be sympathetic to the problem. And a lot of (.) a lot of the colleagues I've got are through British Menopause Society. And it's obviously it's not (.) It's not to do with menopause, is it? But I think it's that interest in hormones that means that they might have a co-interest in PMS?

### P14- How common is PMS?

**Alice**: My (.) for me, my (.) my fellow (.) women. You know, my (.) my (.) with my friends, to women and my, you know, my sisters. To be honest, we don't use ever the phrase PMS. We will talk a lot more about I'm about to have my period or I've got my period or I’m on my period. But that might just be. The term, the terminology that we use and I think that PMS is used by men a lot more than women. That phrase PMS. **Interviewer:** Would you prefer (.) I mean, it sounds a bit clinical, to use in a normal conversation. But how about the phrase ‘pre-menstrual symptoms’? I mean, is that something that you'd be more comfortable saying? **Alice:** I mean, I think my experience when I know I'm about to get my period because I get some pre symptoms and pre-menstrual symptoms, but actually I think most people think PMS is the bleeding. Yeah. You know, people think PMS is right now - bleeding – whereas it is actually, you know, the abbreviation PMS is the before, but no one even ever talks about the after really, it’s sort of an umbrella term is if anything is used as an umbrella term for the whole pre, during and past.

**Beth:** [Long pause] I actually (.) and I feel bad. Erm, but as a doctor, not knowing how common it is, I would guess (.) I don't know if I had to (.) It is a guess. It's based on absolutely no evidence whatsoever. I'd probably guess that about 75 percent of women get PMS, but I've no idea. Really.

**Dani:** Erm, [pause] I don't know, actually, I'd say it's pretty common like. [Pause] I'd say that like probably quite a few (.) people who menstruate and women sort of experience it from time to time, but maybe it's not always recognized as that. Maybe it's sort of (.) it is sort of recognized as being in a bad mood or something or vice versa with your knowl (.) with your education? I don't know. Erm, Yeah, I'd say it's probably like [pause] relatively common, but I don't think everybody who menstruates experiences it or suffers from it.

**Emma:** I think around [exhale] 80 percent of (.) people probably experience PMS symptoms and out of those I would say around 10 percent, 8 to 10 percent have (.) PMDD, so very severe symptoms.

**Faith:** Ooh. I'd assumed (.) now that you're askin' (.) [laugh]. **Interviewer:** [00:35:31] It's not a trick! I just want to hear you to respond (.) **Faith:** Yeah. I assumed it was everyone, but now I'm thinking maybe it's not?

**Gemma:** I actually don't think it's for everyone. Yeah, I think it's I think maybe it is for everyone. Yeah, but different (.) because I think for me personally. My brother 'cos he lives with me. He knew I was on my period. My friends don't like. I've never heard it in my life. I think that (.) it doesn't affect (.) I can kind of control it. Like I cry a lot more. But again, those are moments when I'm by myself watching telly. Those are very alone moments, I think (.) And in the moments my friends have said it to me (.) like they pass a comment, I haven't been on my period, I've just been snappy that day.[laugh] So I feel like with me. Unless you live with me, unless you're very, very close to me, you probably wouldn't know. Whereas with other people because they're less able (.) because they experience it more, you would know? So maybe not everyone feels it. Or maybe people feel it. Maybe everyone experiences it but at different levels? What do you think? **Faith:** In terms of like. Does everyone get it? **Gemma:** [Audible sigh- exhalation] That's a tricky one. I don't know. I was thinking like maybe everyone does. But then at varied (.) like it ranges. So maybe you (.) maybe everyone gets it, but it's like so (.) [interrupted] like such a small thing. **Faith:** Someone might just be craving ice cream or something, whereas someone might be going through emotional (.) [Quietly interrupting] **Gemma:** But I think everyone (.) I think. I don't know. I would assume that most people do. Is there an answer to that question? Cos I'm actually intrigued?

**Helen:** From my understanding, PMS effects 70 percent or more of individuals with a period. I should say menstruating and not all of us have a period, I guess! [Laugh]. Those who are producing eggs. Yeah.

**Kathleen:** Er [long pause] I don't know. I mean, I haven't heard PMS talked about for a while. Um, and I have a lot of very good female friends. We don't talk about it. I can't say that I've ever been around my friends. Definitely not for a very long time where I thought, "oh, you're in a bit of a mood, I wonder if your per (.)" Ach! It just doesn't enter my mind. It's not something we refer to so I don't know if that's because they're not experiencing it or just that they've learnt to manage it in a way. I'm just kind of (.) yeah I'm blind, but it's definitely not something that comes up in my conversations sort of thing (.)

**Aisha:** Very common. And some people don't even know they have it. **Interviewer:** So like most people who menstruate? **Aisha:** Most people, yeah.

**Mala:** I think it's a lot it's very common. It's just I don't feel that people know about it um because (.) for example, my mom (.) um I, she is from the elder generation. She would not know what PMS is, but I can see the symptoms when she's on (.) just before she's going to start her period. Like she's a bit like me. Like she will just go crazy on the littlest things. Um, so (.) **Interviewer:** So would you say like more than half? Most women? **Mala:** Most women, most women. I would think. They just don't (.) they just don't know, that they are [pause] and they (.) just how I used to just feel it. Just get on with life. That's probably how they (.) 'cos they don't think it's (.) They think it's just normal.

**Noor:** I do believe every woman does have it.

**Ria:** Defining PMS as the autumn season, the luteal phase of the cycle? I (.) I do invoke the term PMS because it's like a commonly circulating cultural acronym that people seem to understand and know about, but defining it as more as the autumn season, the luteal phase. And I won't go into it, you know. You know, all those things! [Laugh] So fill that part in. I would say that. It happens in anybody that menstruates. I will say that. Yeah.

### E6- Why do premenstrual symptoms occur?

**Anne:** [Pause] I think it's best to split that down into the (.) er (.) the physiological and then the social and the psychological. So in a particular woman, there will be a complex interaction of those factors that then lead to how she experiences pre-menstrual symptoms. So we'll take those each in turn. Physiological: So lots of work has been done around whether it erm, you know, particular hormones or chemicals contribute. And my understanding at this present time is that there is likely to be a genetic component, which, you know, research is going on about that (.) that is not due to a particular deficiency of a hormone. But put simply, there are variations on this. But put simply, what happens is that there are cyclical changes in the normal menstrual cycle (.) when ovulation occurs. The hormone changes change again. And there are (.) there are sort of feedback pathways up to the brain (.)? And when those hormone changes happen in susceptible women and this possibly is where the genetic thing comes in [laugh] that affects neurotransmitters in the brain. So things like your serotonin, your GABA. And that it is those (.) chemical changes, which can affect a woman's mental and physical health. I think it's more complex than that. I think the physical changes, those are linked in with er adrenal function. So it's there. That's where it becomes quite complex. Erm, I mean, that sort of explains. What's the name of the new drug that has come out, they're researching? Erm, I'll remember it in a minute. But that (.) that is a sort of they're looking at a drug that you inject in the luteal part of the cycle. And that, I think affects GABA metabolism. So looking at (.) so that's an overview of the physiological. Erm, social: This is where, you know, our social situation effects or psychological health, such as, you know how stable we are in terms of our home, our work, our family. Erm, what's going on at work? So any stress is going to lower the threshold for symptoms to be experienced and then psychological: So (.) if (.) if somebody has (.) a woman has (.) er (.) perhaps a predisposition because of her personality (.) or some underlying psychological condition, then perhaps she's more likely to experience premenstrual symptoms. And, you know, that brings me on to the group of women who get the premenstrual exacerbation where they have an underlying psychological or physical problem, but then it does get definitely worse. And that, you know, that's (.) er (.) I'll bring it up now. But you're probably going to talk about it. That's why it's just so important in these women to track their symptoms. It can give you so much information about what is actually happening. And, erm, you know, I have had women who really come and they really feel that they've got PMDD or PMS (.) and if they track the symptoms over two (.) two months, there's just no correlation to the bleeding at all! And you just think that but that is actually quite (.) very useful because to actually see it (.) visually that that's not happening can actually be helpful for them. And also can guide your treatment about what would be the best management for them.

**Barbara:** The etiology [sic] remains unclear. It is hypothesized that the biochemical changes of PMS involve central nervous system-mediated interactions of the reproductive steroids with neurotransmitters. Hormone levels alone are NOT the cause.

**Andrew:** Firstly, I think there is a biological explanation, and that is, of course, also discussed this in terms of various socio-demographic aspects, socio-economic aspects and so on and so forth. I personally believe it mainly that it's a biological course that is related to the hormonal variation in the blood and supporting. This is, for example, first that if women (.) that they are unaware of the fact that a certain cycle has been an anovulatory which happens now and then, then they have no symptoms. That is in spite of the fact that they don't know that this will be anovulatory cycle. So that is one (.) one (.) one argument. Another argument is that if you take away the (.) the sex steroids, with drugs or another way, then the symptoms disappear. If you give back to these women the hormones, then you can elicit the symptoms. So (.) so I (.) I think, A, that the sex steroid fluctuations are the trigger for these symptoms. B, I don't think that women with PMS or P M.D.s differ or PMDD differ from (.) from other women in respect to levels of these hormones. But I think they have a somewhat enhanced sensitivity to these hormones. Finally, I don't think that this is a pathophysiological condition. I think it's a physiological condition that is probably normally distributed. I think it has some (.) the rudiment here is probably the oestrus cyclicity that you see also in various other species in terms of sexual behaviour and other stuff that is a behaviour change associated with the oestrus cycle. I think that this is a reminiscence of that in other species. I would guess I don't think it's then pathophysiological. I think you could have a normal distribution curve that most women have some mild symptoms, some are totally devoid of symptoms. Some have severe symptoms.

**Debbie:** Oh, this is so loaded for me [covers face] I think there's like 18 different pathways, you know, and we're trying to suss that out. And I think it's likely that it's not the same for everyone. I don't want to go into the weeds too much. I think so. Again, I know that we're going to talk about PMDD later, but (.) Yeah, that's kind of the only thing I can really talk about… I don't (.) It's not clear to me whether the mechanisms of these really mild symptoms are like the same, but just a matter of degree or if it's like totally different. But just assuming that it's sort of the same, but a matter of degree [laugh] or frequency or whatever for PMDD. There's a variety of insights that we have from experiments. One is that in people with severe PMS, let's say that is impairing. We know (.) and that it has an emotional component. We know that the (.) um, so the GABA system in the brain is a system of neurotransmitters that's responsible for sort of slowing down brain activity and inhibition of things (.) it has a very calming effect. Usually when you activate it, alcohol works on this system, benzodiazepines work on this system, and it happens that the metabolites of progesterone also work on this system. And in (.) and in most women, they have sort of the same effect as would, alcohol or benzodiazepines. They're calming. They (.) they sort of make you a little bit sleepy [laugh] and slower, right? They're not activating. But in PMDD. The group of molecules that make up the GABA-A receptor where the metabolites fit (.) fit in [physical gesture to show physical fitting]. There's a difference in gene expression where the wrong (.) sort of the wrong subunits are. So it's like if they put together this receptor sort of in the wrong way with the wrong units [laugh] and then because of that it's not acting in a calming way anymore. When those progesterone metabolites hit it, instead, it's agitation, irritability, um, mood swings [laugh]. You know, it's sort of really having this opposite effect where now it's decreasing the ability of that calming system to really work. So (.) so that is something that we understand to be the cause of this. Something sort of more conceptual (.) thing we talk about and that we've found, which is that people with severe PMS/ PMDD, are abnormally sensitive to normal hormone changes. So we've tried in this literature over and over again in biomedical studies to (.) to identify hormone imbalances and with (.) we just don't see them and they seem to be normal. So then we've done studies where we just shut the whole system down and we've put a medical menopause in place with a GNRH agonist and then add back oestrogen or progesterone or both. And for about a month, we see symptoms come back in women with PMS / PMDD, but not in controls who don't have that. But then after about a month, if you keep the oestrogen or progesterone or both stable, then the symptoms go away. So it seems to be really (.) er, and the sort of going back to that underlying GABA-A receptor system. It takes about a month, we think, for those sub units to sort of reset themselves after this acute change in hormones. So that's why you get this surge in hormones in the early luteal phase, you get increase in these sort of bad sub units of this receptor. You get these agitating bad effects for you, maybe, two weeks, three weeks, and then you know, and then it sort of wears off as the system breaks itself. I (.) I think what we believe is that as a field at the moment is that normal women have maybe a few of those changes in the early luteal phase, but their system corrects very quickly. And so they have more what we call GABA-A receptor plasticity, whereas women with PMDD for some reason don't. And it's just not (.) it's very, very slow to adapt to the change. So I think that's sort of the best (.) reason I can give, there's also implications of the serotonin system, which are somewhat related, but that's not my area of expertise [laugh]. So I think it's biological. We also know that stress worsens PMDD. I don't think that it causes it, but it certainly plays a role in making symptoms worse and harder, you know. Worse. You could take it from sort of moderate to severe, if you will. Erm, [pause] Yeah, sorry that was long. That's (.) that's my understanding.

**Celia:** Ha! [Laugh] good question [laughter]. I think that we (.) what we (.) the general concept is that there's a triggering event somewhere based on the rise and fall of sex, steroids with mid-cycle (.) it could start with the pre-ovulatory progesterone blip that occurs. It could be then with the onset of product (.) production of progesterone or other neuro-steroids from the ovary and brain at mid cycle. Having said that [pause] and then changes (.) as far as the research goes, changes in GABA receptor configuration and serotonin (.) serotonergic function. Having said that, there's always a conundrum with women who are taking oral contraceptive pills, for example, who have symptoms that look very much like PMS / PMDD in timing as well. But their hormones are not focussed (.) er not fluctuating and the symptoms don't wait to occur until you stop the active pill and are on that placebo week, they can even start during the active pill. Um (.) and then, of course, the (.) the biochemical changes which are postulated from either models or animal models don't really (.) um we can't combine this with the brain imaging findings because isn't really a Rosetta Stone to translate. We may know that there are some changes in the medial lateral frontal cortex, but we don't know what that means for neurochemistry.

**Sarah:** Well, it's definitely linked to the cyclical changes of menstrual cycles. If we don't have a cycle. You won't get it. So all the women that we saw who identified as having significant symptoms. And some of them, you know, we were able to see who did or didn't because we had their daily rating chart of course. Um but when we asked some other questions like did it happen? What happened when you were pregnant? Symptoms didn't occur! They usually felt terrific over pregnancy. It didn't happen when they were breastfeeding because of menstrual, you know, the cycle is suppressed. It doesn't happen after menopause. It doesn't happen before menarche, it's linked to the menstrual cycle. So it's (.) it is related to the effect that the hormones of the menstrual cycle have on neurotransmitters. And some women are very sensitive to this. And that probably effects their genotype, and there are twin studies demonstrating you know that there is some (.) you know, that's a crude way of demonstrating genetic links, but it does demonstrate that. And then there are, you know, there are other factors that also could make it worse. You know, stress makes it a lot worse so if you get anxious about it it's gonna get worse or some other stress in your life (.) is gonna make it worse.

**Thomas:** Well, at least the mental symptoms are quite well defined as (.) as being caused and now I'm talking about the (.) let's say the pure version, which is different from the one that is an aggravation or an exacerbation of other types of disorder. And in this situation, my (.) my understanding of (.) that's that is a result of our research is that there is a compound that comes from the corpus luteum of the ovary, which is (.) it's active in the brain. It's a very important one with, er (.) it's more potent than benzodiazepines and more potent than barbiturates (.) and it can be used as anaesthetic. So that is (.) actually disorders, where people who are falling into coma due to this and we are investigating a condition called hepatic encephalopathy which is a coma, coma-like disorder or a coma (.) it induces a coma, in fact. And now we know that in (.) in certain individuals are actually reacting negatively on this compound, which in some having its effects similar to benzodiazepines. And also similar to alcohol, so they are they are working on the same receptor, which is the GABA-A receptor. And uh (.) we know that in certain situations and especially in certain individuals, they react paradoxically. And this can also be seen in (.) in anaesthesia, where you give small doses. If you give a small dose (.) benzodiazepine, to (.) to (.) for instance, children, which is a common situation, some of them actually go berserk. Totally become wild and (.) and that is the same type of reaction… It's called Allopregnanolone… Er, about 10 percent, of the cycles and it becomes more (.) if you are older (.) woman in the (.) in the premenopausal period; it could be even up to half the number of cycles are anovulatory. And we have followed women with PMDD with daily ratings. And in these cases, we had eight patients who had one cycle which was ovulatory and one cycle which was anovulatory and in the ovulatory cycle. They had these typical patterns. Of (.) of the negative mood changes during the premenstrual period while in the anovulatory cycles, these symptoms were flat. Nothing happened and the same occurs. If you induce anovulatory, anovulation with er, for instance, with a compound called GNRH Agonist. So that's (.) Several studies have been made by several groups, including our group, where we have given GNRH agonist in a placebo controlled study to patients with PMDD or (.) or PMS, severe PMS. And um they (.) the symptoms disappeared in cycles, and that is a clear cut indication that something coming is coming from the corpus luteum or the ovary, which are provoking these kinds of symptoms. And (.) er to see whether actually that was progesterone or a progesterone metabolite, which was the (.) the provoking factor. We asked post-menopausal women (.) who wanted the HRT to take Oestrogen plus a progesterone pessary or a progesterone oral, micronised progesterone. To see actually what happened with the symptoms and at the same time they did (.) they did daily ratings and we could then induce a similar pattern as we see in (.) in (.) in the PMDD or PMS with menstrual cycle-linked mood changes [pause] and that's (.) is the (.) that is the classical way that endocrine disorders has been being sort of diagnosed or (.) or the parthenogenesis of these disorders has been evolved or discovered. It was the way, for instance, diabetes was (.) was discovered and thyroids, thyroid disorders was discovered and so on. So we are quite confident to say that this is a condition. The cyclicity is a condition which is caused by something which is coming from the corpus luteum and (.) we are quite convinced now that this something is this GABA-A receptor active compound, which is very potent.

**Susan:** I would take (.) what some might call a biopsychosocial approach, or I call a material, discursive intrapsychic approach. And I would say that there is [pause] something happening in the body. We know that there are hormonal changes across the menstrual cycle. We know there are potentially (.) there are changes in autonomic arousal. That's one of the things I did in my own PhD. I looked at um changes in autonomic arousal across the cycle and there may also be changes in neurotransmitters [pause]. Um, we don't know exactly. That [pause] those hormonal changes can lead to, or can be associated with, changes in how a woman experiences her body. So feelings of (.) um, breast tenderness, or swelling, of tightness of (.) um in terms of emotional reactivity, feeling more reactive, feeling more vulnerable. A sense of change in terms of how you feel within yourself, which is often described as mood. Now, that might seem like a really reductionist (.) you know, answer to you. But I would also say that how we then experience those changes is influenced by the cultural context in which we live. As I've already said (.) so in the West we have an expectation of stable mood, particularly for women and being in control of our bodies and our moods all of the time, particularly for women. And so if I am a woman who is experiencing you know, a slight change in how I am this week, as opposed to how I was last week, that can lead to me feeling out of control of myself, which is how women report PMS. You know, that (.) is in a sense what PMS is, because I shouldn't be like that, because I've got this sense of a stable me. That's always nice and perfect and kind and good and always in control of myself (.) and feeling happy. So that can then lead to me feeling bad about myself. It can lead to me um, looking for a biomedical explanation because that's what's given to me in our culture as why I'm feeling like this (.) it's to do with my hormones, which are bad, you know, that are causing a problem for me. Um, (.) and that can then lead to me to feel completely distressed. And to have PMS. Whereas you could take a different explanation, you could say, um for example, if you take a more Buddhist explanation or more Eastern explanation of change, you could say change is accepted. Change is part of life. We're not going to feel the same. Every day, every month, every year, every moment. And in fact, if you take a mindfulness practice and you're actually looking at change, you can actually see there are change (.) changes happening to you over seconds! Never mind (.) over minutes, over hours, over days. And so the notion that change is part of life. And so actually having a change over the menstrual cycle, which you can predict that you might feel slightly differently, could be seen as a really positive thing, because, you can know, when you've going to feel a bit ratty with your partner or not feel great in your body, say you're not going to want to go and do a, I dunno, a movie show, or stand on the beach in a bikini or if you're that kind of person, go to the gym. You know, it's a time when you need to be doing a little bit of self-care and not going and giving a conference paper! [Interviewer laughs] Change is normal and accepted as not a pathology. It's just something that happens. It's part of being a woman in the same way, I'm not having one at the moment. But if you’re menopausal, you get a flush, it's like, what's the big deal? I've got so many really nice fans [interviewer laugh] everywhere in my house and on my desk and whatever hand bag like it's not a big deal. So I think it's (.) it's (.) why it happens. Yes, there is definitely something happening in the body. And as someone who is no longer menstruating, I don't get that regular pattern of change. And that's really interesting as a menstrual cycle researcher. But it doesn't mean I'm never ratty or irritable because I am still, but I can't predict when it's going to happen. Erm, so I feel really emotionally labile at the moment in a way which is quite similar to when I was Premenstrual. But I'm not premenstrual. So other things can give you (.) other things can [pause] um [pause] elicit those changes, those emotional challenges and even physical changes, like if I went out and ate masses, I'd probably feel bloated in a way that you can when you feel premenstrual. So it's not (.) those feelings are not unique to PMS. And I think that's why one of the um areas of research that really excited me, before I did, my PhD and I actually wanted to do in my PhD, but I couldn't for various reasons. Was, um, [colleague’s name] work on attribution theory of PMS and the idea that women attribute moods to the menstrual cycle when they're in the premenstrual phase of the cycle, but they attribute them to other things (.) when they're intermenstrual, when they're (.). And I think that that's a really important piece of research that I think is still really valid today. And she did it in 1983 or earlier than that (.) it must be earlier, because I started my PhD in '83 (.). So I think it's '81 she published that (.) because those moods we get around PMS, those changes we get around PMS can happen at other times and not be associated with hormonal changes across the menstrual cycle. That's why there's that um (.) [sigh] Arg, I can't remember the name of the paper, there's a (.) 'cos I've got a terrible memory for names (.). I'll probably remember it afterwards, you probably know it? It's a paper that came out in 2012? **Interviewer:** Oh! Romans (.) Romans et al? **Susan:** Yeah. When they looked at the you know, changes across the cycle and there is not a predictable pattern. So in answer to the question, what is PMS? I give you the answer that I gave. But what I would also say is that those mood changes can happen at other times. They cannot be explained by a simple hormonal pattern. And that's why the simple hormonal explanation for PMS is not sufficient in my view. So I think for some women, there are clear hormonal changes. The other thing that I think is important, is (.) it's not the same every month. And that women will (.) you know, as someone who's done lots of PMS studies where we've recruited women who do the three month daily diaries before they come into the study, and I've done that a number of times in both [two different country contexts]. You'll get women who come in and say, I have you know really bad PMS. And they fill in the retrospective survey and it shows real bad PMS. And then they do over three months. And then they (.) many of them (.) quite high proportions don't show those patterns. So and there's lots of explanations for that. One of them is the attribution explanation that women are attributing this to premenstrual to PMS, premenstrual phase, When actually (.) there's many other you know other stages of the cycle, they might get those moods but attribute them to elsewhere. But the other thing is it's not consistent. And even if I (.) if I look at myself as somebody who had it, it was worse some months than others. And that was usually to do with what was happening in my life, to be honest. And women (.) I often say (.) my classic question, I would say to everyone I interviewed, with this "how's your PMS when you're on holidays?" And most women would say, "oh, actually, it's not that bad". So there's always an interaction going on between what's happening in the body, what's happening in your life, what's happening in terms of putting meaning to it and what sense you make of it, what you think about it, yourself. And we can't separate those different factors out.

**Marta:** In my (.) according to my understanding, and I'm pretty sure about this. I think this is due to progesterone. [inhale] I don't know exactly how it's (.) how it's due to progesterone because I mean, the (.) the arguments people put forward is that the symptoms only occur during the luteal phase and um what characterizes the luteal phase is that you have progesterone levels at that time point. But then again, it's also quite apparent that the most intense symptoms happen after the progesterone levels have declined. But somehow I still think it's connected to progesterone. And I'm currently analysing a randomised controlled clinical trial that we have done in women with PMDD. Where, we've given them a selective progesterone receptor antagonist and it's really good. It really helps. So progesterone, definitely.

**John:** Um (.) [exhale] I believe that there's probably a number of different conditions that fall under the umbrella of what we call Premenstrual Syndrome. And I believe that it's likely to be a different reason in different subgroups that we haven't really fractionated out yet. There is probably a genetic predisposition and then there is a sensitivity to hormonal changes (.) but I think that sensitivity is likely to differ from one person to the next. So I think some people may be more sensitive to the progestogen increase that occurs at the time of ovulation premenstrually. I think for some people it might be the drop in oestrogen that occurs. I think for other people it's potentially something else. Er (.) indirectly related to one or other of those things.

**Laura:** I think it's (.) I think it's a hormonal withdrawal effect that. Er (.) leads to some changes in neurotransmitter signal (.) signalling… **Interviewer:** Any specific hormone or all of the ones involved in the menstrual cycle? **Laura:** Er, I don't think we know (.) um, it's more likely, I think, to be progesterone and progesterone metabolites.

**Zoe:** Well, I think it's a combination of (.) it's a combination of factors. There's clearly something cyclical and physiological occurring. And um I don't need to, you know, don't need to go into the exact operation of, you know, what, hormones are in flux at what time. But there's clearly something that's physiological that (.) that's actually occurring. And um (.) that then in a sense, [exhale] I don't want to say 'causes' because I don't think it's as simple as that. It's not that linear but that is occurring at the same time um that other things might be (.) that a woman might be experiencing other things. And so as a result, she just has less resources, less cognitive, emotional and sometimes physical resources to actually deal with that increased stress just because of the increased activity that's (.) that's occurring. So there's definitely something physiological that's occurring, but it's that interaction with what's actually happening in the woman's experience in the woman's life. And emotionally, that that makes the difference, I think.

**Geraldine:** Well, um (.) some of them are clearly tied to circulating hormones such as (.) uh, water retention is connected to progesterone levels, for example. I think some other symptoms um are probably more connected to attitudes, beliefs and expectations. Now, I tend to be a social psychologist, so what people are expecting to see is what they notice. And I would also mention that stress is very common. Stress symptoms overlap a great deal with PMS symptoms. So if people are under stress and they experience something, they often attribute it to the menstrual cycle, whether it belongs there or not. And then you mentioned sleep before. If you don't sleep, you don't feel well. There are a couple of studies that seem to show that poor quality of sleep is connected to PMS symptoms. But whether that has to do with circadian rhythm or lack of dream time or just fatigue, which is a PMS symptom, or it's stressful not to sleep. You know, I mean, there are so many explanations. It's hard to know, but some symptoms, a few symptoms clearly have a hormonal connection. But the rest of them, I think, are contested. [Pause] It's not clear and how many symptoms? That's one other thing. Some sources say there are more than one hundred and thirty symptoms of PMS. So, you know, this is getting up to a category of ridiculousness. You know, if we have (.) give people a list of a hundred and thirty symptoms, everybody's going to have something.

**Chris:** OK. It (.) more scientifically than I said just now? So this is unknown. It is either progesterone occurring, sorry, stimulating somewhere in the brain (.) because of the close relationship with progesterone production following ovulation. Um, or it may be a metabolic by product/ breakdown product of progesterones such as allopregnanolone and allopregnanolone(.) um, If this is true, affects the GABA receptor. Um, (.) and that's it!

**Jo**: So it seems to be to do with sensitivity to (.) either, you know, hormones or neurotransmitters. [Inhale] and it's not like there's any (.) measurable difference between women who are affected or unaffected, but it is to do with that individual's response.

### P15- Why do premenstrual symptoms occur?

**Alice:** I think, you know, there are certain probably symptoms that are more common, like I definitely get diarrhoea. Whereas other women don't. And that's apparently to do the amount of hormones that are in your body (.) I said apparently (.) but that's (.) but that's not because [pause] I think this is an area that hasn't been explored. So, yes, there are like any (.) like any. The only thing I would say that I think is important here is it's not a disease or an illness. So like having a period is a natural process. And actually, I think maybe we need to change the language that we use within health and society. And I'm not surprised that you've just said that there's another disorder. That I don't know about. Well, isn't that convenient? [Laughter] **Interviewer:** Yes (.) **Alice:** I think we (.) we just need to look at that (.) women release an egg because they are (.) they have the anatomy. That means that you can bring life into this world, which is quite remarkable. But in that it's such a highly complex, amazing, physical and physiological process that goes on and emotionally (.). There are so many factors that interplay here and our world in the West is even more complex because of the food we eat, the way that we produce food, the plastics in our society, the air that we breathe and the stress that we have, the location that we might live in. You know, all of these factors are likely to impact the way that our symptoms may present. And I don't think it's a disease or an illness. It's just a physical process. And you may get some of those symptoms or you may get more of those symptoms dependent on what's going on in your life at that point.

**Beth:** I think (.) it's really complicated and that they're likely to be loads of contributing factors. With (.) with the ovulation, I think (.) I personally find that a little easier to understand because you have the big hormone spike that triggers ovulation mid-cycle. And. [pause] I would explain the sort of sudden increase in what I call premenstrual symptoms [pause]… Okay. So what's my understanding of what causes PMS? Was that what was the question? Interviewer: Yeah. That's it. The symptoms. Yeah. **Beth:** I [pause] I always will, not always, but you know. With my sort of medical training. I (.) I thought, oh, PMS is due to (.) the fluctuations in hormone levels, and that's what causes these symptoms, but I think (.) obviously (.). Well, I don't know if it's obvious, but I think that's a big part of it. But (.) I was thinking recently about why is it that (.) not just for me, but anecdotally, I've heard a lot of women say, “oh, my PMS has got worse (.) in my late thirties, in the years leading up to the menopause” (.). Is that just ‘cos the way the levels of oestrogen and progesterone fluctuate throughout the menstrual cycle, change as you get older? Is it that or is it because (.) er, other factors that aren't anything to do with your sort of hormonal physiology. And I was thinking, you know, a lot of women (.) who have children (.) around that age (.) their kids are getting older. They might become a bit more challenging to parent. They might be having marital breakdowns. They might be having to juggle working with parenting. So stress from sort of social issues might be more of a factor as you get to that age or that might be contributing to sort of increasing PMS symptoms? Erm, I don't know. I mean, I don't think it's just the hormones. I think it's other (.) other factors as well.

**Dani:** I don't actually know. I think it has (.) something to do with spiking of hormones? But I could have just completely made that up. I don't know! **Interviewer:** That's fine. **Dani:** Embarrassingly! [Laugh] well, at least I'm not a doctor? [Laugh] but yeah. **Interviewer:** [Laugh] honestly, I'm not testing you (.) **Dani:** No! I know you're not. But I'm (.) I'm like testing myself.

**Emma**: From what I understand, it's linked to the hormonal changes and fluctuations. In the case of PMDD. It's almost like an allergic reaction whereby the body can't process those fluctuations. So it's not an imbalance. It's just a difficult and [pause]. Yeah. In the process involved, those peaks and troughs of the menstrual cycle (.) some people, are sensitive to progesterone. So when progesterone is dominant in the luteal phase that can trigger symptoms for a lot of women. And that's why (.) that's why we see PMS in that part of the cycle.

**Faith:** Yeaah (.) I generally (.) I assume it's related to hormones, but (.) I don't know why those hormones react in that way or (.) do certain things for some people, and not for other people.

**Gemma:** I have absolutely no idea [laugh]. It's beyond me. [Laughter] I have no idea. I don't know why it's connected? I don't know why (.) again, I find it very beautiful, but I have no idea why my vagina bleeding has anything to do with why my mind is going crazy and my hormones are crazy. I just don't understand the connection (.) because I feel like your vagina bleeding is like a medical thing? Yeah (.) **Interviewer:** Like biological? **Gemma:** Yeah. It's like (.) your body (.) your system kind of thing (.) but then your mind and your hormones. I feel like that's an emotional thing. So it's like how (.) just how does one affect the other? I know that we're all (.) but you know what? I read something that everything in your body is connected. It's like if you're going through stress, for example, at work you can get spots, I get spots when I go through stress. So that's an external thing that (.) that affects the way you (.) your periods. So because your body so (.) is so connected. Maybe that's why? That everything is [interrupted]

**Helen**: Yeah, I definitely believe it's (.) it's related to the rise and fall, the natural rise and fall of the reproductive hormones, oestrogen and progesterone. I also wonder if FSH and L (.) um what's the other one? **Interviewer:** LH (.) Luteinising Hor- (.) **Helen:** [00:20:32] [overlapping] Hormone. I'm sorry (.) yes, thank you. I do wonder if those are involved as well? But for my understanding it is the natural (.) the result of the natural rise and fall of those reproductive hormones, you know, and that's got to have a change through the whole body. For the physical symptoms, it's going to cause, you know, anything from weight gain to, you know, tender breasts and the emotional side, you're having a chemical change within your body. There's bound to be a response.

**Kathleen:** Um [pause] I'm not sure, to be honest, I (.) I (.) I'm assuming that it is down to the body getting ready for the period. And maybe a slight shift in a hormonal balance [shaking head]? That's what I would think. Um, why that would effect on mood? I’m not sure. But yeah.

**Aisha:** I do feel it's hormone imbalance (.) and why it occurs (.) erm. [pause] I feel as if maybe, I dunno (.) people. (.) people say to me, it's food, but I don't believe it's that. Because even when (.) when I eat healthy, I believe I PMS more. So not necessarily that. Yeah, I just feel as if it's a hormone imbalance. That's it. Yeah [long pause] something's happening in the body that we don't know, basically.

**Mala:** I think it's a hormonal thing. Your hormones (.) um are being regulated and you're going to get a release soon. That's how I think of it. So it's all clogged up. And then once you start your period, it's that release.

**Noor:** I think it's because of the change in your body. **Interviewer:** Any particular changes or? **Noor:** [Pause] I think your body's releasing something, so (.) because of that, your body's trying to adapt to it. **Interviewer:** So you see it as quite a physical thing? **Noor:** Yeah. **Interviewer:** That creates the mood change? **Noor:** Mm hmm.

**Ria:** Why they occur? OK. So again, I view health as including the four components; physical, mental, emotional, spiritual. So physically, why they occur based on my knowledge and work with a doctor who's an amazing endocrinologist, [name of doctor] and her work and school of research that she's been doing for (.) like 30 plus years and is very detail oriented and I think like very accurate, verifiable, trustworthy knowledge and science, is that after ovulation occurs, our oestrogen levels as menstruators go down and our progesterone levels start to rise. And so physically, I understand it to be the rise in progesterone and then when things are like really, really hard on our bodies. So, for example, we might experience like PMS pain or just like a lot of tiredness in terms of body experience. It might be because we're not making enough progesterone? However, again, I don't want to like pathologize bodies. So I think it's just like a natural thing that occurs when our (.) that shift from oestrogen to progesterone happens. So that's physically. And then mental, emotional. I can (.) I'll just like package together because they're quite intertwined; mental health being like the thoughts that our brain and mind is having and experiencing and then the emotions being like how that manifests physically like in our facial expressions, in our crying and laughter in like literally how (.) or even just how our bodies feel. So emotions as being more of that like wave and mood. So what do I think happens then? So as our progesterone is going up, it's also a time (.) so mentally, emotionally PMS for me I think is a time of release. Just like how in the autumn season the trees are shedding their leaves. So it's often a time when like our mental thoughts, for example, are going like all those tiny things that we worry about. Um (.) maybe toxic friendships or relationships, things that have been on our to do list that we keep putting off and keep putting off (.). Um, any sort of stresses in our life,it’s a time when our brain is like really, really thinking about those things as a form of processing and bringing it to our awareness. So that then when we get to the winter and we get to the actual composting and period and (.) and like physical release of blood, then we can shed that alongside. And so I think irritability is also something that tends to happen a lot during that time. Those that's one of 'the symptoms' in quotations. So just being like annoyed at every human around [laughter]. And I think, yeah, that's just again, a response, a natural response that ourselves are going through as like a calibration just to be like, "OK, this is my life. Let's take a little snapshot here. We have 14 days to just get a picture of what is going on and what are(.) what's not working for us". And so that's mental, emotional. So we can do a lot of crying, um laughing, just like processing some of those thoughts and traumas and things that have built up over the cycle. And then spiritually, it really depends on the person and what their spiritual connection are (.) is. And if they want to foster that and what type of rituals and ancestral ceremonies they want engaged in. So, yeah, I think it's an important time to do ritual. It's a good (.) as I've been talking a lot (.) it's a good time to get ready to do the releasing when we get to the winter and period. So just getting (.) I tend to even ask people to like spiritually declutter or physically declutter their space like, go through those drawers, go through your pantry- without fail. Every PMS season, every autumn season, I rearrange my like office or house [laugh] I don't even intend to- it just like my body builds up where I'm just like, "oh, I can't take it anymore. This frigging drawer that I've been like. Yeah. Just like dealing with". And so it's a good time to just like, let go, get ready to let go and compost. Yeah.

### E7- What’s the best way or ways to manage PMS?

**Anne:** I don't think there is a clear cut one answer to that, so I'll just go through how I would approach a person who or the management of a woman coming along to me in my general practice. So I would (.) this is always difficult because you just have so little time in general practice, but you would often get people back to talk more, er, so just try and get an overview of what's happening. As I said, in the end of answering the last question, absolutely essential. Unless (.) unless I mean, the gold standard is to track symptoms. But if you get a woman who gives a very clear history of what's happening, then I don't think it's always essential. But (.) I (.) I think, you know, you have to be very clear otherwise. And the standard is to do two months, over two months prospectively. They've shown that retrospective collection of data isn't very accurate. And so I would then, you know, get it. Obviously, in general practice, you've got the medical history there. But I would explore, you know, just come up to date on get myself up to date on that. What medication shown? Is there anything what hormonal treatment she's on? Because as you know, exogenous hormones can sometimes exacerbate. Has there been a change, as you know, women (.) some women are sensitive to progesterone and progesterone. So it can often (.) and the woman hasn't realized that it's actually (.) was related perhaps to starting the pill. So I'd look at all that and look at her lifestyle. And there is, you know, some evidence that if a woman maximizes the good life style in terms of diet, spacing her food, having the (.) more of the low glycaemic index foods, exercise, some case control studies have shown that exercise is very good, er can alleviate symptoms. And then I would (.) as I've illustrated there's a lot to go through! [Laugh] So I (.) and being a part of NAPS (.) so I would direct them to the guidelines that [colleague name] has written. And because (.) I mean we are planning to update those, but they're still current and so start to introduce possible complementary therapies and then explore what the woman wants. And there are basically (.) errrr, two main groups of treatment. First of all, if (.) you know, based on what I've said about why it happens if you suppress the cycle, then (.) and the woman isn't sensitive to the hormone you're giving to do that. There's a good chance you're going to help her. So I've seen a lot of success erm, giving (.) this isn't licensed for this use. It is like (.) this treatment is licensed for HRT (.) in hormone replacement therapy, but not for PMS. So transdermal oestrogen to a level where you actually suppress the cycle. But you can't (.) if a woman's got a womb, you can't just give oestrogen on its own. You have to give progesterone. And that can be where there can be a problem with PMS because a lot of women are sensitive to that. So that's where they get the benefit of seeing a doctor or specialist nurse who's got expertise in this area is so important. So you know, you can find a regime that helps the woman and doesn't exacerbate symptoms. So that's the hormone (.) Sometimes the contraceptive pill can help because it suppresses the cycle. But as I've said, sometimes the woman is sensitive to those hormones. You're giving (.) the other route is the anti-depressants called the selective serotonin receptor inhibitors, SSRIs. [Laugh] And they, as the name suggests, affect the serotonin metabolism in the brain. So counteract the changes that I was talking about. And interestingly, they've been shown to be just as effective given in the second half of the menstrual cycle as given continuously. So they obviously work in a slightly different way to how they do in depression. And that can be a useful treatment option. I think it's very important to review women (.) in both treatments (.) you've got to really give them sort of three months. And I'd just like to qualify everything I've said (.) er, going back to the original question, how would you manage these (.) a woman presenting (.) if you have a woman who is threatening to commit suicide every month because of her premenstrual disorder, then you don't start with vitamins. You know, you (.) you go (.) you go straight in and treat much more actively. No, not 'active' that's not quite the right word, much more go for something that you (.) you know (.) that perhaps what we could call the more (.) erm, the treatments that you (.) think are going to (.) definitely likely to work. So, for example, you might (.) this is just an example, but you (.) you might start an SSRI at an earlier stage than somebody who's getting not too much of an impact of her symptoms, you might then look at lifestyle for three months.

**Barbara:** Mild-moderate symptoms can be managed with exercise, diet, relaxation techniques. If such approaches do not help, medications may reduce moderate/severe symptoms.

**Andrew:** That depends on the severity and then on the symptoms. The (.) our friends in these different consensus groups that I've been a part of, our gynaecological friends are always very keen on claiming that all symptoms should be regarded as one syndrome. The breast tenderness, bloating is the same condition as irritability and dysphoria. I don't totally agree with that. I think it could be different syndromes. I don't think premenstrual headache is essentially the same condition as premenstrual irritability or premenstrual bloating. So firstly, it depends on what symptoms the woman experiences on the treatment. And (.) but if the dominant symptoms are mood symptoms, irritability, which is the most common one, then I think that mild conditions are defined as PMS according to ICD. Most of them do not require any treatment and one should never give treatment when treatment is not needed. But for the severe cases, I am quite convinced that SSRIs are the best and safest treatment available well in fact the only treatment available. Apart from treatments that abolish the cyclicity. But if you do that, you'll get a lot of side effects, osteoporosis and stuff like that. So I really think that SSRIs (.) and I also think that SSRIs are regarded as first-line treatment around the world for PMS dominated by mood symptoms. If you have a PMS dominated by somatic symptoms, it's another story. And if you have a mild PMS you probably need no specific treatment at all. It's often argued that stuff like exercise and so on can be helpful. And I don't I don't disagree with that. It's not (.) it's not clearly shown, but it's not unlikely for mild conditions.

**Debbie:** [Long pause] as with any [pause] distressing or impairing syndrome [light laugh]? My perspective, which is not the only perspective, but my perspective, is that the most ethical thing is to start with treatments that have been vetted in clinical trials and (.) beat placebo. The best (.) right (.) so some things beat placebo, but only a little bit, right? It's like better than placebo, but only a little bit. You know, I think we should start with the things (.) I think it's most ethical because it's most likely to decrease the most amount of suffering [laugh] to start with. The thing that is vetted in the clinical trials and has the largest effect size. So that would be SSRIs. And then Yaz [contraceptive pill]. And then [cough] [laugh] a combination of both and then GNRH agonists with stable add back. And then if there's some problem with suppressing ovulation that way or that can't be tolerated for some reason or there's co-morbid endometriosis, then we go to surgery [intake of breath]. But the beauty of the scientific perspective is that (.) the evidence based perspective is that there could be evidence that comes out tomorrow that completely [laugh] unsettles that. Right? This [SSRI name] treatment coming from [pharmaceutical company name]. I hope that that goes to (.) pops to the top of the list. You know, so (.) but I would (.) for me, the best way to treat anything is to look to the clinical trials and go down through [gestures movement down a list]. And then, of course, if somebody doesn't respond, you can experiment with other things. And that's great. And people should have access to try what they want to try. But I think from a (.) as a (.) as a provider, I sort of think the most ethical thing is to start with the data.

**Celia:** Well, what I like to do is to start with the two months of daily prospective ratings and during that time ask the individual to do a number of things. Do some, quote, holistic approaches such as um increasing calcium, vitamin D, increasing exercise, um trying to work on sort of self-styled cognitive behavioural approaches, stress reduction, possibly meditation um (.) if they have pain, breast pain and whatever they can consider um a NSAID premenstrually. And er anything that (.) that might be over the counter if they wanted to try. There is some small meta-analysis with low dose with vitamin B6 (.) as long as they stay under 50 to 100 milligrams a day with magnesium. But I don't recommend that they start anything pharmacologic for the first two months. Then when they come back with their prospective rating, then we'll have a discussion about whether they're going to try a hormonal contraceptive such as the one that has FDA approval in the states um the drospirenone 20 µg [e.g. Yaz contraceptive pill] or whether they're going to go with a luteal SSRI [pause]. Um I also, if the symptoms are only a week, for example, discuss the possibility of symptom onset SSRI, or SNRI [Serotonin and norepinephrine reuptake inhibitor], although there aren't many studies on that. If they want to stay with something that they might call, quote, more so (.) sort of homeopathic, there's the chaste berry tree. Studies predominantly in the British literature. I haven't really had anyone who's had a good response with it. But, you know, I think that (.) that's out there and um they can certainly go for more intensive emotional regulation therapy. You know, other sorts of things along those lines, acupuncture, etc.

**Sarah:** Well, you know, again, you've first got to demonstrate that it is actually occurring because of the women who came to us, sometimes we found it was actually some other, more significant problem, present. So you know, you always have to have a complete health check and you know make sure that in fact there isn't some inter-current problem like alcoholism or something else that really needs to be dealt with. So that's the first thing is exclude other disorders. I mean, you really need to know what's going on in this woman's life. For example, if she said she's only had these symptoms for the last 18 months. Well, what happened 18 months ago? You know, was it you know that her cycles changed after she gave birth to a baby and finished breastfeeding? Sometimes that happens. But it might have been that there was some significant stress in her life and if it is stress-initiated then you would be looking at what you could do to reduce that (.) perhaps with referral for cognitive behaviour therapy and so on (.) to see if you could reduce those aspects because you might not have to do anything after that. You need to confirm that there is actually Premenstrual Syndrome occurring before we start any treatment. And that means you've really got to send them away with the daily rating chart for a couple of months. But nowadays with the internet, people often come with their daily ratings. You get the chart already filled out. So it's not quite like when we first set up a clinic. In fact, they come with those charts and you know you can work from there. So if you demonstrate that there is change linked to the cycle linked to menses etc. and there aren't current stressors that you can first deal with (.) then you would be looking at each person as an individual and you would talk to them about the range of treatments that are available. Um, some women would prefer to take a tablet and don't really want to do any work themselves to reduce their overall um background stress level. Other women prefer to do that. So if you really have to find what any individual (.) and generally, a combination of treatments is often the best way to go about it… Of course, there are more severe syndromes. You know, I mean (.) because I had as a psychiatrist had to deal with postpartum (.) with um menstrual psychoses, which is, you know, that can be quite severe. We had a woman in our ward, who um, I was asked to see, because she was self-immolating, she was you know, she was psychotic and um tried to set fire to herself at menses. And it was (.) the problem was (.) she had um four young children. She was you know, a baby, six months old, or something. And her sister had successfully set fire to herself and died the year before, in our ward. So you know, the ward was very concerned about it. And we (.) I suppressed her cycle using very potent you know medications. We didn't have GNRH analogues then but something (.) something similar, Danazole, and the whole thing stopped! And before that [laughing, shaking head] I'm telling you, it was still happening despite giving her the oral contraceptive pill to suppress the cycle. It wasn't suppressing the cycle and she was (.) and she was still doing it. So, you know, there are (.) in those situations. You know, this sort of treatment, you know, is stepped up to deal with the emergency.

**Thomas:** Well, it's dependent on whether actually you are going for the, let's say, chronic treatment or whether you are going for [cough] let's say a short, relief. But there are some treatments which have been clearly proven as effective. And that is this GNRH agonist treatment. Then there is also an SSRI antidepressant which has been used. And the interesting thing with the anti (.) the (.) the depressives is that they interact with this GABA system. So it might actually come down to the same aetiology in the end. But it might also be a different aetiology… And those are the two ones which are or let's say, used in practice usually. Oral contraceptives are not that good in that way, that they usually cause the same kinds of symptoms. And if there is a (.) it's severe PMS, then these patients usually don't stand the oral contraceptives. They develop the same kind of symptoms and they are not feeling well on them. So they (.) they take it for one or two months and then they stop. (.) There is one which is less provoking than the other ones, and that one is called Yaz… So it's a (.) it's a less provocative (.) so it's (.) but I have patients who also can't take that one, so (.) so it's (.) it's not a (.) a let's say a complete relief. [Pause] But I would say that less (.) less severe conditions. They could (.) they could manage with (.) with this one. Then there are (.) are for the less severe cases there are also a different (.) kinds of psychotherapies. Cognitive behaviour, sorry, cognitive therapy, and that is (.) is very effective in situations where the (.) the condition is not so (.) severe (.) that's (.) but in the really severe cases, it's (.) it's not enough. That's my experience at least [pause]… Although we have not made any study on it, so it's (.) it's from clinical experience, for what it's worth? I don't know if (.) if it's worth anything [chuckle laugh].

**Susan:** Um. Ok. Awareness [pause] so having awareness and tracking your cycle, as a first step. I actually did a podcast, with [a period tracking app] recently, um which went a bit viral in terms of the media, and I actually said that, and I think they were so delighted that didn't prompt me to say that [interviewer laugh]. But I do think (.) I think they must've been so happy with me. And they didn't, you know, they just asked me to talk about PMS. But I think awareness, it's so important for us to be aware. So I would say tracking (.) tracking your cycle and making a note, of what the common changes are for you. But also, what's going on in your life, why you might be feeling bad, because that will help to keep track of (.) if you are having mood changes (.) um, are they to do with (.) is there a pattern across the menstrual cycle? And many women, as you probably know, doing the tracking is actually, it's one of the best ways of intervening in PMS, which is a dreadful thing for PMS researchers because you get women into your studies and they fill out the daily diaries and then they're cured! And in fact, in studies where we've done RCTs with PMS interventions and I've done a number of those, the um, control group that's keeping the daily diaries actually do show a positive effect. You know, those women do find a reduction in symptoms. And so, yes, awareness is really important. Um, self-care. So actually making sure at those times, if you do have a pattern of mood change and you find it has a consistent time when you know that you are feeling (.) and I would define it as 'more vulnerable', 'more reactive', um (.) needing to self-nurture or be nurtured, not all women want to be nurtured, at that time. To actually engage in self-care. And that would be (.) that would include things like taking time out. So it might be just taking some small amount of time for yourself, going easy on yourself, not putting the pressure on yourself that you might put on yourself at other times, not having the expectation of high performance, whether that's at work or with your family or with friends, that you might have at other times; actually going easy on yourself. Um, and then engaging in positive strategies around physical self-care. So making sure you're eating properly, making sure you're sleeping. Doing exercise has an amazing impact on health at all times of the menstrual cycle or the life cycle. And I'm not a (.) I'm not a big exerciser, I'm not a gym bunny. I basically walk and do pilates a couple of times a week. But it makes a massive difference. Um, as many women are not eating they're dieting. So trying to be thin. And if you're not eating and you've got really low blood sugar and you'll feeling more reactive, then you are going to be more irritable and you're going to feel more depressed. Um, I think also. If you find that your [pause] PMS is about being angry and irritable, which it is for a lot of women, and that's often why women self-diagnose, um actually thinking about what it is you're angry about or irritable about when you're premenstrual. So is it things that actually need to be addressed at other times in the cycle? That are not (.) that you're not addressing. You're not (.) you're not discussing because you're self-silencing. So, if you're angry at your partner, or really angry with the children, which a lot of women are (.) addressing(.)[interrupted by interviewer having coughing fit].

**Marta:** Er, I think that the best ways to manage it by using antidepressant drugs er (.) and using the cyclical treatment or symptom onset treatment. I think that's (.) that's been proven by a number of studies to be highly effective and it's a safe treatment. I think that (.) which is not yet published, but we hope to publish it this spring. I think that the treatment we are now proposing using progesterone receptor antagonists would be really, really, really promising. But they are (.) that would be off-label use because the progesterone receptor antagonists are used to treat uterine fibroids and they're only used to treat (.) um for pre-operative treatments. I think they're only (.) you're only allowed to use them for three months. So my study is a proof of concept, but I know that there are new progesterone receptor antagonists coming into the market and (.) and that the development program aims to (.) to have treatment (.) long term treatments for (.) for fibroids. So I think that could be a treatment in the future [cough- pause]. But our findings have to be validated of course, and it has to be safe. But as of now, definitely the antidepressants. **Interviewer:** So can I just clarify something? The progesterone antagonist you are talking about (.) about (.) is that the same as GNRH? **Marta:** No! Interviewer: It's a different thing? **Marta:** It's a different thing. And the beauty (.) I mean, they (.) they more or less have the same effect. They induce anovulation. But the beauty with the progesterone receptor antagonist is that they don't have the same side effects as the GNRH Agonists. So um it would be much more um (.) useful for the women. Absolutely.

**John:** I think any medical condition is usually best managed within a biopsychosocial model. And er (.) in essence, what that means is starting off with conservative treatments like looking at people's diets and you know drugs that they may or may not be taking, exercise um (.) and then moving from that. If that doesn't ameliorate things, I mean, for many women, they can actually have a very profound impact on their symptoms by altering their diet, exercising, etc. Um (.) so that's the starting point. Um (.) environmental factors, I think many women that come into this clinic will [pause] describe how their symptoms got worse in the context of something else happening in their life and then feeling stressed or upset about something and the PMS occurs in the context of that so trying to address those environmental things and or the way somebody thinks about them. That's more psychology [pause] Um (.) and if people can get it- CBT and evidence based psychological treatments are certainly top of the list, um there are some non-pharmacological er (.) treatments with some evidence base to support them. Usually before people have come to this clinic, they've tried most of these things, but I'm sure you're aware of things like Agnus Castus and things that have some evidence base. The thing about PMS, though, that we're also aware of is that there's a very significant placebo effect for many of the treatments out there, which in a way is a good thing, because it means that many things can help it. But I guess it also leaves some people a bit more open to (.) non-evidence based, charlatan type things, which [pause] May (.) may or may not be problematic [inhale, almost laugh]. And then there's the medical treatments, which er (.) could be loosely or clumsily described as being psychiatric and gynaecologic um (.) or hormonal or non-hormonal. And right at the end of that, algorithm as you probably know are surgical options, which (.) um, are sometimes recommended, but not that often in this clinic.

**Laura:** [Pause] well, PMS is different than PMDD, so really depends on the constellation of symptoms that somebody has. So for PMS, the best way to manage it really is [pause] depends on the symptoms people experience. So, you know, if they experience bloating and headache and pain, that's a different treatment than if they have PMDD and experience emotional dysregulation.

**Zoe:** Um, I think it comes down to um what if, you know, if the woman experiences interference. I don't think you need to manage anything (.) if it doesn't, if it's not actually causing a problem. Um, people have lots of (.) have (.) or manage (.) or manage is sort of the wrong word there. People have lots of things that they experience. Not all things need to be managed. Some things just need to be experienced. Um, and so um if a woman (.) um does find that it is interfering with her, functioning with her, sleeping with her, with elements of her physiology, she may want to manage that through things that actually target and respond to those physiological changes. So she might want to do something that's more active, something that's around sleep, something um that's around exercise, something that's actually addressing that in extreme situations. If it's interfering quite significantly, she may need to have a look at some sort of hormonal intervention um just to correct or (.) or not to correct but to bring back into balance what might be (.) what might be happening there. If the interference is happening at an interpersonal level, well, then she needs to have a look at what's actually happening at that interpersonal face. But sometimes that might mean managing the physiology first in order to have some clear space. So some clear air to do that. So I think it's (.) it's really down to a woman assessing what's the level of interference or what's the level of distress and then um doing what's appropriate. And that's (.) that can be physiological, psychological; it can be personal. Er, could be walking the dog. It can be a whole range of issues.

**Geraldine:** [Pause] let's see (.) probably with self-care. Extra rest, stress management. Um, things like that. I mean, there isn't really any valid medical treatment. So I would say self-care and probably, you know, if women could be taught some cognitive therapy or, you know, some feminist analysis so they could rethink [emphasis] what the symptoms mean. I think they would be able to manage them and feel better.

**Chris:** Oh, You can't answer that question [amused tone]! First of all, you make (.) you make a specific diagnosis by um (.) and don't treat until you've made a diagnosis because retrospective diagnosis by the patient herself is not accurate. OK? And so you must do a prospective evaluation and even a lot of people say that and then don't do it. But I've always done a prospective evaluation looking at two cycles and seeing if it occurs. So if you don't make a prospective diagnosis, it's gonna start to be in trouble in terms of treating it. So the treatment starts with the diagnosis. Then it (.) it is so varied. You can't say how would you treat it, um unless you cover the whole lot. So, you know, I wrote with others the Royal College guideline. So basically you start simple, which is a pill. And I'll come back to the pill, in a sec or an SSRI. Yeah. And so they're good starting points (.) or maybe even greater, simpler starting point is that (.) to (.) to counsel a patient. Maybe (.) maybe get a [pause] um CBT or something like that, but it's very difficult to get that through general practice. And so (.) so it's just simple things first. If you're going to use um, if you're gonna use an SSRI, it doesn't matter which one; you can use it continuously or luteal phase only. If you're going to use the pill, then some pills because they've got progesterone in them. They suppress ovulation, but you're still giving them a cycle of progesterone. That progesterone could go to the receptors and cause a problem. So maybe pills such as Eloine or what used to be called Yaz has (.) does not to the same extent affect the receptor, I've got a lot (.) I've got a fair bit of (.) got more experience than most people with that and there are patients who will still get PMS with it. Um (.) so that's (.) that's the um milder patients. If they don't respond to that, of course then they're severe. They're severe but didn't respond. So you can stop the hormonal cycle, um you can stop hormone cycle with the pill. But there's progesterone in it, you can stop the cycle with Danazole, but that's an unpopular drug now because it causes male side effects (like hair and baldness and so forth). But it was very effective. It also (.) you can also suppress the cycle with oestrogen only. If you give oestrogen only, it's (.) if (.) it um down regulates the hypothalamus, pituitary, ovarian axis and the symptoms go away. But if you give oestrogen only long term, that also stimulates the lining of the womb the endometrium and you then run the risk of endometrial cancer. You can prevent that by giving progesterone, but of course the progesterone brings the symptoms back. So you are going round in circles. One way of getting out of that is to put the progesterone in the uterus in a Mirena coil or levogestral-containing IUS and that'll protect the endometrium. And the progesterone will suppress ovulation and treat the symptoms (.) so I've treated many patients like that (.) slight difficulty, some patients absorb the levogestral. It goes to the brain and stimulates PMS. And then it's continuous PMS- like symptoms. So for a large number of patients that I was treating, suppress the hormone cycle with oestrogen, protect the endometrium with the Mirena; pretty good. If that doesn't work. You can give a GNRH agonist analogue. They have the disadvantages of stimulating in the first part of the cycle and then they suppress it. And I almost think if you still have symptoms after suppression with GNRH, then you must question the diagnosis (.) Uh, as a long term therapy. It's got disadvantages because it creates a pseudo menopause, gives them hot flushes and all the side effects insomnia and long, long term the risk of osteoporosis. You can give add back, but of course when you're giving add back you're in the cycle again of oestrogen and then needing progesterone. There's a drug called Tibalone, which works in quite a lot of patients, and may not re stimulate (.) the cycle (.) So you're always in this business of having an endometrium. So if the endometrium is there and you give oestrogen, everything's fine, but you can't give them (.) um you can't give them progesterone because of bringing about symptoms. But if you're not giving them progesterone they get cancer of the lining of the womb. So you've got this cycle. So I would sit in my PMS and menopause clinic and half of the time I'd be um causing PMS and the other half the time I’d be causing menopause symptoms! The only way (.) there's only one cure, well there's two cures. One is a natural cure. That's the menopause. And the other cure is take out the uterus, ovaries and cervix. Why uterus ovaries and cervix? Well, if you just take out the uterus, you won't have a period, but you still have the hormone cycles, so you'll still have the PMS, but you won't get diagnosed with PMS because the GP will say you can't have PMS, you haven't got any periods. So um (.) so those cycles still continue. If you just take out the uterus (.) No! That's if you just take out the uterus (.). If you just take out the ovaries, then you've created a menopause. So you've got to give oestrogen and you're back into that problem of giving (.) needing to give progesterone and and (.) er bring the symptoms back. So that's a disservice you could do the patient, if you take out the uterus and the ovaries, you can give oestrogen and you don't need to give progesterone because there's no endometrium. If you do it down a laparoscope: um keyhole surgery, you (.) there's always a temptation for the surgeon to leave the cervix in. But the cervix contains sometimes a little bit of endometrium. So you're back with 'can't give oestrogen'. So taking out the lot and giving oestrogen is the only cure. But of course that's in a very, very small percentage of patients… Okay. Well there's (.) you see if you're a laparoscopic surgeon, the easiest thing to do is take out the ovaries. Quick, quick, easy operation. But you've still got the uterus so you're in trouble. If you're not (.) if you're gonna take out the uterus and you say well we'll leave the cervix. Because it's good for sex (which it's not) but there was a few papers saying that. But if you leave the endometrium in and then you're in trouble because you've got to give progesterone. And then I got a patient. The last, one of the last few patients I had, she (.) she was on my waiting list for the full works. She went off to another hospital because of the waiting list initiative, they had (.) took out just her ovaries, she had severe complications. Um (.) She got a ooph (.) no, she had her uterus out - left the cervix. No, it's (.) can't remember now! **Interviewer:** They left something (.) **Chris:** They left something in and there was a very very (.) no I think they left just the cervix in. And she was still bleeding. I think that was it. So I will always emphasize that there is no logic in leaving in the uterus or the cervix. And in the guideline, I had endless arguments with the chairman of the guideline committee at the college because he likes to just do the (.) er (.) there's no evidence either way on any of this. I wouldn't take out the uterus and ovaries except very last resort and I wouldn't take it out without a GNRH test which tells you what's going to happen. The GNRH test has never been scientifically validated, but if you've still got symptoms after that, then um (.) then the trouble is some patients have (.) um (.) have menopause symptoms and they don't know whether they got PMS symptoms or menopause. So I'll give them GNRH, wipe out the cycle, give them oestrogen because that'll get rid of the menopause symptoms and then you don't need to give them progesterone (.) Well you do because if they tolerate the progesterone, you can treat them with oestrogen, GNRH and progesterone, there's not many like that. Um (.) so it's just (.) it's a good way of finding out what will happen. I say, well, this is a test of taking everything out. Not saying you should have it out, but it's a good test for it. **Interviewer:** Can you give me any rough numbers? As to like, I'm guessing that the surgical is for really very few cases (.)? **Chris:** Yes. Twelve a year? I would (.) but (.) but then I would be. No, not 12 a year. I think maybe twelve in five years. And I would be seeing the worst of the country. Yeah?

**Jo:** I think that's (.) that's the problem, isn't it? So you could have a sort of natural solution, which would be menopause or a medical solution and that'll involve the available options; um, removing the ovaries and the uterus, cervix, the whole thing. It is going to work in women who've got clear cut or core PMS. But at the moment, drug (.) drug options are limited. You know, you see things like "70 percent of women will respond to an SSRI". It's worth trying. But the ones that finally filter through, I think, are the patients where SSRI's haven't worked or using contraception to inhibit ovulation. That's fraught with its own difficulties with how affected women will respond to the hormones that you're then giving them. So, yeah, so I think basically there is (.) there is a real lack of a good treatment.

### P16- How do you manage your premenstrual symptoms?

**Alice:** I mean if you think about it, pre, during and post, you're exposed for like half a bloody month. So it's constant. It doesn't go anywhere. And if you look at the science of what happens in a woman, you know, you release the egg and then everything starts to take off again and you prepare to release another egg, it’s a never ending journey ever (.) and so for me, it's become like learning about my own body. I'm waiting for my body to settle down. And at one point I tried to use drugs to help and have a regular period which didn't work. So how do I manage it? It's mostly through. Exercise - not focusing on it. So I do not let it. As I say, I don't really think about it, you know (.) in the here and now I think about it, what I'm going through, going through what's about to happen or if it's like a horrible one, but I know it will pass. So making sure I now know the triggers so I won't (.) I won’t drink before I know it's coming. I think caffeine makes it worse (.) I'm not a big coffee drinker or anything, but I think like strong coffee makes it worse. I think lack of sleep makes it worse. I think not being active or doing exercise definitely makes it worse. So I try to be as active as I possibly can. I think long haul travel makes it significantly worse and not just that, but unpredictable. So if you think it's coming, then it might not arrive. And I think if you've got stress going on in your life that could make it a hundred times worse. So I've noticed that my pain is much worse when I have had something stressful happen. So, you know, that's like self-management or what you can do in your life. You know, go to some people might go to yoga. Some might go for a swim. Some people might. I don't know. Spend some time friends, whatever, it's just yeah. But, you know, we're lucky because we live in the West, a rich society. You could have a whole other topic on how is this perceived and experienced by people that live in a third world country? And you've probably got a completely different set of experiences and opinions.

**Beth:** It's kind of a work in progress, and I don't know if I actually do manage all of them. I think most of them I just put up with and wait till they go away [laugh], I think just by being aware of them as being down to the menstrual cycle and knowing that they're not going to last forever and knowing why they're happening. Or at least you know, when they're going to happen. It's helpful because it means that (.) you know, I can think 'Oh, this is only going to go on for a few days and then I'll feel better'. I think just that awareness is helpful cause to be honest, there's not a huge amount else I feel I could do about it. You know, I (.) the point of view of, the anxiety, I'm already on medication for that. I don't want to take any more (.) but just being aware that that's going to get worse around ovulation and for a week before my period. I can tell myself, well, it's temporary and then I know when it's going to get better and I try and self-manage it. I do the same things that I do really in general for my anxiety, which is making sure I get enough sleep. I don't I (.) I used to do yoga for various reasons but being busy with other stuff, I'm not doing it at the moment, but I did find yoga really, really helpful. And I still take from that a kind of breathing exercises that you can do because I can do that whenever. So (.) yeah (.) breathing, breathing exercises for relaxation I find really helpful. I rarely drink alcohol. I don't smoke, I eat fairly healthy. So I guess that all helps. I must say there's probably more I could do in terms of getting exercise. Another significant premenstrual symptom, I guess, is, is constipation actually, and I know (.) that (.) there's stuff I should do to help with that, but I don't. Erm. Because I know I don't drink enough fluids and if I did increase my fluid intake. In the week before my period, it'd probably help. I know that in my head. But I just don't. I don't do it because (.) I like (.) some (.) some people naturally get thirsty and drink a lot. And I (.) I just (.) I can go through the day without having a drink [laugh] and that's really bad for you. So, yeah, there's stuff I could do to help that I don't because I'm lazy and forgetful [laugh]. Yeah, so I'm definitely not helping myself… There's other things I do. I take a vitamin B complex (.) actually, because I did read somewhere there was a particular B vitamin that could help with PMS and another B vitamin. A different one that could help with the skin picking behaviours. So (.) so though there's not a huge evidence base for that. I take it anyway. Yeah, to be honest, I'm not sure if it makes a big difference or not, but I feel generally a bit healthier when I take vitamin B complex and vitamin C supplements, so. So who knows? What else do I do? Oh, I take a lysine supplement as well, because I did go through a very long phase a couple of years back, of getting a break out of cold sores before every period, which was just horrible cause it meant. I couldn't really put anything on my face. It was really painful. They wept all the time. So I had to put dressings on them. I got really fed up with it. So, yeah. I still take lysine (.) erm, yeah.

**Dani:** Usually just some painkillers and just being a bit like kinder to myself normally, just like if I'm just feeling exhausted, I just let myself sleep a bit longer. Yeah. It doesn't take very much, but it is just yeah, it's usually just painkillers or [pause] sometimes I know you're not supposed to, but I just need some extra sugar so I just have like biscuits or something that that kind of thing. And sometimes I really crave meat around that time. So, I'll have that. But yeah, I don't really need to do much to manage my PMS as it were. Like it just sort of (.) it just is. And I just sort of accept it and let it be. And that's sort of enough for a lot of the time just to realize that's just because of where I am in the cycle rather than trying to cheer myself up or anything.

**Emma:** So [long pause] for mood related symptoms, I take citalopram I'm on a low dose of citalopram every day, and that just helps to erm, stabilize my mood. So before I was taking that, I would have full blown depression for about four days. I don't get (.) I don't get that now that I take citalopram. I definitely still have low mood. But it's not (.) nothing compared to what it was. I take ibuprofen around ovulation and in the days leading up to my period, because with PMDD one of the (.) one of the views is that the body has an inflammatory response around ovulation and premenstrually to these fluctuations. So I take ibuprofen to try and manage that erm, and anti-histamines as well, which help particularly with erm premenstrual headaches. But I get (.) I try and lead a fairly healthy lifestyle, so I try and cut out gluten. Where I can because I do, I can get IBS symptoms around ovulation and premenstrually. God it's all fun and games isn't it! [Laugh] and I try to eat a lot of vegetables and fish and cut out processed refined sugar and (.) stuff like that, which is just going to make things a whole lot worse. I take oil of evening Primrose. B vitamins, iron supplements, vitamin D. Agnes cactus, ahh Agnes Casta.. Argh, I never get it right. **Interviewer:** Agnus Castus? **Emma:** Vitex root, yeah? What else do I do? Yeah, and I think more recently just (.) we talked about it earlier, but just conscious scheduling. So making sure that. When I'm premenstrual or the days after ovulation, I've got some free time, some downtime where I can just have a nap. Some things so, self-care. Actually planning and scheduling in some time for self-care. Usually for me, that is literally just going to bed (.) or watching Netflix or it's just staying out of my inbox [laugh]. And yeah (.) well, yeah, and tracking (.) tracking the symptoms as well. And that's really helped me. And so I mentioned I'm going to the doctor's next week and that's because every day I'm really thinking about, OK, how do I feel, how is my mood, has my energy erm and doing that allows me to see any kind of changes or anomalies. And then I can go in and speak to my GP.

**Faith:** Erm (.) Tranexamic acid, cocodamol, hot water bottles (.) and I just drug myself up (.) like as soon as I feel an inkling of anything, I go straight to cocodamol which is really bad because I (.) really wanted to (.) um (.) like just through learning through um time, like you just learn about like the effects of medicine like relying on medicine and stuff. But my mom is like "your body is not like everyone else's. You can't like (.) other people can survive. But you can't you actually need it”. It's awful like to think you’re reliant (.) but at the same time. I just can't not (.) **Interviewer:** So, it does help you? **Faith:** Yeah. Cocodamol, definitely. Tranexamic acid makes me vomit. And there's a new one that I had to try recently (.) **Interviewer:** So you don't do that anymore? You tried it and it was just too (.) **Faith:** Yeah, It got too much. There's another one. It starts with 'n' we spoke about it at the forum (.) **Interviewer:** Oh, Naproxen? **Faith:** Yeah. Naproxen. So, that's the most recent one I had to start using (.) but it's not (.) **Interviewer:** Is it not nice? **Faith:** Yeah. I remember being on the train and feelin' like (.) this is how I'm gonna go out (.) I'm gonna die on the (.) die on the tube! [Laugh] like it's just so (.) it makes me really weak. It's really strong, but then it's the one that does the job.

**Gemma:** Oh, I just ride it out. I don't take medicine. I don't take medicine ever, though. I've got this whole negative (.) I studied anthropology (.) [laughter]! **Faith:** Yeah, it's because of you and like (.) a few other people (.) cos a lot of friends I have and family members, like they all have your approach that medicine is (.) [overlapping] bad. **Gemma:** [Overlapping] Yeah, but again, pain it's like I (.) I (.) I don't take medicine by rule but if I'm (.) if I have a very bad period, I'll take it (.) I'll take it if I really need it. Again, like (.) generally they're okay. But there's months where they are bad and I will run to the medicine. So I completely, it's because I don't need to. Do you know what I mean? The pain is manageable. It's hard (.) but it's manageable. But again, I have a day of pain out of my four days it's only one day so I can manage it. And I need to go to the toilet. And that happens. It is excruciating, though. I literally take off all my clothes. I'm sweating. I'm like "I'm givin' birth, I'm givin' birth!" [Nervous laugh] and I need to just get out. But I (.) because I know it's going to end. I don't need to go to the medicine and often for me, as well. When I take (.) I used to take medicine because I used to think that is something you should just do (.) before the pain even happens, my mum takes medicine to prevent the pain happening. With me (.) what I'd find is that when I took the medicine, it would only hold it for like two to three hours. Then the gap that comes when it's worn off was excruciating… it was excruciating. And then I had to jump to the medicine again. And then it would hold it again, but it would come anyway. It just came like lesser and I'd still need to go to the toilet so I thought like, do you know what? I just ride it out now, I'll just ride it out (.) I don't take medicine. **Interviewer**: Mm hmm. [pause] Sorry I'm just taking that all in. 'cos it (.) um, I've met a lot of people who have quite bad pain and they don't take medicine. And I am the same. So I get bad pains and I know all this and I know that taking ibuprofen beforehand really helps reduce the pain and helps reduce bleeding. And I still don't always do it (.) **Gemma:** [00:47:08] Why though? What do you think is going on? **Interviewer:** Well, it's partly laziness! [Laugh] and sometimes it's because I haven't eaten and I think, well, I can't take it unless I eat. And then you sort of forget because it hasn't quite started yet (.) **Gemma:** Yeahh! **Interviewer:** So, it's easy to forget. But I do think there's something about that we naturalize (.) particularly period pain. **Gemma:** Yes. **Interviewer:** As just being like (.) it's just part of life (.) [Nervous laugh]. **Gemma:** My mom thinks it's absolutely ridiculous. She thinks it's ridiculous. She takes medicine the day that she (.) she doesn't have her periods anymore, but the day she knows that it's coming (.)[Pause] [Indicates that she would take a pill]… She never had period pains like that because she said that even in the gaps, it's because your body's just getting used to it. She said the more you do it, the more your body will just be accustomed to (.) It'll be lower because you're in the cycle of the suppressing, of like the pain. But she was just like. “You’re crazy!" She (.) she says, "Take medicine". She forces me even when I've got a cold. "Take medicine. Buy medicine". So (.) I think you're right. It is just naturalizing, pain like it's a cool thing. Like "Oh, I've got through without the medicine" It's silly. **Interviewer:** Well, no. I mean, I don't think that's what I'm doing. But at the same time, I can't tell you why [laughter] (.) I don't do what I know would help. **Gemma:** No, I do it because of that. Which is silly, I do it because I'm just like, "I want to get through this by myself". **Interviewer:** So it's self (.) [Overlapping] Extreme self-reliance? **Gemma**: Yeah! [Overlapping], yeah, yeah. **Faith:** I think it's also the anthropology aspect, though. Because you've studied the effects of relying on medicine. That must've had an (.) [Interrupted] **Gemma:** Yeah. I did anthropology combined with medicine, like natural medicine. Um, And I saw like the effects of kind of using natural remedies, hot water bottles um (.) going through the motions of feeling pain and going out the other side. All this stuff (.) I think is like in my brain. But again, every (.) it is easy to say that. But again, education has the approach of everything is the same way for everybody. And that can be quite negative. They don't look at the individual experiences. So when you look at all these medicine and all these practices, they kind of assume (.) They will work on you based off of a level how you should experience pain. And that's wrong because we all experience pain differently and that we're all unique. So it's not one size fits all.

**Helen:** Poorly! [Laughter] it started on and off over you know, 20 years, 21. Let's say I'm 40 now. I had them out when I was thirty five minus twelve, so (.) wow twenty-three years of periods. You know, we did everything from birth con (.) um oral contraceptives, IUD, anti-depressants, anxiety medication, hypnosis. Acupuncture, dietary changes (.) [pause] What else? And then, I never did get to do Luperon [GNRH agonist], but I had an oophorectomy and hysterectomy (.) [Long pause] Oh, I was even put on (.) So, also um mood stabilizers I tried, as well. And those (.) those (.) nothing worked- it either made me worse or did not work long term. [pause] I enjoyed the acupuncture, though, very much. That I will say (.) **Interviewer:** I keep meaning to try it. I have various um (.) I get bad pain, period pain, but I also get (.) um I have a problem with a disc in my neck and everyone says acupuncture is really good for that kind of thing. **Helen:** Seriously. As somebody who is like, I tend to run a little high anxiety (.) when I go for acupuncture, she puts that needle in and I'm like, you just feel everything like melt away. And I use it for back pain, for insomnia, for anxiety. Like, it's wonderful. Go, go! The first chance you get [laugh]. **Interviewer:** Okay. Will do! Thanks. And did you before you had the oophorectomy, did you go on a GNRH agonist (.)? **Helen:** No (.) my insurance denied it (.) **Interviewer:** Really? So (.) So what your doctors were advising, your insurance didn't cover? **Helen:** Exactly. So it's quite a travesty, in the United States to have such a system. So my options were to pay out of pocket. And I don't quite (.) I remember, again, you know, just feeling completely like this is the end. Like I have no other option. The injections run, you know, upwards to twelve hundred dollars or more each time. So I was like, well, this isn't going to happen. Yeah. The cost is insane. And our insurance doesn't recognize it. I don't believe there's any (.) um, maybe one insurance company recognizes it as an effective treatment and so therefore will cover it. But somehow my doctor still got it approved and my insurance covered it- the surgery I mean. So the requirement was you had to do the GNRH trial before you could have surgery. But somehow she got it pushed through. And I remember it was very important to me that the reason was PMDD [pause] it just meant like (.) I didn't (.) she (.) so we had to say the reason for (.) they wouldn't cover my uterus for PMDD. We also couldn't leave it in, knowing what I know [implying womb cancer risk] **Interviewer:** Yes. **Helen:** So we had (.) I I quote unquote "luckily had fibroids"[laughter]. So she was able to use fibroids as the reason for my uterus removal, for the hysterectomy and PMDD for the oophorectomy. **Interviewer:** So the insurance were happy to cover (.) the oophorectomy on its own, for PMDD? **Helen:** Yeah **Interviewer:** God, it's so bad! [Shaking head and laughing] **Helen:** [00:24:54] Oh it's terrible, you've got to like market your body parts (.) **Interviewer:** It's very interesting (.) **Helen:** Yeah. I mean. It's insane [laughter]. It is absolutely insane. The loops you have to twist yourself and to (.) to fit through in the United States for health care is beyond anything [shakes head] Man!

**Kathleen:** Um, I just (.) I mean, I just try to make sure I'm changing regularly, so I'm not feeling worried about bleeding too heavily [big inhale] I [pause] I try to eat regularly. I think that helps. And I try to kind of think past it [short laugh]. So I'm one of those people that I don't like (.) I don't like to be kind of led by my emotions? Does that make sense? So if (.) if I identify that I might be feeling a little bit low 'cos of my period (.) um (.) then I try to just think. “Actually, I need to get this done, and this done today. I'm fine. You know, your body is (.) you might feel a little bit tired or a bit fatigued (.) but you'll be fine. Just keep going”. Um that's what I tend to do. Actually, as we're talking about it (.) I mean, I should say that those (.) those um feelings tend to come very close to my period or whilst I'm on it. I don't know if that's what you're expecting. But it's not like days before, I don't know what it's like with other women? But it tends to be just as I'm about to come on or whilst I'm on my period, yeah.

**Aisha:** Definitely about tracking it. Tracking my Periods. Um. Obviously, let people around me know that, you know, I'm gonna start. Um. Also, staying out of people's faces when I'm PMSing definitely. And again, my relaxation baths. And if I feel as if I can't be bothered to do nothing, I will do nothing before I used to push myself. But now I just (.) whatever my body wants. I allow it [pause] then deal with the consequences later [quiet laugh]. **Interviewer:** So the 'staying out of people's faces'. So while you are PMSing, you know that you are? **Aisha**: Yes. **Interviewer:** So you are able to like step away a little bit? **Aisha:** I never used to be able to. It's taken a lot of years to come (.) to do that. For example, to certain people (.) like my household people, I won't be able to stand them, so I'll go out with my friends… So you pick and choose certain people at that time, and you just know.

**Mala:** Um (.) [laugh] I just feel (.) sometimes I feel (.) sometimes I try to block it out because I fee l(.) I feel like I've been too (.) I'm being irrational. And I'm (.) I don't want to be hurting anyone around me [laugh]. So I have that. I still keep my relationships intact and I can't allow my emotions to override it. So I try to um yeah regulate my emotions. But sometimes I just let it (.) let myself feel it by myself. **Interviewer:** So would you stop yourself from saying something? So you're kind of feeling angry and you just know why? **Mala:** Sometimes, my brain will be like, okay. Don't say it. Or sometimes I won't even (.) it's like I don't have control over my body [laugh] and I just say it. And then I'd get the reper (.) repercussions after. Yeah, but I just feel like maybe people don't understand that you are going through something, so they don't understand (.) They won't understand. If I was to have a lash out at somebody. They won't understand where I'm coming from because I'm PMSing. And I'll have to (.) It's like I have to make an excuse as to why I'm talking like this. **Interviewer:** So you wouldn't say to your family (.)? **Mala:** So like they would not understand me (.) **Interviewer**: Like leave me alone or (.)? **Mala:** They would not (.) my family would not understand that (.). I've got to stop being silly. Get on. Move out my way. Or 'Fix yourself up!' **Interviewer:** OK so you just sort of manage it on your own? **Mala:** Yeah.

**Noor:** If I need to eat I will eat whatever. I literally (.) I would like watch my Netflix with my earphones and just have myself (.) time to myself. **Interviewer:** And what about any mood changes, do you do anything about them? **Noor:** Well, I just don't talk to anybody [laugh]… D'you know my family they'll know when I'm moody so, they'll be like "OK stay away from her!" [laugh].

### E8- PMS stereotype

**Anne:** [Long pause] I think it would be useful at this point to just tell you about an event that NAPS when we were represented at the RHS, at Hampton Court, we had one of the gardens about three years ago and for a couple of days we went down to man the gardens and (.) which was challenging in a way because people were asking me a lot about the plants, which I didn't have a clue about (.) [Laugh]. But there were people who actually wanted to know about PMS as well. And I would say there were two distinct groups. And I think this describes the social structure very well. And I came away thinking that. So you get the (.) there were a number of women who were sufferers and really appreciated just chatting through, er, being given extra information and often shared with us the difficulties they've had in the workplace, erm, sometimes in relationships, actually trying to explain (.) Erm, one; I think there's a lot about (.) they don't feel that they can explain things or they feel that this is a 'normal' thing, so they shouldn't be complaining about it. Erm, so maybe that's what comes through in the workplace and in their home situation at times. So it's just very, very appreciative that people were actually taking it seriously. So I think that in a nutshell, that's one thing I think a lot of people don't take it seriously. And the other group of people (.) either didn't know about it or almost [pause] erm, [pause] used it as a as though it's 'women making an excuse to be irritable or angry'. You know, it's almost as though there's a little bit of stigma, and that may be why a lot of women find it very difficult to be open about things, about all the suffering (.) how it's affecting them. **Interviewer:** So particularly around anger and sort of that emotion, anger and irritability? **Anne:** Yes, yes, yes… You know, just suddenly being moody.

**Barbara**: There are many jokes in circulation. They are not funny to someone who is truly distressed by symptoms.

**Andrew:** Social stereotypes? Errr, I am not very familiar with that, but I assume that when PMS is described in (.) in media and so on, it's usually the irritability factor that is displayed. These women are regarded as not very pleasant [laugh] during the premenstrual phase, and I think that is the most common popular concept of this condition. And to some extent this is also true. We have done a study that we (.) we have not published where we asked women from the normal population, a large group of women. First, they should answer if they believed that they had premenstrual symptoms of a such (.) such an extent that they are a major problem for them. And then within that group, we asked, which symptoms do you feel is the most problematic? And then irritability was absolutely number one in that (.) in that questionnaire. So (.) so irritability is (.) I would say the dominating symptom more than depressed mood and more than other things. And (.) and I assume that that is also (.) er, what how these women are often unfortunately described in (.) in fiction and in movies and in media and so on and of course it's not the entire truth about the condition, because some women, although it is the most common symptom, some women do not display irritability, but sadness, for example. And [in] some others tension is also common (.) an inability to relax and stuff like that. So (.) so it could vary, but if you should list the symptoms in the ranked order in how common they are, then irritability is number one.

**Debbie:** Yes. The crazy female who is irrational [inhale] irritable. We would say 'sort of bites your head off', meaning like, you know, you say something really small that, you know, isn't a big (.) isn't [pause] maybe mildly poking fun at them or something. And they sort of like really overreact [smiling]. So, just can't control your emotions. You know, "hormonal" [air quotes]. Right. Like mood, I think (.) I mean. Interestingly, I mean, I do think that the PMDD, the main, like the most common PMDD symptoms are sort of like what the stereotype is (.) like mood swings, irritability [pause]. Yeah. Overwhelm. Yeah (.) but just sort of like 'irrational woman' [laugh]. I would say it's like [pause].

**Celia:** Well, I haven't heard it recently, to tell you the truth. I remember when I first started researching this area. One of the (.) some of the (.) ideas in my talk would start with things like (.) how male pilots would say they didn't want to ever have a female co-pilot because they couldn't trust her during the premenstrual phase. And a lot of information along those lines, a lot of jokes about women being on the rag, which really was on the pre rag, I guess [laugh]. But I (.) I haven't actually heard that recently. I'm not sure why [pause] I remember this from being in the early 80s, really around the time when [Katharina] Dalton was, you know, out there.

**Sarah:** I don't know what that would currently be. Really. I haven't looked at the literature for a decade now, so I wouldn't like to hazard a guess on that (.) **Interviewer:** So you haven't seen anything in the media or like in lay lit (.)[Interrupted] **Sarah:** Not recently. It doesn't seem to be a thing in my country. It was (.) around the time that we were doing research, then it was in all the women's magazines all the time. And so you would think it was extremely prevalent. But now it doesn't seem to be so much, so whether that reflects that er women are now more comfortable to go and talk to their GPs and gynaecologists about it, and get treatment and those treatments are well known, I don't know. But I don't really see as much in the media anymore.

**Thomas:** Not really. What do you mean by social stereotypes? **Interviewer:** Well, perhaps in previous times rather than now, the kind of jokes or cartoons and things about somebody with PMS being crazy? **Thomas:** [overlapping] Oooh! **Interviewer:** You know, that kind of (.) slightly sexist (.) uh [overlapping] **Thomas**: Oh, yes, that's common. That's something which is even shown by (.) by scientists who want to do a presentation. I don't know if that's (.) but I think to my mind at least they (.) they only make the case worse. **Interviewer:** Yeah. **Thomas:** No, it's (.) I never show that kind of things but. Oh yes, of course. I mean I didn't understand what you meant by stereotypes. I thought certain personality. **Interviewer:** Oh yeah. No I meant more the lay perception (.) **Thomas:** Yeah. Well. No, that's (.) that's of course. I'm sorry, I'm sorry to say, but it's very common.

**Susan:** Well, it's somebody that's neg (.) that is, the sort of mad, bad and dangerous, really. That's a woman is irrational and out of control, violent, crazy, not to be taken seriously.

**Marta**: That would be women (.) angry women, of course. And yeah.

**Ria:** Yes, definitely. So the social stereotype that I can base it on is U.S. American mainstream Hollywood movie stereotypes. That's sort of like mostly where I get exposed to them. And also, I can be (.) I read a lot of romance novels. It's like my favourite thing ever. I do a lot of that during PMS! [Laugh], actually, more so during pre-ovulation. So (.) so. And then as a decolonial intersectional feminist researcher, I'm all (.) I'm reading it. And then I'm like, critique, critique, critique. So I hear and read a lot about the stereotypical PMS symptoms in romance, English language, romance novels as well. And so how they tend to be described is. 'Angry' for the most part. So angry and irritable, um (.) crying and sad. A lot of like the low vibrational emotions, I would say. What else do people say about PMS? It's been a while since I (.) like I try and just like block it out now (.) Personally, I don't really care like "you all. Just do you". But that's what I get for the most part. It's like crying, sad, angry, and therefore, because of those symptoms, supposedly not be able to perform the expectations and societal roles of what it means to be a menstruator and typically operating on a gender binary. What a 'woman' should be able to do. So like (.) if you have PMS, then you're not able to show up into the capitalist productive labour force and go to work, or if you are there, you're disrupting the expectation of neutrality, of being emotionless as a worker and then not being able to quote unquote show up for the expectations in the private household, in the reproductive sphere by like keeping up with cleaning, etc. For example, again, I'm in my PMS season. It's like we're two weeks into the New Year and I'm like, "Oh, I'm tired already" [laugh]. And so like, I didn't do my dishes for like a day. And so I think that's maybe something that is assumed of people and like kind of stereotypically presented as that they aren't able to show up and perform these things that we expect of them in our modern society thinking, yeah.

**John:** Yeah [emphatic]. I think most people probably have a social stereotype of a (.) a sort of unhinged, irrational female. Um [long pause] yeah, in a less empathic and more derogatory way.

**Laura:** I think they're (.) I think the stereotype is of reproductive age woman who is out of control and angry and [pause] that's probably the stereotype.

**Zoe:** Er (.) yeah. There's (.) there's a couple of representations of the woman with PMS and you see a lot of this (.) especially (.) well, they've been around forever. Um, you know, cartoons and images have always had them, poetry's had it, songs have had it. But now we see them on YouTube and Instagram and things like that [laugh]. So the images that are out there um tend to be of either (.) and either (.) and either/or (.) and sometimes both the mad OK, so the mad, erratic, um, crazy, fly off the handle. So the mad um, or the bad, the bad can be, you know, quite dangerous. Quite, quite um (.) the bad can also be depressed. So that's that (.) there tends to be that sort of (.) the angry representation, the bad representation. And there's also the sad representation. And so and I think the (.) the idea that a woman or the representation of (.) of a woman oscillating or flicking between these very randomly and quite erratically. So just the erratic (.) Um, how these are presented is interesting. I think increasingly now they're represented in a comic way. So they're represented often with comedians through humour, which I [emphasis] think is actually creating the potential for a bit of a (.) a power shift. So it's (.) it's (.) it's allowing some (.) some women, if they choose, the opportunity to actually claim and own that identity as something that they (.) they (.) they actually want to (.) they want to be able to attribute to themselves in the same way that black power became an issue for African-Americans. It's that same sort of thing or with a lot of um (.) into mental health issues. You know, people claiming and wanting to adopt the label and the tag of lunatic and things like that. There are some women who are quite happy with this um portrayal and are actually now um taking it on with it with a degree of agency. But [pause] otherwise, I don't think they're necessarily very realistic or very helpful representations.

**Geraldine:** Oh, yes, of course! [Laughter](.)Yeah. So I have (.) this is one of the areas where I have done research on stereotypes about premenstrual women. Um, so they're angry. They're screaming all the time. They're highly irrational. They have a tendency toward violence. You know, those are probably the main ones that are out there in Western culture.

**Chris:** Stereotype? No, I don't think so. The research would say that patients with an underlying anxiety are more likely to have PMS. Then you're into that complicated business of the ISPMD classification because there's the purest of the pure PMS, a core PMS, 'PMD'. And then there's the ones with an underlying psychological problem where it gets worse. Premenstrual exacerbation. And then you got another group of patients who have an underlying psychological problem and the PMS/ PMDD entirely separately where there's this co-morbidity. So (.) um (.) So I think this is (.) the PM- (.) type of person who has the absolute pure thing, which means severe symptoms complete really by the end of menstruation, I think um (.) I think they are (.) don't fit a stereotype. **Interviewer:** So actually that question was more about any kind of media stereotype or something in popular culture? **Chris:** Oh, okay. No. Sorry do you mean er (.) Young Middle-Class White women, for instance? Because you don't get many (.) you don't get many um Asian. You don't get many non-middle class (.). No, you don't (.) yeah, well, a lot of my practice was (.) um (.) private practice towards the end. So that's predominantly white middle class women. Let's think in my NHS practice, hmmmm yeah, it tends to be. But I don't think that means necessarily which patients get it. It's which come to the clinic. Yeah?

**Jo:** [Pause] Um. That's an interesting question. No. I just think you know, you hear about sort of women being described as mad or hormonal or "it's just your hormones" but in a medical capacity I don't think that that's something I (.) I've really come across? I mean, I think in severely affected women with PMS, they will often come not on their own. So I think as soon as more than one person comes into the consulting room and the woman is of a (.) of reproductive age. I'm already thinking actually maybe this is what's wrong. But um, not really, no. **Interviewer:** Can I just ask you about that. Do you mean that if there is a partner there, then it is likely to be a relationship kind of thing? **Jo**: Well, it might be a partner or it might be parents, but it's mostly a partner I think. **Interviewer**: And that's different to say, a mental health issue? **Jo:** So, I mean, just a straightforward, like depression or something, do you mean? **Interviewer:** Yeah. **Jo:** I think so because I think a lot of the time in in severe PMS, there will be (.) the ability for women to control themselves in certain settings, but to let go where they feel more comfortable, which is you usually with somebody that they are in a relationship with. **Interviewer:** I'm very interested because there's quite a lot of research on the interpersonal factors in PMS. And so if it was noticeably different that people coming to you for perhaps PMDD, even if they know it or not, tended to have partners or parents with them more often, that would be quite interesting. **Jo:** And I think the other thing is that I think sometimes when women will make um several appointments. So they'll make an appointment when they feel horrendous and then they feel better, and then they think "Actually I don't need to go". And they know (.) they know that there is a recurring cycle going on. But it's like when you feel, well, you just want to be well, don't you? And you don't want to think there's something. Well, that's what I think, anyway. That they don't want to think that there's something wrong. (.) I think the other thing was I think we saw an incredible number of actually (.) maybe it was just the nature of recruitment to clinical trial? But (.) but women who were into (.) very intelligent and very in touch with their symptoms. It was (.) it was interesting, having recruited lots of clinical trials. This particular group of women were very frequently medically (.) in some way medically connected. But that might just be that (.) I don't know. It might just have been a (.) it's interesting, though, isn't it? I don't know whether it is to do with their condition?

**Ria:** Um, so physically. I highly recommend. And I don't do one on one client work for (.) several reasons. But if I were to do that sort of thing and give that kind of one on one personal advice to people, it would be to physically take vitamin D, magnesium and zinc. These are all and (.) again, I can say a lot about the pharmaceutical industry and like how vitamins are made and all that stuff. So you can either take it as a supplement or eat foods that really boost those levels of vitamins and our (.) and vitamin D is considered a hormone as well in our bodies because just the way like ancestral food systems or modern food systems work is that our food and nourishment that we get today is very different, even if it's the same exact like food or carrot or wheat, for example, that our ancestors a 100 years ago. It just like it's very different. And so we don't get as much of the (.) they're not as nutrient dense. So if possible, supplement your eating plan or just food and build it into your menu to get vitamin D, magnesium, zinc. Um and then spiritually and emotionally, how to manage it? Do things that make you that bring you just a lot of joy and do them by yourself. So I like to prescribe a good dance party to people. So just like put on your favourite song, dance it out, release it and let yourself just have a night in bed where you eat your favourite food, you watch maybe a movie or you read a book or whatever it is that you can just like get into and that you enjoy. These are things that I like. So I encourage people to do things that they really like. Maybe they like crafting, maybe they like baking, maybe they like dot, dot, dot? So mean different things. So for mental and emotional, do things that you really like and do it by yourself and let yourself sometimes, especially if you're going to cry like just let it out. And then I (.) some (.) like in my class, I teach at a university as well. I teach a process called regulating that I've learned from a friend of mine who's an energy healing practitioner. And basically, it's a body movement and a practice where you like, you go breathe in, breathe out, breathe in, breathe out, breathe in, breathe out. And you can move your hand, pedal your hands in whatever way or you can pedal your feet. And it's a way to bring your body, mind and spirit from being really activated, let's say, and like overwhelmed in the sympathetic nervous system and bring it to be more parasympathetic dominant and like a little bit more relaxed and grounded. And so, like, for example, when I was on the pill, there would be times where I was just like I would cry for like an hour. And it was just I was so upset over a certain thing. And in those moments, you know, there's a line between crying as release of trauma and crying as a coping mechanism to deal with some sort of underlying mental, emotional, spiritual, physical pain. So both releasing and self-regulating release, self-regulate and then spiritually, I encourage people to do whatever ceremony they're called to do, whether that's drawing tarot cards, whether that's going outside by yourself for a walk and just breathing and taking notice of like the beauty of the earth and more than human beings. Reading scriptures, if that's something that you do in your practice, just any kind of spiritual ceremony. And if they're not into the term spiritual, then we can come up with different ways to talk about what that means. A lot of reflection, that sort of thing.

### P19- PMS stereotype

**Alice:** I think the only thing that I’ve ever seen is what to do when you bleed. So, you know, use these (.) you never see any tampon adverts! You only ever see ‘wear a nappy!’ This one's amazing (.) you won’t get any leak, you can wear your white trousers and hope for the best! [Laughter] after the second day of your childbirth… Yes, so for me, it's just let's promote nappies [laugh] on social media. I probably don't go looking for social media (.) on this topic, to be honest with you (.) I mean, I never see any like public health campaigns about how to deal with (.) I dunno if you want to call it PMS symptoms (.) ever? It's not like you ever see (.) you see smoking cessation. You see obesity and weight gain. You see mental health (.) I mean, it's connected to mental health. But actually, I think in a way, if you categorize it like that, you're also just fobbing it off because it's just part of being a woman. I think it’s (.) it's still a bit of a taboo subject and it's not talked about (.) it’s just seeing something that is normal: Get on with it! But it's also a bit of a joke still. People sort of snigger, even if you do see the nappy advert.

**Beth:** I'm struggling to think of an example of any way in which. You sort of sit down to watch the TV and see a portrayal of a woman with PMS. To be honest, I mean [pause] I think (.) sort of (.) there's a lot of anecdotal stuff that goes on in conversations within families and between friends of 'Oh. You know, when so-and-so's got PMS, then they feel like throwing frying pans at their husbands because they get so angry'. And I think that's the stereotypical image of a woman with PMS is someone who's like raging unreasonably because she's due her period or as someone (.) in fact the only (.) I've just remembered a TV example of PMS; in the sitcom New Girl, which is an American sitcom, [with] Zoey Duchanel. And there's one episode that focuses on her having PMS and she goes to a job interview and cries over (.) a photo on the interviewer's desk of a little cute puppy in a mug [laugh] (.) and then her under a blanket with a hot water bottle crying [laugh] I (.) That's the only sort of media portrayal of PMS I can really recall! And it's just of her like sobbing at a job interview. Which I'm sure most women wouldn't do if they were experiencing PMS symptoms and went to a job interview. That it's just so ridiculous. It's quite funny because no (.) no one would really behave like that [laugh]! Yeah. So I guess. Yeah, media portrayal of PMS is just (.) I guess portrays women as either angry and unreasonable or over-emotional and stupid [laugh]… But there's not any sort of portrayal of the physical symptoms you can get. I don't think (.) apart from the sort of (.) vague implication that you might need to hug a hot water bottle because you're getting some tummy aches… Yeah. I don't think (.) I don't think the other sort of symptoms that a lot of women experience with PMS are given any sort of portrayal whatsoever (.) I mean, no, right? No one wants to address the fact that women poo, anyway (.) so any sort of bowel symptoms don't get any kind of attention or anything that makes women look sort of unattractive! [Laugh] so, that's not going to get any media portrayal. Yeah, I think (.) I think a lot of the sort of information out there is (.) focuses a lot on the emotional side of things. And is a bit misleading?

**Dani:** Yeah, of course (.) there's like the moody, angry, irrational woman. The rational thing is the stereotype, which actually really fucks me off because I sometimes feel the most rational when I have PMS. I just (.) I'm just not [interviewer laugh] I'm just being less kind. And being less like glossy about stuff. I'm just like (.) or like I just feel more like straight to the point about stuff. But yeah, that's very much the stereotype. Right. Irrational yeah, I think irrational and angry is the most (.) is the most pervasive stereotype.

**Emma:** [inhale] I think. I think there is (.) in that (.) we tend to think of it or this (.) this is my perception (.) we tend to think of PMS in its extremity of (.) a woman being out of control or completely full of rage or bawling her eyes out or an emotional wreck or (.) and it's a spectrum. It's a spectrum of severity. And I think sometimes it is (.) perceived very negatively. But it is (.) it is common and pause] I haven't articulated that very well, but I know what I'm trying to say [laugh]. We tend to picture a woman who is like a monster with PMS and there are lots of these memes on the Internet. I'm just thinking of one that I saw. 'I've got PMS and a GPS. That means I'm a psycho and I'll find you!' [Laughter] It stuff like that, which I think has really stigmatised not just PMS but people who do have PMS and yeah. I think sometimes it is pooh-poohed because of that (.) when it is serious and (.) that's (.) that's really sad.

**Faith:** [Pause] hmmm [Pause] I think (.) like when (.) like if you (.) when you're like ‘oh yes, she's going through PMS, or whatever?’ Yeah. I think it links to like what you were saying about your brother (.) I guess if somebody's like emotional, or annoyed. I'd say that (.) that more so it's like the hormones so the emotions like if you're annoyed they'll be like "Oh she's on her period" Or "her period must be coming", because like she was sayin' before, you do hear it a lot from men [inaudible whisper 0.3 seconds] So I think it's a harmless (.) well, that it is not necessarily a negative stereotype, but I guess it is kind of a stereotype, assuming that [long pause] showing emotion equals PMS.

**Gemma**: Yeah, I would agree. I've heard it more so from guys, [pause] just the stereotype of like a woman who's very emotional and snappy must have (.) be experiencing PMS but it's more so from guys that I've heard it from.

**Helen:** Yeah, I think, you know, there's just this perception that [pause] I think it's funny. I feel like society attributes like we yeah, we get this is part of your biology, your body's like doing its thang. But we also think you're being weak minded at the same time. Like get over it! You know what I mean, it's like we're going to pretend it's all (.) it's equally there and not there, that it's out of your control, but also in your control [laughter] you know what I mean? Like it's just (.) it's just so much expectation! [Laughter] you need to control this thing that we understand is not under your control. You know, it's (.) it's (.) it's mind boggling… Over emotional. Yeah. Like all those things. Oh, you must have got your period. Quit being so irrational, you know, overemotional, irrational.

**Kathleen:** [long pause] um (.) not that I (.) er (.) there probably is, you know, to be honest I haven't thought about PMS for quite a while. But I do remember the stereotypes, you know. Like an angry woman, um someone who goes, you know, just flies off the handle very quickly. Or just be really upset. So that I think is the stereotype. I don't know if it's still out there? But um, that's definitely the one that was around you know, a few years ago.

**Aisha:** No [quietly] I think, everyone just says, "oh, there's no such thing". Everyone's ignorant to the fact (.) about PMS. It's so (.) taken so lightly.

**Mala:** No, I'm not. **Interviewer:** So, you haven't heard any (.) **Mala**: [00:14:09] [overlapping] emotional? **Interviewer:** Jokes or anything like (.) nobody's sort of (.) or any cartoons or anything like that? **Mala:** No, I haven't. I mean we (.) we make jokes! [Laugh] me and my friends. “Oh, you're defin-(.) we say like you're definitely (.) are you PMSing now? Do we need to leave you alone? **Interviewer:** And what's that sort of saying? That you were being a bit irritable or? **Mala:** When in their view (.) it's probably they're being irritable. And we're just trying to make (.) normal, normalise it (.) so they don't feel like (.) because when you are PMSing, you're very emotional and everything gets to you and you have to gauge how you act. But if you know, like if one of my friends are PMSing and she's OK, then make a joke out of it so she doesn't feel too bad about it. So, it's normalized like it's something (.) you're not (.) you're not abnormal for going through it. It's okay for you to go through this.

**Noor:** Yes. So [pause] people would just think your abnormal, if that makes sense, but (.) like, for example, if someone's acting really out of line they'll be like "Oh, what's wrong with her, something wrong with her mentally, etc." but really it's just PMS and I think (.) people forget, obviously, there's different stages where people change their moods. But that's generally me seeing it, seeing it (.) if that makes sense? **Interviewer:** So you think like the sort of stereotype like that would maybe be in the newspaper. Would be (.) um (.) **Noor:** I think, like if you see a female celeb just suddenly pigging out they'll be like "Oh she must be going through something mentally or depression", they wouldn't think, oh, she's PMSing. **Interviewer:** Mm hmm. So definitely with the food that's not (.) **Noor:** Yeah (.) **Interviewer:** (.) associated with PMS. What about mood changes? Do you think people are a bit more (.) aware? **Noor:** Well, I think they are aware, but they take the mick, if that makes sense? Like if you've (.) like for example, at work. If a female's moody, they'll be like "Oh, I think she's on" do you know what I'm sayin'? And you're just thinking. "OK. You just pissed me off now". So, I think things like that. I don't know how you would explain that (.) **Interviewer:** Yeah. And that's quite a common one particularly at work that you might be angry for a work reason. **Noor:** Yeah. **Interviewer:** And then other people might be going (.) **Noor:** "She's on, just leave her alone".

### E9- How many symptoms?

**Anne:** Over 200 have been described [pause]. Yep, I think that's why when we're looking at the Montreal Consensus, the International Association of Premenstrual Disorders. That's why they didn't say in their definition (.) criteria. They said that you don't have to have particular symptoms because there are so many. It just needs to be recognized. Obviously, there is (.) some are much more common than others that they wrote about.

**Barbara:** More than 200 symptoms have been associated with PMS in the literature. When symptoms are carefully monitored for their relationship to the menstrual cycle and cause significant impairment, there are perhaps 6-12 symptoms that qualify. Mood symptoms are usually the main complaint (irritability, anxiety, tension, feeling out of control); behavioral [sic] symptoms (fatigue, poor concentration, poor sleep) and physical symptoms (breast tenderness, abdominal bloating) are frequent. It should be emphasized that many disorders, both physical and psychiatric, are exacerbated premenstrually and may account for many symptoms that are attributed to PMS.

**Fran:** Um, I think there’s a large number (.) Um, I think there’s (.) there are several emotional symptoms which are largely captured by the DSM 5 criteria. There’s maybe ten (.) several physical symptoms and behavioural symptoms which are less emphasized in the DSM-5 diagnostic criteria. In the last 30 years of literature describing PMS, there have been 50-60 symptoms described, but most are not included in daily ratings used in studies.

**Andrew:** Oh, a lot, I would say. Well, there are also different names of the same symptoms, so it's difficult but say between 10 and 20 or so have been named as possible symptoms. But as I said before, I think I'd I personally do not think that all are parts of the same syndrome. I think that premenstrual epilepsy, for example, is not the same as the other stuff, premenstrual headache. Also, I think breast tenderness and bloating is another condition then irritability and, so on. But if you should list all the symptoms that have been claimed to be (.) could or can appear in the luteal phase, I would say at least more than around 20, perhaps something like that. You know, in in in the PMDD definition in DSM there are eleven symptoms, but the number eleven is a mixture of different somatic symptoms. So already there you have thirteen, fourteen symptoms and you could definitely add more to that list.

**Debbie:** Oooph! (.) I mean [laugh] [pause] the correct answer to that question depends on the context. You know, for the purposes of public health and measurement, we wanted we wanted to design not me personally, but people who have been doing this work for, you know, 50 years (.) wanted to design a set of items that were most representative, but that wouldn't create like if we have to do daily ratings with people, we can't have 100 item list. Right. We have like reasonable (.) a reasonably small checklist of symptoms that basically cover it [laugh] [pause]. I don't (.) I mean (.) so I think for the purposes of (.) measurement [pause] for [pause] PMS/ PMDD. I don't think there's a right number of symptoms, but I would use no more than 30 (.) that I'd think could sort of cover 90 percent of it. And then there I would have an understanding that, of course, there are idiosyncratic symptoms that we're not going to capture and just hope that. You would be able to sort of get the basic idea anyway? When it comes to a patient sitting in front of me. I think that's different. I think when I make the daily rating form with them, we go through and go through all the symptoms. We eliminate the ones that they never have. And then we add their own idiosyncratic symptoms. We add side effects if they're worried about having, you know [inhale pause] so [exhale pause]. Yeah (.) I dunno [laugh]. I don't have a good answer. The correct number is the right (.) is the number that it takes to get the particular job done that you have sitting in front of you! [Laughter]. That should be set, and specialized and calibrated for the test.

**Celia:** Ha! [Laugh]. Well, I think my understanding is that it's not specifically the symptom, it's the timing. So that could mean that there are, you know, large numbers of symptoms, really. But, you know, when it comes down to it, it usually falls into a clustering of the more common ones. But I think theoretically it could be many different symptoms. And unfortunately, that would have to be parsed out from the fact that most underlying disorders are worse premenstrually. So if someone has lupus and they have more joint pain premenstrually, it's (.) you know, it's hard to say if that's a PMS symptom or an exacerbation. And I think that's true with some of the confounding, let's say less typical symptoms.

**Sarah:** [Raises eyes upwards and inhales] I dunno. I think in our study that we asked people to list symptoms there were, I think they came up with about one hundred and fifty. Now um (.) how many (.) what the most common ones (.) if you (.) I'd have to go back to the article, to see if it reduced, them down to (.) I mean, the most common ones that we looked at um (.) we were able to limit it to about, I think about (.) seven symptoms and about three control symptoms that we just put in there just to see what happened to them [laugh] as well. Um (.) but (.) um I think you'd need to go and look that up.

**Thomas:** Well, Katherina Dalton, If you have read her? She describes one 150 symptoms (.) and I have a lot of experience with the different types. I had a (.) a clinic with only patients with acute intermittent porphyria. [Coughing] Sorry. Sorry for my coughing. I haven't (.) I have a bit of a cold (.) **Interviewer:** I'm the same, so feel free to cough! **Thomas**: Yes. Thank you. Anyhow, [cough] that is one condition. I have had lots of patients with epilepsy. Catamenial Epilepsy. I have had patients with urine incontinence. That turns out to be menstrual cycle related. And of course, I mean these psychiatric symptoms of different kinds and many of these symptoms that have exacerbation or aggravation of (.) of their psychotic disorders. I've had quite a lot of children which are having psychotic episodes which are related to the menstrual cycle. So [long pause].

**Susan:** Well, the list of symptoms that are on symptom profiles. There are multiple symptoms. I mean, there are (.) it's not like there's a standard where we can say 'there are only thirty six' there may be hundreds? Um, but there are core Symptoms which are commonly reported; psychological symptoms which tend to be anxiety, depression, irritability and then there's symptoms which are potentially more psychosomatic like sleeplessness or dizziness. There's classic physical symptoms would be breast tenderness, feelings of swelling, bloatedness. But one of the arguments as to why PMS is not an (.) not a 'syndrome' in the way of how syndromes are defined. Is it doesn't have a core set of symptoms that all women report (.) there are many, there are multiple symptoms. And if you talk to different women who report premenstrual distress, there are, you know, multiple (.) whole ranges of different symptoms that women report. So, you know, as I've argued many times in writing, PMS doesn't meet the core definition of the syndrome because it doesn't have a core set of symptoms that everybody has.

**Marta:** Are you asking them about the eleven symptoms that that make up the list in DSM 5? Or are you asking me to choose between these eleven or can I add extra symptoms if I want? **Interviewer:** You can add extra symptoms (.) this is up to you. Some people have (.) this has really varied according to the person. So maybe a little bit beyond the PMDD (.) well, maybe not beyond, but for instance, in the PMDD criteria, there's number eleven, which has all the physical ones all in together. Some people would separate those out (.)? **Marta:** So, I mean, I think that that one thing that hasn't really been stressed in the diagnosis is that (.) I mean, in my understanding and when I see patients, I really see that the two (.) the two dominant symptoms are depression and (.) and irritability. And (.) and that strikes me as quite a (.) that's quite an odd combination of symptoms that doesn't really happen in (.) in any other parts of psychiatry. I mean, irritability is a symptom of anxiety, but irritability does not belong in the depression diagnosis, for instance. So though those two (.) I think they're not emphasized sufficiently, but they (.) I think more or less all my patients have kind of a mixture in-between these two. I once tried to see if we could separate, separate, different subtypes of PMDD (.) looking at how many have the depressive-genic PMDD and how many have the irritability- PMDD. But it turned out that almost everyone had had combinations of these two. As far as symptoms that are outside of the diagnostic criteria. I don't really have any opinion now because I haven't really systematically asked women about their symptoms over the past 15 years. I've just used the scales that are available, so that has never been any of my research concerns. And it's (.) I don't (.) if I think back to the women I'm meeting what kind of symptoms they describe on (.) on open questions, they usually fall within what is described in the (.) in the current criteria.

**John:** Roughly how many? Well, depends which diagnostic criteria you're gonna use? Er (.) in DSM 5. Er [pause] I think that's about 12 or 13. I can't (.) um around that (.) the majority of which, let's say there's thirteen, twelve of which are psychological, one is basically a lumping together of a bunch of physical symptoms. In reality [pause] certainly the people who come to this clinic and I see are here because of the psychological far more than the physical.

**Laura:** [Intake of breath] that's a little bit of a dicey question because, you know, people have identified dozens of symptoms. And just because it has occurred during the premenstrual phase, they say it's a potential premenstrual symptom. Um, I don't think that's really the case. So I think in terms of candidate symptoms that really reproducibly, are found in women during the Premenstrual phase and lead to some degree of impairment, it's probably within 15 to 20.

**Zoe:** Arghh. Well, on (.) on (.) on the list. I think you kno (.) so (.) officially um (.) or diagnostically if we go through, you know, standard diagnostic um clinical tools. It's a (.) [exhale] I haven't looked at it for a while now. And I know that it is written (.). I think it may have changed, but there's a (.) you need to have a constellation of I think about four or five out of the list, a nominated list of (.) of around 10 that have to be to (.) moderate to severe levels. But there (.) it's probably around 20 symptoms that generally would (.) would uh (.) tend to be clustered around PMS. So a range of emotional changes, um some cognitive changes and a range of physiological changes and any emotional I, also include there as 'interpersonal'. So (.) yeah. So I would say there's around probably (.) a hard-core of around 20. But it will vary from woman to woman.

**Geraldine:** Well (.) I don't know. In my understanding, I can't give you a number, but it's a lot fewer than 130. I can tell you that! [Laugh] some of them are just you know, things that people made up. For example, I once read I was reading um in the late 1980s, I read all of the popular media articles about PMS and one of them said, "Your perfume smells different" [laughter]. Yeah. So I just imagined a bunch of women sitting around in a magazine editor’s office just talking about their own experience with their menstrual cycle. And somebody said, you know, [puts on high pitched voice] "my perfume smells kinda different when I'm premenstrual" and they wrote that down and put it in the article. And now women think that that's a symptom [laughter]. So there's a lot of nutty things like that.

**Chris:** Oh, the strict definition by the ISPMD (.) is that there's no (.) now there are specific symptoms for PMDD. Okay. And I can never remember what they are (.) you'd have to go through the thing. **Interviewer:** Yeah. **Chris:** Yeah. There's this 1 -5 and all that business. Um PM (.) in the (.) in the (.) one/ two (.) second I think or the third consensus of the ISPMD we did a Delphi thing and we (.) we decided that (.) um (.) er (.) Oh no, no it's actually in the first one! So any symptom. Physical. Or psychological. And so it could be infinity. OK? So whereas (.) whereas PMDD is very specific and they have eleven symptoms and subcategories and all that (.) with (.) with (.) PMS in the ISPMD thing, it was any symptom of sufficient severity to cause stress, distress and (.) have an effect on relationships, effect on work, effect on normal functioning and hobbies and so forth. So (.) so that's a (.) that's a group of symptoms. Meaning that the symptoms have to have that effect.

**Jo:** Something like 22, if you look at you look at the daily severity (.) at the record of symptoms.

### P22- How many symptoms?

**Alice:** I think it's there's probably not (.) there's not probably a defined number, I think. Again, like I said before, I think it's very individual. I think you could give an umbrella category of symptoms. You may experience. I don't think it's black or white. You know, it's a bit like if you Google something that you think you might have (.) they'll say, you know, you may get this, this, this, or this? I think it’s similar. And you might you might get a temperature change. You might get hot and clammy and sweaty. You might put on some weight. You might feel lethargic. You may experience abdominal discomfort. You might get constipation. You might get diarrhoea. You know, it's a bit like that. (.) You (.) you may feel flat. You might feel emotional. You may get sleep problems (.). Erm, You might feel less engaged to communicate with people, you might feel socially isolated. I think there isn’t a defined number (.). I think, you know, there are certain probably symptoms that are more common, like I definitely get diarrhoea. Whereas other women don't (.) and that's apparently to do the amount of hormones that are in your body (.) I said apparently (.) but that's (.) but that's not because [pause] I think this is an area that hasn't been explored. So, yes, there are like any. Like any. The only thing I would say that I think is important here is it's not a disease or an illness. So like having a period is a natural process (.) and actually, I think maybe we need to change the language that we use within health and society. And I'm not surprised that you've just said that there's another disorder (.) that I don't know about. (.) Well, isn't that convenient? [laughter] **Interviewer:** Yes (.) **Alice:** I think we (.) we just need to look at that (.) women release an egg because they are (.) they have the anatomy. That means that you can bring life into this world, which is quite remarkable. But in that it's such a highly complex, amazing, physical and physiological process that goes on and emotionally. There are so many factors that interplay here and our world in the West is even more complex because of the food we eat, the way that we produce food, the plastics in our society, the air that we breathe and the stress that we have, the location that we might live in. You know, all of these factors are likely to impact the way that our symptoms may present. And I don't think it's a disease or an illness. It's just a physical process. And you may get some of those symptoms or you may get more of those symptoms dependent on what's going on in your life at that point.

**Beth:** Are we talking self-reported? Or are we talking? What? There's evidence for what the guidelines say (.) so far? **Interviewer:** What's your feeling about (.) the experiences of people? **Beth:** Well the experience of people, gosh, it's probably loads! I think several tens. So 50 to 100, I'd guess, if you're talking about every woman's experience combined. But whether all those symptoms are definitely PMS or (.) something else, I dunno. I guess we don't have enough evidence at the moment because there's not enough research to say that for sure. **Interviewer:** that's great. **Beth:** but I think there are probably lots! (.) Not very scientific is it? 'Lots'! [Laugh]

**Dani:** Ooh. [Pause] I've absolutely no idea. Ten maybe? genuinely no clue.

**Emma:** [Exhalation- sigh- pause] I wouldn't like to guess. Ehm [long pause] **Interviewer:** That's fine. I mean, it's kind of ballpark. So, like 10, 20, 50, 100, more than that? **Emma:** You know, I think around 30?

**Faith:** Well (.) um [pause] so I'd say (.) emotional, mental, physical [pause] can I do it like that? **Interviewer:** Yeah yeah. **Faith:** So, I'd say emotional, mental, physical. Yeah. So physical is like the cravings and stuff and dehydration. Emotional (.) just being emotional (.) and then mental, when you're feeling low and sort of subtle things (.) **Gemma:** I was actually going to just say three. Yeah. And I'd say emotional, mental and food like that's all I'd say. **Interviewer:** That's great. Thanks. **Gemma:** Also emotional. Physical and food. That's probably what I would say.

**Faith:** How many are there [whisper]? [Laughter] **Interviewer:** So some people say like 200 (.) **Gemma:** REALLY? [Loud] **Interviewer:** But it's really interesting for me to see who says what.

**Gemma:** OK. **Interviewer: S**o I really liked your response! [Gentle laugh].

**Helen:** Oh my gosh! I mean (.) so you're saying premenstrual, not just PMDD (.) right? Because (.) it relates to the DSM **Interviewer:** [Overlaps] Yeah (.) **Helen:** OK. Yes. So PMS (.) oh gosh, I think there are 100, 200 some recorded? But you know, being that anything can be premenstrually exacerbated. It's so (.) you know and I think this leads back to what you were saying about there's not a good definition of PMS unfortunately. You can't like (.). PMDD (.) we have a very clear diagnostic criteria that must be met to define it whereas PMS (.) it's like everything's PMS and everything is not PMS, you know?

**Kathleen:** [Long pause] 50? [Unsure voice]

**Aisha:** Symptoms (.) oh, gosh, over 20? [Pause] it's a different thing every day isn't it so it must be a lot (.)?

**Mala:** Oh, um what do you mean (.) like as in, what do I? Like my food thing? **Interviewer:** Yeah? **Mala:** Okay. So the food, a lot of (.) food cravings. It'll be like specific stuff sometimes (.) like cuisines or (.) yeah, it will be specific stuff that I (.) I do eat normally, but it'll be intensified. Um, and then emotional would be being irritated by someone. Um and whatever they do. Like sometimes what I do get is (.) what (.) I get really (.) I always want (.) whatever I think needs to happen. I don't want nobody else sayin'(.) Like if I've made a plan it needs to be my plan [emphasis] (.) and nobody else's plan. And if they plan on changes, it really, really (.) it irritates me. **Interviewer:** Yeah. I'm like that all the time! [Laughter] **Mala:** It just really irritates me, like "Why can't we just do it the way I said it"? **Interviewer:** What about any physical symptoms like (.)? **Mala:** Oh, I get spots and bloatedness really really bad bloatedness?

**Noor:** I think [pause] I think it's uncountab (.) like you can't count it because literally (.) someone else could have something different (.) we might not know of (.) I don't know. I don't think there is a number (.)? **Interviewer:** But like if I say it's 10, 20, 50, 100, more than 100, what do you feel? **Noor:** I'd say 50?

**Ria:** Hmmmm (.) I think I would just break it down again into like the four major aspects of health which are physical, mental, emotional, spiritual. So I think there are four general categories, let's say, and then people experience their own unique expressions of those depending on where they are at in life and what (.) whether they're on the pill, for example, etc., etc. Yep.

### E10 Most common symptoms

**Anne:** Erm, if you don't mind, I will, just (.) so the study that I did (.) Is sort of put together (.) What we thought were the top eleven, I think (.) So, you know. And I think that that would [Page finding](.) You know, I believe that that would still stand. So (.) so irritability. Probably group this one together (.) but of loss (.) of loss of efficiency and difficulty concentrating. Let's put that one together. Tiredness [pause] Mood swings [pause] Tension (.) So feeling stressed [pause] I'd put as a definite one, depression, low mood. And then we went on to describe some physical symptoms. So we had a range across physical and psychological (.) Erm, feeling, bloated [pause] Headaches [pause] Food craving [pause] Acne, so skin changes [intake sigh] I mean, we did include period pain as well, but erm, I'm not sure that (.) no probably wouldn't include that (.) That's a slightly different area, isn't it? Really?

**Barbara**: See above [Answer to E9].

**Fran:** Err, irritability. Anxiety or tension. Mood sensitivity. Mood being low intermittently (.) Um, some people call it mood lability, but it’s not like manic lability (.) mood can be pervasively low during the premenstrual days but that is less common, and er, maybe food cravings or increased appetite?

**Andrew:** Yeah, well, that that depends how it (.) what priorities you have (.) if you have (.) how common they are so that they are experienced. And maybe some of the somatic symptoms are just as common as the mood symptoms, breast tenderness, bloating, for example. And if you rate the symptoms that are regarded by the patients themselves as the most problematic, then as I said before, definitely irritability is the most common one, followed by some other mood symptoms. So many women do have somatic symptoms, but don't regard them as very problematic. Also, many symptoms [women?] have irritability then do regard that as problematic.

**Debbie:** Yeah. Oh, overwhelm, emotional overwhelm feeling your emotions are out of control, irritability. And I would (.) I would actually clump with irritability, something that is not in the (.) a lot of the symptom checklists, which. But I think goes with irritability (.) which is sensitivity to sensations, not wanting to, you know, sensitivity to sound, sensitivity to touch since it to, you know, just this sort of like irritable, like feel (.) like almost like embodied irritability where it's like, oh, I can't [hand gestures to show restless irritability](.) nothing like (.) certainly depression, anxiety. Mood swings. How many did you ask for? Sorry. **Interviewer:** It was like five to ten. You've done [pause] you've done seven, OK? **Debbie:** Yeah. Fatigue. Certainly physical symptoms for many people. You know, broadly?

**Celia:** Irritability, anger, mood swings, anx (.) Er, depression, anxiety. We see a fair amount of fatigue. Um, (.) some food cravings, um, (.) overall feelings of achiness and that sort of thing, although I tend to look at it differently. Pelvic pain is one of the more common symptoms when you look at the epidemiologic studies. When you look at research studies, I think those with significant pelvic pain premenstrually tend to be put in a different bucket. So but that pelvic pain is as one of the symptoms in general that women may express (.) er headache. (.) Um, difficulty sleeping, some women have (.) I think those are probably the top ones.

**Sarah:** Yeah. Well, I mean, the most frequent reported symptoms seem to be those; irritability, depressed mood, feeling of like they were losing control of their behaviours, er (.) breast tenderness, breast soreness (.) um (.) and bloating, general bloating. I think they're the most common ones.

**Thomas:** Yes. Top five or top ten? Well, it's the main (.) Sorry (.) [cough] for me (.) for me, it's mainly the psychological or psychiatric symptoms which are the top ones which are the most common with irritability and then depression as the main ones. Um (.) loss of control is a very common and anxiety [pause] That's (.) that's the most ones. And then after that comes the physical symptoms of breast tenderness and swell (.) swelling; bloatedness [pause].

**Susan:** Well, I've just kind of said that, so for speeding up (.) we can 'see previous answer'? [Answer to E9]

**Marta:** Not with any scientific certainty. I mean, depression, irritability, definitely mood swings (.) also very common (.) anxiety (.) very common. But for the rest of the symptoms I'm un (.) I'm not really sure. I would say that (.) appetite is very common. Or I mean, appetite disturbances is a very common symptom. I would also say that fatigue or lethar (.) lethargy? I don't know how to pronounce it. I think that's a common symptom. But that's a common symptom in all women. So, I'm not sure whether it's (.) it's really PMDD-specific or not. I think that the physical symptoms are also quite common, but that's usually not what's (.) what's er (.) the greatest problem for the women.

**John:** Yeah, I mean, in essence they read a bit like a list of the symptoms of depression. You know, the diagnostic criteria for depression. They're not that dissimilar. But er (.) the reason that most people present would be low moods, tearfulness, irritability, anxiety, suicidal thoughts, getting into arguments with their (.) er (.) peers or people at work? That's quite often the thing that actually leads them to coming here. But if you go through the (.) the other list and you ask people about it, they will say yes. So people don't usually come in and say, I'm sleeping more or less, but if you ask them if that's the case (.) or eating more or less. And they will usually tell you they are eating more premenstrually of things, they probably are not so good for them. Er (.) their concentration gets worse. But again, people don't tend to turn up with concentration issues as the primary thing. Um, I mean, I could go through the rest of the list, but I think the top (.) I've probably listed the top five.

**Laura:** So [long pause] probably the top one is (.) er bloating and breast tenderness? And I would say irritability is the most commonly endorsed (.) um emotional symptom (.) and depression. Um, changes in appetite. People crave carbohydrates. Um [long pause] Fatigue. Those are probably the most common ones.

**Zoe:** Um (.) the top (.) the top ten ones would be um (.) irritability, um, (.) emotional instability. It can be um mood changes. So, you know, I’ll call them mood changes. So sad and depression, um, anger. They can be um (.) cognitive changes, forgetfulness. Um, they can be cognitive changes such as heightened awareness and (.) and heightened attention. Um (.) and there are some (.) um (.) there are some physiological changes that that are associated, so there are some feelings of bloating, feelings of swelling, feelings of um breast tenderness and discomfort. So it's just a general um discomfort um (.) within and around the body. Um, there's interpersonal difficu (.) there are some interpersonal changes, so some um difficulties (.) er, wanting to be alone and feeling a need for isolation rather than um needing to be in company or wanting to be in company. Um, I don't know. I can keep going, but I think there would (.) they would be at the top (.) sort of the ones that come around.

**Geraldine:** Yeah, so water retention definitely is one, breast sensitivity is related to that, irritability is another one. Acne. Sometimes women say weight gain, but that's probably water retention. People don't really gain five pounds every month and then lose it again in a couple of days. So sometimes you hear people say things like "I feel kind of blue or sad or anxious". I'm sure you know that the original name of it was premenstrual tension, and so tension or feeling or easily stressed was uh what was being reported by women to their gynaecologists, initially?

**Chris:** Oh, yeah. OK. So, yeah, maybe (.) I may not get this right now, but er they are the ones on the top in the PMDD, of course. So they're depression, anxiety, mood swings, anger, aggressiveness (.) er (.) anymore? [Laugh] **Interviewer:** Um that's five (.) so you're alright with a top five. **Chris:** That's five. Yeah? [Pause] And so (.) so this (.) of course there is also the question of how common they are and how important they are, 'cause suicidal ideation is obviously less common, but more important than anxiety. Perhaps?

**Jo:** Um, suicidality (.) premenstrually (.) um, I think mood disorders (.) I think the psychological symptoms are the ones which tend to be most destructive. Anxiety. Depression. And then sort of physical symptoms, I think are less of an issue. Breast tenderness, abdominal bloating, that kind of thing. And then of course, there's the impact that that has on functionality (.) day to day life. Managing to (.) to be successful. And the comparison between the premenstrual phase and the post menstrual phase is often the thing. I think that's the most stark. And I think that's why. Well, I think that's why women don't always try to (.) actually achieve suicide because they know this happened before. That if they can just get their head down and get through it, then they'll be okay for a bit.

### P23- Most common symptoms

**Alice:** I think the common ones like on, you know, in (.) on the NHS website or whatever it is, things like even (.) they'll say things like ‘mood swings’. Even that is questionable. And so they'll say mood swings, fatigue, pain. (.) Some water retention, some bowel changes, bleeding, Change in temperature. That’s probably some of the most common ones (.)

**Beth:** (.)Oooooh. I would say tiredness. Skin changes. Abdominal bloating, Fluid retention. Either constipation or diarrhoea. I guess, mostly constipation. I think some women would get diarrhoea as well. Lower pelvic pain before period starts (.) irritability, increased emotional lability, becoming more easily tearful. Gosh, what else? I've lost track of how many I’ve said so far!? Breast tenderness. General muscle aches (.) **Interviewer:** You've done 10. So you can feel free to stop or any more? **Beth:** Appetite changes, increased sugar cravings, increased carbohydrate cravings (.) there's lots (.) I probably I (.) I think there are a lot more. And I just can't list them off the top of my head at the moment.

**Dani:** I would say the most common are irritability, but I don't like saying that because I think that's unfair on how the person is feeling. You know, it may (.) may be a sort of, yeah, I'm going to say irritability. But what I mean is a sort of less (.) less kindness extension. Maybe? Er, pain. Cramps. Sensitive breasts. [Pause] what else? (.) Tiredness, unsociable-ness. Erm. What else? [Pause] I'm not sure (.) I think that's all I can think of.

**Emma:** Breast tenderness, headaches, mood swings, irritability, tiredness. [Pause] Food cravings. [Pause] Change in libido, would that even be classed as PMS? I don't even know [laugh]? I might have made that up! [Laugh] I think that's all I can think of.

**Gemma:** I'll start with that one (.) um, cos it's easy for me. Food craving (.) like food cravings. The empathetic thing. So like for me, crying (.) so a range of emotions and feeling very insecure. um, gaining weight. And what's another one for me? And having (.) feeling pain. Like experiencing pain.

**Faith:** I'd say for common (.) what I assume a lot of women go through (.) is cravings (.) um [pause] I don't want to call it 'snappy' um (.) **Interviewer:** Irritable? **Faith:** (.) reactive, irritable, Yeah, irritable! Empathy like (.) the emotions are easily triggered. Um, I'm trying to think what have I had experience of? Oooh, something that I didn't touch on before. Like sometimes like getting period pains before like getting like some sort of like pain or feeling like "Oh, am I on my period yet?" and not even just the pain like sometimes I feel like I'm (.) let me go and check my pants because I feel like my period might have started (.)? But I don't know, maybe that might be common? Like having the physical pain and I don't know if it's moisture (.) or I don't know what to call it? Before the (.) **Interviewer:** Yeah the sensation of the discharge or the flow (.) but there's nothing there? **Both F&G:** Yeah! **Gemma:** [I definitely get that! **Interviewer:** Phantom discharge! **Faith:** That's it! [Laughter] **Interviewer:** That's what it should be called (.) **Faith:** It's got a real ring to it! [Laughter] **Gemma:** That makes sense.

**Helen:** Oh, sure. I would probably say, you know, weepiness, irritability, breast tenderness, cramping and probably bloating.

**Kathleen:** Yeah so probably I hear from women talking about swelling of the breasts, um (.) er (.) [long pause] Bloating of the stomach, the tummy, Um (.) maybe a downward mood swing, um [long pause] um (.) Oh! Spots, acne, I think sometimes, um (.) general tiredness.

**Aisha:** Anxiety, depression, suicidal thoughts, the cleaning, the food cravings, the anger, um and (.) um what do I know (.) how many did you say? **Interviewer:** Top five. I think you've got five. **Aisha:** Yeah. There we go [laugh]!

**Mala:** Okay. So the food, a lot of (.) food cravings. It'll be like specific stuff sometimes (.) like cuisines or (.) yeah, it will be specific stuff that I (.) I do eat normally, but it'll be intensified. Um, and then emotional would be being irritated by someone. (.) Um and whatever they do. Like sometimes what I do get is (.) what (.) I get really (.) I always want (.) whatever I think needs to happen. I don't want nobody else sayin'(.) like if I've made a plan it needs to be MY plan [emphasis] (.) and nobody else's plan. And if they plan on changes, it really, really (.) it irritates me. **Interviewer:** Yeah? I'm like that all the time! [Laughter] **Mala**: It just really irritates me, like "Why can't we just do it the way I said it"? **Interviewer:** What about any physical symptoms like (.)? **Mala:** Oh, I get spots and bloatedness really really bad bloatedness?

**Noor:** Mood swings, food, bloating, your body just feeling weak, and the pains.

**Ria:** Mm hmm. So the drop in sex drive! [Laughter] I'll put that as number one! Because I feel like I notice it. I personally notice it the most and then in just talking. I like to always ask people about their menstrual cycle. So that's what I hear a lot as well. So drop in sex drive, um (.) greater (.) um, like more fluctuation in experiences of emotion. So like (.) yeah, greater (.) like greater changes and fluctuation as opposed to (.) yeah (.) maybe just having like a few waves up and down from like high vibe to low vibe in PMS. It seems to be like the changes are quite drastic. Three; increased food cravings, which is great and important because for the most part what I hear from people who are fertility awareness educators and do a lot of client work, especially with people who are trying to conceive, is that they're like, where's the food? Well, you're not eating enough [laugh], which is so contradictory to (.) um (.) yeah. What I see is a lot of focus on making (.), things like making people feel shitty about their bodies and body image. And so increased food cravings and then decrease in energy. So just feeling a bit more tired, feeling like you might need a bit more sleep, which again, totally OK, very natural. And then the fifth one. I would say would be just like a general slowness, a slowing down.

### E11- PMS v PMDD?

**Anne:** [Long pause] so [pause] so, I think I have gone into that, that PMDD is a premenstrual disorder that (.) and to be diagnosed as having that (.) it's a definition that was put together by the (.) the American Psychiatric Association as in the 'DSM', the 'Diagnostic and Statistical Manual of Mental Disorders' number five, and those five out of eleven symptoms need to be demonstrated. One out of the first four, which are all psychological symptoms and [pause] the true definition of PMDD (.) actually, it doesn't include exacerbation of another psychiatric disorder. So again, I think that excludes quite a number of women, whereas PMS premenstrual syndrome. Erm, that I mean, if we're looking at the actual definition, I know people refer to PMS in a lot of situations, but the premenstrual syndrome, that's the American Congress of Obstetrics and Gynaecology. And that definition is one out of six mood symptoms and one out of four physical symptoms (.) does include exacerbation of another psychiatric disorder. Or (.) both do require significant impact on quality of life. So I think what I've described is the (.) specific criteria for the definitions of PMDD and PMS. But I think we do use those terms much more loosely across the board.

**Barbara:** PMDD is a severe dysphoric form of PMS that is defined in the Diagnostic Manual of Mental Disorders. The diagnosis requires 5 of 11 SPECIFIED symptoms. At least 1 must be a mood symptoms and only 1 physical symptom can be included as a qualifying symptom. The symptoms must be documented in relation to the menstrual cycle for at least 2 consecutive cycles.

**Fran:** To me, PMDD is at the most severe end of the spectrum of premenstrual symptoms, again, as I was saying in my first answer, maybe 80% of women have some premenstrual symptoms, but 20% of women, they notice it, it lasts a couple of days, it’s not that severe that they can’t get out of bed or go to work but in 5% of women it does affect their functioning and quality of life for several days, and they often seek treatment for the symptoms, and that’s PMDD.

**Andrew:** Yeah, that's easy to understand. I try to explain (.) at first and that is the severity criterion that you don't have in the normal PMS definition. According to DSM. There should be a clear cut burden. It should have a social impact or a marked distress, et cetera. So that that is an important distinction. And I think that is important because I think you have an over-diagnosis if you don't have that that criteria. Secondly, the and of course, by (.) by (.) by definition, you erm (.) for the DSM PMDD diagnosis. You must have one of the four cardinal mood symptoms. And that is quite reasonable because DSM is a, of course, at list of psychiatric conditions. So someone with only breast tenderness or only bloating wouldn't fit into that context. So (.) so you should have (.) and the other major definition, of course, is that you should have (.) you should have at least one of the major symptoms should be one of the mood symptoms. Then they have kind of a compromise. They still have the somatic symptoms in the list of symptoms. But it has a (.) they are all lumped together in number eleven. So they give the somatic symptoms much less emphasis than the mood symptoms. And I know that this has annoyed some gynaecologists regarding the somatic symptoms (.) as very important. So they are not very pleased with that. There is kind of a debate in this PMD researchers. Where, the gynaecologist camp mostly believe (.) they don't very much like the DSM definition because they think the somatic symptoms are given too little emphasis. And you have the psychiatrists that (.) some of them would exclude these somatic symptoms altogether. So this is kind of a compromise [laugh]. I don't know if you are aware, but there is also the ACOG criteria. The American College of Obstetrics and Gynaecology. And that is in some extent similar to the DSM. But they require only one symptom that should be severe enough, and that could be either a somatic or a mood symptom. To this (.) I could add that I (.) it's a (.) I'm a bit sceptical, though. I have no good alternative, but a bit sceptical generally for the tendency in DSM to (.) to demand a certain number of symptoms for this condition. There should be five symptoms. That is, of course, entirely arbitrary. It could be four or three, six or two or so. So in that sense, I think (.) I think they have a point in ACOG that the one symptom, if sufficiently severe should qualify should meet the criteria. I think that but I then think that you should have different names for (.) for the somatic complaints versus the mood complaints and some have both, of course.

**Debbie:** [Intake of breath] Well, I'll preface this by saying I think some people say PMS and mean PMDD and some people mean mild (.) some people say mild PMDD and they mean PMS. I don't think that they're (.) functionally different things. I think that (.) by the time somebody gets to a level of severity, you know, sort of this like bell curve, right? Of you've got PMS somewhere down here and then it turns into PMDD. But what I would say about my (.) way of thinking and talking about it is that PMS is like a rather a small chunk [laughter] over here that is (.) truly not impairing. And the reason I say that is that a lot of people are like, "oh, well, you know, I don't really meet this like big criteria set, you know, whatever. But it's really interfering with my life". And I'm like, okay. Then you have PMDD (.) like that is good enough, right? Like if it's interfering with your life. You probably do have (.) maybe you're not using the same words that are in the (.) the thing. But if you (.) if it's interfering with your life, if we dug deep like you probably do have five or more symptoms that turn on and off, you know. Oh, so (.) so (.) yeah. So I guess my (.) what I would say is that PMS is the like very mild left most tail of the bell curve that is PMDD biology and symptoms. And it's, you know, a large section of women that have some cramping and even mild irritability for an hour or something like that, you know. But then. But then the rest is sort of like anywhere from. you know you start to move around the bell curve. And it's like, okay, now you have people who like every third month will have, you know, a more severe (.), for whatever reason will have a more severe set of symptoms. And they're really having a lot of cramps and stronger irritability where they might have a fight with their partner. And but then it kind of goes away after a day, you know, and then you move over where there are like people basically have a fight and, you know, you have problems with productivity for three or four days, but they can still sort of get away with it. And then, you know, it really goes over to the like suicidal every month and like, really can't cope for two weeks. Right? So I see all of that as a continuum. And to make things nice and complicated, I don't think people necessarily stay in the same place on the continuum. Like, I think a lot of people say, like, "oh, after I had kids or as I age like (.) it got more severe before, it was like really mild and it never bothered me". Other people say like, "oh, you know" [pause] "You know, I used to have some of that, but it's gotten better". You know, I have heard that from people. So, yeah, that's how I would say I would say it's all just a continuum. But I'm (.) I don't disrespect or think that there's anything wrong with people who use PMS instead of PMDD to describe. It's just the (.) it's just the way that my culture and community kind of talks about it. So it works better for me.

**Celia:** [Pause then audible intake of breath] Well, PMDD originally came about as a (.) as a psychiatric er addendum. So in that sense, an individual had to have a moderate to severe psychological or psychiatric symptom such as anxiety, depression, irritability, tension, that sort of thing. Whereas based on the umbrella of PMS, you could theoretically have two severe physical symptoms like fatigue and breast pain, for example, and not have any mood symptoms. And if as long as they're bothersome or intrusive, that could be considered PMS. So my impression is that the PMDD is a subset which (.) which includes at least one moderate to severe emotional symptom [pause] and has to include five symptoms as opposed to maybe three symptoms or two symptoms (.)

**Sarah:** Well, um that's [PMDD] more tightly defined. So now we're getting to the more serious type of disorder. That's the 5 percent (.) I was talking about before. And er, these er, to qualify with this they must have the mood component symptoms. Sometimes (.) you know the majority (.) the most prevalent symptoms are actually the physical symptoms. That's something you get from our epidemiological studies in different countries, it's the physical symptoms that are most prevalent. Um, but for the psychiatrists [laughter] of course, that's what they're most concerned about (.) it's not women coming with [laughter] mastalgia. They're going to go to their gynaecologist or a GP but (.) but you know, they're gonna be referred the woman with the really problematic depression who may be suicidal at that time. Um, you know, that becomes a real issue.

**Thomas:** I think it's (.) well, that's my opinion, there might be different opinions, of course, but my opinion is that it's a question of severity. It's actually the same condition. I would say. And it's only that certain persons are more, let's say, sensitive to these hormonal changes than others. And we have actually shown that there are (.) that patients with PMDD are more sensitive or differently sensitive than the controls which have with the contrast group, which are those without any symptoms, any cyclicity in symptoms. So, so and those of course, exist as well. And whether (.) and it seemed to be a genetically (.) a genetic factor, because if you ask the patients, it's very often that there are PMD (.) PMS in their relatives, mothers, sisters.

**Susan:** Severity. Well, on the one hand, I’d say severity, but I would say briefly the difference between PMS and PMDD is that PMDD is in the DSM and PMS isn't. Um, PMDD is used as a justification for positioning women within the psychiatric discourse much more formally. Um, it's used as a justification for giving women psychotropic medications. So SSRIs and officially women, particularly in the U.S. where the DSM operates primarily. But it also is used [elsewhere]. PMDD is a formal psychiatric diagnosis, so that's the difference between PMS and PMDD. But in terms of what it (.) how menstrual cycle researchers tend to use it is they'll say women with severe symptoms have PMDD, as if it's a thing and women with moderate symptoms have PMS as if it's a thing. But they're both social constructs, they are both diagnostic labels that are created by clinicians and yeah know we know the diagnostic history, you don't need me to go through it. From going back to Frank and Karen Horney in 1931 to try to Dalton to a LLPD to PMS and PMDD. We've got a whole history of psychiatric nosology here, which actually is giving a label to women's distress. So how it's framed is that PMDD is the extreme end of the continuum.

**Marta:** In my understanding, I mean, I see PMS as a milder condition. And I think of it. I mean, from my clinical practice, I think of it this way, that women who take (.) who bother to come and see me, I (.) I simply just assume they have PMDD because otherwise I mean, you have to wait long time to see a gynaecologist for your problems. And I would expect then that women who specifically seek medical (.) medical care for (.) for [indicates air quotes] what they call PMS, they really have PMDD and I (.) I'm also guessing that the great majority of women with PMS I never see in the clinic because they find ways to cope with it or they can probably handle it by use of contraceptives or (.) or over-the-counter drugs or physical exercise or other sort of lifestyle interventions. That's (.) that's just the way I see it from (.) from a clinical perspective. I mean then of course we have the different criteria for 'scientific' purposes. But if you ask me how I see it, I think it's a matter of severity.

**John:** Well, I think PMDD is an attempt to er [pause] fractionate out the subgroup of women that have got the worst [emphasis] symptoms, but also a group of women where it's not an exacerbation of something else (.) premenstrually but something that is (.) uniquely separated from it and (.) Yes. So I think that the key differences are the severity. In as much as one needs to have (.) er (.) several different symptoms, um three of which need to be from er (.) a specific group. Um, in addition to (.) it not being exacerbation of something else. But that's what differs it from (.) that differentiates it from other diagnoses.

**Laura:** So there are two cardinal features that differentiate them. One of them is the obligatory emotional symptoms that occur in PMDD and they're not obligatory in PMS. And the second is the degree of functional impairment. So impairment is much greater with PMDD than PMS but PMS is kind of (.) or PMDD is a subset, if you will (.) of PMDD [correction] of PMS. So there's this larger group with PMS and then there's this subset of people who have emotional symptoms and it's really impairing, you know. And then there's nuances like you have to have 5 symptoms out of whatever. But. Yeah.

**Zoe:** [Pause] [cough] I'm sorry for that cough. Well, clinically, there's I (.) I (.) I think legally and medically there are differences um that come down to um classification and status. So (.) so (.) so one set of differences are around um the need in some jurisdictions and under some insurance schemes to actually receive a diagnosis in order to have access to services and access to care. So that's one difference between them. Um, simply the difference could be seen as one of severity, but then that suggests that they're on a continuum. And I don't necessarily think they are on a continuum, but I think people would assume they're on some sort of continuum. Well, many people assume they're on a continuum. Hence, um PMDD is just the extreme end of PMS, I don't necessarily think that's the case. No, I don't think there's the evidence for that. It's a difference (.) [sigh] I don't know they (.) they are blurring because especially again, in some cultures. In some. [skype delay] some women believe (.) some women who may have something that is much more like premenstrual distress or just premenstrual symptoms may choose to identify and classify and adopt (.) labels like PMDD because they're looking for um (.) there can be comfort in a diagnosis, whereas there's not necessarily a comfort um in just a set of experiences. It's natural that they're finding them distressing [pause]… Um, I think there are real differences in in terms of how (.) what it means for women who are either positioned this way or take up that positioning. And we can have a really long (.) you know, that's a long one there. As I said, some people find comfort in a diagnosis and some people don't. Some people (.) and some people are labelled and can be stigmatized with the diagnosis and but others may not necessarily have that experience. Um, I think they are different conditions. I don't actually (.) the evidence that I have come across and in the research that we've done ourselves. Women with PMDD present differently to women with just severe PMS. I don't think that (.) they're at the end of (.) um (.) it's just a more extreme form of PMS. I think they're actually something very different.

**Geraldine:** Well [exhale] the psychiatrists say that PPDD is more serious. But, you know, a smart alecky comment about it would just be "Who are you going to to get some help?" So, if you're going to a psychiatrist. You're going to get a PMDD diagnosis. If you talk to your general practitioner or your OBGYN, you (.) you're going to get the PMS definition or diagnosis. They overlap so much. I mean (.) [Exhale with slight laugh]

**Chris:** Er, that's in the (.) that'll be in the consen- (.) So um (.) my understanding is what came out in the Delphi consensus, which is PMS is the widest definition of the widest amount of severity for (.) for which if you don't consider PMDD, there will be a very severe group which are identical with PMDD that's 3 to 8 percent. With five to 8 percent, let's say 5 to 8 percent. And the PMDD is the (.) there (.) there are three categories of symptoms/ of patients, ones with purely [pause] the psychological symptoms; ones with purely physical symptoms; and ones with both and PMDD can include the most severe end of the spectrum of psychological ones where they can have physical symptoms as well. But the (.) the (.) the (.) the (.) they (.) they're not really considered to be important. **Interviewer**: So to your mind, PMDD is almost a subset of PMS? **Chris:** That's what (.) we that's what we said. It's the it's the (.) it's the severe subs (.) sub (.) subgroup, predominantly psychological.

**Jo:** I think that's just um, [pause] UK/ states thing. I don't think they're any different. I think it's just um how it's been identified in different countries. And I think, now, actually, women are becoming quite drawn to the whole PMDD as a diagnosis, maybe because it's new and maybe because it would be given more credi (.) credibility, but they're [laugh] in my opinion, the same thing.

### P20- Have you ever heard of PMDD? If so PMS v PMDD?

**Alice:** No.

**Beth:** I have heard of it. I'm not sure I would have heard of it, if I wasn't a doctor, although (.) well, it's difficult to say because as someone who has PMS I've Googled a lot and PMDD does come up on Google searches. So I might, I might have heard of it, even if I wasn't a doctor. But what (.) what I understand in relation to your other question is that it's (.) it's low mood akin to the symptoms of clinical depression. That occurs (.) premenstrually (.) but not for the rest of the cycle, so I guess it would be symptoms that are confined to the luteal phase of the menstrual cycle, so this is the latter half after ovulation. But the woman was okay the rest of the time. So it wasn't like a (.) persistent depression (.) but was sufficient to cause (.) so the mood disturbance was enough to cause problems in day-to-day life and functioning. That's what I understand. **Interviewer:** So how is that different to PMS or what's the relationship then? **Beth:** [Long pause] well, you can get a bit irritable and tearful (.) before a period (.) PMS (.) but not to the extent that it (.) might be classed as a clinical depression. Whereas PMDD would be a more significant mood disturbance, but the timing of the symptoms would be the same for it to be classed as premenstrual. If that makes sense? **Interviewer:** Yeah. Brilliant. Thank you. **Beth:** PMDD is actually classed as a psychiatric disorder, I think, whereas PMS, isn't (.)? Am I right with that? I don't know (.) **Interviewer:** You are, yes! This isn't a test, this is this kind of because (.) **Beth:** Oh no, I just like to know these things! [Laugh]

**Dani:** Yeah, I've definitely heard of it. I think that it is a much more extreme version where like the person suffering from it can actually feel suicidal and [pause] incredibly unstable and unhappy at certain times. So right before their period. But (.) I have a couple of acquaintances who've suffered from it. And it's basically sort of, not ruined but basically upended their careers because they were unable to be in the workplace because of it. But yeah, very under (.) under known about. That's not a word! Erm, problem I think.

**Emma:** Yes. I have heard of PMDD. And the way I see the difference. I'm not sure if this is clinically accurate, er but it's the (.) it's the severity of symptoms and it's the impact of symptoms. So PMS usually can be self-managed and it usually doesn't cause that much of an impact in everyday life. But PMDD has (.) some severe psychological symptoms that that are debilitating and that do impact everyday life. It is disabling. It affects relationships. It affects (.) jobs, careers, friendship, family, life, work. It just impacts every part of life. It's very difficult to self-manage. But I think that's what the difference is and also the fact that it only affects a small number of the population. Whereas PMS is (.) fairly (.) well, it is common and I guess experienced by the majority of women. PMDD is only really experienced well we think (.) only experienced by around 8 percent of the population. So (.)

**Helen:** Yes. So as I said before, you know, my understanding of PMS is it's a collection of symptoms that may or may not impede with your quality of life, depending how severe they are. But when we start crossing into PMDD is when you're having a severe emotional reaction or psychological reaction to (.) to the rise and fall, of your reproductive cycle. So some big red flags are going to be interpersonal uh relationship (.) you know, trouble with interpersonal relationships. So big problems with other significant others, with work, your (.) you know co-workers and family members, your friends. You know, in the most severe cases, we're going to see, you know, depression, suicidal thoughts and behaviours. And that's when we know we're probably dealing more with something like PMDD. Unfortunately, you know, while research has some good leads. We don't know why there is a difference in those with PMDD. We generally see everyone has the same level of hormones with and without PMDD. There's, you know, everyone pretty much has the same level of hormones. But there is something in the brain that is responding in a very different way to those hormones in those with PMDD.

**Kathleen:** [Long pause] I want to say no. I feel like I probably heard it at one of the workshops at the women's health things [interviewer and interviewee are both members of the same network], but I don't (.) I don't know.

**Aisha**: I know that it's a lot more intense. You feel more like high emotions, like suicidal, which sometimes I feel I have (.) 'cos I've felt really suicidal. It's lower mood. Stronger feelings. Is that correct? **Interviewer:** Uhuh, yeah. **Aisha:** That's what I feel. Interviewer: And have you ever talked to your doctor about maybe having that? **Aisha**: Erm I think I mentioned it but again he's just been [pause] I've not been diagnosed with that. I've been more diagnosed with borderline personality disorder instead (.) **Interviewer:** Uhuh. And so did you see a psychiatrist for that? **Aisha:** Yeah **Interviewer:** And did they ask you about PMS? **Aisha:** No, no. not at all. **Interviewer:** And they didn't ask you to track your symptoms? **Aisha:** Not at all. **Interviewer:** So that was just based on what you were saying (.) **Aisha:** Yeah **Interviewer:** Without thinking about your cycle (.) **Aisha**: So it annoys me to be fair. **Interviewer:** Yeah. So are you on any medications for that or is it just you get the diagnosis and that's it? **Aisha:** No treatment, nothing. **Interviewer:** Hmmm. that's not very good. **Aisha:** I know. And I went through the whole 'getting assessed'. And then they're like, oh, they feel as if obviously I do have a borderline personality disorder. But treatment at this time would not be suitable. And I was really, really angry. But then I asked questions like "how many people a year get to get this treatment?" And it was about 15 a year. So I'm just thinking maybe that's possibly why? **Interviewer:** It's like the lack of resources? **Aisha:** So, it's resources and stuff. And then now I'm gettin' (.) because it's been six months since I've been diagnosed with that. So I'm getting referred to that again, so I have to go through the whole assessment again. And hopefully (.) **Interviewer:** Um, definitely bring up that it gets much worse (.) **Aisha:** During my periods (.) Interviewer: And the suicidal thing. Definitely mention that because for PMDD now, that's one of the key kind of things (.) they look for (.) **Aisha:** Yeah. So it's like [sigh] so annoying. **Interviewer:** No, it's not (.) I mean, it's really not good to get given a kind of label. A diagnosis and then for nothing else to happen (.) **Aisha:** Yeah (.) No I've (.) all my life. Because I feel as if in the past they've also done Cyclothymia (.) So my moods will change every three, four months. Again, I think that's a lot to do with PMS. Do you see what I mean? The older I’m getting the more exposure I'm getting to this stuff (.) book (.) more books. I'm reading about periods. I'm realising (.) I've been misdiagnosed. And you know when you have it (.) if that makes sense? **Interviewer:** Yeah. I mean, there is (.) so it's very difficult to know whether someone is pure PMDD or whether the menstrual cycle is like triggering (.) **Aisha:** Yeah yeah yeah (.) **Interviewer:** A mental health issue, because in some people it could be that, and in some people it might be the other. But at least if you know that there are different options for treatments (.) **Aisha:** Because then again, the borderline personality disorder, it does make sense because obviously, I've been raised (.) by my mom, single parent. So then that (.) abandonment has always affected me. So (.) then I think matching up the whole history. They're probably thinking, oh, right. So I don't know. **Interviewer:** Yeah, they're already putting you in a particular (.) **Aisha:** I don't know. I really don't. But then again, my sisters haven't been affected at all. And recently, I know my sister has PMS [laugh] if that makes sense? **Interviewer:** Yeah yeah. **Aisha:** Because the more I'm telling my symptoms, I'm really close to my sister. She's realizing 'Oh my god' she's been tracking it and she's PMSing, too. And um, yeah, my older sister's is totally in denial about it. So, yeah. I dunno. **Interviewer:** It's hard to know, I'm the same (.) my mom bought us up alone. And whenever you mention that to a psychiatrist, you sort of see them (.) Aisha: Mental health [Overlapping] **Interviewer:** [00:24:55] Think, oh, 'trauma' you know, you were traumatised as a child (.) When really, where I grew up. Everyone only had one parent. **Aisha:** Oh! (.) **Interviewer:** So it was very normal. **Aisha:** Yeah. **Interviewer:** And sometimes, yeah, I think maybe they stop listening after they have decided [laugh] **Aisha:** This is interesting (.) it really is interesting.

**Mala:** I haven't, no.

**Noor:** I have, but not like in depth just of that. The PMDD… I don't know, but I think that one is more of the intense one. So, people that have the PMDD find it much harder?

**Ria**: So I have heard of PMDD and the first time that I heard about it was going (.) joining a couple Facebook groups on (.) or looking up menstruation basically on Facebook and seeing what Facebook groups there were. And I noticed that there were a few PMDD support type Facebook groups. And so I asked to join them because I was curious about what people were talking about. And from my understanding, I mean, mind you, Facebook is already biased and just has like spiritually, there's just a lot of anger and frustration and et cetera in that space. It was (.) it was honestly heart-breaking because I think it's people who (.) what I imagine is something is up with their progesterone, maybe their progesterone levels are really, really low or whatever. I can't (.) as I'm not like a clinical researcher, so I can't comment on that. I don't test their hormones or anything. I'm just basing this off (.) on my own observations. But yeah, I noticed that they were very, very angry, very sad, very depressed, really like low, low vibrational emotions. And so I guess I can say that the difference between PMS and PMDD, according to my understanding, is that PMS is commonly used phrase that people understand and associate with the autumn cycle of an average menstrual cycle. And then PMDD is a word for the autumn phase for people who not only experience an average menstrual cycle like the physical aspects of it, emotional, mental. However, I think that it's um (.) because of what's going on with their body, mind and spirit. They're experiencing an extreme case, an extreme feeling and sentiment of that shift and drop that happens when oestrogen comes down (.) and progesterone hopefully goes up and helps bring up some of those serotonin and the neurotransmitters and all that stuff as well. So that's the physical piece. And then I would have to talk to them individually, probably to figure out where the spiritual and emotional piece of it is, because it could be, you know, like maybe they've experienced an intense amount of trauma in their life, sexual trauma. And so that's manifesting in this way. And then they go presumably go to see a doctor because they're like, "I feel fucking crazy". And the doctors, like you have this thing called PMDD because it seems to line up with the autumn phase. So that's my short, I guess, understanding of what it could be. And then there are few folks in my network who feel like they strongly identify with that. And it gives them (.) that it like helps them cope basically with it.

### E12- Do you consider period pain to be a premenstrual symptom?

**Anne:** [Pause- sigh] Yes, I do, because it is one of the common physical symptoms [pause] and I suppose why some people may question that is that they regard most premenstrual symptoms as being psychological in nature. But I would say that in premenstrual disorders. You do have to take on board the physical symptoms as well. And you know, if a woman is suffering with premenstrual disorders, to have premenstrual pain can be (.) erm, can have significant impact [slight laugh] on her quality of life. And it's important to know about (.) because, again, there are some very good treatments out there to address that. And, you know, the symptoms, some of the treatments, that I've talked about to approach a woman's management with PMS will also help premenstrual pain as well.

**Barbara**: NO. This is dysmenorrhea. The treatment is specific to the disorder. Why?

**Fran:** Do you mean during the flow or prior to the flow? **Interviewer:** Um, I suppose either? So, would you if it was before but not with the flow? **Fran:** I think cramps can be a premenstrual symptom but I wouldn’t call it menstrual pain unless flow had begun so, cramps, or abdominal or pelvic pain can be premenstrual symptoms, sure.

**Andrew:** I don't. I don't. And I think there are few that would do that. Even those that have a very broad definition of PMS, they would usually not include dysmenorrhea, that (.) this would be a pre-menstrual thing and it should even if it doesn't stop immediately at the first day of menses, it should be (.) it should be gone within one or two or three days after menses have started. So (.) those are different things (.) most would claim.

**Debbie:** If they're premenstrual! [Laugh] **Interviewer:** So, it's just the timing? **Debbie:** Yeah. And you know, from the perspective of the DSM 5 and I think also the ICD 11 now, too. The idea is that we sort of ignore what happens for the first four days of menses and anything that happens like (.) as a (.) when it comes to diagnosis. So if you have really severe premenstrual cramps that continue into menses, as long as they're sort of minimal to absent by day 5, then that's gonna be a PMDD symptom. But if somebody has like no symptoms until their period starts, then technically I think we would call that dysmenorrhea. But I don't know that we have any evidence that the biology is different. It may not be a real distinction. But from a like current diagnostic standards [laugh] like that, that's what we would say.

**Celia:** [Pause] I have to say that (.) that I wouldn't necessarily. I would like to evaluate and look at it in a different context. But when women are asked about their premenstrual symptoms, that's one of the more common ones. So I think there's some disconnect there. But particularly from some of the studies that [colleague's name] did potentially with the [pharmaceutical company name] group, I think they did find a lot of abdominal pain complaints. But I tend to look at those patients with two different problems, or at least I try to see if there are two different problems, potentially (.) a gynaecologic aetiology (.) and then the PMS /PMDD aetiology. **Interviewer:** That's interesting. So it's not the case (.) or the fact that there are different treatments available for that? It's more that you think there could be two different (.) or co-morbid, you know, co-morbid, physiological gynaecologic things? **Celia:** Well, that would lead to two different treatments. Yes. So if someone (.) if we thought someone had endometriosis, for example, although they both may be treated with hormonal contraceptives, they wouldn't treat endometriosis with an SSRI.

**Sarah:** [Inhale] No. Um, dysmenorrhea (.) I would see as a different condition, different aetiology.

**Thomas:** Not really, not really [cough] it's (.) it's very (.) well, it's (.) it's not uncommon that they are combined. So they both have PMS and let's say it's dysmenorrhea. But there are many with dysmenorrhea that don't have PMDD. So it's (.) it's not the same condition. That's according to my mind.

**Susan:** [Inhale] well, period pain, no. It's dysmenorrhea because that's happening during menstruation. But many women do experience changes that go from the premenstrual phase through to the menstrual phase. But technically, any (.) PMS stops when menstruation starts. But I think in terms of understanding women's experiences of their bodies I wouldn't make that distinction. So some of the work I'm doing at the moment and working with PhD student [name] where we're using body mapping to look at PMS and women's experiences with their bodies, how they see their bodies (.) pain is something women talk about a lot. And so I would from that point of view, I wouldn't say, [puts on stern voice] "no, no, you can't include that because that happens when you menstruating. So we're going to draw a really big red line here and say, you're not allowed to include that as part of your experience". But of course, it's part of women's experiences. If they're feeling emotional changes and feeling bloating, then they start bleeding and they have pain, then it's (.) they (.) they're not drawing a great red line through that experience. That's all part of it for women. And I think anticipation of dysmenorrhea, for many women, could be a cause of anxiety, particularly if they have severe dysmenorrhea or they have endometriosis. And we're getting more and more aware of the number of women who do have endometriosis.

**Marta:** No, I wouldn't because I'm a gynaecologist. I would say that's dysmenorrhea or potentially endometriosis… I think it's (.) it's a big misunderstanding to include cramps in the PMDD diagnosis, first of all, the cramps, don't (.) they usually happen (.) once the menses start. And I think it would be unwise to incorporate it in the PMDD diagnosis because that would mean potentially we would miss (.) er the opportunity of an endometriosis diagnosis instead.

**John:** Erm (.) no. That would be dysmenor- (.) that would be yeah, dysmenorrhea. For which there are a different group of treatments.

**Laura:** No. [Definitively spoken]

**Zoe:** No. I see it as a menstrual symptom. Um, If you're talking about period pain, then there are changes pre period, which are menstrual symptoms, but no, I don't consider period pain a PMS (.) to be a PMS symptom, no.

**Geraldine:** No. [Immediately] **Interviewer:** Why is that? **Geraldine:** Well [pause] because it happens during menstruation and not before menstruation. However, you know, when I talk to women, particularly when I would talk to my students about this, they would always mention cramps, as a symptom of PMS (.) you know, I would try to explain to them that that doesn't make logical sense. But, you know, it's another example of how fluid the boundaries are across the cycle phases. You know (.) at what time in the cycle are symptoms considered PMS? And also I think dysmenorrhea is just something that most women don't know that term. You know, that we used to talk about cramps a lot when I was young. That was the main thing people talked about, not any of these other things. But now it's all wrapped up into one giant lump called PMS.

**Chris:** Technically, it can be if it's premenstrual. Except that it's not typical um (.)PMS. It's pre (.) premenstrual period pain i.e. before the period (.) more typically associated with endometriosis. The definition does allow that (.) of PMS, it doesn't allow it for PMDD. [Pause] so it's not (.) it's not uncommon for women to have both severe PMS and premenstrual pelvic pain.

**Jo:** Well, it is a premenstrual symptom, but I don't think it's part of this diagnosis [long pause]. It can be a premenstrual symptom.

### P24- Do you consider period pain to be a premenstrual symptom?

**Alice:** I mean, for me, it's not because I think I think there's some confusion generally about ‘premenstrual’. And I think if you are to ask a layperson, I mean, I don't want to sound sexist, but if you were to ask (.) that doesn't ever experience periods, which is the opposite gender. So, men, they often just think of the period and PMS, as the bleeding time. So that five days of that week they think of it as that. I think that's what they think. So when you talk about pain. Well, for my experience is that the pain only happens when I start when I start that bleeding process. So that in a way that's not premenstrual pain. I don't experience any pain before the bleeding starts. I might get some pain before the physical sign of the blood arrives, but I know I'm about to bleed that day, so it might be a couple of hours before the (…) or the morning before the blood arrives. But I consider that as the bleeding day because I know it's going to come that day or might be four in the morning when that happens (.) eight the next morning… So for me, that's when the when the bleeding will start (.) the pain. If you wanted to talk more about the pain, [sigh] the pain. So I suppose for me, the pain is immense. At that time and the pain can vary from if I'm having a normal period or just be (.) it'll be painful, but I never feel I really need to take any drugs. But that could be because I know what it's like for it to be extremely painful that I just manage that type of pain and that’ll be cramping, throbbing. Like a few sort of fireworks down in the sort of lower abdomen area. I suppose you could describe it like that and it will come in waves. So it will happen and then it will get a bit of relief and then happen again. And get a bit of relief and that’s happening on day one or day, two. And then I won’t have pain for the rest of the week. But if it's like one of those terrible experiences. The pain is like more than 10 out of 10 pain and it will start gradually and then it will build and then that build will happen for a good couple of hours. And I've not ever had a baby yet, but I imagine it's a bit like having contractions. **Interviewer:** So like you have waves again? **Alice:** Yeah, so it's all waves and then I'll get maybe 30 seconds of off. I can relax and then it’ll come again and then it builds and builds and builds and then I'll vomit. Oh, and the other thing that happens is I like when, you know when you're gonna pass out for whatever reason, you've got an illness. I get incredible (.) I know it's happening because I get so clammy and sweaty and hot. And I think I'm going to (.) I can’t stand up, I have to lay on the floor and I will get that layer of like (.) I will get drenched. I will be absolutely pouring sweat. And then I will just projectile vomit and vomit and vomit, but I need the toilet at the same time. And I know when I reach that point, which is just horrible, I've reached like [laughter] a finale and then I'll be like, phew. It's over. But getting to that point is absolutely horrible. And then I'll be exhausted. So for hours, because it is just this bit of the process. And then I'll be fine. **Interviewer:** It sounds horrible [laughter]. Very well-articulated. **Alice:** Thanks, yeah. And then I'll go to work! [Laugh]

**Beth:** Oh, yeah. (.) Yeah, I think for a lot of women, it can be that the pain they get associated with the period starts before the menstrual flow starts. Yeah.

**Dani:** When it when it's pre bleeding, I would (.) but when it's actually during the period, I wouldn't I'll just call it (.) I'd consider it as period cramps. Yeah. **Interviewer:** So I suppose what I mean is, do you think period pain is part of PMS? **Dani:** No. No. I think it's (.) I think it's part of your period rather than pre. **Interviewer:** Ok, so it's about the timing for you? **Dani:** Yeah. Yeah. Well, just because it's premenstrual, it would suggest that if it's menstrual, then it's not premenstrual. For me (.) I guess. Yeah.

**Emma:** Huh? That's interesting. Because I didn't mention it. No, because in my (.) in my head I view premenstrual as before (.) the period and period pain I consider as part of (.) the bleed phase but (.) that being said, I get cramps around ovulation. I think (.) I think it is a premenstrual symptom (.) but the way I view it personally, is I (.) I seem to separate the two? **Interviewer:** Yeah. Well, this is why I'm asking the question, because it's commonly sort of seen as different somehow. You know, I mean, some people even get pain a day or two before they get the blood. But they still don't count it as premenstrual because I think it's basically a sign of the blood, if you see what I mean. So it's just a very interesting (.) **Emma:** Yeah, well I (.) I do. I wouldn't say it's pain, but I get twinges and spotting but again (.) I don't (.) I don't link that with (.) Hmmm (.) that's really interesting because I guess for me, that part is almost like a relief. **Interviewer:** Mm hmm. **Emma:** So maybe I (.) I (.) yeah (.) I've somehow compartmentalized it as something else?

**{Faith:** Yes, yeah, yeah (.) yeah.

**Gemma**: Same, Yes.}

**Helen:** I would, yes. **Interviewer:** And can you tell me a bit more about why you would? **Helen:** Oh, really, from my personal experience, but also because it's one of the symptoms we most commonly hear in those without severe PMDD. But I think again, it can be a result of exacerbation of an underlying disorder. For myself, I had such horrible period pain because I had fibroids, undiagnosed fibroids. I literally just thought everyone's periods hurt that much. But I didn't find out until I was pregnant and my fibroids enlarged and they were like, “Oh, you have these fibroids here. This must be what's hurting you”. So, yeah. So it's hard. I would say yes, it is. But again, it could be a premenstrual exacerbation of something else.

**Kathleen:** [Long pause] Um [long pause] I suppose it could be, yeah! I dunno, I wouldn't associate it very much with (.) yeah, when periods (.) like in the middle of the period. Or Yeah. I suppose so, yeah.

**Aisha:** No. [Pause] **Interviewer:** Why is that? **Aisha:** Because I don't necessarily (.) I find that (.) that must be another issue rather than PMS? **Interviewer:** Yeah **Aisha:** Because I feel that premenstrually it is more emotional rather than physical [pause] and that can ease with high dose of like medication, whereas PMS, you can't get rid of it. **Interviewer:** Uhuh. And do you ever get pain before you start bleeding? **Aisha:** I do. But it's not all the time, but it's not pain. Pain. Pain. If that makes sense? **Interviewer:** Like cramps? **Aisha:** Yeah. No, not even (.) I don't get that much pain, but I know that's a sign of it's coming. **Interviewer:** Yeah. So you feel it before it starts. **Aisha:** Did not this time round though. Oh my god, I've been gettin' slight, cramps but it's just not starting (.)

**Mala:** Yes, I do, because I tend to get it before (.) before my period. I don't really get much period pain throughout, only before and on the first and second day. That's it. My period pain is gone and um (.) it's not really. It's not really a hard (.) Like it doesn't (.) It's not really intensified. Shall I tell you what period pains I get(.) I get mainly back pain and thighs. My thighs ache and sometimes (.) I get pins and needles (.) that's it, really.

**Noor:** Yeah. **Interviewer:** Why is that? **Noor:** Only because the pain comes when you're on your period. **Interviewer:** So do you ever get pain before your blood flow starts? **Noor:** I do, yeah. That's true, actually. **Interviewer:** This is why (.) this is why I'm asking this question (.) it's difficult to know what's premenstrual and what's menstrual (.) and pain has traditionally been always associated with the flow. But actually quite a lot of people can get cramping before (.) **Noor:** Before.

**Ria:** I think it depends on the person. So I think for some people it might be. And I think it also changes cycle to cycle, because that's (.) one thing that we haven't touched on really. Is that every season of the cycle influences all the other ones. So if we think of it more like it's a cycle. But if we think about it linearly. We've got period, pre-ovulation, ovulation, PMS. And what we do during pre-ovulation and in our periods, like the foods we eat, the medicines we use to cope with trauma. The toxins we're exposed to, they I find that they show up the most during (.) Just (.) Oh, yes (.) [Connection problem 5 seconds] Sorry what was the question? **Interviewer:** Period pain. Does it count as premenstrual? **Ria**: So yes is the short answer. And then it depends on what was happening for the person in that particular cycle. And then also just dependent on the person as a whole in general.

### E13- Bloating

**Anne:** Tummy. Your stomach. So (.) erm, a feeling of sort of tightness (.) around the abdomen. I think, you know, if it is a pre-menstrual thing, it's sometimes related to fluid retention. I mean, there are lots of different reasons why women feel bloated premenstrually. So it can (.) can be associated with breast tenderness as well. But no, I would bloatedness. I would say is (.) more (.) if somebody said that, I'd be thinking that they're getting fullness around their tummy or stomach,. **Interviewer:** So do you mean trapped gas, maybe? **Anne:** Well, that's another cause of it. Yes. Yes. Just as in irritable bowel, it's very common. Or after a big meal [laugh].

**Barbara:** A feeling of enlargement or “fatness” in the abdominal region.

**Andrew:** Well, I would say that it's a sense of bloating, a sense of swelling. And I on the one hand, I am (.) I have never studied this. I've always been focused on mood symptoms. But on the one hand, I have heard from patients that have they have difficulties to remove the ring from the finger, for example, these days. So they have claimed that there is a (.) actual factual bloating, on the other hand. I know, for example, there is a gynaecologist researcher now retired, [colleague's name]. And I think he has done attempts to measure this bloating and failed to detect any actual bloating. And this (.) I (.) this guy that I (.) that once introduced us to the field of PMS a gynaecologist, I think he in his thesis, had similar data in that he couldn't actually measure any bloating. But I'm really not an expert on that topic. We have never studied that in detail.

**Debbie:** I always think of it as water retention, feeling sort of puffy all over. I think for a lot of people that it's sort of localized in the gut, you know, abdomen, maybe lower abdomen? Um [pause] Yes, I would say like could be like, "oh, my face is like puffy. I'm retaining water" or (.) oedema or, you know, that sort of abdomen bloating. **Interviewer:** By abdomen, do you mean kind of gas? **Debbie:** Yeah, yeah. Or sort of gas and but also just like the size of your stomach. It's like you're both upper and lower abdomen sort of feels larger. Like it feels like there's like swelling of some kind. That may or may not be gas.

**Celia:** Abdominal distention, um in general. **Interviewer:** So in general, do you mean both gas and maybe water retention or would you differentiate? **Celia:** Patients tend to say they don't feel more gassy and they don't necessarily complain of diffused water retention. But when (.) I think when it was studied years ago, they did find that there is more fluid retention in the wall of the bowel and the abdominal wall. So I think it probably is a fluid retention phenomenon. But considering it may be in the bowel, well also that may be why it's more problematic than just, say, water retention in your ankles or fingers?

**Sarah:** Um, women are vague about this, but they do have a feeling of abdominal fullness, would be perhaps one way of describing it. Um, they're not really talking about bloating of the legs or arms. Really, it's more around the abdomen. And they've often said they feel uncomfortable. You know, they don't wear tight jeans on those days or whatever? **Interviewer:** So would you think it's more kind of water retention or gas? Or both? Or (.)? **Sarah:** It seems to be a fluid (.) a fluid based symptom. I think that there have been various studies on it (.) and I think it's to do with (.) it’s a perception about the (.) um (.) it's not necessarily that they gain weight, but they feel like (.) that they have because of the bloating. **Interviewer:** Yep **Sarah:** So it's something that's happening with fluid moving in and out of the cells and how uncomfortable (.) some sensory mechanisms are triggered, which makes them feel uncomfortable

**Thomas:** Well, distension of the stomach and also the size of the stomach actually can. You can measure in centimetres with a ruler or a (.) or not a ruler [laugh] ruler, they say (.) **Interviewer:** A tape? **Thomas:** A tape. Yes. That's better [laugh]

**Susan:** Feelings of tightness and fatness in the abdomen, which for many women is incredibly distressing because it makes them feel fat and it makes them feel ugly and it makes them feel as if they don't conform to the expectation of a tight firm, slim, ideal female body, a woman's body. And I think it's been really overlooked as a psychological experience. And that's something we're looking at in the current work, because when it came up for me (.) I was (.) for a lot of our work we were interviewing women around PMS and so many women said, they feel ugly and hate their bodies. They hate themselves, but they hate their bodies, when they are (.) premenstrually. I think because they hate their bodies, they hate themselves. Because as women, we're so tied up with our bodies. So I think bloatedness, even though it's often seen as a physical symptom, I think it has incredible psychological implications that have been overlooked by a lot of psychologists working in PMS.

**Marta:** Um, The feeling of being swollen like you're (.) you're gaining (.) er (.) the women say they have a sort of extra fluid in their body. They feel almost like they're having a very mild oedema.

**John:** Yeah. It (.) it to me refers to a feeling that people have physically (.) er (.) experiencing a sort of expansion of their abdomen. And um people would say they will physically notice that. And so I think it's both a feeling and an experience of (.) yeah.

**Laura:** I think just a sense of like swelling, like your clothes (.). You know, some women will tell me that their clothes don't fit the same. They change a dress size. They just hold on to water. You know what I think if you're eating a lot of carbohydrates or salt, that can certainly (.) you can feel bloated.

**Zoe:** [00:18:10] Um, It would be. I haven't experienced it myself, but from accounts, um women describe it as a (.). feeling of fullness, a feeling of being distended, a feeling of um (.) er yeah just (.) just they also use words as (.) they use emotional words to describe when they're bloated as being 'ugly'. They see (.) they (.) they associate 'ugliness', 'fat'. All of these things are associated with being bloated. And they are the same sort of words that they (.) they're the words that they'll use when (.) often when they describe being bloated, they don't just describe being bloated in (.) as a physiological change they (.) they use a lot of these sort of emotional words as well.

**Geraldine:** I think it refers to water retention. Yeah. You know, feeling your belt is a little tight. Your bra is a little tight, maybe? Your ankles are a little swollen, so I think probably when people say bloating, they're probably talking mostly about abdominal. But again, you know, you hear that phrase and it's not well-defined. Kind of like. Another thing that women talk about a lot, at least according to popular sources, is feeling out of control. And when I asked women out of control of what, they can't really answer the question. So presumably it's emotional control, but they just say "out of control! You know, out of control!" [Puts on emphatic voice/ tone] [laugh] So, yeah, it's one of those things we hear and we don't really think about what it is.

**Chris:** Ok. It's abdominal distention. It may or may not be associated with weight increase. Patients feel like they've got a weight increase. I did some research where we looked at weight, abdominal dist (.) abdominal dimensions, breast size through the cycle. And we didn't show much change. So it was a symptom rather than major physical changes. And we also looked at the (.) total body water and the sodium and everything like that (.) we showed no changes there. What I actually think bloatedness is due to is- this is a thought rather than a fact- could be to do with redis (.) redistribution of fluid. But we didn't show that in the one study (.). It could be the effect on the bowel? And so if women get very distended abdominally and they (.) and they're not putting on weight, then progesterone acts on the receptors in the gut and relaxes it. And so you can get a build-up of gas and faeces (.) And it gets distended and then many women when their period comes they get diarrhoea as well. And a lot of gas, and that's what I think is happening. But I couldn't tell you that was factually shown.

**Jo:** Abdominal distention, discomfort. That's not bowel-related. Difficult to tell sometimes. **Interviewer:** So (.) so, you would be more along (.) some people sort of say 'gas'. Other people say more like 'water retention' in the (.) in the cells? **Jo:** Yeah, I suppose it could be either actually. Possibly to do with smooth muscle relaxation due to progesterone? I think that there are a lot of things that we just really don't know about PMS [laugh]. I mean, you ask me what cause and I'm thinking, "Oh, could be allopregnanolone. It could be anything to do with GABA receptors or serotonin receptors. But, you know, I don't think we really we know for sure.

### P25- Bloating

**Beth:** [Pause] I'm aware that it means different things to different people. But I would say I felt bloated if I felt bigger around the tummy. But I know other women might say they felt bloated if they felt more swollen overall, like they have tummy swelling and, you know, ankle swelling too and just felt more generally puffy. Well, I think there's a couple of causes, of premenstrual bloating, just feeling a bit more swollen that you tend to retain fluid. Like I know it can be usual for some women to, like, gain five or six pounds in fluid in weight because of fluid retention before a period. And that can just make you feel a bit more puffy overall. But also, if you tend to get (.) gut problems before a period, you can get more gas if you're constipated. You tend to get more bowel gas, which can also make your tummy feel bigger. And if you're more anxious, you swallow more air as well. So that can give you more bowel gas too. So I think there's a few factors in premenstrual bloating.

**Dani:** Oh that's another symptom. I forget about that [laugh] Just (.) just feeling like full of trapped wind basically.

**Emma:** For me specifically, it means water retention. It means [pause] uh (.) putting on a good few pounds, having a distended abdomen, I get bloating around my face, I get puffy eyes. So it's not (.) it's not just (.) bloating in the lower abdomen. To me, I feel like the Michelin Man [laugh]. Sorry, I shouldn't laugh, but I feel like a fuckin' marshmallow [laugh]. It's like, yeah, it's horrible. Really horrible. Yeah. **Interviewer:** And just to clarify again, when you say distended tummy, do you mean kind of trapped gaps that kind of (.)? **Emma:** Like gas (.) and I mentioned earlier, I get IBS. So constipation. Just generally heavy. Full. [Pause] that is (.) yeah, heavy is the word I would use, just heavy and almost like I'm carrying an extra stone, which is weird, but my face looks different. It bloats to the point where it (.) it (.) it actually looks different. Premenstrually.

**Faith:** Yeah, that feeling of like fullness and you know what you said about weight? Sometimes you feel heavier and you just feel like gravity is really pulling down on you and just that feeling of fullness. And sometimes like constipation goes with it. And just like even feeling like your body's (.) like your belly's firmer. So I think all of that contributes, in my personal experience, of feeling bloated (.)

**Gemma:** Temporary weight gain. Just temporary weight gain for me. Cos I just feel much heav (.) and I know (.) I know it's coming. So I know it's gonna go, so it's like a temporary weight gain.

**Helen:** Yeah, I'd say for myself, my gosh, I'd go up five to ten pounds during the premenstrual phase, just water retention stomach (.) it would be distended and just felt awful. I remember (.) yeah.

**Kathleen:** Um, it's when my stomach just gets much bigger in size and [long pause] Yeah, and that's (.) there's just a feeling of general heaviness (.) yeah, I think (.) I think that (.) I'm just trying to think if it feels in any other way? **Interviewer:** Do you feel like gassy? Or is it more like water retention? **Kathleen:** [Pause] Eh (.) mine doesn't feel gassy (.) but I dunno! It also doesn't feel like water, either. It just feels like there's stuff inside [laugh] It just feels really heavy.

**Aisha:** Oh I do as well! Um, if I'm really, really bloat (.), the term bloating is just feeling heavy, feeling fat. Yeah, I do get that. Just two days. If it sometimes gets really, really bad, then then I'll just start [menstruating]. **Interviewer:** So do you think it's kind of like gas or more like water (.) water retention? **Aisha:** Water retention. That's the worst. **Interviewer:** Yeah, I don't like it. **Aisha:** And then you weigh yourself (.) Oh, God!

**Mala:** So my stomach is (.) so um (.) what's that word? [Long pause] I find it really hard to go to the toilet (.) **Interviewer:** Constipated? **Mala:** Constipated! I'm constipated. My stomach goes really hard and big (.) and it's just really uncomfortable because (.) first of all (.) I feel like it's because I'm not going to the toilet. But then it's like empty air in my stomach because I'm not eating much (.) yeah, my food intake isn't very high (.) prior to it. I mean, during (.) after my period, when my period starts, my food intake isn't high- it is prior. So I'm eating a lot, but I'm not (.) unable to go to the toilet. And my stomach is bloated. So, I'm just like, "what is going on?" I need this period to start now! **Interviewer:** And then, do you get (.) when your period starts do you get a little bit of maybe diarrhoea? Like that it kind of releases that as well? **Mala:** Yeah. Yeah, yeah, yeah. I do get that as well. But that's only sometimes, not all the time.

**Noor:** When your tummy blows up and it doesn't feel the same as usual? **Interviewer:** Would you say it blows up because of like gas or maybe water or what do you feel (.) or like constipation? **Noor:** I think gas and the water is definitely (.) the top ones.

**Ria:** Ahhh yes, bloating. So bloating for me is (.) for the most part, it's the expansion of like the uterus is taking up more space. Which is great because that's what the uterus does and it's taking up space just, you know, in doing what it's doing, menstruating and getting ready for a period is a pretty intensive body process. And then when it gets to the point where it's like uncomfortable or painful for people, I think it's a combination of that just expansion of the uterus, plus things that had been going on during period and pre-ovulation. For example, one medicine that a lot of people use to cope with trauma, etc. is various forms of alcohol. So depending on how much alcohol you drank in pre-ovulation or in the ovulation season. And your body type and all that stuff, very individual to the person. However, in general, I find that alcohol does tend to create a little bit more inflammation during the PMS and autumn phase. And so it's that inflammation that's like, ah, you know, the standard inflammation process, which also includes an expansion and pain. And so I think that bloating feeling that people get is is the expansion of the uterus, plus the effects of detox. The natural effects of detox that are body is doing [pause] and the snacks! [Laughter] you know, we're all snacking on some stuff. And as I mentioned earlier, our food systems now are different, to like our ancestors probably used to snack on, you know, fresh fruit that's in their (.) my ancestors, at least in their village or like whatever, maybe they had access to sugar cane that people would chew on and that sort of stuff. And now we're like, my go to snack is nachos. So I get like corn chips then then cheese. And then salsa. And then, you know, every once in a while I'll make my own salsa. My partner is working on making homemade cheddar right now, but for the most part, I get those from like the big store and the quality and nutritional value of them are questionable. So it's also (.) it's great and I'm happy to eat it. But then it's also like bloating as a form of detoxing from the stuff that's just in all of our food. Basically, unless we grow it or make it ourselves.

### E14- Chronic health issue exacerbation- do these count as premenstrual symptoms?

**Anne:** Definitely, yes. Yes, very much so. And again, I think the Montreal Consensus (.) describe that very well. The premenstrual exacerbation of symptoms and I've seen it both with respect to psychological and physical symptoms, I've seen it with things like asthma, epilepsy (.) as physical symptoms (.) of physical conditions as well as psychological.

**Barbara:** NO. See #1 above. Treatment is more likely effective treating the primary disorder, not the secondary premenstrual symptoms.

**Andrew:** No. And I think that's important not to do because the treatment would be different. And I think there is a general agreement among researchers, both in the psychiatric camp and the gynaecology camp, that you should not include those you can call them, they are sometimes called premenstrual exacerbation, or premenstrual aggravation or premenstrual magnification. But I think that should be kept apart from true PMS.

**Debbie:** There's a paper by Sally Hartledge. I think it's (.) I think (.) it's 2000 and (.) that's called a Method's Dilemma, where she talks about this and I really like her view on it. I (.) and her view (Uh, 2001!) [Finds reference] “Differentiating (.) differentiating PMDD from premenstrual exacerbations of other disorders and methods dilemma". So she talks about basically going symptom by symptom. And that is where the [diagnostic tool], which is the like algorithm that makes the diagnosis. That's where that (.) was (.) that's what inspired this idea of like there might be some symptoms of depression, for example, that are there all the time and get worse. But then others that yeah, technically they're symptoms of depression, but they're only there. Premenstrually. Like suicidal thoughts, Right? Like maybe somebody is depressed the whole month, but has a totally different quality of their depression [laugh] such that now they have mood swings and suicidal thoughts and want to eat a lot. Right? Whereas the rest of the month that's just like not part of their symptom profile at all. I would include those symptoms and those individual symptoms as PMDD. But if (.) but if there's a symptom, for example, low mood that is that is of the same quality. The whole month but just gets worse (.) I (.) my view is that's the sort of exacerbated underlying symptom. Now whether that has anything to do with biology or is useful, I don't know. But just from a sort of like trying to make definitions of these things that work for research, that's sort of where I've landed is with her approach there. So that somebody could have chronic depression with PME and also PMDD, where some of the symptoms are depressive symptoms, but they're just not ever there the rest of the month (.) It's not a great (.) I'm not (.) I'm not (.) it's not an area I feel particularly confident about [laugh] I don't think we really (.) we're not (.) we're not there yet with it, you know?

**Celia:** No, I think that they have to be differentiated and that you can have two different syndromes. I mean you can have an underlying medical condition and PMS / PMDD, but I wouldn't say that the exacerbation of one of these conditions premenstrually is part of PMS, no.

**Sarah:** Um. No. but I think it's (.) it's fair to say that a number of disorders are (.) can be worsened by the menstrual cycle and you need to be aware of that (.) I don't think they are specific Premenstrual Syndromes, though. But they (.) it's just an important aspect to know about [long pause]. **Interviewer:** Right (.) **Sarah:** [Interrupting] so, you know, you could get worsening of um blood pressure in pregnancy, prior to delivery or gestational diabetes, or whatever (.) So it's, you know, it's something you need to know about. **Interviewer:** Yeah (.) **Sarah:** [Interrupting] but you might be (.) what you might end up doing is modifying the cycle (.) so that those symptoms aren't worsened.

**Thomas:** No, not really. We (.) we consider them to be premenstrual aggravation of that condition. And it could also be treated by the original treatment of the condition, and not by treating the menstrual cycle, but on the other hand. Usually when they come to me, at least these patients, they usually have tried everything. Migraine, for instance, is a very very common disorder. Well they have tried everything and (.) it's not good enough (.) they still have this menstrual- related migraine. It's not premenstrual in that way. It's more menstrual [during the bleed]. So it has a similar pattern (.) as the (.) the uh Epilepsy. So it's (.) it's more. There is a term actually catamenial epilepsy perhaps you've heard that one? **Interviewer:** Yeah. **Thomas:** And catamenial migraine [pause].

**Susan:** [Long pause] Er (.) I suppose for the individual woman, if you've got asthma or headaches, you know migraines, which I know are two (.) that are chronic conditions, which have been shown to get worse? Well, so I'm doing some work at the moment, actually, about bipolar disorder. And we're particularly looking at menopause. But there is some evidence that bipolar symptoms can get worse premenstrually. Um, for those women, yes, they are symptoms, but they are not standard symptoms of this thing ‘PMS’. But I think that I would say as part of the premenstrual experience, there does seem to be some evidence that if women have other conditions that those experiences can be exacerbated (.) premenstrually. There's not a huge amount of research on this, which I think is interesting. And I suppose what I would say is if this was happening to men, there would be masses of research, and masses of funding on this, because if you have a chronic condition and it gets (.) it gets (.) it (.) it (.) it (.) gets worse once a month. That's a really pretty bad thing. **Interviewer:** Yeah **Susan:** We need to understand why. And we also need to understand why and um how the treatments for those chronic conditions might interact with premenstrual experiences. And we have very little understanding of that.

**Marta:** No, no, not from a clinical perspective, er I think (.) I think it also has to do with the fact that I rarely see patients who have physical conditions that deteriorate prior to menses. So from a clinical perspective, um the women who come for PMDD, they usually come because of the mental symptoms, at least, at least to me. And I mean [long pause] Yeah, that's I (.) I (.) I can't even recall referrals for premenstrual worsening of (.) of underlying conditions outside of the psychiatric diagnosis. **Interviewer:** So for you, something like perhaps a possible bipolar or depressive condition (.) you would just rule it out from the daily rating process? **Marta:** Er, Yes! that's (.) that's (.) I think that's one of the most important tools (.) reasons why we use the daily ratings is actually to rule out underlying mental conditions. Yes.

**John:** Do I count those as premenstrual symptoms? Er (.) yes. And it becomes very difficult actually to decide whether somebody has PMDD as strictly defined by DSM 5 or whether they do actually have an exacerbation of something. And even if somebody doesn't think they have an exacerbation of something, there's always a question mark as to whether or not it's just below the level of their errr (.) conscious or unconscious um recognition. But I would say that many of the people that I see (.) when you drill down, even though they might not complain of those symptoms during the first half of the cycle, will acknowledge that they're there to some degree. Um, and the way that I describe it to many people is it's a bit like you've got a fire burning and then premenstrually what you're doing is chucking petrol on it. So you've got two choices. You either put the fire out or you stop the petrol and (.) for some women, the fire is not significant enough to want to put out. They can put (.) just stop the petrol, that's enough. For other women they would acknowledge if you could put the fire out. That would be very helpful because it ain't great all the time, even though it's a lot worse (.) premenstrually. Erm I dunno if that answers your question? **Interviewer:** Yeah, just to clarify (.) so, for you, PMDD you know, the most severe symptoms are quite similar to perhaps in terms of categorizing to maybe things like epilepsy or asthma. That are significantly worse or could just be cyclically experienced. Or do you think there is this (.) Because there's a kind of divide in the literature between whether PMDD is a completely separate and hormonal, you know, sex-hormone, I suppose, dependent mental health disorder or as you are sort of implying there that it could be possibly other mental health disorders and then this trigger? **John:** Yeah. And as I say. I think there's a bunch of different conditions that we all give the same name **Interviewer:** Yeah. **John:** And I think there probably is a pure form of PMDD. But I also think there's probably a lot of people that have (.) something else that's bubbling away that's exacerbated premenstrually. And some people where it's not bubbling away, they've got another condition and it's exacerbated premenstrually.

**Laura:** I think [exhale] that [long pause]. We don't know if a number of conditions actually (.) worsen during the premenstrual phase, or whether people experience some premenstrual distress and that makes the other condition worse? So I think that's pretty complex. Um, you know, there is a literature on premenstrual magnification of depressive disorders. I've (.) I've published a paper with [colleague's name] to see if bipolar disorder worsens premenstrually. And we were unable to show that. So I think it's (.) it's inaccurate to say that all conditions worsen during the premenstrual phase because I don't think that's the case. I think there probably are some conditions that do and some that, you know, at any random period of time, it's going to be worse.

**Zoe:** Yeah. Um, generally no. The exception in that list, I would probably say would be premenstrual migraine. I think that does seem (.) there seems to be evidence that premenstrual migraine is a standalone condition because there are people who don't experience migraine at other times, but only experience it (.) premenstrually. Um, if someone also experienced it at other times, I probably would see it as something that is exacerbated during this period of instability and an increased sensitivity. But I would not see them as premenstrual symptoms. I would just see this as the (.) the premenstrual (.) that during the premenstrual stage that they say these things may be exacerbated. But I would not view them as premenstrual symptoms.

**Geraldine:** Well, I would (.) I would not. I mean, so, [exhale] Nancy Woods - you probably are familiar with her term PMM. She says Premenstrual Magnification of existing symptoms. So, you know, an example of a disease or a disorder that is affected by menstrual cycle phase is multiple Sclerosis. So symptoms are more likely to flare up during certain points of the cycle than at other points in the cycle. But that is how you sometimes see these lists of one hundred thirty symptoms- will sometimes have things on there, like strokes or migraines or other things that are really related to problems that women have in general but are affected by changing biochemistry. Even depression. You know, that's one of the arguments that a lot of feminists made about putting PMDD into the psychiatric nomenclature, is that these women may be depressed, you know, need a diagnosis of depression not PMDD, but their depression might be worse or more salient at certain points of the cycle.

**Chris:** If you could assume that (.) then again, if you have symptoms that are unique to the premenstrual phase, then that'll be a premenstrual symptom. If they're symptoms that you've got all month but get worse premenstrually, then that's premenstrual exacerbation. Of an underlying condition.

**Jo:** I think it's all possible. And I think if it happens recurrently, that's what's important. You know, it's that that cyclical nature to things.

### P26- PME?

**Alice:** Never had migraines with it at all. Although some women, I think, just get migraines. I haven't mentioned that as one of the common symptoms, but that's because my experience is not of headaches. So, no, I don't (.) I can't comment on that because I haven't got any predisposed conditions. I think my mental health, although, [laugh] you know (.) who are you to judge your own mental health, you have to ask everyone else [laugh]? I think, um, I think my mental health fluctuates when I’m about to have my periods. And people around me would say, you know, you get a bit emotional, you know. But I only accept that from people that know me very, very well. And I don't (.) think that's like preconceived. I think that's just me having (.) having that change in hormones, if that is what it is. But I can’t really comment, because I don't have any of those other conditions.

**Beth:** [Pause] I do. Yes. I mean, I've got generalized anxiety disorder. And that's what I find it difficult to know whether to call the anxiety (.) the increased anxiety I get around ovulation or a period PMS or whether it's a premenstrual exacerbation of my pre-existing anxiety. But that's personally for me. I know that anxiety can be a premenstrual symptom and I know anxiety can be part of PMS in women who don't otherwise have generalized anxiety. If you see what I mean? **Interviewer:** Yeah. **Beth:** So, I think for me it's not simply PMS but that it can be a PMS symptom for other women. **Interviewer:** Yeah, that's great. **Beth**: And likewise, with the skin picking thing I know that's not PMS, it's a separate condition I have, but it gets worse before my period. **Interviewer:** So you wouldn't count that as a premenstrual symptom? **Beth:** No, no, it's a condition I have that is aggravated by premenstrual changes, but it's not simply caused by PMS. Well, none of it's simple. But I mean, I wouldn't say it's PMS. No, because it's an issue at other times (.) it just gets worse around my period.

**Dani:** I guess so, yeah (.) I mean (.) I yeah, I guess so. If it's (.) if it's related to your cycle, I guess it would be (.) ‘cause I guess well (.) in that case I would sort of see that PMS isn't as cut and dry as like 'it's only related to your cycle, and it's only to do with your womb'. Like I wouldn't be surprised if it affected other parts of your body. So yeah, I mean I would count it. Yes. As premenstrual but also [pause] aggravated by or (.) yeah (.) I don't know. Yeah.

**Emma:** Yeah. So I would class that as premenstrual exacerbation. Where the menstrual cycle's actually makin' that health condition worse in some way. Um. But yes, I would (.) I would class that as [pause] as part of the premenstrual symptoms I can't think of the word (.) **Interviewer:** Grouping? **Emma:** Yeah. Category. Yeah.

**Helen:** Yeah, no, I wouldn't say I got any of those things. I mean, every now and then I get a migraine or something. But I wouldn't say it was like a consistent enough thing to call it a PMS thing like a PMS symptom in itself. It would be like just an occurrence. You know, the things that were consistent were the more emotional socio- (.) you know, the psychological, emotional symptoms I was experiencing and the cramping and the bloating. Those were my constant. So it's hard, but it is hard to say. It's like what is being (.) what is a premenstrual exacerbation? See it's like I would file PME under PMS almost, you know? Because you can't really say, oh, sorry. I'm not. I was just going (.) **Interviewer:** [Overlapping] this is just what I am trying to get at (.) these slight kind of tensions, for want of a better word. It's like what's in and what's out? **Helen:** Yeah, I think if something exists in the absence of a period like if we stopped your menstrual cycle and the condition is still present, even if symptoms aren't as severe, it is not a premenstrual symptom. It's not a premenstrual (.) PMS. It couldn't qualify, but the exacerbation of it. Yes. Would qualify.

**Kathleen:** No. Particularly if they suffer from them at other times (.) I dunno, that would be generally asthmatic. Oh, right, I see what you mean. If they get worse at that time? [Long pause] Yeah. Actually, I'll say yes, sorry. If they're (.) if they're just changing at that particular time of the month and actually at other times it's very different, then yeah. Something's happening in the body around that time that's probably triggering it.

**Aisha:** Do you know, it's not a (.). You know what? I forgot I had, you know, my thighs that stretching feeling that you need to constantly stretch? **Interviewer:** Like they're restless? **Aisha:** Yeah. Oh, my God. I forgot to add that! What symptoms get worse? None. Other than the mental health (.) wellbeing.

**Interviewer:** Do you have any other health conditions that get worse at certain times in your menstrual cycle? Things like asthma can be one or headaches? **Mala:** No. I don't.

**Noor:** So I've got in an (.) anaemia so (.) when I was younger, that's why I used to be more painful and my bones really used to hurt where I used to get the um(.) do you know Restless Leg Syndrome? **Interviewer:** Yeah **Noor:** So, I couldn't sleep because my legs were in pain, but I didn't realize it was because I was going to start my period. But now, because I'm taking my vitamins and stuff [laugh], it's much better.

**Ria:** Yes, OK. So then definitely I think there's the shift that happens during PMS; physical, emotional, spiritual shift, especially the physical piece of like basically progesterone taking over, as our (.) the main hormone that our ovaries are producing and working with. I think that does like trigger a big shift physically and then. Yeah, it's (.) it's definitely, I would imagine, interrelated. You would know more than me and people who do a lot of client work where they really know a person's experience and (.) and what they're going through in terms of their own (.) well-being. They would be able to tell like, "OK, this is like this is definitely a pattern that we're seeing with this particular thing". And then in terms of I'm trying to think of what people have talked to me about. Yeah, I don't think I can comment too much about it other than speculate and based on the research that I've done, that that's probably the case. And so it's a time then where we can, rather than stigmatizing it and pathologising people more. Maybe we can emphasize greater self and collective care as a whole during that time. If we do have this information and even backed up by you know the idea of scientific research that things are more heightened during that season. So then how do we like build in more support and care for people during that time? So if they're not just experiencing standard PMS symptoms like bloating or low sex drive or etc., they're experiencing more (.) um more challenges to their wellness, then how do we support that rather than making them feel shitty or like ashamed about it? Yeah.

### E15- Positive changes?

**Anne:** Oh, no (.) er, yeees, I think you do occasionally come across women that (.) premenstrually do you mean? **Interviewer:** Yeah? **Anne:** Any (.) anything at any time in the cycle? **Interviewer:** Yeah? **Anne:** Ooh, yes. No, definitely. Erm (.) it's quite a tricky one, really. I think it is balanced against the negative things we've talked about (.) women can feel very good at certain times in the cycle. [Pause] and I think looking at it another way, I've seen a lot of women who are going through the menopause who have noticed in a drama (.) often dramatic changes in their mental and physical well-being because of their declining levels of oestrogen. So turning that round in the menstrual cycle and the normal menstrual cycle, that's really important for the well-being of women. And the other example is testosterone, which is important for energy, for libido. The general well-being and you know, women who, for example, have an early removal of their ovaries and therefore removal of their testosterone, it's (.) it's so important to (.) to give them add back replacement (.) erm hormone replacement, both oestrogen and testosterone. So, you know, what I'm saying is in the day to day, all those hormones are really important for mental and physical well-being.

**Barbara:** Some women experience greater creativity, closeness, etc.

**Interviewer:** Great. Erm, do you know, of any positive premenstrual changes? **Andrew:** Pardon (.) the cognitive? **Interviewer:** Positive (.) as in, not negative (.)? **Andrew:** Positive! Oh yes, we have that a lot that that that is for some women an increased activity level during these days. So they got more things done or performed than they usually err (.) do. So (.) so absolutely. What is sometimes called tension and described as being on edge and difficulty in relaxing some (.) on the contrary, describe this, that they are super active and they get a lot of things done during these days. So, absolutely.

**Debbie:** I think ovulatory changes for a lot of people are positive. Not everyone but pre-ovulatory and ovulatory. Many people find increased energy, you know, increased drive, better focus (.) sort of people who have a positive response to this oestrogen increase. Certainly other people don't do well with that! [Laugh- intake of breath]. So, yeah, I think there are some people that have [pause] feel better at certain times of the month that it's not just relief from like the PMDD or PMS symptoms, it's like an actual enhancement. I don't [long pause] really, know of like in the realm of like people with PMS or PMDD saying, "oh, I have this (.) um, I have this (.) these symptoms, but I also have this other positive thing that doesn't happen the rest of the month". I don't think I've really heard that from people. One thing I hear is like, I don't take anybody's bullshit [laughter] You know? Which is if it can be harnessed in a way that like doesn't destroy your life. Could be (.) could be great. Right? [Smile in voice] Like I have (.) I don't have PMDD, but I do when I take certain oral contraceptive pills, I have the exact same (.) same symptoms. And I (.) so from that, I know exactly what it's like. It's horrible. But for me, the irritability sometimes (.) on good (.) on good days when I would be on that or feeling a little better, I would be glad for the irritability because I felt I could draw a clear boundary around what I wanted. But I (.) I (.) I suspect for a lot of people that that's sort of a difficult line to walk [laugh] because (.) because of the irritability can be so severe. **Interviewer:** And who you are, whether you're allowed to be irritable or not. **Debbie:** Oh, absolutely, yeah.

**Celia:** Ha! [Laugh]. Some women describe that, I'd have to say this is more in the lay literature, you don't hear people coming into you as a patient with any of these statements. But in the lay literature, some women say they feel more creative. They feel more sexual. Or maybe that's just at ovulation (.) um of course once the bleeding starts. You know you're not pregnant. That's always a good thing [smiling] unless you want to be pregnant?

**Sarah:** Yes, absolutely. I mean, if you look at our work that we did (.) um, because we included. wellbeing or feeling (.) feeling positive moods as well as negative moods. In our daily rating charts. We were able to see that (.) where women felt best across the cycle (.) and women do feel best in that follicular phase (.) and um you know just around the time of ovulation. Leading up to that and (.) um and sexual interest is highest then. So sexual interest changes across the menstrual cycle (.) [shrug] and I think that's less boring then if it was just the same all the time, which I think is probably what men have, you know (.) they don't have that sort of you know change in their cycle. You know it's (.) the problem with that is that, um of course, there's the um so called Billing's method of um contraception in which you're not supposed to have sex until you're in the luteal phase. And the problem with that is that happens to be the time when women who aren't taking hormones of any sort, least want to have sex. So that's (.) [laugh] that's a complete reversal of what women want to do. So (.) but at least by studying it, we know we know when women do want to have sex and should be able to have sex but in a protected way.

**Thomas:** Oh, yes. Oh, yes. And there are a number of individuals which actually are feeling better during the luteal phase than during the follicular phase. And I would say that (.) uh (.) but they are less and they are not seeking help for (.) the (.) the(.) they are not suffering from these symptoms. They are only happy with them. So (.) so we don't see them in the medical. But if you do population studies. Like theyhave done in in Iceland, for instance, more or less the whole population of Iceland was participating in that study that had about well, twenty percent of individuals that actually felt better during the premenstrual period (.) and during the ovulation, most people feel better. So it's also a (.) let's say, a variation in the wellbeing in relation to (.) to the ovulatory period and we made our scale (.) scale (.) You know every scientist in this area more or less has made their own scale for daily ratings and we made a scale and in that scale (.) we had also positive symptoms and they showed very clear cyclicity. But in the opposite (.) except for around the ovulatory period (.) where (.) where they showed this peak of well-being.

**Susan:** Yes, there are and they're often overlooked, as I'm sure you know. And [colleague's name] and colleagues have done some really good work around this. Where, they've shown (.) And we (.) we've done some work around it as well. Um [colleague's name], who was a PhD student working with me, did some really interesting work around this. So some women feeling increased (.) increased, sexual arousal, um sexual response, increased energy, creativity. Some women athletes talk about feeling better in terms of sporting prowess. And we found in a study, this study that I did with [colleague's name], that there were changes women report (.) one of the changes women reported was around increased tidiness, which seemed to me a kind of strange positive symptom, but that's something women talked about. And because some women feel that their breasts get larger premenstrually and that's distressing for some women, but other women like it. So, yes, there are, and I think (.) that's something I always talk about when I talk to the media about PMS and premenstrual change. And I know myself it was something I (.) that energy that you can get premenstrually, which can be anger, can also be channelled quite positively. And we've interviewed a lot of women who've talked about it (.) I don't know whether it's a kind of self-righteousness, but that sense of (.) that anger that that's like a kind of real female energy, like a primal energy, which can be a rage, but is also something that can be channelled positively.

**Marta:** [Long pause] Not (.) again, coming back to what I see in the clinic. I don't see those patients probably because they don't seek medical attention. But recalling this old study from (.) from Iceland that was done, I think in 1980s or beginning of the 1990s. They (.) they (.) they reported on (.) on women who actually felt better in the luteal phase, because I think the scale they used also incorporated a number of positive symptoms. The scale I mean, the DRSP scale, which is the most commonly one (.) used one. Er, only has negative symptoms. So I don't think we've really captured that.

**John:** [Very long pause- approx. 15 seconds] I mean, I'm thinking about that. The reason why people come to a clinic like this is because they've got a problem. Not because they've got something that's helpful. Um, but if you speak to people with bipolar disorder, they will quite often tell you that the manic bit of their condition is something (.) if they could just have that, up to a certain point, they (.) they would value it and rather not have that treated. And I have had people who premenstrually have been on the manic side- that they would not say is a problem, but they would say that what then happens is problematic. And so I don't know whether that answers that? **Interviewer:** Yeah. **John:** But they wouldn't be coming here telling me that (.) that "They were here just to say how wonderful things are premenstrually" [quiet laugh].

**Laura:** They certainly are reported in the literature. I mean, we don't tend to (.) as (.) as a physician and somebody who takes care of and treats patients. I wouldn't see (.) nobody would come in and see me and say I'm having problems because I feel so much better when I'm premenstrual. But the literature certainly endorses that (.) um, In terms of research, I wouldn't even see it in research because we actually ask for people who have distress, not people who are feeling better.

**Zoe:** Yes. And again, not an uncommon number of women report this. Um, interestingly, we've also found that women don't necessarily (.) many women may not spontaneously nominate positive changes, but when you ask them to think about positive changes, then they will actually go, "oh, yeah well. Yeah. This happens as well". So um it can be associated with increased energy and increased drive. And so for some women, that can be uh quite reinforcing and can (.) can be quite useful. That can lead to increased (.) increased creativity, increased productivity, just increased energy. Women can report increased sex drive and increased libido at this point. So that's (.) that's really common. That's not uncommon at all. So they'd probably be about the main ones. But as I sort of mentioned earlier, I think there is also a [pause] there are some women who [pause] have repositioned or reclaimed um experiences like irritability or angriness or being more forthright. Things that can be positioned as 'not positive', they can actually claim these as positives and say, "well, it's a time when I actually do speak out more or when I'm less likely to take shit from others". So there are some of those experiences which in and of themselves are neither positive or negative, but women will claim them as a positive because of the effect they have on them that actually help them do things that otherwise they wouldn't do (.) at different times during the month.

**Geraldine:** [Laugh] Well, since we so rarely ask women about them, we don't really know. Also, we are so trained to look for negativity. You know that phrase from social psychology, the 'illusory correlation'. You know, if you're expecting to see something like when the moon is full, you expect to see bad drivers on the road. So you notice them. But if the moon is not full, maybe you don't notice them even. So, that's how we categorize a lot of the premenstrual symptoms. I think we expect to experience them. And so if we experience one, we say, "Aha! No, I'm getting my period in a few days", but we don't say, "well, I’m really joyful today or I'm full of energy or I'm feeling really sexy". But there are some studies where women, you know, keep filling out forms every day across several cycles. And you do notice certain things like feeling more interested in sex right before menstruation. Some women report greater creativity, before menstruation or during menstruation. So there are some (.) there are some things, but we don't ask about them. So we don't really have a good handle on that. There's only a very few studies about positive aspects. And one thing that researchers tend to report is that the participants are so surprised to be asked that they don't really know what to say [laugh].

**Chris:** Ohhh (.) Yeah, I think so (.) but people don't come to doctors with positive changes, and that's rare (.). But I think some (.) some women get more drive and become more efficient and more drive. But I think that's a (.) that's I don't know of as an expert because people don't complain of good things.

**Jo:** Um [laugh] no, no, not in my experience for women with PMS. Except that they know it's going to get better.

### P30- Positive changes?

**Alice:** Well, getting pregnant [laugh]. And I have to say, I've sort of (.) I've sort of already talked about this a little bit, but because of (.) because we've gone through a quite traumatic journey in the last year trying to have a baby and again, like I've had three pregnancies. But if I did have endometriosis, you struggle to conceive. But we haven’t had that. It's just you know, I think it's just unfortunate what's happened. But I've read some amazing books. In fact, they've all been from professors of (.) from America that have sort of talked about erm (.) taking charge of your own fertility or understanding your own menstrual cycle. And at the age of when did I start reading? Thirty four, so I’m thirty five now. I'm mean, I’m quite old to say this, but (.) I've only recently really understood (.) the actual science exactly of what goes on. So I can describe, like I did at the beginning of the interview about what happens, but I've really learned about, you know, the bodily fluids and the secretions and the temperature changes (.) your sleep changes and your tracking and other things that can interfere with all of that – diet, and environment (.) Just simple stuff that I’ve stated, but they these books have really (.) highlighted the kind of natural magic of the process of periods and egg releasing (.) that process and fertilisation. It’s only after I've done my own research and I've really kind of understood my own body and that's for me. It's been (.) kind of a breakthrough in its own right, and I don't think we educate people. **Interviewer:** So do you think that knowing more has actually improved yourhealth? Like (.) **Alice:** [interrupts] definitely! **Interviewer:** (.) like physically and (.)? **Alice:** Yeah, yeah, definitely. I'm not a big drinker or big coffee drinker anyway before, obviously. Now I'm not at all [due to pregnancy]! But I think all of the stimulus that can happen in your diet and your environment (.) you know, it's become a bit trendy to talk about all of that stuff. You wouldn’t have talked about all that a hundred years ago (.) but I think knowledge gives you empowerment. And if you've got that, then you can self-manage anything.

**Beth:** Well, I guess the positive changes are the relief from the PMS symptoms you get when the period starts. I mean I do feel pretty rough on day one. But then again, I do get really rapid improvement in the anxiety and constipation. I mean, I look forward to my period starting to feel better from (.) from those symptoms. You know [pause] a positive for me is that I have very regular periods, so I know when to expect these symptoms. But yeah, I think (.) I can't think of anything else in particular, the biggest positive is the relief from the PMS when (.) when the period starts.

**Dani:** Yeah. After my period, I feel a lot more energetic and I just feel generally brighter. Like it (.) like it feels sometimes like a light switch is on in my brain post period, which is always a positive thing and not in just the way that "ooh thank god the period's over". Like I genuinely feel different. Erm (.) so that' erm (.) yeah, that's pretty much it.

**Emma:** Yes. So usually (.) around day four, day five of my cycle, I get this lovely oestrogen high where I just feel like I can conquer the world. Do anything I want to just [pause] go to every event and meet every person and do everything. I'm full of beans and energy and it's great. And my skin glows. I look healthy and I feel healthy. That lasts until around day 10 when I ovulate usually. So I have that that window of ridin' the oestrogen wave and I'm super productive in that phase. I'm really creative. So there is there's definitely a positive to the menstrual cycle. It can be really hard to remember that sometimes. Yeah. And also (.) at that time before and around ovulation, I just feel more confident and I want to (.) I dunno, socialize and meet people. Yeah, that's a really nice place to be. And I wish that lasted the whole month.

**Faith:** Um (.) the one thing that we said about (.) just before, my period. That's when I'm like really (.) wanna go to the gym, maybe be active, let me eat my food and make my smoothies and juices in the morning and then the period comes I'm like 'Oh' (.) [interrupted] Scrap that idea! (.) Scrap that idea!

**Gemma:** No, not positive. No.

**Helen:** My babies. You know, it's part of my reproductive menstrual cycle. Definitely my babies. Yeah.

**Kathleen:** Hmmm [Very long pause- 15 s] that's a good question. Erm, I don't tend (.) I don't know if I do. And that's me thinking that you know, my period is a good thing. Yeah, It's just I think definitely at the moment, because it makes me just feel a bit more (.) a little bit uncomfortable with the bloating. A bit more tired, maybe. I'm not associating it as a positive thing. But, on the other hand, I'm not kind of wishing the symptoms away, but you know what? You know, I just see it as a natural part of, you know, of who we are. So, yeah, I mean, maybe some days if I'm like that it means that I stay at home and rest. So that's a positive thing [laughter] the outcomes are positive! Um, but (.) yeah. I don't know. No, I (.) yeah. I haven't got um (.) euphoric feelings before. I know that after my period there's definitely some kind of hormonal, pick up afterwards, I dunno, maybe that's another study maybe? And I've always noticed that (.) so my hormones do something very different just after I (.) you know, stop. **Interviewer:** So (.) so you mean like a good mood (.)? **Kathleen:** Yeah. [overlapping] **Interviewer:** Or energy? **Kathleen:** Yeah. It's kinda even a better mood than I am normally. If that makes sense? It's almost like it's (.) bit like the mood is down here, then it goes up! [Uses hand to illustrate fluctuating hormones] I dunno. That's what it feels like.

**Aisha:** Yeah, like sometimes I feel more productive. Sometimes I feel like, oh my God, I can do everything, I can meet everybody. Did I (.) and I feel so happy you know? I have like a list of (.) I have a bucket list anyways, and just to get them done [excited tone] and start planning things or I want to cook.

**Mala:** Oh, yeah (.) sometimes I'm really energetic. Is that (.)? That's what I mean. Like, I feel like sometimes my mood changes. Either I'm irritated or I'm really happy. There's no in-between.

**Noor:** Some of my friends, when they actually start their period, they are really happy (.). So some people do have positive (.) **Interviewer:** You don't think you do? **Noor:** Once I start when it's midway, when I'm finishing off, I'm fine. But that's (.) I don't know if that's positive cause? **Interviewer:** It's more like a relief? **Noor:** Yeah [laugh] like.

**Ria:** Yes, definitely. I think (.) I mean, I am grateful to not experience things like that are very, very painful, like endometriosis or a lot of pain when it comes to PMS or things like IBS. So I definitely like as a person can be like, yes, it's totally positive. If you ask somebody else who did have got body experience and (.) and mental emotional experience, they'll be like, "no, there's nothing pos (.) I don't like any of it!" [laugh]. "There's nothing positive". And so I think that's the (.) that's part of the work that I'm trying to do with how can we at least try and reframe it as neutral? And then when we get to that neutral stage, be able to reframe things as positive. So some of the positive aspects that I think are really important about PMS is an awareness of which relationships are nourishing you like human relationships, friendships, romantic relationships, fam- bio family, your chosen family, your relationships, which ones are uplifting you and supporting you? And then during PMS I find that I tend to be aware of like and more sensitive to how I'm reacting to how people are talking to me or treating me. So an awareness of those relationships so that in the next cycle we can be like, "OK, this person makes me feel this certain way. So I'm either going to spend more time with them or less time." So it can be a time where we can figure out where we're going to turn our energy to and where we're going to pull our energy back in from. And then I also like it because I like to do it as somebody who tends a little to like workaholic tendencies. I've gotten better at meal prep and like making sure I'm eating and getting the nutrients that I need (.) Um, one positive thing during PMS is that because my food cravings are so high that I do (.) I'm able to get like a lot more of like the calorie and energy intake that I need because I'm just like I'm so hungry [laughter] I could eat all the time. I'm going to take the afternoon off so I can like snack for four hours [laugh]. And so I really like that aspect of it. And then I also like being able to give myself the space to have more sleep and encourage other people who I work with or who I talk to to take that time to get more sleep. Because I think that in the modern world, as we become more and more reliant and addicted to the digital world and digital devices, sleep is becoming an increasing challenge maybe for people. It's because (.). I mean, I'd have to do the research to back up that claim. But from my own observations, I do see that a lot of people are (.) are struggling with getting enough sleep, in part due to just the demands of modern life and having to work and pay rent and all that stuff. And then in addition to that, the increased presence of screens and devices in our life. So one positive aspect of PMS is leaning in to the tiredness and giving yourself the space to get the sleep and rest that you need.

### E16- Male experiences of same symptoms? Different mechanisms?

**Interviewer:** So obviously men can experience nearly all of the same symptoms (.) really other than period pain or cramping of the uterus. But obviously they don't tend to have any kind of cyclical pattern in those symptoms. So does that mean that the same symptoms have different biological mechanisms depending on the patient's sex? **Anne:** [Pause intake] yes, they do. And again, it's in (.) you know men (.) don't have (.) I'm not an ex (.) I'm not (.) I don't have expertise in (.) er about men's health. So (.) er (.) I don't (.) I can't go into detail. But men do have hormones circulating and you know, testosterone. We talked about (.) plus they have much higher levels of testosterone than women. And that's important in terms of libido and cardiovascular health. But I would say, the big difference is that their levels are more stable. They even though there is a very gradual decline with age and there is a lot of work out there now and information about the andropause as men get older and the levels of hormones are declining, but they don't go through as distinct a phase as women do in terms of the menopause (.) as women going through the menopause. I think the other things that we talked about applies well, the social and psychological state at the time (.) erm, of getting symptoms. But the intrinsic difference between men and women as well, that they er (.) I'm very much generalizing now, but they often react to things in different ways, perhaps emotionally. And I think that has some effect as well on how men experience problems. **Interviewer:** Great. **Anne:** Like Venus and Mars! [Laugh]

**Barbara:** If there is no cycle pattern, it is not PMS. Most symptoms in this world are non-specific and must be explored in relation to the individual and his/her situation to understand a diagnosis.

**Fran**: I would assume that in women it is due to the interaction between their neurotransmitters and hormonal fluctuations and in men, uh, they don’t have hormonal fluctuations in the same way [inaudible]… I’m (.) I don’t (.) I think they’re different because in women the symptoms are because of a vulnerability to hormonal fluctuations.

**Andrew:** Yeah, I think and sometimes it's (.) it's the (.) this is the claimed as an argument against the concept of premenstrual syndromes. And I (.) I have never shared that view. For (.) for premenstrual symptoms the female sex steroids are clearly very important. For male aggression, which in many instances is of course is more a more common (.) common societal problem than female aggression. Then I am convinced that testosterone also plays an important role. So (.) so I think there is a corresponding hormone driven influence on mood in both sexes, and it's very well-established that (.) that (.) that that androgens in men both provoke aggression and also sexuality, of course, and so on. So (.) so I think I think there are hormone driven, some to some extent similar (.) erm behavioural influences in males and females, but they are also to a great extent different, which is not surprising since it's different hormones that are important for the two different conditions. In fact, we (.) we for some years, many years ago believed that andro (.) testosterone could be involved in premenstrual syndrome in women, but other groups have not confirmed our findings. So I don't know about that. But (.) but (.) but I I (.) I (.) I (.) I don't think men display the typical constellation of symptoms characterizing premenstrual dysphoria, but certainly some of the same. All of the symptoms could of course be apparent in men, and some of them are clearly hormone dependent in men such as irritability or anger.

**Debbie:** [Inhale] I don't think we know that [exhale] (.) I would say potentially [pause] different (.) um (.) so there's like the near term. Brain correlates, right? Like right before something happens, does irritability look the same in males and females? My money would be on like probably more yes than no. But in terms of the like, if we back up to like the things that provoke that same symptom, certainly I think they could be different in men and women to some extent. And people with this hormone sensitivity of PMS or PMDD would be one example of that (.) being um (.) being different (.) on the other hand. There's one paper showing that (.) um, that when you put healthy men into a hypo gonadal state, you give them GNRH agonists, a certain percentage of them develop (.) with this rapid hormone change, develop depression, irritability. So I think hormone sensitivity is certainly something that men are capable of. It's just that they don't [laugh] experience the cycle. But if you create a cycle in them [laughter], then they will just as readily show the symptoms. **Interviewer:** I'd love to see to see the ethics approval of that study! [Laughter] **Debbie:** Yeah, I think it was done in people with prostate cancer or something like this where they needed to give this drug anyway, but I'll have to find it.

**Celia:** Yeah, definitely (.) well, [audible inhale] depending on the sex or even the time of the month, I mean, you can have bloating. That may not be, you know, and you can have irritability. That may not be the same mechanism. So I think the symptoms are not really specific along those lines.

**Sarah:** Well, they don't have a cyc (.) I mean, all the symptoms we've talked about, it can happen in women at other times, too. It's the cyclical, nature of it (.) Now, men can induce cyclical changes. I don't know if you're aware but in New Guinea there was a cult, an island of menstruating men. So men in this tribal situation (.) um feared women menstruating (.) and so couldn't shake hands with a woman 'cos she might be menstruating and have her evil curse put on them. And they sort of figured that women had some sort of power so they were cutting themselves, ritualistically on the genitals to produce menstruation. Of course it was not real menstruation (.). So [laughter] you can you can fabricate things too, if you wanted to. It's just ridiculous to even suggest that men have similar (.) [Fades out] **Interviewer:** Yeah. Well, but like say if they get irritable. Um that the mechanism behind that is different than the irritability that we would get before menstruating. **Sarah:** Well, I mean, if you want to do a PET scan, you'd probably find that it's a similar part of the brain gets activated when any one gets irritable (.) you know in certain sorts of behaviours. Um, so what we're talking about is not the end result. But we're talking about. Why a constellation of things changes with the menstrual cycle. It's a different thing. We're not talking about specific symptoms as originating from the menstrual cycle. Even menstrual migraine, you know people get migraine at other times, it's not necessarily linked with menstruation, which becomes important for aetiology. The mechanism of migraine is the same. And you could still treat that migraine with the same triptan or whatever you'd use to treat a migraine at another time? But if it's only occurring in association with menstruation, well then you may want to look at evening out the cycles. So they don't get that triggering (.) Do you understand? **Interviewer:** Yeah, yeah. It's just um people have very different ways of describing this so (.) you know, that's what I'm trying to gauge, how you would put it.

**Thomas:** We did actually a study on partners. And they (.) they did daily ratings. And they showed similar pattern in their mood as their partners. Well, so (.) so they (.) well, I don't know whether (.) how that should be interpreted, but we thought that perhaps it was, a (.) a (.) a (.) a related to the fact that they actually felt in the same way as their partners, they experienced what the partners had had (.) **Interviewer:** So my question really is, is, does this mean that the same symptoms can have different biological mechanisms depending on the person's sex? **Thomas:** Well, in that case, in in those men's I think it is psychological, it's not biological. On the other hand [pause] on the other hand, there are (.) are also, let's say, stress related conditions, which are, of course, also appearing in men, and these stress related conditions are according to my mind, are also based on the same kind of, let's say, provoking compounds, but then coming from the adrenal instead (.) and they (.) they are not showing this menstrual cycle pattern. They are showing different types of patterns. Diurnal patterns and seasonal patterns. So (.) we know also from (.) from the many animal studies that are that testosterone on mammalian hormones are showing season (.) especially seasonal patterns. And these male hormones are also having metabolites which are active on the GABA receptor in the same way as (.) as (.) progesterone and allopregnanolone. So (.) so it's (.) it's not unreasonable to believe that that these kind of (.) of patterns can occur. Also, in men and different than men. And hepatic encephalopathy, which we are now investigating, this is mainly occurring in men.

**Susan:** Well, I've kind of already answered it in terms of saying that the moods that women get and changes that women report premenstrually can also be reported at other times. So they're not (.) there isn't a single (.). There isn't a linear causal relationship between the female reproductive organs or the fe (.) female reproductive cycle and premenstrual change. It's (.) it's not a single linear relationship so, the fact that men can express all of those changes doesn't mean PMS doesn't (.) that you know, there isn't such a thing as premenstrual change. I think that because (.) what (.) so I don't (.) I think it's a bit of a non-argument (.) really. Um, when I (.) um one of my PhD students supervisors [name]. He did a lot of (.) he did a lot (.) he's a psychologist in the UK. He went into private practice (.) or, consultancy, but he (.) that was kind of one of his arguments was that men get cyc (.) well, he argued that men get cycles, but they're not menstrual cycles, and that looking at cycles for men is much more about days of the week and things like that. And so I think you can look at cycles that people have. And I think that's a whole other area of research, you know looking at cycles across, you know, how people feel going back to work after having had a break. Like it's pretty hard getting back to work. So you could have a cycle in terms of work and there's cycles (.) we know that people feel much better on a Friday than they do on a Monday. So there are other cycles. But the fact that men get those (.) that many of the(.) what are seen as symptoms of PMS, are also experienced by men, it's the same that many of those experiences (.) symptoms are experienced by menopausal women. But it's just not in a regular cyclical pattern for post-menopausal women.

**Interviewer:** OK. Erm, so obviously, men can also experience the same symptoms, just not in any kind of cyclical way because they don't have a menstrual cycle. Does this mean that the same symptoms have a different biological mechanism, basically, depending on the person's sex? **Marta:** [Long pause] can you repeat the question? Is this a question about men because I don't meet men? **Interviewer:** Yeah, it's kind of (.) obviously (.) erm, men obviously also experience, anxiety or depression, but not in a (.) they don't have a menstrual cycle. So it's not triggered by that (.) **Marta:** [Overlapping] Do they experience cyclical symptoms of depression? **Interviewer:** No. **Marta**: OK. **Interviewer:** So, I mean, most of the people I've spoken to have talked more about physical symptoms as well. So bloating and blood pressure changes or whatever. So obviously, all of those changes that can happen, and be triggered by the menstrual cycle can also happen at other times or um can happen to men, or menopausal women. **Marta:** Yeah. **Interviewer:** So, It's just asking really about (.) does that mean there's a range of biological mechanisms that can lead to these (.) experiences? **Marta:** Yes and I (.) yes, that's (.) that's the way I'm seeing it (.) and (.) and I would say that the key trigger for all of these; both physical and mental symptoms would be the hormonal changes.

**Ria:** No, it's all good. It's all good. So I'll use male to talk about it. And then also just recognizing that sex is not binary and it actually exists. Like on imagine like two normal curves, it's actually inter overlap with each other. So there are people, for example, who identify as intersex who are in that overlap section. And then even like my vagina probably looks different than your vagina and my ovaries are slightly different. So acknowledging that there are diversities in the idea of sex. And so this is something that I'm very interested in because in a lot of ancestral teachings from all over the world, indigenous teachings, this idea that we all have masculine and feminine kind of pulls inside of us is like commonly understood. So masculine and feminine energies and power. Sometimes you've probably heard this. And then the English translation of like queerness or trans and or transness in [Turtle Island] indigenous languages is 'two spirit', meaning that there's again, masculine and feminine inside all of us. So I've been reading about that. And then also reading how the moon symbolizes the feminine and the sun symbolizes the masculine. And so the moon cycle, we can easily kind of pair to the four seasons of cycles of menstrual cycles. And then the sun is a daily cycle. And so from what I understand and I'm not (.) er, I don't do research in like male sex hormone expressions, but I can imagine and speculate. And from what I remember reading about testosterone, which we all experience, everybody, no matter what their sex, has testosterone and we need it. And it's really important. However, it's just like a higher expression in people who are assigned male at birth. That testosterone seems to be really high in the mornings when the sun is rising and then as the sun goes down, testosterone levels go down as well. And so all that to say that I think males, people who are assigned male at birth, who have these very specific hormone patterns, experience things more on a daily cycle. And so that's why it's almost seen as more steady, because if we, like, took a snapshot of every single day at the same time, it might seem quite similar. However, I think there's room to do research in the shifts that happen at various parts of when the sun is up and down and the same with testosterone. And I also encourage people who are non-menstruators to use the Four Seasons framework. However, you if you don't have a menstrual cycle. So even people who are taking the pill and aren't experiencing like the change in hormones, they can use the lunar calendar to go through the Four Seasons. So i'll invite you to go to my website. [name of website] and there's a free checklist that I have that lists the Four Seasons and some tasks or ideas of what you can do during that time. And so even people who don't menstruate, I think they do experience PMS (.) as well like as the autumn season, however, it's just like people just don't do research on it or haven't yet. To my knowledge. So I think there's (.) there's room to do more research on that so that we can then see how people do who don't necessarily fit within that normal curve of femaleness. How do they experience PMS? Because I think I would imagine that they do. It just looks differently than people who like really strongly experience the Four Seasons.

**John**: Um (.) [pause] I'm just trying to think of how to answer (.) just say that question again? **Interviewer:** It is a tricky question. It's, you know, obviously, apart from really period pain and maybe breast tenderness. Nearly all of the symptoms and changes that people get premenstrually men or in fact, menopausal women, children can also experience. So it's thinking through. Does this mean that there's a specific biological mechanism for these premenstrual ones that is different somehow very different to the mechanisms underlying these symptoms experienced either by other people or by people after they finish menstruating? **John:** Well, I suppose men can experience these symptoms in a couple of situations. So men, if they have prostate surgery, get their hormones switched off and they would experience some of these symptoms. As you probably know, they did try to invent contraception for men, which was effectively a progestogen (Depo) shot. And that led to (.) well, the reason that those trials were stopped was because quite a few men became suicidal. So it would seem that those mechanisms are in place in men, but they don't have that being triggered in the same way perhaps that women do. And as far as depressive symptoms go, which make up many of the PMS symptoms, those can get triggered by other things if they're not hormonal and are probably pretty similar (.) I mean if you're feeling low in mood, hopeless, and wanting to kill yourself is a symptom. You can have premenstrually, but it's certainly a symptom of (.) or symptoms that you can have for other reasons. So (.) **Interviewer:** I mean, there isn't a definite answer to these questions it is just sort of trying to hear how you would describe it (.) **John:** Yeah, well as you probably know, there's another group of physicians out there who treat men who have the andropause, and many men who have the andropause will describe (.) similar symptoms in terms of low mood, low energy, but perhaps at a lower level (.) **Interviewer:** Yeah, and they ascribe that to testosterone, don't they, generally (.)? **John:** And they go get testosterone supplements, yeah.

**Laura:** Well, I mean, you know, there's some models, for PMS and PMDD. That have administered gonadal steroids to try and provoke symptoms [in men/ menopausal women], so I'm not sure if that answers your question? You know, in men their (.) the brain development is just different. So I think it's really hard to. To say what's similar and what's not similar, but I think there's a lot. My suspicion is that there are a lot fewer similarities.

**Zoe:** Um (.) I don't (.) I don't (.) I wouldn't agree that men can experience the same symptoms or biological men would experience the same symptoms. I think menopausal women can. But I don't think men can um because whilst I think there is definitely something physiological going on. So I absolutely believe it's something physiological going on. But what is occurring physiologically for a woman, whether she's, you know, pre-menopausal or menopausal or, you know, during the menopausal transition is very different to what's happening for a man. I don't think that men have the same cyclical changes. They do have hormonal shifts and changes, but they don't have the same cyclical changes that are producing the changes in women. The fact that they may experience irritability or anger is not what makes it a premenstrual symptom. What makes it a premenstrual symptom is the fact that it is cyclical and it's occurred in that cyclical fashion, not just experiencing anger. Doesn't make it a premenstrual symptom. So I would I would challenge that men actually experience it. But if the essence of your question is, is there an underlying physiology to what's going on here? Yes, of course there is an underlying physiology to what's going on here. And I think it is uniquely related to the female reproductive cycle and of the female reproductive pattern. **Interviewer:** Can I just clarify then? So I'm trying to think of a good symptom, so let's say men feel bloating, a feeling of bloating. That is not going to be cyclical or, you know, I'm talking about cis male people here (.) **Zoe:** Yeah **Interviewer:** and (.) so the mechanism behind that bloating is going to be quite different then, to the bloating as experienced cyclically? **Zoe:** Yeah, yeah.

**Geraldine:** Well, I suppose there are some that might be. But in general, I would say no. So, you know, as I mentioned before, there's a big overlap between the symptoms of stress or signs of stress and other so-called signs or symptoms of PMS. So, you know, I would often tell my students that, you know, a man and a woman wake up in the morning and experience some symptom. And she thinks it's related to her menstrual cycle and he thinks he has a hangover or is getting a cold or, you know, he's worried about his biology test in the afternoon. You know, it's (.) a lot of it is about attribution of the symptoms. Like what? What they mean to you, what you think they are.

**Chris:** [Pause] Hmmmm. Yeah, I would have thought they'd be lots of different mechanisms for anxiety, and so (.) I think the answer to that is yes [pause]. Of course (.) when I see patients. They may say they've got PMS and then more likely (.) as time goes on (.) to say they've got PMDD because then people will take it more seriously. And [pause] and so that (.) that's the biggest difficulty, really (.) separating out women who've got symptoms, for other reasons, like you say, as opposed to due to their progesterone.

**Jo:** I think so. But again, I (.) I just think we really don't know enough about it to you know, there are all kinds of theories I've seen of jigsaws with five pieces and different causality for PMS which you (.) it doesn't mean that men or women without a cycle can't experience exactly the same symptoms and maybe they do have a similar causality. It's just not cyclical.

### E17- PMS as controversial diagnosis, what's your understanding of why that might be?

**Anne:** [Long pause] I think I probably answered that in the question of when I was talking about the RHS Garden that I think every individual will have (.) a perception, a view of what PMS is (.) which is based on their underlying knowledge, which is based on how interested they are, what experiences they've had, whether it's touched their lives. Erm, (.) and so (.) I don't think you can generalize. You will get some people who are very understanding and I think it's just that really reflects why peer support groups can be so useful. We have one. I have a colleague who is very err (.) set up a peer support group, which I go to. And it's just so helpful for people, actually. Women actually talking about their own experiences. But then it's a bit like the menopause. I think the more we can get it out in the open, the better. It's a lot around understanding. It's about [pause] some (.) you know, why do people view it negatively? A lot of that will be because they just don't understand. So it's a bit like what's happened with the menopause, a lot more teaching in the workplace, making colleagues aware of the problem. I think would be really helpful because I think there is still a lot of lack of information and knowledge out there. And I think that reflects in how people view it. **Interviewer:** Yeah, and just to pick up on something you said previously about (.) about the RHS garden experience. Was that in some ways (.) it was that it was normalized- If people aren't talking about it, then you're less likely to know that what you're experiencing might not be normal or, you know, might be an extreme experience. But also (.) you said that it's kind of used as an excuse. So this is kind of getting at the controversy that I'm (.) that other people have spoken about is that it's not real or that it’s 'seeking attention' (.) like kind of 'imagined' or 'exaggerated'. That kind of thing. Is that something that you sort of noticed? (.) Maybe not if you're mainly dealing with patients who are actually experiencing this? Basically, are you aware of (.) anyone saying, "oh, it's not really real" or, you know, sort of dismissing it? **Anne:** Oh, yes, I've definitely come across people like that. Both friends or relatives of women or health professionals, to be honest. As I said, I think that just reflects a lack of understanding and you know many (.) people often make fun of things because they don't they don't want to face it themselves. They don't want to face or er even, you know, it's a lack of understanding. But for some people, they don't want to know what it is. They're not interested. So I think it's about it it's about empathy isn't it? It's about compassion for that person, you know, giving sympathy, but also understanding how they're feeling.

**Barbara:** It lacks a clear etiology [sic]. It has been widely misused for complaints that are not PMS/PMDD.

**Fran:** [Pause] you’re saying that PMDD is controversial? **Interviewer:** Well, it can be. Erm, so, sort of thinking of people who might think that it is the medicalisation of women’s moods (.) or, you know, there are lots of different academic and erm, different disciplinary perspectives on these experiences (.) **Fran:** Right. I don’t (.) I was on (.) participated in the ISPMD committee that met to review diagnosis and aetiology and the ISPMD consensus meeting on treatment for PMDD. I don’t think that there was a consideration that PMDD was a controversial diagnosis. What I do remember from the original meeting is that er, on purpose, they didn’t specifically define what premenstrual symptoms should be included in the diagnosis of PMDD. Clinicians in mental health in the group thought (.) felt that the emotional premenstrual symptoms are what is likely to make a woman seek diagnosis and treatment, while clinicians in gynaecology seemed to think that some women present with more problematic premenstrual physical symptoms such as cramps, or breast tenderness. The committee was not able to say that PMS comprised specific symptoms in their view. I think everyone on the committee was in agreement that what was important was the “on-offness” of the symptoms through the menstrual cycle and the interference in a woman’s life.

**Andrew:** It's a mix of two ideologies. One is that there is a (.) a feminist approach claiming that this is to label women expressing a rightful annoyment [sic] of various examples, from lack of equality in society that this kind of that that the women expressing anger that they should express are (.) are getting a diagnosis. And therefore, that's been been (.) been argued from feminist camps that this is a negative thing. On the other hand, are other feminist groups that have said that PMS is a typical example, that female conditions are not it's not done research on female conditions as much as for male conditions. And the fact that there are not more treatments for PMS and so on is a (.) also an example of lack of equality. So there are two different views on this from the feminist camp. That's definite that there is one important argument that that this should this is a labelling of a (.) err (.) er (.) er (.) labelling healthy women with a diagnosis and the other ingredients in the in this mix of all of (.) this. Ideological stance is that a general scepticism, in respect to psychiatric disorders that is common in society and from different angles there is of, for example, a questioning of the ADHD concept. Many people believe that that this also should not be used at all. And they are sceptical to the entire DSM activities. And they say that DSM is just acting on behalf of the drug companies so that they should be able to sell their drugs and they are all (.) all corrupt and bribed and so on. This is an entire fake altogether. So I think that, ah, this is a mix of these two tendencies in (.) in the questioning of the (.) of the PMS. Yes. And of course if you question PMS then you don't (.) that that is not the DSM concept of course. And that is not coming from say, psychiatry. So then it's more like a something coming from the feminist stance. But if you particularly criticize the DSM concept, there is for example, I think her name is [colleague's name] and she has been an advocate for that view. When I know that she has, I think just been on previously been on a DSM committee and tried to stop PMDD from being included. So (.) so and that I think it's a mix of (.) of both tendencies because I think the same debate that I maybe I may be wrong, but I think the same debate has also been argued against, for example, ADHD. And so (.) so ah (.) yeah.

**Debbie:** When I first thought about going into PMDD training for the postdoc, I was resistant to it because I had this feeling that (.) it was stigmatizing (.) women or it was (.) somehow by studying this. We were saying that on some level all women had it (.) and now I don't feel that way about it at all. After having learned about it, you know, the (.) the prevalence of (.) distressing or impairing premenstrual symptoms, is you know, under 10. Certainly under 10 percent. So (.) in that case, I think [pause] but, you know, I think without that information, it's very easy to hear this and think (.) you're just trying to point out ways in which women are inferior and weak and untrustworthy. And I think I felt that way about it at one time, but decided to take the training anyway because I was curious about this and (.) now having learned so much about it. I'm like, "ah no, it's this disorder", right? So then if it's a disorder [pause] it can be treated. And if we can treat it, then it's not a problem anymore [laugh] And we can say, "see, this is just a misconception. You must have met one person who had PMDD and thought all women have PMS and are really irritable and angry. Let me educate you [laugh] It's not like that. It's this small group who have it. And then most women don't". And so in that way, we can then sort of (.) uh what's the word vindicate? We can (.) we can unburden the rest of 'women' [laugh- exhale] from this idea that probably came from a few people who were suffering with this disorder, which we can now treat. So something like that. But, yeah (.) **Interviewer:** And do you have any feeling of any controversy between, for example, like gynaecology, background versus psychiatry? **Debbie:** Only [pause]. Well [exhale] in different ways, in different parts of the world. Interestingly, so working with IMPMD it's like (.) I didn't realize like there are all these like local controversies, right? I feel like in the UK from what I've heard, there is a lot of like controversy, but the form of that controversy is um, gynaecologists are the ones who are willing to treat it as a biological disorder. And psychiatrists are sort of less knowledgeable about it (.) and at least is what I'm hearing. And I suppose want to (.) you know. Perhaps they'll diagnose [prescribe?] SSRIs, but then they won't prescribe other things and they won't do hormone stabilization interventions like GNRH agonists or Yaz. And so, of course, you know, then people get shuffled into therapies that haven't been tested for (.) you know psychiatric therapies, that haven't been tested for PMDD before they are given evidence based things. So from that perspective, you know, if that's the cult (.) the culture, I think it's very admirable and correct for gynaecologists to (.) to fight for a greater understanding and to fight for (.) the way I see that kind of going is like the gynaecologists then say, well, this is our job. And she shouldn't be (.) you shouldn't be treating these people. We should be treating these people. But I think everyone who's an expert knows and agrees that it's a brain disorder [pause]. Like, I think the people who I've talked to who call it a gynaecologic disorder, when we (.) when I drill down, I'm like, well, what do you mean by that? They understand that the pathologies in the brain that at least that our best evidence is that what goes wrong is in the brain. They just (.) what they're saying is we want gynaecology to be in charge of this. So that's kind of interesting. And also, of course, women love it when you call it a gynaecological disorder instead of a brain disorder, because people have all this mental health stigma and they think you're calling them crazy, it's not what we're doing. We're brain disorder experts. We're just as biological as everybody else. But they don't get that ownership. OK, so that's in the UK (.) in the States (.) there are a lot of similar um dynamic (.) some of the similar dynamics. But I would say that psychiatry is really the (.) are really the experts over here in PMDD. We created the diagnosis. You know, the DSM 5 is a psychiatric manual. Psychiatrists were the ones over here that did all the seminal experiments to show the unique hormone sensitivity. Psychiatrists prescribe GNRH agonists. They prescribe Yaz. They do all of the same hormonal interventions that gynaecologists would do in the UK. And so and (.) so that (.) that differentiation between like, "oh, no, gynaecologists need to do it because we need to flatten out the cycle"(.) Well, psychiatrists can flatten the cycle too. That's no problem. Right? So I think that is a little bit less over here. I think over here. Gynaecologists just don't want to touch it [pause] over here. Gynaecologists are like, "yep (.) psychiatrists, you got this. Go for it. We don't want"(.). They (.) the ACOG retracted their guidelines. The American College of you know, like your RCOG - they retracted their guidelines. And they also they refused to take any premenstrual dysphoric disorder um presentations at their conference. **Interviewer:** Oh, right! **Debbie:** Because I've tried to go because I think it's so important to educate gynaecologists, but they are just very anti this. So I think the (.) I think there's a lot of different points of conflict. Who (.) who is willing to administer these Evidence-Based treatments all the way through? Who (.) which specialty is more stigmatizing for sufferers? You know, obviously, gynaecology is less stigmatizing, but that doesn't mean that it's not a brain disorder. Right? So I think there's a lot of (.) I'm a clinical psychologist. I'm actually neither [laughter]. This puts me in a nice position. I mean, I’m in a psychiatry department. But, yeah, I think both need to work together, you know, because I've seen so many cases where there are complex endo[metriosis], you know, co-morbidities with like physical gynaecological stuff. And, you know, then the psychiatrist will be like, "I don't know what to do!" [puts on high pitched voice]. You know, so I mean, you know, and then sometimes on the same hand, gynaecologists trying to do the cycle flattening with the GNRH agonist will have somebody who becomes suicidal or struggles with that process. And then they're like, "argh!, we need support on this". Right? So I would love to have a (.) team that sort of (.) everybody, you know, and we sort of have that, but it's hard to get the gynaecologists to care, over here. So it's weird. It's very cultural. It's very. Yeah. **Interviewer:** It's interesting (.) it's similar even for postnatal depression and for pregnancy, depression or exacerbation of psychoses and things that are of course (.) are biological. And. You know, mental of physical symptoms will happen but then (.) who owns it becomes a different problem. **Debbie:** Yeah. I mean, I would love to live in a world where everybody takes equal ownership and a woman could go anywhere and get good care [laughter]. I don't see any reason why not?

**Celia:** Well, I think initially that there is a thought that there is some cognitive impairment associated with that time period, decision making, er judgment. Um, there was (.) we did some studies on cognitive functioning in the premenstrual phase I think in the 80s and er we were hoping not to find anything. And I honestly don't remember the results. I don't think that we did find very much. I think and then some others did studies as well. And mostly what they found was a little bit of difference in fine motor coordination. So I think that's the main aspect: judgment, whether judgment would be impaired either by the emotions or by the um physiological state. **Interviewer:** So do you mean because (.) because most women have a menstrual cycle? Well, women of a certain age that it could have implications for gender equality (.) like it is not the kind of cause that you (.) **Celia:** Yeah, I mean, for (.) um as I said, aeroplane pilots, surgeons, anyone who has to be very precise has to make judgment, decisions that have implications. Life and death implications. Yeah.

**Sarah**: Well, I think it's like many things to question, for example, it means different things to different people. If you start talking about a major depressive disorder as defined by DSM Five, we're all talking about the same thing. So it does come back to the definition. So, for example, we (.) I did some work with international colleagues to come up with definitions for Premenstrual disorders, because this term 'PMS' was just bandied around in the media and everywhere else and had different meanings for different people. I couldn't compare my research with somebody else's really until you know we started to get the DSM 5 crit (.) you know diagnosis that at least we were talking about the same thing, even if we are only talking about a small subset of people. So yeah I think I think that's a problem with the term 'premenstrual syndrome' as a cause of contention, I think lay terms that are used in various ways by various people. It doesn't (.) doesn't really help, you know, a lot in terms of diagnosis. You are still trying to sort out well do they need a diagnosis?

**Thomas:** Well, it's (.) it's because er (.) it's (.) it's a sort of (.) it's [pause] it's a less severe condition. In many cases and in those cases, of course, one should (.) should. Consider it as being (.) a part of life (.) being part of normality. And if (.) if one then is saying that this is a disorder. Of course. I mean, then then you are in trouble because then it will actually cause some confusion. Among the population, confusion in relation to [pause] what is a cond (.) what is a disorder and what is not a disorder? So I would say that the main benefit you could do in this one is to actually define when (.) is actually this cyclical mood changes related to the menstrual cycle (.) to be con(.) is considered as a condition? And when are they actually (.) to be, when should they be considered as normal? **Interviewer:** Yeah. Yeah. **Thomas:** And that is not being clearly pointed out. **Interviewer:** Yeah. **Thomas:** In (.) in the clinic where we have the (.) the saying, at least we say it. And I think we are (.) I am quite (.) I can talk for the most of the doctors that are (.) are treating these patients that if there's this (.) if the symptoms are so bad that the patient actually seeks help for that. Then we consider it worth helping and treating (.) so (.) so that becomes some (.) some kind, of line or a border where you consider it to be something which is needing help. Whether one should call it a disorder or not, it's something else. PMDD a disorder so severe that that (.) that has to be considered as one. But that's three to five percent. And then (.) then the other ones, the PMS it's a question of (.) who should be treated and who should not be treated and then and who should be given advice about [pause] living and (.) and so on. As a doctor. **Interviewer:** Yes. **Thomas:** Or (.) or when one should we consider that. And if you (.) if I say and actually that's the reason why I wanted to talk to you. Because I actually think that is a quite important issue. And also (.) also to be considered where [tut slight frustration] and (.) and I think we should we should define it differently. I think that the word PMS is (.) is too established to be (.) to be taken away. So it's more to add on a prefix like severe PMS and severe PMS. Then perhaps it's (.) it's something that should be (.) given help for (.) and then, of course, one can define it depending on what kind of condition is the basis (.) if there is something else (.) one should have the (.) That's (.) that's my (.) my advice that I (.) I teach my (.) my students or the (.) the doctors in training that the first-line treatment in those conditions is actually to treat the underlying condition. Because if you can't treat the underlying condition. I mean if it's actually goes away, usually the menstrual cycle linked symptoms are all so minute. And they also all usually also goes away, or at least so small that perhaps they don't need treatment [pause] and my (.) my general view is that one should not treat anything that is not needing treatment. Of course [laughter] that sounds like it's obvious, but it's not obvious.

**Susan:** Because it pathologises normal changes that happen for some women across the menstrual cycle because it positions it within a psychiatric discourse and implicitly in many accounts, positions it as a bodily disorder that needs to be treated through (.) by (.) by (.) my (.) by (.) sorry (.) by biomedical practitioners and often through pharmacological means and big pharma have played a huge role in pushing that. And you know, there's really good critical work and I've written about it and [colleague's name] has written about it um, the way that Big Pharma actually started to market SSRIs with PMDD and marketed them through pink packaging and basically telling women with premenstrual change, they needed to go on Prozac, on SSRIs. And so psychiatric diagnoses of premenstrual change I think is a very dangerous road to go down. At the same time, we need to acknowledge that some women do experience very severe distress at that time of the month. And having that diagnosis can help them to get (.) help through therapy or through psychiatry or through pharmacology if it can help them. So I think it's a real double edged sword for women. I think we do need to acknowledge the severe distress that many women do experience and I work with many of those women clinically, and I've interviewed many of them as part of research. And I'm not in any way dismissing their experiences.

**Marta:** I don't see much of that. To be honest. I think that er (.) there used to be a professor who (.) who was very critical to the concept of PMDD or PMS, er (.) but I think she probably retired by now because I haven't heard anything from her er (.) in recent years. And I mean, she was claiming that this was something invented by the pharmaceutical industry to sell drugs to women [pause] and I think it's easy to have that kind of opinion when you don't meet the women. So I don't see it [pause] I never meet with psychiatrists who (.) who don't believe in it or think that it's phony or (.) and I certainly don't meet gynaecologists or women or journalists or so (.) very little of controversy. Actually, I would say.

**John**: I think there's a general misunderstanding of lots of mental health conditions, and I don't think this is peculiar in that regard (.) so I treat adults with ADHD as an example. And there's still a debate going on as to whether ADHD really exists. Some people will say the thing about general depression- that doesn't exist and people should just pull their socks up [exhale]. So I don't think it's peculiar to (.) to PMS. **Interviewer:** So really, you're talking about whether this is a real illness or whether it's a kind of (.) er (.) **John:** Well anything that involves the mind. Leads some people to believe that you should be able to control it yourself. As in, it's a (.) organ that is under our control. And if you just think a certain way (.) things get better.

**Laura:** I know that there is a concern that it stigmatizes women. And I would just say that (.) most people who I have heard (.) make that claim are not clinicians who treat patients who are suffering. **Interviewer**: And what about within medicine? Do you think it's controversial? **Laura:** I think having treatments for it and having it in DSM 5 has actually normalized it. I think there was a history in medicine, to (.) to denigrate people who complained of PMS and say they were just character disordered, or crazy, or whatever.

**Zoe:** Again, it's. It can be controversial for lots of reasons. Personally, I find it a controversial diagnosis because of how it labels and positions women. Um, I do think it is um [pause] an experience (.) women do experience (.) some women can experience premenstrual distress. We don't need to pathologize that in order to (.) to work with women or to assist women or to lead women to their own (.) to their own devices [slight laugh]. You know, experiencing distress is (.) is you know, is something that occurs in this instance it's occurring around premenstrual change (.) it's occurring around the premenstrual period. But distress is (.) is (.) is a part of life. I don't (.) I don't think that's something we need to necessarily pathologize. And then in terms of what the social and the legal and the economic ramifications are of that for women. And I also don't think we need to do it to medicalize it either. I think there's a whole set of medical interventions that come into play once we make something 'a diagnosis'. So I don't think we need to do that for PMS. And um (.) yeah (.) yeah. Have I lost (.) Have I lost your question? I can't remember. **Interviewer:** No. Well it's considered by some to be controversial. So you know what (.) what's your understanding of why it's controversial? **Zoe:** It's also controversial because some (.) some people challenge or contest, whether there are (.) they (.) whether there are those changes? And they can (.) they contest those changes. Some contest them within a culture, some contest them across cultures. So it can (.) So it's a contested condition. If nothing else. So (.) so some people (.) yeah take it from that perspective. I think yes, there are (.) my experience in research would indicate that there are definitely changes. Some women report distress. And but whether we have to actually classify that and position that as a treatable illness or an illness that needs to be treated or untreated is a different matter altogether. **Interviewer:** And again, just to clarify, is that including that small percentage of people with quite significant experiences? **Zoe:** Um, I think (.) going back to a previous answer, I think PMDD is different. I think PMDD is a different set of experiences to just severe PMS. That's not to say that some women who experience severe PMS may not want to do things to manage that interference. But I do think it's actually something very different to PMDD.

**Geraldine:** Well, of course, there's the question of whether it's a culture bound syndrome. So, you know, a lot has to do with our beliefs about menstruation, our beliefs about women's nature. So that's one element of controversy. Another element, I think, is how it contributes to stereotypes about women. And these can harm women's ability to attain leadership positions in society. For example, when Hillary Clinton was running for US president, in 2008, I Googled just for the fun of it ‘PMS and Hillary Clinton’ and I found thousands of hits and she was, of course, post-menopausal. There was no way she could have been premenstrual or had PMS but you know, this is just the kind of thing that people believe and so it's controversial because it can be a problem for women, who are diagnosed. But if you talk to the women who suffer, you know, and experience symptoms that they believe are related to their cycle, they often feel that they're being somehow punished if it's not recognized. So that's another controversy. You know, getting a diagnosis is helpful to some women, but it's not helpful to others. And, you know, this belief that's become so common that 'all women' have this is harmful to all women because most women have mild to moderate symptoms (.) premenstrually and some women have none. And so it doesn't affect everybody. But yet the assumption is that it does(.) And then, I should also mention that because we don't know how to treat it, that's part of the controversy. Women have been treated with hormones that have lots of side effects. Women have been treated with hysterectomy, which causes lots of other problems for them. I mean (.) [exhale] right? … Right. Well, I would never tell a woman that nothing is happening to her [exhale]. First of all, how would I know I'm not her right? My interest has been in (.) I'm a social psychologist and not a clinical psychologist. So my interest has been in (.) this stereotype notion that 'all women' have the same experience, that 'all women' go crazy right before their period, which is not true. But that's not to say that no women suffer. Because we've all talked to women who have suffered to various degrees. And so, you know, when I was talking to you before, I said most women have mild to moderate symptoms that they can cope with and manage. But some women have more severe symptoms. Now, you know, it's possible that those women might have experience of trauma early in life that could relate to this. It's possible that they have a form of depression that waxes and wanes and is affected by biochemical changes associated with the menstrual cycle. So they may feel suicidal at certain times of the month, but maybe generally depressed overall. I mean, there's a lot of possibilities. And so treatment really has to be related to individual patients. There's never going to be, as far as I can tell, after studying this from the 1970s. It's never going to be one thing that is going to work for everyone.

**Chris:** Controversial diagnosis? OK, if we're (.) with General practitioners. It's because they don't understand it. If we're with a gynaecologist, it's because they want to avoid it. Or they specialize in it. So if they (.) if they want to avoid it, they you know, if they're a cancer surgeon in gynaecology, they don't really want to be bothered with PMS so it's (.) and they probably don't understand it that much. So there aren't that many people who understand it very well. And I don't think I understand it that [emphasis] well, but I understand it more than most. And so um (.) it's(.) it's probably more of wanting to avoid the condition rather than saying what was it, what was the actual phrase you used? **Interviewer:** Why it's a controversial diagnosis? **Chris:** Yes, it's a controversial diagnosis because (.) and one of (.) the other reason is because once you diagnose, it's hard to treat. When you say controversial, you mean does it really exist, type of controversial or? **Interviewer:** It's any type (.) Any type of controversy. So, um a psychiatrist might answer differently to you (.) You know, so this is interesting to me (.) for the way in which you see it (.) **Chris:** Yeah, well, I've had a lot of trouble with psychiatrists! [Smiling tone] So they (.) they (.) they (.) they want to label it as (.) don't want to label it as ‘hormonal’. They want to label it as (.) what's the word I'm looking for? Errr (.) psychiatric personality disorder, bipolar disorder. And they want to treat it with lithium and things like that. But it's easy, so what we should really do is you get a patient who's got severe problems, it's affecting their lives. Probably (.) you know, if it's complex. Give 'em a GNHR analogue, if they've still got it afterwards, give them to a psychiatrist! You know, that's almost (.) It's slightly cynical there, but it's almost true. Yeah?

**Jo:** And I think in some situations it's not properly diagnosed. So that would be very controversial then (.) I think it's really, really important that women have a proper prospective diagnosis. And it is quite an uncomfortable place to be as a clinician when you've got somebody in front of you who's saying "every month, I feel horrific". And you're asking them then to go and record (.) their record (.) their symptoms and bring them back to you. But I think for those women who may be going to have surgery, it's absolutely crucial. I had a patient in very recently who was told by a gynaecologist that she had PMS. She had had no children. She had a hysterectomy both ovaries removed. And then they changed the diagnosis to rapid cycling, was it rapid cycling, bipolar, bipolar disorder? And so, you know, she's well, she's going through a litigation process but had that gynaecologist shown that they had gone through all the steps to make a clear diagnosis. I think there would have been less of a case to answer to. I think it's a big step to take somebody's uterus out, and ovaries, when you haven't got anything to prove your diagnosis. Apart from that, you thought they had PMS. **Interviewer:** Well, that's something I've noticed- a difference between the clinicians, I have spoken to (I'm only speaking to a few people because it's a qualitative thesis). So all the experts are saying "you must do it prospectively". Like "this is very, very important". But when I speak to patients. I can't think of any of them that were actually asked to track their symptoms prospectively. And as somebody, you know, I just run a website, I ask people to do it anyway, just to know what is normal for them to know about their length of cycle, blood flow, everything else. But as you're saying, there are lots of reasons why you might not be asked, sort of practical reasons, but also ignorance of the (.) And I think also wanting to believe women, female patients because there is a history of not believing female patients about these sorts of experiences. You know, you can't trust that it's not a chronic condition that's being worsened. I think that's a very difficult thing to differentiate. **Jo:** I think there is a bit of pressure from patients when they're desperate to just (.) to just take it all out! Now, I'm not a surgeon, so I'm never gonna be in that position. And therefore, you know, if I'm going to refer one and ask somebody else to consider doing that, I would I would definitely want to be able to show them evidence that there was a real problem. But, you know, I tend to use an app because it allows women to send me graphs and it's there in black and white. And it is a good way, I think, of communicating with them. But you can do that on paper as well. It's just easier to email graphs that are generated.

### P29- Disbelief? Or controversies?

**Alice:** Do you mean that what you're saying is health professionals don't know if it should be a diagnosis or there’s some discrepancy… or? **Interviewer:** Yeah, I mean any kind of argument (.). I mean, one of my sort of examples is that someone once told me that my period pain was all in my head (.) and I had to explain that all pain, when we really get down to it, is processed by the brain (.) but that doesn’t mean it is imagined, or not real in any way! **Alice:** So as a health professional, I think pain is something that is a continuingly (.) it's constantly being investigated and researched. But I think the context of that is really important. So, you know, somebody might have their leg chopped off and get phantom limb pain. And we know that that is the processing and mapping of the brain that doesn't go anywhere (.). So. whilst there's no physical leg there, I'm sure that the pain is horrendous, you know. And who are we to anyway, to judge if somebody is experiencing through their experience and their physical (.) erm, feelings (.) pain? No one can say to us that that doesn't exist. I think we don't really understand how that works yet. And I don't think we can categorize pain. Full stop. I think it has to be context specific. Based on that person's experience and what's happened to them in their life. And I think there is some crossover in my own experience of treating people between that journey and their mental health. First, it’s their physical health (.) I mean (.) personally, the pain I experience (.) you know, if someone said to me it doesn't exist. I would say, well, when I'm having one of those horrendous experiences, just come and see what it's like, I guess (.) I think the physical associations of that pain that occurs to me (.) so, you know, the vomiting isn't painful and diarrhoea isn’t painful, but that for me is the consequence of the pain I'm experiencing. If somebody said that I was making that up and causing that myself (.) I think that would really upset me. Erm, but I'm sure that somebody might say it [laugh]. **Interviewer:** I think I mean, we've kind of covered this as well. But you're saying that you wouldn't ever describe yourself as having ‘PMS’ and that there is a reason for that (.) **Alice:** Yeah. **Interviewer:** (.) that it's got this connotation. So that's kind of what I'm asking you about (.) how (.) **Alice:** [interrupts] I think (.) I think it's dependent on who treats you. And that's been my experience (.) well, two things (.) which is that on one side, I think women, who experience periods and period symptoms. I think that on the one side, women would (.) would appreciate it if healthcare practice and research, or if more research was done, first of all, but if there was a better understanding of what pre-period or period, or post-period presentations are just full stop and that there’s variability amongst women. And I haven't even touched on the fact that there’s probably variability amongst different ethnic women (.). So I think that that's an area of health and medicine that hasn't really been explored yet sufficiently to develop and create understanding of, you know, of even just terminology, because I think you have used the word, ‘diagnosis’ and stuff like that, to me, ‘diagnosis’ is again associated with something that's wrong with you. Having periods are normal, you know, and there's nothing wrong with you and you will have a straight line where you're lucky that you just have a simple bleed and you get back to normal life in its last three days and that's every 28 days that you tick the box at complete regularity. Great. Brilliant. Now, I wish I was that woman, but we know that they can happen between 20 and 21 days and 32 days. So you might be a woman that has them every two or three weeks. You might be a woman that has them every four or five or six weeks. If on that scale you (.) you may present slightly differently whether you've got pre-morbidities like they say or preconditions or a previous journey or previous complication. All (.) you're just having a period, you know, and you will be placed slightly differently. I am one of three sisters. My experience is different from the other two sisters. Why am I any different? I don't know. So it is not about (.) I think it's about a real gap and lack of insight into that process. For women (.) and again, I would say that that happens for the menopause as well. I think there's more research has been done on the menopause, but I think they’re massively connected. And I wouldn't be surprised that if you've experienced having periods in a certain way that you then experience having a menopause in a certain way. Who knows? I mean, they may be completely different. But the (.) but the research also comes from money. And we know that when you hit menopause there’s the HRT drug, which drives research, which creates money, which drives the economy. So why wouldn't we research that? There isn't any money for [research into] women having periods apart from contraception and the pill so that our lives are researched on that- one solution is to go on the pill because it apparently can ease symptoms better – I in the past did not believe in that because you then induce even more drugs into your system. So I think it's like it's the words that we use and the language that we use to describe the releasing of the egg and what happens to a woman's body during that time. And it's, uh, it's still a very male dominated field. In medicine, I think I think that's changing. And I think the (.) that the (.) emphasis and the time that is required to (.). It is ironic (.) ‘cos we've been going through this for thousands of years, you know [laugh]? But I don't think it's seen as a priority area of health. Actually, you could suggest that it is because I think some associated symptoms that some people experience to the extreme, which does cost the healthcare system huge amounts of money. And actually, if they if they did research this more, they might find that if they got this understanding better (.). So I don't mean like diagnosis because it's not a diagnosis, just a process, a physical process. If they understood that better. Other associated things that do happen to some women may mean that they (.) they don't go down that line of healthcare. Say, for example, like complex pain or mental health or whatever it might be. And actually those associations are dealt with in the forefront to give women better, more understanding and self-management and empowerment to take care of themselves better down the line. I hope I answered that question? **Interviewer:** Yeah, that was very good. Yeah, It was about (.) well, it's kind of what you hope needs to happen. You know, what could be helpful rather than what is kind of lacking at the moment. **Alice:** The one thing that I would say is, you know, I'm a health professional myself. But I do not think we have (.) health care (.) full stop in the UK which is open to me as a woman going to see my GP, which is where everything starts (.). To be able to say ‘this is what happens. What can you do?’ because having done that (.) twice or three times my experience has been it's a shut door (.) and actually the only and I don't want a diagnosis, ah, I mean, maybe I do have endometriosis, but, you know, I don't think I do because I (.) I've looked that up. I just think that (.) maybe the fact that we even go to the doctor to say what's wrong with me tells you a lot about how society views periods.

**Beth:** No, but then that's probably because I would only tend to discuss these symptoms with other women who would (.) have awareness of PMS (.) anyway [laugh]. I don't think it's [pause] I don't think I'd bother having a conversation about PMS symptoms with people in general, I can't think of a situation in which that's happened anyway, in which I've been dismissed as not having PMS. No. I don't know whether it's due to a self (.) self-selecting (.) group of people I talk to, are people I know are going to be sympathetic to it. **Interviewer:** So it (.) kind of related to that (.) are you aware or have you been made aware at any point that PMS is some sort of controversial diagnosis? **Beth:** [Very long pause] No, I don't (.) I don't think so. I mean, it's not (.) I'm thinking about conversations with other medical professionals. I don't think it's really discussed much at all among medical professionals, as a diagnosis. And (.) I mean, I can imagine that some women might feel dismissed if they were told they had PMS as being told they had something insignificant or that couldn't be treated. But that's just me theorizing. Really, I haven't been in a situation where I've been told it's a controversial diagnosis. No.

**Dani:** Erm (.) Have I? Good question [pause] I don't think so [pause] I'm sure I've met people who don't understand what the pain feels like because it's not just like having the stomach ache, it's like (.) it's almost like you can feel your womb working. Sometimes I think people don't quite understand, that if they don't have it. **Interviewer:** Yeah. Are you aware that PMS is considered a controversial diagnosis by some people? **Dani:** I don't know if I knew that, but it doesn't surprise me. **Interviewer:** Why would you think it might be controversial? Again, I'm not testing you [laughter] **Dani:** Well, I think because it's so variable. It probably is the kind of thing that maybe like the scientists don't like because it's not like (.) but, you know, it's (.) it's harder to test as well, probably. But yeah, because it can be so variable and it can change from month to month. I guess it could be to do with other things as well. But yeah, I'm not (.) I'm not surprised that it's considered that. But it doesn't make any less real.

**Emma:** Yes. So when I think back to when I was at school, I played a lot of netball. And did dance classes and things like that. I remember one of my friend's moms. I couldn't play in a netball match or go to practice or something like that. And I remember she was just incredibly dismissive about it and was like, oh, it's just (.) just a bit of cramp. You can you can get over it or something like that. And. I guess that that's stuck with me because I remember it, so it must've hurt at the time. Yeah. And then. More recently, in fact, very recently, I was at an event and had a discussion with someone after talking about PMDD and had presented (.) erm, some (.) some brain scans to show the difference between PMS patients (.) and (.) er women in the general population and I had a discussion with this person who (.) who [pause] was questioning whether or not we have been socialized into believing that PMS is a (.) is a cult (.) is a socially constructed thing, and it's not a biological thing. And that was really difficult to hear. Yeah. So, yeah, I've come across people who don't believe in it or don't believe it's a thing and don't understand how it can affect people. **Interviewer:** So linked to that. Are you aware of PMS being a controversial diagnosis? **Emma:** In what sense? If it's okay to ask? **Interviewer:** It can be in any sense a little bit like you're just saying that that person thought that it's a social construct only, that there's no biological basis to PMS (.) **Emma:** Um, I think so. The same person was also [long pause] concerned about (.) about portraying women to be weaker because of the menstrual cycle. Talking about PMS in that capacity, she thought that somehow we were almost (.) I was almost victimizing women. And so I think it can be controversial from (.) from that perspective [pause] and I don't think it's (.) necessarily seen as a [pause] as a medical diagnosis [pause] either (.) so I think that aspect of it is controversial, and maybe that's why there are so many people who go for years un (.) undiagnosed livin' with PMDD. **Interviewer:** Do you mean that it's seen as like PMS is just a natural (.) **Emma:** Yeah (.) **Interviewer:** Part of the menstrual cycle (.) so that it can't be severe enough to actually count (.) Is that what you mean? **Emma:** Yeah, that's exactly what I'm getting at (.) and [pause] this goes back to yes, with the majority of people. It is (.) it is a normal thing and it doesn't have much of an impact and it goes unnoticed. But for others, it (.) it really does have an impact and it (.) [audible tapping of fingers on table] it is disabling in some cases and (.) we don't (.) we don't often consider it through that lens.

**Interviewer:** Um (.) we've touched on this a little bit. Have you ever met someone who didn't believe you were really experiencing these symptoms? **Gemma:** Yeah. Doctors. **Faith:** [Nervous laugh] Yeah, so um yeah. Doctors and also working with men [laughter] **Gemma:** Yeah **Faith:** So there's been times where I've been in like (.) let's say for example at [employer]. I would have to go in with a hot water bottle, and I'd literally just sit there and be like "I'm dying" and it would be the whole sort of "imagine if men said that!" and just that whole "girls, or all you women exaggerate. It's just a belly ache". But that's understandable because again, they haven't really been exposed to like the realities of having like a period (.)[Laugh]. **Gemma:** But is it understandable? [Laugh]. **Interviewer:** Yeah, I dunno. I mean if a male colleague needed a hot water bottle, I wouldn't put him down. **Gemma:** Yeah. **Faith:** Yeah. And doctors just not (.) and the extent, too (.) **Gemma:** Yeah. I think just me. Doctors, definitely doctors. **Faith:** And the school. **Gemma:** Yeah, schools in general. Yeah, they don't get it. **Interviewer:** Are you aware of PMS being a controversial kind of diagnosis? **Faith:** No! I thought it was just something that everyone knew about (.) I guess [whispered]? **Gemma:** In what (.) in what context? Like, if you was to say, I'm not going to work because I'm experiencing PMS? **Interviewer:** Well, some people think that because the menstrual cycle is a natural and a healthy thing for people with female reproductive bodies to have, that, it's not like an illness. That it is just that some people get more severe experiences. So that's one controversy. Is like should it really be a medical (.) thing with medical treatments or not so much medical, but should it be this kind of idea that all women kind of get emotional, whatever, if it doesn't affect everybody in the same way? **Faith:** You know, that's interesting. I never thought of it as an illness (.) **Gemma:** Yeah neither have I, ever! **Faith:** I think I thought of it as an experience. **Gemma:** Yeah **Faith:** So, not the same as an illness. **Gemma:** Yeah. I never thought about the illness at all.

**Helen:** Yes. Many [laughter] many, many people. **Interviewer:** And was that like friends or family or doctors? **Helen:** So I would say friends and fam (.) not so much friends. It was more family and my partner. I mean, I hate to say that. I don't mean to throw him under the bus. We're still married. But he had I mean, he'll even admit he's become a huge advocate as well. But before, because he had never experienced anything like this outside of me, like he even admits he's like, "there was just a time. I was like", he thought I was just being weak minded. Like he absolutely subscribed to the general view of all things premenstrually or mental health-related. Is "You can think your way out of this. You can't be as bad as you say. You're just being irrational. You're being overemotional". I think that was to this day, the hardest one to swallow [pause] is the lack of believing from my own partner [serious tone] **Interviewer:** Hmmm **Helen:** Yeah. I mean, it's changed [laugh]. **Interviewer:** Kind of related to that, are you aware of PMS or PMDD as being controversial diagnoses? **Helen:** Oh, yes, absolutely. Thousand percent [pause] just everything we just discussed [laughter] about [pause]. Yeah, about (.) I think there is a concern. You know, there's the concern of over-diagnosis, which even I (.) yeah, I talked about this like a month ago. Maybe, you know, every time there is a suicide of a woman in the media, there is within the community I work, I feel like there is the habit to want to posthumous (.) what is that word? Post (.) Gah! I can't think of the word! But after someone's passed away, you diagnose them (.) **Interviewer:** Post-mortem? **Helen:** Yeah. To try to go and say, oh, "maybe they had PMDD” and I see that. And it almost (.) it's a little scary because, you know, I think the community is looking for (.) I think what happened with Gia Allemand [US actress who committed suicide in 2013] when she passed away. In our organization, it was happening for a while. You know, we worked with them for a while [The Gia Allemand Foundation became IAPMD]. I think there is, you know, almost a (.) not celebratory, but there's almost this like hope of, oh, we'll get somebody that (.) "we'll get somebody". Gosh, that's (.) I'm doing air quotes I dunno if you can see me? I don't know how to explain it. I think there is. I think what I'm getting at is out of desperation of the patients. I think there is a real risk of in order to validate their own diagnosis. And I think even with doctors, because even gynaecologists have the ability to prescribe, you know, anti-anxiety and antidepressant medication, I think there is an absolute you know danger of (.) in addition to mis[diagnosis] and missed diagnosis. You just gotta (.) there needs to be (.) one day. We just need a definitive test that isn't based on symptom (.) reporting symptoms. Does that make sense? Like we need a blood test. We need a DNA test. We need some type of test that definitively can diagnose PMDD I don't know what it is (.) based (.) you know, obviously. But it's so needed because if we just go trying to diagnose everybody based on their retrospective, you know, symptom reporting, we're gonna have a lot of (.) lot of problems as we've had throughout the history [laugh] of this disorder.

**Kathleen:** Um (.) No, no. I mean, I haven't really (.) I don't really talk about it to be honest with people, not (.) not my period. I'm just trying to think because me and my sister are quite close. But we've never, it's never been that bad that I felt like "Oh I need to (.)" You know mention it. Obviously with the fibroids, it's a little bit different. But um, yeah (.) and even now. I mean, I think I've told you about the change in my moods. But I haven't told anybody else. It's not that dramatic. It's just that I've noticed it. Um, yeah. **Interviewer:** And again, with your fibroids, you had the anaemia (.). That was your very believable beginning. **Kathleen:** Exactly. Exactly, yeah. **Interviewer:** Um, are you aware at all of PMS being a kind of controversial diagnosis? **Kathleen:** I would (.) So it's not that I've read anything in particular, but I would think it would be. Er (.) I get the sense that, you know, it's probably not investigated, researched as much as just other conditions. And because there is you know, and I (.) I (.) these stereotypes of women and, you know, going on their period and "Oh don't talk to her, when she's on her period" or you know, actually I have (.) I have had (.) sorry I should have said this before. I have had men ask me, actually, when maybe I've had a disagreement with them and I have had someone say, "Oh, well, you (.) are you on your period?" [Laughter]. **Interviewer:** And what did you say? **Kathleen:** I said, I'm not answering that question and I can't believe you just said that. **Interviewer:** And was this in the workplace? **Kathleen:** No, this is personal. **Interviewer:** Oh! Personal. Oh, god! A brave person, indeed! [Laugh] [pause] A few people have said this and there's this stereotype of PMS and sometimes in the workplace. people go "Oh, you know it's her time of the month" And quite often they mean menstruation. So, they don't mean premenstrual at all, they mean the bleeding. **Kathleen:** That's right.

**Aisha:** All the time! **Interviewer**: So who are these people? **Aisha:** My manager [laugh] Um (.) My big sister. Um. Yeah, close people, close relatives like my uncles and stuff. Men. (Some men get it! [laugh]). And a lot of older women like my aunt, for example. They (.) they find that's so normal. **Interviewer:** So they think because they didn't get it (.) **Aisha:** Yeah. I**nterviewer:** That you're making it up? **Aisha:** Yeah exactly. **Interviewer:** So are you aware of PMS being a slightly controversial diagnosis? **Aisha:** Yeah **Interviewer:** Could you tell me why you think it might be a bit controversial? **Aisha:** Some people feel it's normal. Some people feel it's got nothing to do with your periods, your mood. It's a mental health condition, it's your environment, it's what you eat etc. So that comes before that diagnosis. Um. Some people don't even see it as it should be a diagnosis. They think it's a part of your symptoms and (.) yeah, that's it.

**Mala:** [Immediately, almost overlapping whispered speech] My mum. [Short pause followed by laughter]. **Interviewer:** [00:20:52] So what does she say? **Mala:** [00:20:53] So if I say I'm PMSing, that's why I'm actin' like this, she says "You're just overreacting". **Interviewer:** So, she doesn't like count it at all? **Mala:** [Overlapping] She dismisses it! [Laugh] yeah. 'Cos you're trying to make an excuse for your actions. So I just ignore her (.) **Interviewer:** And anyone else? **Mala:** Um, no (.) not anybody else has picked up on it. Really. **Interviewer:** Um, are you aware of PMS being a slightly controversial diagnosis? **Mala:** Yeah, well, in terms of what? Controversial? **Interviewer:** Well, things like, is it real or not? Or like is it really an illness? **Mala:** Yeah, I think in my community (.) I think it's because we come from (.) Um, I come from an Asian community. We do dismiss a lot of things, um especially if it's not measured or put down on paper. You can't really say there's an actual diagnosis. So it's seen as an excuse to get out of things. **Interviewer:** Right, like a sort of (.) yeah. An excuse not to work or to go to school or (.)? **Mala:** Yeah or (.) just excuse for the way you're acting.

**Noor:** Yeah, it's more my female colleagues rather than the male ones. **Interviewer:** So because they don't get it? **Noor:** Yes. **Interviewer:** So they don't believe you? **Noor:** Yeah. **Interviewer:** And how do they (.) how does that happen like. Do they say that to you or? **Noor:** So once what happened, I was like "I'm not feeling really well. I think it's because of been my period". And then she's like, "oh, you'll be fine. You'll be fine. Just get on with it". But my colleagues could tell I was struggling. And then she was like "you'll be fine". And in the end, she left. So the other lady that took over said “it's, OK, go home". **Interviewer:** Mm hmm. So they kind of minimized it (.)? **Noor:** Yeah. **Interviewer:** Are you aware of PMS and actually PMDD as well, being a controversial diagnosis? So one that people might say it's not really an illness or (.)? **Noor:** Yeah. **Interviewer:** Where have you heard that? **Noor:** I think people are just not aware of those terms.

**Ria:** I didn't (.) I don't spend a ton of time on the deep interweb of medical jargon, so maybe people who are like more versed and aware and sort of staying on top of that might? However, I am you know, I have my critique of the DSM and psychiatry and diagnose (.) psychiatric diagnoses as a whole. I think they're very beneficial for certain people to just have that moment where you're like, "that's what's going on!" and have that affirmation and then find medicines that help support them, balance that or recover from it or whatever they're individually defined goals are with it? So to answer your question, I understand that it's a controversial topic in popular culture and also in the sense that women's reproductive health and not even just reproduction, because that's not the only thing the menstrual cycle is for. Just women's health in general [laugh] is a controversial topic in medicine because of the ways that, you know, the (.) Not just women, but all menstruators have been excluded from a lot of clinical research for basically since time immemorial, since research started. Now, obviously, that's changing, but it's still like a lot of research is based on prior research. And so in that sense, I do think that because there's (.) a lot of people are starting to talk about it out loud now and see the importance of honouring femininity and the menstrual cycle in the world, that because there's more talk about it, there's necessarily then, as all humans do, going to be people who are critiquing it and thinking that it's controversial and all of that.

### E18- Any symptoms?

**Anne:** [Pause] I think it was [pause] very good (.) because there have been so many different definitions that it's been (.) difficult when it comes to, say, in the research field, comparing studies because different criteria have been used. So the main aim of the Montreal consensus was to come to a consensus on a definition so that it could be applied consistently both in the clinical field and also research in the future. I mean, I know a few of the people who were on the group, and I know that it was very, very difficult because everybody was coming from different schools of thought about it. So it must have been very difficult to come to a consensus. I think the other thing that I like about the Montreal Consensus is that you've got the core premenstrual disorder and then the different variants as well, because it is very complex. But that (.) that I think they did [pause] group that very well to include premenstrual exacerbation, to include premenstrual disorder, even with an absence of menstruation, say somebody has got a hormone coil or they've had a hysterectomy. And so I thought it was very good in that respect as well. And (.) I think one of the problems around premenstrual disorders is you've got these two disciplines, you've got the psychiatrists who favour the psychiatric symptoms and you've got the gynaecologists who will tend to focus more in on the menstrual symptoms, physical symptoms. And so I thought it was good in that it brought together both disciplines.

**Barbara:** This seems to be the definition given to PMS as well. If the symptoms are carefully monitored to provide evidence of their pattern and occurrence, it will likely result in what is termed PMS.

**Original Fran:** I think we (.) there was a lot of discussion about that and as I was saying, I tend to (.) if you ask me what I think are the most frequent (.) those are emotional symptoms but because a large number of gynaecologists on the committee feel that women present more to them with the physical symptoms [inaudible] it could be a bothersome symptom that [inaudible]. But those of us who do PMS research in the mental health field feel that [inaudible] and we may just try and support them to [inaudible].

**Edited Fran:** I agree with the definition as put forth by the ISPMD consensus meeting.

**Andrew:** And that was the strong opinion from our friends in gynaecology. So if I had written those papers myself, that would not have been my (.) my understanding of the situation. I'm more in the camp that want to divide these into different syndromes. But what we said, I think was a typical consensus group compromise that each and every symptom may qualify for PMS, but that there are important sub categories of the condition. And so it's kind of a compromise that (.) that it's still acknowledged that there are different subtypes that are quite distant from each other. And then it's merely a semantic question. If you want to have a common heading for all these subtypes or if you want to regard them as entirely different conditions. And I think we would never have reached consensus in any of these groups if we had not agreed to have some kind of umbrella term for all premenstrual conditions, because this is how they have traditionally been dealt with within gynaecology. And to some extent, gynaecologists have owned this condition because it's usually (.) these are the doctors usually treating these patients who they have (.) have (.) it's part of their repertoire of disorders. And that is how they regard it.

**Debbie:** I think it's the same as what I talked about because they said resolve after menstruation. So I think that what they I think they're talking about this (.) I mean, I think they're saying exactly what I said, which is that it doesn't matter if the symptom is a disorder (.) of another disorder, you have as long as you don't have it the whole month [laugh]. I think that's what I mean by that. As long as it resolves. Right? Because what they mean by resolve is like it goes away. **Interviewer:** So they just state 'any' and then they don't list any symptoms as a guide. So (.) **Debbie:** I'm fine with that. **Interviewer:** Yeah, you're fine with that (.) cool! **Debbie:** Well, I mean, I think (.) I think with the caveat that (.) that all of the evidence base for treatment is based on the PMDD criteria. So to the extent that your patient is experiencing something that is not emotional, not like (.) a total like, I don't know, skin itching or something. Right? Like, I'm not sure that we would say, "oh yeah, just use the PMDD treatment guidelines!" [Makes noise to imply crazy doctor] You know, it's probably got to have some emotion (.) something in there.

**Celia:** Yeah, I think that sounds reasonable. Again, I think you have to separate out in [medical] history what (.) what's underlying and what may not be, and sometimes that's very difficult, particularly for someone who has underlying depression or anxiety disorder, bipolar disorder or anything like that. But I think it's important because the treatments as you say may be different. [Pause] I think if you're concerned about giving someone a label, then it may be an issue. If you're just saying you have one physical symptom and you now have PMS. But I'd like to see the pejorative nature of the label disappear. Now, I don't know whether that's possible and I haven't (.) as I said, I haven't heard much about it recently.

**Sarah:** Well, It just does go back to what we found in that paper I told you about. It's very idiosyncratic, what women put forward and the order in which they put it forward, you see? So you can find the same sort of symptoms being mentioned. You know, in that long list that I’ll send you. You know, and I would do this with people in the clinic I'd say "now (.) tell me about all the things you notice (.) ahh are there any more?" you know? Sort of (.) instead of getting bored with their first three [laugh] and limiting them to that. But just trying to you know, so if you really do try to drag it out, you actually do find that people talk about a range, a large range of things. So then you've really got to look at well what are the most prevalent of the symptoms (.) and people talk about a lot of individual symptoms.

**Thomas:** Well, it's again, a question of severity. So if you have one symptom like you had nausea, if that nausea is so severe that it's actually hinders you to work 2, 3 days per month [pause] then it's worth treating. So it's (.) it's (.) it's all it's a question of severity all the time, and that question of severity has not been resolved completely. So (.) so that is an important issue for research to actually define. How severe should the condition be to be (.) be treated? And in that case, I think that (.) one something (.) there's another issue which is also interesting in that regard, and that is if (.) if you have these symptoms in 14 days every month. Is that worth (.) worse than if you have it in three days (.) but very intense (.) in three days?(.) In 14 days. But let's say a (.) of a lower degree. If it is (.) Intense in (.) in 14 days, of course, it's worse (.). We actually made a trial of this in the 80s. We made a score trying to elucidate the number of days with symptoms and without symptoms and the intensity in our ratings scale, how (.) how intense they had rated their symptoms. So the mean rating of the or (.) the median rating of the intensity combined with the number of days they had symptoms. And that made the score which showed out to be normally distributed [long pause].

**Susan:** I think it's a good one. I think it's taking women seriously and not trying to fit women into (.) um, you know (.) one of the things that's really difficult about PMS research is that so many women are positioned as false positives. If they say "I've got PMS" and then they're given a standardized symptom checklist and they don't have, you know, X number of criteria on the checklist that they're expected to have and then we dismiss all of those women and say, "oh, you don't have PMS, you're not coming into the study" and if that's happening clinically. For women who feel that they have PMS severe enough to need help, then I think that's appalling. So I think what we do need to do is actually acknowledge (.) but it moves us away from the notion of a syndrome because a syndrome has to have a set number of core symptoms. So it really (.) but I think if we actually say that women have premenstrual change and it's on a continuum and some women need support and actually let's talk to them about what's happening and their pattern and whatever their symptoms are, we take seriously then I think that's a good thing. But I think if it's used to then (.) pathologize all women. Then it's dangerous. But you've got (.) my understanding of those consensus guidelines. And of those definitions of PMS is you'd need to do that tracking and that daily diary (.) those daily diaries to see what my symptoms are? And if somebody was saying, you know, I felt I had an itchy foot for (.) I'm just trying to think of something ludicrous (.) that my foot was itchy, you were nearly driven out of your mind? Well, that's not PMS. Like, you might have a change that happens. Or, you might be feeling more sexy or more energetic. Well, that's not PM (.) that's not a pathology.

**Marta:** I think it's (.) I think it's OK. I mean, we have to acknowledge that that women are different [from each other] and that we don't know everything. And I mean, if I would ever meet someone who came to me with a symptom that I hadn't previously heard about, I would, of course, still count it as a symptom. Although I would say in real life practice, given the way I'm using open questions when I see my patients, I don't see that many patients who come in with symptoms out (.) outside the typical ones. [Pause] One symptom that I think is not sufficiently captured in any of the questionnaires that are typically used in PMDD is suicidal ideation, which I think is far more common than (.) than people think about. And I think I would absolutely vote for an item like that to be incorporated in the diagnosis because I think (.) looking in my own data now, I think it's (.) it's almost around 50 percent, 45, 50 percent [cough] of the women we include in this progesterone receptor trial, who acknowledge they have suicidal thoughts, er at base line.

**John:** I think it's unfair to [pause] restrict treatment to people who (.) fulfil a group of criteria that one bunch of people have decided is correct and not to another group of people who are suffering. So within reason, I would say that if somebody is suffering and wants treatment that it's appropriate for people who can deliver that to deliver it and not get too caught up with definitions and classifications. **Interviewer:** Yeah, I mean, pretty much all the clinicians I've spoken to have said they don't really stick to the PMDD criteria. So if somebody has very severe (.) one symptom or two symptoms and they’ve got to the point of seeing them, they count that as PMDD (.) **John:** Yeah. And the people that come here, I would say that (.) the crit (.) they usually end up ticking, actually (.) most of them. But er (.) the area that they would fall down on with regards to the PMDD criteria would be the 'not an exacerbation of another condition'. Or at least that would be one where I would say it's unclear to what degree it's an exacerbation of something else. **Interviewer:** And that would affect treatment options? **John:** No. Well (.) **Interviewer:** [Overlapping speech] So it's just in terms of the diagnosis? **John:** I said it wouldn't effect treatment options (.) but if somebody came here and for example, they had bipolar disorder that was exacerbated premenstrually, I would try and treat the bipolar disorder more effectively before going for the hormonal approach. Or if they were psychotic and that got worse (.) premenstrually, you'd want to treat with psychotic symptoms first. So it does influence it in that way.

**Laura:** Well, that's their definition. It's not a definition of PMDD. It's a definition of PMS I rarely see anybody (.) who (.) has functional impairment because of physical symptoms. **Interviewer:** So for you, PMS is (.) it isn't debilitating or just (.) because you said before that PMDD was a sort of subset of PMS (.) and that is obviously more severe and mood related. So I'm kind of interested in what is left for PMS? **Laura:** I'm just saying, I rarely see anybody who is functionally impaired by just physical symptoms, and I know that this was years ago, there was an attempt to try and (.) study treatments for women who had primarily physical PMS and they were (.) it couldn't complete the study because it couldn't find people.

**Zoe:** Um, I think that's (.) that's fine. It's more the definition is fine because I do think it is very much around (.) there's a range of experiences and I think that's capturing the idea that there are a range of experiences. My concern is more in how definitions are used or what the purpose of such labels or definitions are. But as a definition, I think yes it's (.) it's (.) it's fine because it does capture a range of experiences or allows for a range of experiences. It also allows for you not to adopt the label if you don't want to or adopt the classification if you don't want to. So, yeah, I think it's fine as far as labels go. We do need them in certain circumstances.

**Geraldine:** Well, I think that the timing for the symptoms to start is wide. That's (.) that's the main problem that I have with it. I also think (.) you know, they don't (.) the definition doesn't say that it has to happen regularly. So if it happens once, do you have PMS? Or does it have to be something that routinely you experience in the time before menstruation? One other thought about that. In the US, the National Institute of Mental Health had a very similar definition. And I do like the phrase 'severe enough to impact a woman's daily life'. But when I talk to my students about that. You know, they (.) they think that just experiencing it is impacting their daily lives. You know, I have to point out to them that they get up to go to class and they go to their sports team practices. They do (.) they study and they do everything. And if you can do everything, it hasn't impacted your daily life. But one time I had a student yelling at me. That she gets headaches (.) premenstrually, and she has to take an aspirin. I said, "so take an aspirin". But she said, "well, that impacts my daily life. I don't take an aspirin every day", I mean, so you know, people interpret these definitions in so many different ways. It's really hard, I think, to come up with something that is clear and precise.

**Chris:** Oh, I think that's the definition I would go with, yeah. **Interviewer:** So you're happy with that? **Chris:** Yeah, that's the definition. For WHO, the ICD Eleven. It's the same as the RCOG guideline. It's just that I think it's pretty much the same PMDD APA guideline? So I think that's perfect. Yeah, but (.) but (.) but also you've got to think of the subcategories or the atypic (.) the atypical variance. **Interviewer:** So it's almost standardised then, across these formal (.) [overlapping] publications **Chris:** I think it's pretty standard. Not (.) not ‘til relatively recently. But it's (.) it's pretty standardized. I think.

**Jo:** I think that's a bit woolly and I you know, I think there is no difference between (.) in my opinion, no difference between PMS and PMDD and the ICD Eleven definition probably is the better one in this country. I think, because the problem of accepting a diagnosis of PMDD is that is a psychiatric diagnosis. And we don't know that this is necessarily a psychiatric illness. It causes symptoms which could be classed as psychiatric symptoms, but it (.) they go away completely. So these are not women who've got, you know, continual mental health problems. And that in itself, it could be quite stigmatized. But, I think there's a big issue with the classification than the diagnosis and acceptability. But at the end of the day, this is just a name, isn't it? It doesn't matter what it's called. This understanding, if we can, as time goes on, try to understand more about it. I think virtually all women, I mean, me included, will have had some sort of premenstrual issues, whether it's sort of irritability. But it's not catastrophic, it's not impacting on day to day living. I don't think it's reasonable to include that in a diagnostic category.

### E19- DRSP suitable for PMS, as opposed to PMDD?

**Anne:** Right. Yes. Yeah. No, they are very weighted towards psychological symptoms, aren't they? So no, I agree. [Pause] I think (.) that I must admit, in our (.) we based our menstrual calendar or diary, on the Moo's menstrual questionnaire as well, which is one that goes back a long way, and I can (.) I think one of the (.) **Interviewer:** Was it the really long one? Because there's a full one and there's also the shorter one (.) **Anne:** It was based on the short one, because the eleven symptoms that I was talking about earlier on is what we extracted from that. And I think that's one of the things that we were looking at how we could have done things better in our study; that we emphasized the psychological symptoms too much. So, no, I think the ideal questionnaire would (.) conform more to the Montreal consensus and have a range of physical and psychological symptoms. I don't think they've actually produced a questionnaire. Have they? **Interviewer:** No (.) and I know that there are other issues. It's about what's been clinically proven and what hasn't. And I think that's basically why these are the tools that are currently recommended. It's because they have met those clinical quality criteria. But it's just interesting that at the moment there's a little bit of a mismatch. **Anne:** Yes. Yes. But whether you could know whether a useful thing would be 'any other symptoms' or something where people can actually record what symptoms they have. But, you know, the question does need to be validated, doesn't it? So that in itself is a big thing to take on.

**Barbara:** There are widely used tools for PMS also (Not PMDD). Any symptoms can be added to a daily symptom list. If it is an unusual symptom, it should be a signal to investigate other possible disorders.

**Fran:** Well there aren’t other criteria for PMS and most people feel that PMS is a less severe form than PMDD- maybe not quite five symptoms, maybe just lasting a couple of days, maybe less severe symptoms. We do not have a validated daily rating scale that differentiates PMS from PMDD. My view is that most of the symptoms of PMS are included in the PMDD criteria.

**Andrew:** Yeah, I think that's (.) a good question. And I think again, it was a (.) a matter of compromise to some extent. And also the lack of good (.) good instruments, the best instruments are probably to date, DSM-based. It's also a question of what are the instruments that have been used in the clinical trials for the drugs to date (.) accepted. And, you know, if you have one drug accepted by the FDA for a certain condition, then one knows that the instrument used in that study is regarded as OK by the FDA and then it has got some kind of official status. So it could be that also to take into consideration here. But I really don't think that anyone would object to an instrument if someone developed an instrument for covering all symptoms. And I think, in fact, the DRSP or what it's called, I don't recall. We haven't ever used that scale. But I think that, in fact, it's not DSM based. I think that appeared before the DSM. So I don't (.) I'm not an expert in that. We have never used any of these scales because we prefer another way of rating the instrument, er rating symptoms. But I think that, again, if you ask a gynaecologist, they would prefer to have a scale comprising all symptoms. If you ask a psychiatrist, they would prefer a scale focussed on the DSM criteria… That is, by the way, I could (.) why ACOG introduced their own definition of PMS. That is, they (.) they didn't like the DSM criteria because it's so (.) so you could have a (.) a (.) an instrument. But if you have an instrument based on the ACOG criteria, it should be quite similar to the other one, but somewhat different.

**Debbie:** [Colleague's name], who is, you know, really looms large, he's wonderful (.) a wonderful man. I really like him. I've met him multiple times. He's been sort of like the grandfather of PMDD and he really dislikes the word dysphoria… So he's fought really hard against this and just wants to make it all PMS. And I think it's just a (.) it's just a matter of words. And I don't [long pause] yeah, I think that by PMS they mean the spectrum that I was talking about. That's how I. (.) And so they would say "Yes. So there's really, really mild PMS and there's really, really severe PMS". And, you know, they would just sort of not put the PMDD thing in there. You know, that's how I read it.

**Celia:** Well, I like to see validated questionnaires used, and so that's what's been validated so far, if other ones came up, I think it would be of interest to look. What I tend to do with my patients when I take the history is if I find that they (.) have one or two columns that are more or less blank, that they can put in a symptom that they have that they can track. Um (.) so I either have them cross out one that they don't have and put in their symptom or add to those other columns so that you can track them.

**Sarah:** Well, I mean, you can adapt. You know, we used to adapt the rating charts we use. We would hand them a chart, it had 10 symptoms to (.) to rate each day. But we would say now if you don't really notice any of these. Would you like to cross a couple of these out and put in the ones (.) any others of your own? I mean, you can adapt these things. It doesn't have to be so proscriptive. But you have to start somewhere.

**Thomas:** Well, as my experience is that the difference between PMS and the (.) and perhaps I may repeat myself. Now it's mainly due to the severity. And if (.) if it is the same condition and the same symptoms are the main ones, which (.) which is my experience with a lot of exceptions, of course. But like, let's say, the core (.) core symptoms are (.) are more or less the same. So (.) so my experience is that (.) that is (.) that is (.) I agree with the consensus in that way that (.) that the core symptoms are or more or less the same. But some people have it very seriously and others don't. They have it less severe. Oh and then in (.) in addition to this, there are a number of all symptoms which are related to other disorders or other (.) other factors or other organ systems like increased urine production, for instance, which is the reason for the (.) for the increased incontinence. And (.) and so on (.) they (.) it's something which (.) which of course, is (.) is related to the basic problem and not so much related to the menstrual cycle, per se. Not only caused by the menstrual cycle and (.) and by that I mean we do the categorisation of pure PMDD or (.) or core PMDD or what we now or would like to call it. Or core PMS and core and an (.) premenstrual aggravation, of whatever condition or premenstrual exacerbation or whatever the original symptom or (.) or condition and (.) I think those are the cate (.) cate (.) categories. Not whether actually PMDD and PMS is different. That's (.) that's my (.) my view of it.

**Susan:** I think that's problematic. And, certainly I think that the ideal would be to (.) um have to talk to each woman herself and ask what her key symptoms were, or her key changes are. And to use the tracking of those, and use the tracking of those and the level of distress associated with them. So not just the changes, because it's about how problematic are they. Like I might experience changes, but it's not a big deal (.) like there's days of the week where I'm more energetic than others. But it's not a really big problem. I don't get in a state about it. Whereas for some people I know, it is. You know, other people close to me who are really (.) some of whom have experienced, chronic fatigue syndrome. And who are were very tightly into monitoring their levels of energy and how much exercise they could do, and things like that. And it's a real big issue for them if they wake up feeling tired or can't go for a walk (.) and can't go for a walk. Whereas if I wake up one day and don't feel like going for a walk 'cos I feel tired, well it's not a big deal, I can do it tomorrow. So I think you've got to always bring that psychological element into it. You've always got to bring in. What does it mean to the person? So, if I feel bloatedness. Personally, it was never a big issue for me. I just wore looser clothes. But some of the women that we interviewed, it's a really massive issue for them! But they (.) it's catastrophized. And that's because of what the meaning is of being fat. One of the reasons is about the meaning of being fat and how they feel they're being seen and how they feel in themselves and their bodies… So, I think go back to your question. You need to actually use the symptoms of the woman. And the level of distress associated with them.

**Marta:** Uhhh (.) potentially. But I don't think it's a major problem. I don't think that er (.) I'm missing patients (.) because they have a symptom that's not on the list. I mean, from a clinical point of view, I rarely count (.) to see if they have five symptoms. I just assume if they come to see me in the clinic, they have really severe symptoms. And then if they just say it's irritability, and depression, I'm fine with that. So I have a very (.) I mean, you have to be pragmatic when you're working with women.

**John:** Not particularly, I mean, I think that the [pause] I think that the symptoms that are described in the DSM 5 criteria are pretty inclusive. It's just how you then use them.

**Laura:** Well, we'll see what they find (.) I mean, I think (.) we need tools to diagnose the condition and to help women. So I don't see any (.) I don't see any problem with that. And all the power to them, if they can identify a group of people who have primarily physical symptoms that need treatment. I mean, they may need a different treatment than the ones that I'm used to using. So all the power to them.

**Zoe:** OK. So if it is if it's being used in in a more therapeutic context, in a medical context, I probably would be safer with it actually being a more a more constrained and restricted list, because whilst I do like the (.) as (.) as I do agree with there being a much broader range of experiences, if you were talking about diagnosis, we need to ask for what purpose of diagnosis. And if it is in a medical context, for potential intervention, then I would always caution on (.) I would always be more cautious. I'd probably go on a more (.) more restricted. I would probably um lean towards a more restricted, restricted sort of list rather than medicalizing a broader range of what our natural common experience. I would find that actually more dangerous in that context. But on other as I said, that there are so many of these tools, you know, menstrual trackers I think they are about the third or fourth highest frequency app that is out here. So there are lots of these menstrual trackers and various different forms of (.) of those sorts of things. Yeah, a broader list is (.) is useful in those contexts. Not for women to diagnose as such, but just for women to be aware of what's happening in their body, their changes. I think that's fine. But for diagnosis of (.) if you're talking about it potentially being used by general practitioners in that sort of a context, I would I would actually (.) er on the side of a more cautious one to avoid over (.) medicalizing common experiences.

**Geraldine:** Well, [laugh] that's just some further evidence that PMDD is not something different (.) than PMS, right? [Laugh]

**Chris:** The Daily record of Severity of Problem (.) which is the one that the RCOG suggests is used? It's cos it's (.) it's broadly used. It doesn't have much about physical symptoms in there at all. So when we devised our app, we put in lots of physical symptoms and we also had the ability right at the outset for the patient to go through the app symptoms. And if there wasn't anything there they had, they could electively put it in. So I think my app (as I would!) is better than the DRSP because the DRSP is almost all psychological symptoms and doesn't allow physical. I don't know that my app actually (.) would fit you directly? You'd have to add in symptoms (.) yeah. **Interviewer:** So (.) so I guess you're saying there is a bit of an issue then, that at the moment the PMS definition is ‘any symptoms’ but, then you're using a tool that is quite (.) a little bit restr (.) limited? **Chris:** Yeah. In fact, the DRSP I think has at the end of it somewhere right at the end just a little line of physical symptoms, which includes all of them, which may be enough? I don't think so though. And I think the essence is (.) my app calculates symptoms (.) it draws up all the symptoms if you want it to. But it also does a calculation based on what I'm about to say. At the outset. It says, which of the following three do you think most (.) has the most impact on your life? And that's the work, relationships and hobbies. And they choose that. And then all the calculations are done on that single figure. So I reckon although we do all these symptoms and DRSPs, I reckon you could get away with saying how bad is your PMS today? 1-10 and if it's bad, bad, bad and then gets better, better, better (.) that may be enough? [Cough] We do the calculation on that. And we haven't validated it yet to show that that does actually produce a diagnosis. So on the app, it says it does calculations. It says (.) um the app suggests your symptoms might fit. Not PMS, pure PMS, premenstrual exacerbation, etcetera. But this is subject to being reviewed by a health professional. Yeah? Then they go to the health professional. And they ought to understand the app or PMS [laughter]? **Interviewer:** So that's a little bit more aligned with the [ISPMD] definition, in fact (.) **Chris:** [00:35:57] [overlapping] Yeah. **Interviewer:** Because it's anything. Anything goes really (.)? **Chris:** [overlapping]. Yeah. Yeah. Yeah. Yeah. **Interviewer:** It's the timing, not the symptoms? **Chris:** Yeah. You know, you can't (.) you can't develop an app that measures Mrs Bloggs on her anxiety, Mrs Jones on her mood swings. So we use the impact that (.) the degree of impairment and the patient right at the outset has chosen what they think is their symptom group, which is the most impairment. And so we calculate on the basis of premenstrual impairment and preem (.) post menstrual recovery.

**Jo:** Um. I think that. Is going to make it difficult for the women who are severely affected. I think they become lost then in the bigger group of what really are nor (.) normal women with a spectrum of how they feel on a day to day basis.

### E20- PMDD as a core PMD, not PME. What do you think about this?

**Anne:** I (.) as [pause] I said earlier, I [pause] I don't (.) erm, I think a lot (.) quite a proportion of women who I've seen who've been given the diagnosis, of PMDD have underlying (.) psychological symptoms, all through (.) throughout the cycle and they just get an exacerbation and, you know, in the (.) erm, The International Association for Premenstrual Disorders, which where there is very much an emphasis on PMDD, they talk a lot about PME as well, don't they? **Interviewer:** Yeah. **Anne:** So that doesn't (.) that isn't part of the PMDD definition. So I think that's a little bit (.) I think there (.) there are some women who I feel are severe enough to warrant that diagnosis but still get symptoms (.) even though it's less severe, less symptoms or throughout their cycle so (.) but by definition, they can't have PMDD because (.) that's what we wanted to emphasize in the statement on the NAPS website. Not only that, but also there are some women who are severely affected that don't conform to the DSM criteria, and yet they've still got very severe PMS. **Interviewer:** Yeah. I mean, this is why I'm asking these questions. Within even single definitions there are tensions sometimes. **Anne:** [00:56:35] Yes. Yes, that's right.

**Barbara:** PMDD is its own diagnosis. It is NOT another mental health disorder that is linked to the menstrual cycle.

**Andrew:** Absolutely. Yeah, I think there are two (.) two ways of defining this. First. You have to get rid of all the variants that are not really PMS that are not exclusive for the luteal phase where you have aggravation or exacerbation, also where they are elicited by oral contraceptives and stuff like that. That is something else. And then you have a core PMS or PMD’s, and within that you have those two conditions as (.) as reflecting the thinking of the gynaecological camp and the psychiatric camp where the gynaecological camp are more for the PMS definition and the psychiatrist more for the PMDD that those are (.) both belong to the core category because both are restricted to the luteal phase.

**Debbie:** I mean, I think everybody is doing their best to like integrate [laughter] [sigh] I mean, I would love to live in a world where we just, like, scrap all of it and come up with some kind of single dimension, because I do think PMS has weird connotations that probably we need to leave behind. And PMDD is maybe too restrictive? You know, I mean, maybe like 'premenstrual mood disorder', right? Spectrum. And then we can sort of rate it on severity and quality. But yeah, I do like that they include progestin-induced mood disorders in there as well. I have that [laughter]. Whatever that is? Like (.) that's what I was talking about is that I can't take (.) um oral contraceptives because I don't have PMDD, but I have definitely triggered (.) um have those symptoms triggered by progestin. So yeah but I (.) I think they're doing their best to sort of integrate it all. I think it's an imperfect way of talking about that spectrum and acknowledging that some people really have this much more severe thing that (.) you want to give another name to. Yeah.

**Celia:** [Long pause] No. I mean, the other issue is that (.) I haven't looked at it recently, but at one time a company came to me and asked if I wanted to do a study on a diuretic for the physical symptoms of PMS (.) and we literally could not find many patients at all who had severe physical symptoms without, say, endometriosis or some other being (.) you know a pain problem, without having moderate to severe emotional symptom, at least one. I think it's pretty uncommon. And having said that, if they just have severe breast pain premenstrually. I wouldn't give someone a PMS diagnosis, although by definition they (.) they would fall in that category. But (.) Anyway, I forgot what your question was? [Laughter]**(.)** Well, I was hoping that the definition that the consensus conference came to, under and the paper that was published, I think in the Journal of Women's Mental Health, the paper with [colleague's name], I think and his group as the first authors, I'm sure you're aware of those papers (.)? **Interviewer:** yeah **Celia:** That (.) that the concept of premenstrual er (.) disorders, that that could end up becoming the definition of PMS. I saw that ACOG withdrew their PMS practice bulletin and I don't know that another one ever replaced it? So I agree that I don't know that there is a medical PMS definition now, and I think that is a problem. [Pause] On the other hand, you know, maybe it should be left in the lay area and just call it premenstrual disorders and (.)?

**Sarah:** Well, I think that's fair enough and just given that the PMDD is just a small subset. And you know, they are gonna be those (.) that have the more severe mood symptoms that you may need medication to help. So I think it's a reasonable thing.

**Susan:** Ok. So I think the first thing I'll say is I think there's a problem in reifying um (.) psychiatric diagnoses as if they are a thing is if we're measuring a thing within the woman, in a way you might measure a cancer cell or whether someone has influenza or not or whether someone has cardiac (.) cardiac problems. But PMS and PMDD, as I said earlier, are discursive constructions that are given to a set of experiences that women report. And so the idea of there being this thing, PMDD and this thing, PMS, and that they're very different to me is nonsensical. But what I would say is that we have (.) and I've said it many times, so I won't labour it here is that there is a contin(.) that many women experience premenstrual change. For the majority of women, it's not problematic and that there is a continuum of distress which is dependent on the interaction of physical, psychological and socio-cultural factors which might determine whether a woman is at the extreme distress end of the continuum. And if it's helpful to label that as PMDD to identify that particular group of p (.) women that are needing support, professional support, whether it's psychological or medical, and if having that label helps them through getting insurance through legitimation of their distress, then I think it's not necessarily a bad thing. But from a feminist point of view, the idea of using PMDD as a label that you might apply to all premenstrual change, which then implicitly and indeed explicitly pathologises all women of reproductive age, who have any rep(.) premenstrual change, I think is incredibly problematic. And I think that there is clear evidence. I mean, it was contested that big pharma and in terms of the drug companies well, specifically Eli Lilly, actually were advertising SSRIs and using a very broad definition of PMDD as if it (.) as if it included all levels of premenstrual change. So that has been happening. And I think in that sense, the diagnosis of PMDD is really problematic.

**Marta:** [00:27:56] Er (.) no, I think (.) I think it was (.) I mean (.) I (.) I think I was (.) I wasn't part of that (.). I was part of one of the errr (.) conferences (.) they had (.) but I think I was part of (.) on the (.) on the one on the treatment, but not on the one on diagnostic criteria. So I (.) I don't know exactly how the discussions went. But er I think that these two disorders, they were (.) both put in under the umbrella to sort of accommodate for the fact that some of the people in the group were gynaecologists and other people were psychiatrists, and I don't think they're really founded in in real science. **Interviewer:** Yeah, it's definitely a tension at the moment. It doesn't (.) um (.). Yeah, like you say, it doesn't really help (.) because are you talking about level of severity on like a normal curve or (.) or are you talking about different types of you know, both have a similar mechanism, but different types of things or diagnoses (.)? **Marta:** Yeah, that seems that (.) that really seems unlikely. And I think that er I mean, in a sense, we (.) I mean, for a range of physical conditions, we just use arbitrary cut-offs like diabetes, hypertension. So why wouldn't the same case happen for (.) for PMDD or depression or anxiety?

**John:** Um [pause]. Well, I think anything that sort of is more inclusive is better. Just because of the reasons (.) mentioned in terms of not (.) preventing people that need treatment, getting treatment. I mean, I (.) I know that there is quite a lot of talk about the semantics of these different definitions, but (.) I'm not sure if people really are getting that hot and bothered about it? Clinicians don't seem to (.) someone comes to you and they've got the symptoms, you treat it. Um [pause] I think that maybe it's more of an academic debate that perhaps (.) maps less well on to what happens in clinical practice in reality. That doesn't mean that I don't think that there should be some attempt to categorize these things, but [pause] [quiet laugh] yeah.

**Laura:** But my view is (.) so I think what the attempt was, was to segregate out PMDD. And then the rest of the premenstrual disorders. I see (.) I still see PMDD as a subset of PMS because anybody that meets criteria for PMDD is going to meet criteria for PMS, right?

**Zoe:** Yes, at least they're different (.) as I said, I don't see them as a (.) on a continuum, which many people do. I do actually think they're different conditions. So yeah, I don't know if I can add too much more to what I've already said (.) yeah.

**Interviewer:** Yeah. Um, so the Royal College guidelines and I think probably other guidelines as well, now have PMDD and PMS as almost parallel (.) **Chris:** Erm, Severe PMS and PMDD (.) **Interviewer:** Sorry Yeah (.) **Chris:** I would say severe PMS. **Interviewer:** They are both PMDs, though (.)? **Chris:** Yeah. Correct. Yeah. Yeah. **Interviewer:** So how do you feel about that, this kind of idea that they're aligned (.) as separate categories (.)? **Chris:** That's fine. **Interviewer:** But of the same kind (.) **Chris:** That's fine. Yeah. Because it's a subcategory and I suppose I made the mistake in (.) if you think about it, of introducing on top of PMS & PMDD - PMDs! [Laugh]. So that's um (.) that's almost negative except over (.) So they're all PMDs. Yeah. **Interviewer:** So (.) so it could be PMS at the top? **Chris:** You can have PMS. It doesn't make (.) you have more patients with PMS, I think. But you'll have exact (.) severe PMS. And yeah, let's just go over that definition again. So this is the third consensus paper and it's also my opinion that PMDs can be divided into patients with severe psychological symptoms which are also PMDD, severe psychological symptoms and physical symptoms which can be PMDD only [pause] erm. I'm not answering your question. **Interviewer:** Well, it's a tricky question. **Chris:** I think severe PMS and PMDD are synonymous [long pause] and PMDD (.) yeah so virtually synonymous. Yes, you're right. **Interviewer:** I mean, what might help is (.) some people have said that they think of it as a normal curve (.) and that PMDD is the most extreme end of that? **Chris:** Yeah, yeah, yeah. I mean, that's what we always (.) you're right. That's what we say (.) **Interviewer:** Rather than it being um (.) You know, that would be different to premenstrual exacerbation, because that's just something else. **Chris:** Yeah, that's a different category. **Interviewer:** It is, yeah. So that would make PMS, not as severe (.) that would therefore make PMS not as severe as PMDD (.) **Chris:** Well that's the same as saying severe PMS is PMDD. See, PMDD has a couple of problems with it. It excludes patients with a small number of symptoms. Let's imagine (.) it's hypothetical. You have a patient who only feels suicidal from day twenty five to twenty eight and never feels suicidal (.) um after the period she wouldn't fit the category for PMDD. So she wouldn't (.) in America be able to claim it from psychiatrists because that's why it was (.) I think that's why (.) partly why it was developed so they could say it was psychiatric. And you come to us with it (.) um, so they would be excluded (.) if they only had one symptom. Then they'd be excluded as a diagnosis with PMDD but they wouldn't for PMS. So that's another (.) that's another element, yeah? **Interviewer:** I'm interested in (.) there are these tensions between practice and these guidelines and obviously guidelines are just guidelines, they are not the law, for example (.) um (.) several physicians I spoke to said they don't do the '5 symptoms'. You know, if someone says I have severe anxiety, irritability, and suicidal thinking (.) **Chris:** And it gets better after the periods. **Interviewer:** Yeah, [overlapping]. They are not going to exclude them (.) **Chris:** Yeah. Well to me they've got severe PMS, OK? I don't care if they've got PMDD or not. It's irrelevant. Patients tend to come and say "I've got PMDD" because they think it's the severe end and they'll get taken notice of (.) That's the reality. **Interviewer:** So you think that (.) basically severe PMS and PMDD are the same things; PMDD, is literally the DSM (.) **Chris:** 5. Yeah. **Interviewer:** You know, version? **Chris:** Okay, let's just (.) let's just say what you said. I'll say [pause] severe PMS and PMDD are almost certainly identical, except patients with severe PMS and only physical symptoms aren't PMDD. Yeah? **Interviewer:** Yeah. Great. Thank you.

**Jo:** I just think it becomes all becomes less and less clear. And it's really, really unhelpful. I think we need to agree (.) a definition because I genuinely think PMS and PMDD are the same thing. And it's just what people are comfortable to call it.

### E21- the role of non-biological or external life experiences as contributing factors in menstrual cycle-related health e.g. ‘psycho-social’ factors.

**Anne:** [Long pause] I suppose they might have (.) er (.) felt that they've covered that when they talk about counselling and CBT as part of the treatment because, you know, within that you will be addressing those issues (.) I suppose where (.) you know I hadn't really picked that up. These are from the RCOG guidelines, are they? **Interviewer:** Yeah. I mean… CBT is mentioned as a treatment. **Anne:** Yes (.) which would cover those things. But you know, where I think it's a shame that that that's been missed out (.) is for the GP really because (.) you know, just actually teaching them that it is important to look at the whole (.) I mean GPs do, that's what they do, they practice holistic medicine. But, you know, really important that actually the social situation, some (.) if somebody has a poor mental well-being, then the threshold for getting the PMS symptoms will be lower. Yeah. You know, that's a good point. If you don't mind, I'll take that on board when we're doing our guidelines?

**Barbara:** The diagnoses are symptom-based. That does not exclude the fact that symptoms may be due to life events. A good diagnostician will likely explore all.

**Fran:** Erm, I’m not really sure which guidelines you are talking about? I myself have published on the effect of stress and it making symptoms more prominent. So, I don’t think stress is considered a direct risk factor. I**nterviewer:** So, the guidelines I am talking about are (.) in the UK the clinical guidelines for primary level doctors who would see a patient first. And it basically goes straight into pharmaceutical rather than covering in detail the role of lifestyle factors and changes that could be made to improve symptoms (.) **Fran:** Most review papers that I read or have been involved with is that dietary recommendations, exercise, relaxation, and CBT could deal with the external stressors, so I think all of these treatments are as accepted as pharmacological treatments.

**Andrew:** I haven't seen those recommendations first so I cannot comment on them. I think this is the same (.) partly the same problem that you have in other psychiatric conditions that you have for mild conditions. There are certain recommendations that are likely to be positive but that [pause] but often the evidence base is not perfect because it's very different (.) difficult to have a reasonable control group in those studies. You should have a control group to diet change and so on. How should that control treatment look like? And so and some of those writing recommendations, they don't take this with this evidence based aspect that seriously. So they feel free to include various recommendations of that kind, things that definitely could not harm and might be helpful, such as exercise, diet, things like that. Others may be very (.) feel restrained by being evidence based. And then it's difficult to claim that these interventions are really effective. So I think it's (.) it's (.) this is not (.) this is not unique (.) for (.) for premenstrual syndrome. It's the same in various other psychiatric conditions that you (.) you have this problem. But I haven't seen I haven't seen this information. We have some other factors in play here. One is that particularly in U.K., there have been some influential gynaecologists that have been very much in favour of hormonal treatment. And that has been fairly unique for U.K. That's not been that (.) that hyped (.) in other countries but they have suggested various oestrogen treatments and other hormonal treatment. And that is one aspect that might have influenced particularly the English accommodations. I haven't seen them, but I guess that would not surprise me. And on the other hand, there (.) we have the fact that no SSRI is, in fact, approved in Europe and they are approved, officially approved as an indication in the United States and one of them in Sweden, in fact, but none in Europe. And that has a commercial background that the drug companies never really tried that because it was too late for them to (.) the patents were running out. So they didn't care about the European market for SSRIs. So it's I really don't know how the various English and English writers or recommendations deal with these various aspects, both the fact that SSRIs are usually regarded as first-line treatment but not officially available. And then the local influences for hormone treatments. So I haven't seen them, so I cannot comment on that. And I would say in most review papers and consensus documents, where I have been co-author or read, usually these (.) these non-specific treatments that you mention diet and stuff like that and avoiding stress and so on are usually mentioned. So I don't think it's (.) it's not controversial to (.) to mention these possibilities for the mild conditions.

**Debbie:** So my read on all the lifestyle factors smoking included is that they've got the causal direction wrong. And that actually I mean I (.) I don't I can't say this for sure, but I'm on a grant with [colleague's name], who just got a (.) We got a grant to look at smoking across the cycle. And the pilot data that we have are just so clear that people who have more irritability, premenstrually, really have massive increases in smoking when they're irritable and it's like the self-medication thing. So I (.) I'm not saying that smoking couldn't make it worse. It certainly could. I think that's very plausible. On the other hand, I think at the very least, it's bi-directional where (.) You know, like probably smoking reduces your overall health, which doesn't do your mood any favours [laughter]. Then, you know, probably it's a way of coping with PMS/ PMDD too. But (.) um I don't know. I mean, I think that it sort of regardless of where symptoms come from, I think there's this idea that your treatments always have to target the underlying cause. And sometimes that's true and (.) and warranted. But sometimes it's (.) it makes it unnecessarily difficult. Like sometimes you can take a pill that interferes, you know, at some later stage of the process and still sort of short circuits, the whole thing and the symptoms go away. And so it depends on how much somebody is suffering. Right? If it's like mild to moderate PMS where they're like, "I'm not I'm not feeling great some of those days, but like, I'm not it's not bothering me so much that I really feel I need treatment" then. Then absolutely. You know, the lifestyle changes. Great, you know. But for most people that I meet who identify as having PMS or PMDD, I would say like they're suffering enough that they really deserve something a little heavier hitting than that. And that often what I see is once they start SSRIs or Yaz or GRNH agonists or whatever it is that works for them, then they can stop drinking, smoking, fighting, [laugh] then they can start sleeping. Then they can start eating right. You know that (.) is just my my thought.

**Celia:** Well, I think during the two months of doing the prospective recording, patients, I think benefit from the recording because it gives a sense of control to patient and family and whatever. But I don't like to give anything prescription based before I have a diagnosis. So I think because there is some evidence in the literature; not always frequent randomised control, but some evidence. And because they're I feel fairly harmless. I think it's reasonable for patients to do that. And some of them find it to be very effective and really don't need to have anything further. Generally not the ones with the more severe symptoms. But, you know, I think they (.) I think they're reasonable to (.) to try.

**Sarah:** [00:29:58] Yeah, I think it's (.) well, I think it's an important thing to know about. You know, if people have got a really dreadful diet. Or if there's been some major stress, some major change, it may still be ongoing that they're trying to deal with. Then I think you do need to do (.) take note of that in a holistic way of treating the whole person. So I don't see why that would be left out of good clinical care (.) would be to make those inquiries. I mean, interestingly, when we saw people at our sessions clinic um the majority of them had already been through all the things that were available in terms of um (.) um (.) Evening Primrose oil, you know, various herbs, you know, diuretics. You know, I mean, they listed for us everything they had already tried I mean they had already been through all of that. By the time they got to us, but what they may not have been considering is that's the role of these other stressors and the other problem I saw often was this sort of alcohol abuse. That is certainly imp (.) it's important that we've found [pause]… Because people are often abusing alcohol and drugs to self-medicate. So it comes back to what are they medicating against and where is the distress really coming from? You know, I've been spending most of my more recent years seeing the adult survivors of childhood sexual abuse. That wasn't something we asked specifically about premenstrual tension clinic many years ago and realised how prevalent it was. It caused some (.) we also didn't realise in my country anyway, that this is also prevalent for boys as well as girls, those sorts of things. All in a very long clinical career (.)

**Susan:** Well, it's not surprising because they're being developed from a very biomedical perspective. So the focus is very narrowly, um (.) very narrow and reductionist and focussed on the body. And so it's conceptualising PMS as a bodily disorder, that originates within the body. And therefore, that you treat the body. And I think that's a very narrow biomedical view. So if those guidelines (.) I haven't seen those particular ones that you're talking about (.) the consensus statements do actually acknowledge that's cognitive behaviour therapy can help. They don't say a lot about it, but they do acknowledge it. And they do acknowledge that, um you know, giving women some sort of support or counselling as you know, an early form of intervention is a positive thing. But if you've got [new] guidelines, I'd be interested to see them. I haven't actually seen them (.) if they're coming at it, kind of obst & gynae fields are taking that perspective. Then I think it's very unfortunate and very narrow.

**Marta:** Oh, no, well it's not surprising. I mean, this is from a scientific perspective. This is a very, very underdeveloped area of research. So I think it has to do with the fact that simply too few people are interested in PMDD and that's why we haven't seen any of the other interventions. I mean, there's been studies done on physical activity or yoga. What have you, but usually not really well executed. And um (.) so I think it's just (.) not it's (.) not that many people in the business. So I'm happy for (.) happy that you take on this challenge! [Laugh] **Interviewer:** Yeah! I'm having second thoughts, I must say (.) [laugh]. So for you, it's about this kind of evidence based medicine the fact that we might know that some lifestyle changes could have an effect (.) but there isn't that body of evidence there yet to formally recommend it? **Marta:** Mmm Hmmmmm (.) but I'm (.) I'm sure that at least physical activity would be really, really good. And (.) yeah.

**John:** There would be if there was more studies. But the fact is, the studies that have been done are pretty poor (.) underpowered. And therefore, there isn't an awful lot to say about them specifically with regards to PMS. I think if you look at those sorts of studies, as they've been applied to other mental health conditions. There's more of a literature. So again, I think it's (.) um [pause] It's common sense to apply literature that's out there on the benefits of lifestyle things as it relates to mental health more widely, to PMS. But if you want to go and find studies that have been specifically done on PMS and these lifestyle factors, you're not going to find many RCTs that have been done. (.) So I don't think people can talk about those more because there's less to talk about. There have been more studies done on pharmacological interventions. I mean, in part probably because they're easy to do. You've got something that is going to be the same (.) that you can basically replicate in part because you've got a system that's set up whereby you've got doctors and clinicians and people that are using those things and they're actively involved in research. The lifestyle stuff is slightly outside of that domain, isn't it? **Interviewer:** Yeah, but there is this tension that I think a lot of clinicians do actually, depending on the severity, I think, of the patient (.) do actually suggest some of these lifestyle changes or at least take them into account in the history of the patient? **John:** Yeah. **Interviewer:** And I suppose what it is, is when I've spoken to GPs if they're just reading the NICE guidelines or the Royal College guidelines, they may not be aware of this kind of (.) things that they could try? **John:** I think most GPs are pretty aware of the fact that diet, exercise, help mental health. And if somebody is coming with anything, that's got that (.) er, aspect to it then it would be reasonable to (.) to look at that. I don't (.)I don't think they are gonna really pick up the guidelines. and say "well, It's not in there. Therefore, I'm not going to be recommending that, you know, stop eating 88 chocolate bars a day, and you know, sit on your sofa and don't do any exercise and expect any medication is going to help". But they would say that. So, again, I don't (.) I don't I mean, I could be wrong, but I don't think clinicians are that (.) um (.) caught up with guidelines for making that sort of suggestion. As I always say to people anyway, that they're guidelines they're not kind of (.) written in stone.

**Laura:** [overlapping speech] I think that (.) I think there (.) they are in those guidelines. I think for mild PMS they do recommend exercise and dietary changes. As I recall, I mean I haven't looked at them in a couple of years, but (.) **Interviewer:** I think clinicians do recommend them but some of the guidelines aren't including them anymore, and I think it might just be that (.) that's presumed as um 'already known'. **Laura:** Well, I think it's also fair enough to say that. There are no (.) the data on exercise, actually ameliorating the symptoms is weak (.) are weak. The data are weak. So now there are some dietary (.) treatments such as what the Wurtmans [famous carbohydrate and serotonin theorists] looked at. This PMS diet, which boosts serotonin and that actually works quite well. So there are (.) there is a basis to some of the dietary instructions, although the dietary instructions are the opposite of what one would assume that they should do, like we assume that eating healthy means that you eat a lot of greens and, you know, protein and you don't have a lot of carbohydrates (.) and their diet (.) that empirically validated diet is a complex carbohydrate diet, which is not what people would probably think of if they had to change their diet. So there are (.) there's evidence for that. So that should be articulated in guidelines.

**Zoe:** We have actually just in our own research, but also in the research we know of colleagues and others. I actually think that there is a strong evidence base actually for the efficacy of some of these what you're calling lifestyle interventions. So, yeah, I would definitely (.) um, I think they need to be available and they should be made available in the end and provided as part of the toolkit that you (.) that a woman can access. Women's experiences are so broad. And it is my firm belief is that we need to actually rather than classifying and clumping. And that's the problem. Once you clump people or classify or diagnose people, it implies that their experiences are all the same and their experiences are not the same; two women who might meet criteria for PMS are still going to have very different experiences. And I think that's where you need to make a range of things available to them and our experiences that these lifestyle changes and lifestyle interventions can be and are very effective for some women. Um, so yes, I'd support their inclusion.

**Geraldine:** Well, a lot of women do feel better if they get more sleep, if they learn stress management techniques so they can take some downtime like get away on their own from the family. The stress of family life. Go out to a movie by themselves or talk to a friend about how they're feeling. So, yeah, I think it's a (.) it's a problem that that's not mentioned, especially since, you know, we don't know the cause of most of these symptoms. And so many of them are probably related to stress in women's lives. And then there was also that study showing that women who had experienced trauma early in life are more likely to complain of PMS. So, you know, that's kind of important as well?! [Laugh]. What people need treatment for (.) you know, It's not necessarily an antidepressant, that they need.

**Chris:** Well, the RCOG guideline does say that these women could have CBT, which will which will (.) at a tim (.) really should have it before going on to hormonal treatment (well, if available?). And therefore, in CBT, the whole spectrum of symptoms would be addressed. So therefore, if they're (.) if they've got an underlying issue that'll be addressed. And of course, probably a woman who has severe PMS doesn't like her husband, has a terrible mortgage rate, has seven children who are behaving badly. Might be more affected by her PMS than somebody who is um, on a yacht going around the world with her new boyfriend! Yeah? So the (.) so those (.) those sort of (.) the underlying (.) I think (.) I suspect that not many women who are refugees will notice their moderate PMS while they're coming across the channel in their boats. Do you know what I mean? So other things must [emphasis] play a part in it. I don't think they're really in the guidelines, as you say. Except that in terms of treatment, then that maybe well (.) be covered by the CBT but nothing else. And of course, if you treat someone with (.) who's got depression and PMS and you treat them with an SSRI, then that's addressed in that situation as well.

**Jo:** I think that it's really important for a condition like this that all (.) all therapeutic interventions are discussed and patients are supported to use whatever is going to make them feel better and they'll almost self-select eventually. But I think it would be unreasonable not to point out that, say exercise might help for some women [pause] yeah. And I think [pause] I think sometimes that these discussions about what you call something [laugh] the actual patient gets lost in all of that. You just want to make sure that, you know, losing women who might have a better quality of life if they had the right support.

### E22- Normal menstrual changes in the DSM

**Anne:** Yes. I suppose they (.) they've (.) they've acknowledged that there are physical changes, but I very much regard the DSM diagnosis as more psychological psychiatric symptoms. Yes, I suppose they have just acknowledged it to (.) to exclude those completely I think would be wrong. But they've weighted it very much towards mental health, haven't they? **Interviewer:** Yeah. **Anne:** And I don't know whether you have to have a physical symptom in that? No, you don't, do you? **Interviewer:** It doesn't differentiate them (.) you don't have to (.) and in fact, most of them are in one line in one of the eleven criteria. It's kind of (.) **Anne:** Yes. **Interviewer:** Six or seven (.) are usually listed in one box. **Anne:** Which isn't helpful particularly. Is it? **Interviewer:** No **Anne:** Like because (.) it doesn't differentiate (.)

**Barbara:** Again, diagnostic criteria are invariably symptom-based. Many if not all mental diagnoses have physical symptoms. Anxiety is one example of a mental issue that manifests in many physical symptoms.

**Fran:** Um, that is definitely one of the criticisms from gynaecological colleagues and academics – that physical symptoms should be expanded and given more weight. **Interviewer:** Oh no, I think I’ve lost you now [disrupted network connection] **Fran:** No, I’m here… you can’t hear me? **Interviewer:** Erm, yeah but definitely mid-sentence your voice disappeared. Erm, so you said it was a major criticism from the gynaecology side of things – but I didn’t hear how that was resolved or what your thoughts were? **Fran:** That is why the ISPMD didn’t specify any symptoms. The gynaecologists felt that the physical symptoms could be as prominent as emotional symptoms for some women.

**Andrew:** Absolutely! And I think again, that is what I mentioned before, that I regard this as a kind of compromise. On the one hand, they did a strong emphasis on the mood symptoms. You need to have at least one of the four and the somatic symptoms are only given one of eleven items. So that is a way of downplaying somatic symptoms. But still they do include them not to annoy the gynaecologists too much, I assume. And I (.) if I (.) if I were king, I would (.) I would have not regarded them as part of this at all. What I would say that there are two different conditions. One is (.) or maybe several conditions. I think (.) premenstrual headache is one, I think perhaps bloating and breast tenderness is one. I think mood symptoms is one, and I don't think there is today strong evidence to claim that they belong together (.) that a women that has got breast tenderness is more inclined to also have irritability or headache in the premenstrual phase. I don't think there's any strong evidence for that. And I think so (.) so (.) so (.) er I (.) I (.) I believe that it's a (.) I think we should regard item number eleven, in the DSM as a compromise. And it's perhaps not that er (.) there's no robust scientific basis for that.

**Debbie:** It's interesting [pause] because the idea is that overall the person needs to find [pause] I think (.) my read of the DSM 5 is that the person needs to find the collection of symptoms that they experience distressing or impairing, right, but then it needs to be moderate or greater. But what's a moderate cramp for me might be a mild cramp for you? You know? And maybe (.) maybe the only thing that's really impairing about my cluster of symptoms, even though I have 10 of them, is my irritability. Right? You know, um (.) I don't know. I don't think I have a good answer to that. I think we do have some evidence that the number of symptoms that show this on/ off pattern is (.) strongly predictive of whether or not the person will (.) will have impairment or not. So there does seem to be sort of a linear relationship and we did something called a ROC curve, which tries to identify the number of (.) the number of symptoms showing this sort of on /off pattern in the daily ratings before the person also showed the same pattern in impairment. Does that make sense? So how many symptoms turning on and off do you need to have to optimally predict having impairment that turns on and off and that was four (.) And (.) and so that is interesting because the DSM 5 uses 5. But a lot of people have argued like, "oh, just one is enough", you know? [Shakes head] I don't know. It's really hard. I think [pause] I think it's okay for them to be normal [slow speech]. But then I would also say I would challenge the idea that it's normal for somebody to have moderate premenstrual symptoms, even if they are things that are common, like I think it's normal for somebody to have mild cramps. But I don't think it's normal for somebody to have moderate to severe cramps every month. I don't think that's normal. So that, you know. Yeah. Sorry. That's rambly! [Laughter].

**Celia:** I think it's sort of an artificial dichotomy. If you ask (.) if you do look at studies or you ask patients who have depression, most of them have pain. In fact, it's very common to have pain when (.) physical pain. And so to say that it doesn't belong in a mental health diagnosis I think isn't true. And also the fact that the SSRI's can help those physical symptoms. Studies where they were, they always have categories for physical symptoms. So it's hard to say whether they have different aetiology. Presumably they might. But if you're looking at a syndrome and you have symptoms that come into that based on frequency of women having them than I can see why they put it in there. I think it's not a bad idea for the PMDD that it's only one category. So in other words, you can't get five symptoms by having four physical symptoms (.) and one mood symptom. Um (.) I (.) I think the (.) um (.) there just haven't been many more treatment trials since the time when the pharmaceutical companies were funding these studies. So we really don't know. Take a PMDD diagnosis and compare, say, an [sic] hormonal contraceptive with an SSRI. No one wants to pay for that.

**Sarah:** I don't know if I've ever seen anyone who had (.) the mental changes without any physical changes. So, you know, I think they should be there. I think they could occur more frequently in the population then do the severe mental health symptoms. Um [pause] look, you know, these (.) these (.) the way in which consensus is reached for something like DSM is just, it's fraught. You know, it's really based on a lot on the literature, but also on who the panel is and how they drive it. You know, there was a lot of problems with that particular panel and other panels in the DSM 5. You probably know about that (.) This is not a religion and it's not an exact science [pause] **Interviewer:** Yeah (.) **Sarah:** [Interrupting] But all the symptoms can occur. I mean, you've got (.) I mean normal people who aren't suffering a depression, a depressive disorder, can feel depressed at times. Right? So it's (.) it's every single thing can happen at times to normal people as part of normal life experiences. It's only when it is actually causing distress and interfering with the way in which you can conduct your life. So that is; with your relationships or your ability to work or study (.) whatever is important to you in your life that it becomes a disorder. So you might have some breast soreness. You know, I did have a little bit of breast soreness. I'd never think of that as being a disorder. I thought it was a helpful hint. Thank you very much. Right? But if it was so bad that I couldn't bear anyone to touch me, and I had to get special bras for it and I had to keep my husband away at that time of the month. You know, I couldn't have a cuddle or anything or I'd be screaming in pain. Then I reckon that's a disorder, right? So that's the way you really have to look at these symptoms. Not you know a little bit of water (.) But is it (.) is it significant? And I think that's (.) what DSM says all the way through, it's, you know, that these symptoms should be enough to be really causing interpersonal distress or affecting the person's functioning.

**Thomas:** [Immediate response] I think it's wrong. **Interviewer:** Ok. **Thomas:** [Pause] Because there are conditions which are only having breast tenderness, only having bloatedness, only having urine problems or incontinence and only having diarrhoea, constipation and nausea and whatever. And those are (.) are not to be categorized as PMS. I think they should be categorized as a premenstrual aggravation or something else. Whatever. That's my view. **Interviewer:** Yeah. Great. **Thomas:** But I'm not saying by that they don't need treatment or help. **Interviewer:** No. Just a different categorization. **Thomas:** Yes.

**Susan:** [Pause] I don't know if I can say any more than I've already said, to be honest. I think that, you know, different women have different physical changes that (.) most women seem to (.) the common physical changes women, report are breast tenderness, bloating, problems with sleeplessness. Some women report dizziness, some women report um changes in terms of diarrhoea (.). Um, they are commonly reported so I don't know what (.) what you want me to say about them. I think that there may be some hormonal connection to (.) I don't know. **Interviewer:** I suppose for me it is, if this is a mental health disorder, the DSM definition of PMDD, I think it's a bit problematic to have normal menstrual changes listed as one of the crit (.) the diagnostic criteria or (.) or even just slightly illogical, because these are commonly experienced changes. **Susan:** Yeah. No, I agree with you, and I think that (.) I think that's (.) I mean, I (.) I can't (.) I mean, I don't think I can say any more than what I've already said [during the interview about the medicalisation of the menstrual cycle] (.)

**Marta:** Err (.) I can kind of sympathize with that. Er (.) again, coming (.) coming back from a clinical perspective, again, most women (.) most women who come to me, I mean, they come for the mental symptoms, [inhale] but I still think that there's a place for (.) for the physical symptoms, because over the years I have met women who have had tremendous physical symptoms, really, really severe symptoms. And then together with the mental symptoms. So I think I (.) so I think there's a place for the physical symptoms, although for most patients, they are not the major issue and not the (.) the major complaints.

**John:** Well, some people would say it's not a mental health disorder. Full stop. Wouldn't they? **Interviewer:** Yeah. **John:** Maybe you need to have some physical things in there to (.) um, reflect that? But I think that if you said (.) if you picked any of those things like (.) um [pause] sleeping more, or sleeping less. Er (.) you could say, well, isn't it inappropriate that sleeping more, that could mean, you know, half an hour more you're going to call (.) or half an hour or less and that, you know, you're going to suddenly pathologize that? Well, again, you're kind of becoming a bit concrete in how that's meant. So if people are complaining of breast tenderness and they're really complaining of breast tenderness and bloating and those are problematic, those would be things that certainly I would consider to be relevant. But if somebody is just saying those things just happen to have them and they're not a problem or happening to a degree, that's not that significant. I probably wouldn't count it. So I think it's all about whether it's a symptom (.) or a problem. Or something of a degree that somebody is complaining about rather than (.) something more trivial?

**Laura:** Well, I worked on the DSM 5 and I chaired the subgroup on this, so I guess that tells you something! **Interviewer:** [Laugh] so, you think they are of value within the DSM? **Laura:** Well, they are part of the syndrome.

**Zoe:** Well, I have I have thoughts on the whole. As I said, pathologising of (.) of menstrual distress as a (.) as a whole. Yes. I have lots of concerns as to how the diagnosis or how the labelling, of PMDD occurs and the classifying of women then as a result with a mental health issue or mental health concern. So I do have real concerns with that in terms of what that means socially and culturally and in terms of women's lived experiences and daily lived experiences. But there's also another side that I appreciate that (.) we don't set the rules on how health authorities and how medical authorities and insurance companies um (.) determine access to services. And sometimes, you know, you need to do what you need to do in order to access a service or need to access a treatment or a regime. And, you know, for many (.) many women with limited access and limited resources, this may be the only way in which they could actually receive support (.) and services so (.) so I get that there's a bind. I get that there's a reason why sometimes we need to be able to classify, I say 'classify' rather than (.) than 'diagnose'. I get that there's a reason for that. But I'm very uncomfortable with those two situations. I don't like that (.) in no way do I believe that this means that a woman has a mental health issue or a mental health concern. But if that's the only way she's going to get services or get support, then you take the label. So I take an (.) an expedient approach, I’m quite, yeah. I'll be Machiavellian in(.) in (.) in my approach to this, because I think sometimes it's the only way that women can actually get access to services. And that may not be so. And in that, they they're receiving the care and support for a whole range of experiences that might be using PMS as (.) as the inroad or PMDD in this instance as the inroad for getting a range of access to services and support. And I would not (.) I would (.) I would never say women shouldn't have access to that. If that's her only way in.

**Geraldine:** Yeah. They don't belong there. [Laugh] yeah. I mean, that is where they overlap with PMS.

**Chris:** Well, I think. Let's take the breast one because that really feels more hormonal, doesn't it? That can be a very important symptom for some patients. It's a matter of degree. So let's try this one. You go down the motorway and you know, there's not going to be a service station for a while. You're desperate for a pee and it gets more and more painful as time goes on. You'll get bladder pain. That's normal. But if it's intolerable, then there's probably something wrong and therefore maybe a condition. That's the best I can do. **Interviewer:** Yeah. See, for me, I can see why it would be in the PMS (.) anything goes in PMS. But in relation to PMDD, I feel it's a little bit (.) **Chris:** Oh I see what you mean! It doesn't need to be in the PMDD. Well that's a (.) that'll be pragmatism on the side of (.) the psychiatrists said "oh we'd better pay a bit of attention to the uh, gynaecologists here". And they bunged it in! That's my real view. **Interviewer:** Somebody did say it's more (.) What's it called when you make a pact with somebody? **Chris:** Yeah, I know what you're trying to say, well, that's the same as I said (.). **Interviewer:** It is consensus, but it's kind of (.) to bring people in (.) **Chris:** Yeah. Yes, it's (.) it's (.) it's. Yeah, it's ‘not exclude them’ in a way. Whatever that phrase that neither of us can think of? OK. **Interviewer:** Compromise? It's a little bit more like compromise. **Chris:** Yes, OK. There's a better word than that isn't there? But I cannot think of it. So we both know what we mean. **Interviewer:** Yeah. Ok.

**Jo:** Um [exhale] [pause] I think (.) I think that's a very fair point. Is it absolutely necessary to include those? Possibly, not? I don't (.) out of all the patients I've seen. It's not the physical symptoms that are causing the distress, it the psychological. So, no, it's probably (.) It's probably something that needs to be discussed and decided on. I'm not (.) I'm not sure it's (.) it's absolutely crucial. Whereas the other (.) the other things I think are important.

### E23- **[Optional]** Diuretics (Spironolactone) in the treatment of PMS?

**Anne:** Yes [name of colleague] that was one of his first studies around PMS. He did lots of you know, he did lots of (.) and his team did lots of erm (.) systematic reviews of the different treatments. But he did do a study in the 80s about Spironolactone (.) Well [pause]. Gosh you're testing my physiology now, but I think for (.) there's some evidence that for (.) [pause] fluid retention. It has a positive effect, but I must admit it wouldn't be one of the first line choices. There are other drugs now that have an anti-diuretic effect. You know, there is drospirenone in some of the combined oral contraceptives that have a similar (.) work in a similar way. And so I think most clinicians would favour giving that, you know, combined oral contraceptive with drospirenone and that out of this (.) now, the story around combined hormonal contraception is (.) a complex one because the original studies didn't show benefit. But more recent ones have shown that giving long cycle therapy and using combined oral contraceptives with drospirenone in can have a positive effect on premenstrual symptoms, particularly with respect to fluid retention, which is what the spironolactone did and erm (.) anti- androgenic effect so like for acne. So good for that side of things. Yeah.

**Barbara:** The primary symptoms of PMS/PMDD are mood symptoms. Spironolactone is not likely to greatly improve these symptoms. There is little scientific evidence to support its use for clearly defined PMS/PMDD, although, as always, some women may find benefit.

**Andrew:** Yes. I have not. I have no experience of that myself. We haven't done research on it, but I can (.) I'm happy to comment on it anyway, because I think that spironolactone (.) and also perhaps the oral contraceptive named Yaz/ Yazmin one of those erm, have some effect better than placebo. But they are probably mostly effective for the bloating. I would guess (.) and I don't think they can compete with the (.) with the SSRIs (.) for the mood symptoms or rather I'm quite convinced of that. But I don't think they are totally devoid of effect. I think they might be effective for bloating.

**Debbie:** I think the evidence base is that it can be helpful for bloating [pause] and acne. So if (.) somebody has those symptoms. And (.) if those are the primary impairing symptoms. I think it makes sense to try?

**Celia:** Well, I think [audible exhalation] it's useful for people who have a lot of bloating, um fluid retention symptoms or androgen excess symptoms um because it has activity as (.) it's an anti-androgen as well. So I think it's very useful for those patients. The question about whether it will also help mood symptoms. There was one small study suggesting it did. But it's not my go to for mood symptoms. But I think if they have a lot of predominant congestion, bloating, water retention type symptoms, it's a quite a safe medication to use.

**Sarah:** [Interrupting] that's a relatively old treatment. Um, I can't remember. I mean, I may have used it back in about the early 1980s, I suppose. But before we had any other treatments really available, I mean, look, [laughter] the problem is that there's a very high placebo effect. So what do you think of any treatment? Well, you've got to get above a placebo effect for it to be effective. That's a problem. There's a very high placebo effect in this condition. I mean, way way way back when we first had the clinic and before we had informed consent. I made up a (.) I talked to the pharmacy. And had them produce a sugar pill with a fancy name. And I can tell you a lot of people got better on it. I just wanted to see what effect a placebo had. So would it have been maintained if conducted it for a while, I don't know. I mean, equally? We ran a trial of Alprazolam for PMS, you know many years ago and we had to give the informed consent. So there was a whole string of side effects. Well, so many people got side effects from it in a single blind month (.) erm, beforehand (.) that I went to our hospital pharmacy and accused them of stuffing up the blindness of the trial [laughter] because we just couldn't have this number of effects occurring on what was the placebo month. And they were all placebo-induced from the informed consent form, so you know (.) you know, it's very difficult. That's what has made treatment evaluation (.) difficult in the end is the very high placebo effect. And what does that show? It shows that really you can modulate a lot yourself. And that's why, you know, the psychological treatments need to be considered as well as the pharmacological. Right? And but you've got to go with the woman herself (.). We offered our women (.) that they could take part in um cognitive behaviour program, which did have terrific effects. So, I mean, I think it was you know, certainly more effective than the various control groups that we had and helped a lot of people. But you have to be willing to commit yourself and put the time in. The majority don't want to do that, they just want a tablet, thank you… Similarly, nobody ever complained about filling out those rating charts, except the control group didn't (.) who didn't have PMS. It was so hard for them to do it. But the people who had it were intensely interested in doing it, and also in the results because sometimes we could show that look here's your menstruation but you're getting these symptoms as regularly over here as you well as you are over here [indicating different places on a monthly chart]. And I would often say to them, just put an arrow when something else major happens. You know, like, you know, some crisis at home or with your kids or whatever at work, just whenever there's a stress, put an arrow. Just show me what's happened. And after a while, they were often picking up that their symptoms were related to these other stressors. That would, you know, nicely get them to go to counselling and deal with learnt techniques to, you know, to deal with that. So I found the charts very therapeutic.

**Thomas:** No, not for PMS or PMDD. That's (.) that's my view. I have experience of oh diuretics in relation to weight increase because there is also a weight increase in relation to the (.) the premenstrual period. Some individuals get an increase during production and some individuals get a smaller urine production. It's (.) it's fascinating that it can be the opposite. More or less I don't know why, but I'm sure it has something to do with the control of (.) the (.) of the urine production. Anyhow, in those situations, I used diuretics with some success. Clinical experience. No science. I've observed that [laugh] but I have not done any science on that it is only clinical experience, for what it's worth?, I'm not sure it's worth anything.

**Susan:** Um, I haven't used them, so I don't (.) I think (.) I don't know (.) I don't know how (.) they're used (.). I think if women (.) if (.) if (.) if I don't know, I don't (.) I haven't used them or been involved in using them. I know that feelings of bloating are a problem for a lot of women. And if diuretic's help women. I don't know if it's any evidence that there's more water retention at that time, but I'm not a medical practitioner, so I probably shouldn't comment on that.

**Marta:** Oh, I have experience from that (.) of that! [Laugh]. So I'm (.) I'm (.) quite old [laugh] and when I started as a gynaecologist in the (.) in 1991, I think spironolactone was probably the only treatment available for (.) for PMDD. At that time. So that was what we prescribed and it was really crappy. **Interviewer:** [Laugh] so particularly on the mood symptoms or just it didn't work? **Marta:** Um, I think particularly around the mood symptoms, I think that er (.) for some of the physical symptoms, potentially also the swelling, they were maybe good, but er (.) not for the mood symptoms. And also I use nowadays, I use spironolactone to treat hirsutism. In women with Polycystic Ovary syndrome. And then I use four times higher doses than I did for (.) for PMDD in the 1990s. And it's also a very crappy drug [laugh] for (.) for hirsutism. And I've never had any patient coming back saying that (.) they 'Oh you know, as a side effect, I've noticed that my (.) my PMDD also disappeared'. So (.) so they tend to have side effects from Spironolactone but I've never heard about mood improvement.

**John:** I don't use it. **Interviewer:** And you never have, or? **John:** I never have. **Interviewer:** And is that because you don't think it's going to be effective or? **John:** It's not an evidence based treatment.

**Laura:** Um, I've used diuretics and you have to be careful about potassium. But for people with a lot of bloating, it may be helpful. Particularly (.). The data on the use of diuretics is older, but there is also some research to suggest (.) that androgens may be involved in PMDD and some of the diuretics have an anti-androgen (.) um have anti-androgen properties, so (.) so I've used them.

**Zoe:** Um, I don't have too much knowledge of it, so I'd be loathe to answer it. Yeah, so sorry.

**Geraldine:** Hmmm so I'm not aware of any recent research on it. And as you know, I'm not a clinical practitioner, but of course, if people are experiencing particular symptoms like if water retention is the main symptom. Of course, try a diuretic and see if that helps. I mean, that's what we used to do. Before PMDD, we used to treat it symptom by symptom. So if you have a headache. You take an aspirin. If you have water retention or bloating. Take (.) try a diuretic. You know? It's worth trying. It's going to help some women, of course. And with fewer side effects. Probably than an antidepressant would have.

**Chris:** [00:46:01] Yes. OK. [Pause] um (.) depends on the symptom (.). Well, OK, my study, which I published in 1979. And there was some studies later (.) showed that it was (.) it showed that there were no differences in any of the hormones. No difference in aldosterone. No differences in progesterone, really. But therefore, the logic for giving it weren't there. But it did seem to resolve symptoms, both psychological and particularly physical. So (.) so 100mg given in the luteal phase of the cycle seemed to improve it. There's been studies since and I think the general consensus is choose it for physical symptoms. But it may work for psychological? I've not used it often since doing my study, but I have used it and it can be effective. There is something that's come out since which long term therapy of spironolactone might have a carcinogenic effect somewhere (.) but you'd have to look that up because I can't remember it. **Interviewer:** And some of the (.) like Yaz and Eloine, they sort of act like a diuretic (.) **Chris:** Yes. OK. So the drospirenone in that is derived from spironolactone. And this is the (.) and it has retained its anti-androgenic and anti-aldosterone effect. So therefore, it's licenced in the states for PMS in patients, for PMS (.) sorry, for contraception in patients with PMS and as contraception for patients with what you call it? Hair? Hirsutism! And um (.) there is no licence independently for it. And it's not licenced in this country. In fact, virtually nothing is licenced in this country for PMS. And if anything works, it is unlicensed. If the (.) the only thing is progesterone is licenced, which causes it! (.) So (.) and so there's nothing licenced. So anything that's (.) **Interviewer:** And is that just the UK or an EU thing? **Chris:** No, it's not an EU thing. Not an EU thing. I think it's a bit more accepted in the EU. I think Eloine is licenced in the same way as America in, say, Ireland and some European countries, but I'm not absolutely sure.

**Jo:** I think if somebody has really severe symptoms of fluid retention, then there is a place for them. I think they are quite controversial, but I think Yaz or Yasmin or any pill with drospirenone has made it much easier to provide a treatment that's not going to create any controversy at all.

### E24- Surgical options for PMS/ PMDD?

**Anne:** Erm, it's (.) you know if somebody (.) if a woman has [pause] the (.) has a severe premenstrual disorder (.) and it is (.) it is I suppose, a last resort if you've tried all the other measures. Erm, then I think it should be considered. I think a woman should definitely have a trial of GNRH analogues prior to it, because if those don't work (.) I mean, they are strong cycle suppressants. So those don't work. I think you've really got to question the diagnosis. **Interviewer:** Yes. **Anne:** Though. But, you know, it's a very big decision, particularly if a woman hasn't had a family. And I think the other thing I would say, I think this is something that's come out from the local peer support group is that that's not the end of the story, that often these women are sensitive to hormones and if a woman's premenopausal, which both will be by definition. Then they need careful management afterwards to get the hormone (.) the hormone replacement (.) right. One to help manage a new range of symptoms that are likely to happen because you've basically put her into the menopause and going back (.) it's important to replace testosterone as well in the younger women or clinically indicated. But also, I think something that's very much come out for me from the local peer support group is that a lot of these women have what they consider er, they have lost a number of years of their lives because (.) well (.) half their lives, because they've been getting symptoms each month for how many years the diagnosis has been delayed. And these are very formative years. These are years from adolescence when they go through puberty through into their twenties. You hear some (.) just such sad stories about the struggles that they've had. So, again, I don't think it's just like. I don't think it should be right (.) we're going to do this for you. Give you some HRT. Go away. I think, again, those women need the support to almost, you know, go through this grieving of (.) of (.) of what they've lost and coming to terms with this (.) this new phase, which hopefully is very, very positive because you see very dramatic improvement in a lot of women. But I think it's the whole picture really not just thinking, well, that's it. That's a definitive treatment. Get on with it. Now, you can't possibly be struggling. I think, you know, those women do need a lot of support still. **Interviewer:** It's the irreversibility of it (.) so you might want it to happen and understand everything. But it's still something big. **Interviewer:** Yes, absolutely. So it's guiding a woman through that. I mean, to be fair (.) certainly for the colleagues, I have (.) this is not something that they undergo lightly in any way, shape or form. You know, they (.) these women do get very detailed counselling and (.) beforehand and (.) and support. But I think it's possibly that bit afterwards? That [pause] you know, and that's where the GP should be (.) should come in as well to do them justice, not just assume that they're going to be fine because they have been through so much.

**Barbara:** It is difficult to justify any non-reversible treatment for these disorders.

**Andrew:** I think that is a very harsh treatment for a condition that could be managed in a less dramatic way, so I would not encourage that. Also, if you remove the ovaries, that would be the option here, then you would have to give add back hormone treatment and that add-back hormone treatment might induce premenstrual symptoms. So I don't think surgery is an option here, really. I could also add that in fact, the effects of the SSRIs on the mood symptoms is very big. It's a good effect. It's a big effect. It's a large effect. We have (.) we have, you know, normally one (.) one (.) regard point zero as a no effect size. Point five is the median effect size. Point eight as a good effect, size in (.) in (.) if you look on the focus on irritability and look at the SSRI. We have an effect size (.) of about 1 or 1.4 or something very high effect size with a response rate of 95 percent. Well, all self-rated irritability, for example. So (.) so I think if (.) if the mood symptoms are the dominating ones, I think intermittent SSRI administration is in most cases very effective. So I really don't see any room for such a harsh treatment as a surgery.

**Debbie:** I think they're absolutely necessary for a lot of people. I think that, you know, I've (.) I've referred a lot of people for that. And I have written a lot of letters [laugh] to argue that people need that. [Pause] I think that somebody has to want it. First of all, you know, we would never (.) sort of force somebody to do that. [Long pause] in 2017, there was a paper that came out showing that when you do add back of oestrogen and progesterone on top of the GNRH agonist. Right. So you put somebody with PMDD in the menopause. They're fine. Then you add back oestrogen and progesterone. Their symptoms come back (.) because of that. We had thought for a long time that if somebody has PMDD, we use the GNRH agonist trial to find out if surgery will work. Right. So we use medical oophorectomy with the GNRH agonists to figure out if surgical oophorectomy will work. And then we immediately put them through to surgery because we can't give them oestrogen and progesterone, which they need for heart and brain and bone health. So we just have to, you know, we just have to use it as a test to make sure the surgery is going to work. And then we put it, but we can't put them on this long term because they don't tolerate it. Their symptoms just stay there. But then in 2017, this paper comes out saying, "oh, no, it turns out that if you suffer through [laugh] the first month, of add back and you don't say, hey, doc, I can't stand this, I have to get off", which would be understandable. If you suffer through that. Then when you come out the other side, as long as you keep things stable, you can tolerate the add-back long term. And why not (.) in that case, why make somebody go through major surgery if you can just keep them in a medical menopause and add back the hormones in a stable way on top? That seems more sensible. So that's what we're doing now in my clinic. That's what we recommend. And some people don't have adequate ovarian suppression with the GNRH agonist. And we see that they're still ovulating [exhale sigh]. Some people have co-morbid endometriosis or some other really painful physical condition that makes surgery more appealing. But I think that my thoughts on that have evolved a lot since that paper came out, because I (.) and so I (.) I (.) the difficult thing about it is that month. And I have people come in to see me, you know, every week and sometimes more frequently just to like get them through it. Right. Like, you know. And everybody wants to come off. But then four and a half weeks in, they're like, "oh, I feel better". So that's kind of (.) it's kind of evolving. But I think it's a necessary tool to have. I'm hoping that it's necessary for fewer and fewer women as time goes on.

**Celia:** [Audible exhale] I think that the more we understand about how important the ovary is, even in the post-menopausal years, the less we are interested in removing ovaries. If someone also has another indication, say they have (.) um [pause] severe endometriosis or other aspects (.) then removing the ovaries in the 40s after childbearing and giving the (.) removing the uterus as well so that you can give unopposed oestrogen (.) is reasonable. But if (.) I think it would have to be someone who has very severe symptoms and who other aspects have failed, and I usually in those patients like to try them on a GNRH agonist first with oestrogen add back (no progestin for six months) and make sure that they do well.

**Sarah:** Well [pause] I wouldn't say never. Um because I think that there are some people who (.) who just have failed to respond to everything else. Um, but I mean, this is really for the most severe group. It would be a very, very small number. And you would always be trying every other type of treatment first. [Pause] but the woman I told you about, for example, I mean, anyone who had, you know, such a significant change. I mean, you could (.) you can control that now with GNRH analogues and so on. It would only be if there was some reason that you couldn't give those that you would be thinking about what you would do surgically. I mean surgically. You're going to have to, you know, to do a bilateral oophorectomy to (.) to stop it. So there might be reasons that (.) why you can't give drugs.

**Thomas:** Yeah. I've seen that in the literature. In a situation when you have a condition which is life threatening [pause] which acute intermittent porphyria is. (.) So we had a patient who actually died in (.) in (.) in her acute intermittent porphyria in the luteal phase. And (.) and in those situations, I could think of (.) of an oophorectomy, but in other situations I think it's (.) it's a bit too much. On the other hand, if it (.) if now it turns out that nothing else is helping and they are suffering a lot. And especially if they also have pain, which is not an uncommon that they have (.) have endometriosis, for instance, that also can happen. Then one could (.) think about it. I have never done an oophorectomy or hysterectomy on the (.) on the indication PMS or PMDD. But I have used GNRH agonists, which are, let's say, a medical oophorectomy. And that has been very successful. It medicates (.) **Interviewer:** And then do you use add-back oestrogen? **Thomas:** Of course! Of course (.) always.

**Susan:** [Long pause] I've certainly heard people talk and probably some of the people that you're going to interview about hysterectomy, as you know, the ‘ultimate cure for PMS’. I know there's some research (.) Well, you'd have to take out the ovaries as well if you (.) if you're going to take a really biomedical position on it. And I seem to remember although, I haven't seen it for a while that there is some research showing that women still might position themselves as having PMS even when they have had their ovaries removed. And certainly women (.) um certainly position themselves as having PMS when they're on hormonal interventions, such as oral contraceptives. When you'd think they wouldn't be getting those changes as monthly cycles? So I think that what (.) it's really the extreme end of positioning premenstrual distress as if it's an entirely embodied um experience, I would hope that most clinicians wouldn't do a hysterectomy on a woman lightly for any disorder. I suppose, that would be my comment on that. I think just going back to your diuretic question, though. Um, I think if women are experiencing so much distress around bloating and PMS that it's also important to look at the meaning of that bloating for women. As I've already talked about previously, not just the bloating itself, but if a simple diuretic could help and it's not having any other adverse effects on women, then it's probably not problematic.

**Marta:** Er (.) [laugh]. Er, yeah. I'm not really fond of it [laugh] And I've never (.) Um, I've never(.) um [long pause] what's (.) erm, I've never used it for any of my patients (.) I've (.) I've used it once for a patient who had premenstrual epileptic seizures and I cured her [smile and laugh], which was really, really rewarding both for me. And, of course, for the patient. But that, I think, is the only time I've ever had (.) made an oophorectomy. **Interviewer:** Um, That sounds like an interesting case. Did you do um hormonal add-back after the surgery and that still didn't affect the epilepsy? **Marta:** No, I didn't do anything. It was a really tragic case. This was a woman who (.) she was born normal, but I think she had an incident like this when she was at the age of one, two, three, very young. And that also meant that she was not (.) she also (.) she was also slightly mentally retarded? And she was having petit mal seizures and sometimes also generalized seizures from those. And she was really, really suffering. And she came to me in the clinic three times and two times before the surgery and once after the surgery. And she had several seizures just waiting for me in the waiting room. And the staff were really upset. And we discussed the possibility. But for her, it was just too troublesome to start taking any more drugs than the ones she was already taking for epilepsy. So we (.) we thought it best not to provoke seizures again with any hormonal treatments because she was so happy that she was improved.

**John:** I think for some people it's appropriate, but it's at the end of the line.

**Laura:** So those should (.) that should be a last [long pause] ditch effort.

**Zoe:** [Pause] I could see no need for a surgical intervention for PMS or PMDD. Now, that's not to say that a woman may not need a surgical intervention for another condition and she may also be having PMS. And PMDD, and there may be a resulting improvement or exacerbation. But for PMS and PMDD, no there can be no reason for a surgical intervention.

**Geraldine:** Well [exhale] I'm not aware that there's any cause for doing that or that it's especially helpful. So I'll just end there [laugh]. You know, first (.) do no harm. Right? So. Yeah.

**Chris:** Um (.) last resort [pause] unless the patient's got something else going on as well? So if you've got a 40 year old patient who has completed her family. She has endometriosis, severe heavy periods, severe dysmenorrhea, and severe PMS. You might take out her uterus and her ovaries. In a woman with very heavy periods and nothing else. You could probably just take out her uterus. If she's got heavy periods and PMS you might take out her ovaries as well. So the question is, if you're taking out, just the (.) just the uterus or uterus and the ovaries. And I would, in my view, is that I wouldn't never do it without doing a GNRH and oestrogen add back test. You can give an oestrogen add back for a short period of time, even up to three months without giving progesterone. And it won't cause (.) you can just give oestrogen but you won't cause cancer. So (.) so what you do is you (.) you do um (.) you do a test drive, which is (.) here's your test drive. You're gonna have (.) you're gonna have GNRH, which is like taking everything out. You can have oestrogen back to just see if you tolerate it, because I've got two patients who have not tolerated the oestrogen add back, which is a problem. And so that's why surgery is a last resort after a (.) after a test drive.

**Jo:** I think for women who've had an accurate diagnosis and who are at the severe end of the spectrum and who have been provided with GNRH analogue so that they know exactly what happens when you remove any cyclical influence, then there is a place for surgery. But it's for a very small number of women. And I think the problem is that for severely affected women, actually at the moment, there are no other treatments.

#### Bonus patient answer:

**Helen:** Yeah. You know, immediately after surgery, I think I just felt this huge sense of relief. I was so nervous that it was going to not work, that it was going to be painful (.) like everything that you're scared about surgery. But I was scared the most. It wouldn't work. And I was doing this huge decision. So when (.) I remember waking up and for like two weeks, I just felt amazing and I felt so clear headed, like all the incessant chatter in my brain had stopped. It was just all this space. Um, But then after two weeks, I was on no HRT. And I absolutely crash (.) I don't know if it would've been the same if I was on HRT, but I just crashed. I crashed so hard. It was awful. I felt like everyone was looking at me, expecting me to be normal, like every day, ever since and that wasn't the case. Um, it was several months. I just went up and down and up and down and up and down until the ups and downs became further spread out. And then I started to go like a month and then two months. And I was (.) you know, just one day you stop checking in with yourself, asking, how do I feel today? And then you realize "Oh, I haven't checked in with myself in a while, actually must be doing pretty good". And then so now, five years later, I'm finally on an HRT level that works well for me. And, you know, I think still (.) still I think there is an unfair expectation, even post (.) post-PMDD that now women that have had the surgery should now be emotionally sterilised in a way (.) like you know, we should be like men now [laughter] you know! **Interviewer:** Yeah, I know men are a bit rubbish at expressing their emotions, but we know they feel it! Like we know they commit suicide (.) [overlapping] **Helen:** I know! Yeah there's just this like weird (.) you know, like just gosh, three days ago. And I know. I mean, even I am attributing it to a patch change when instead of just, hey, I was really having just a bad day and I had some emotions about things happening that day, you know, but it turned into (.) like a PMDD flashback between me and my partner. It was stupid, you know? And I resent that [laughter] I'm like, I've given up every part (.) I've given up organs! Like can we just accept that life happens and we still have emotions and women are going to express those emotions. So anyway, I'm going on a tangent, but [laughter] I do. I definitely (.) OK. So I just sold that very poorly. And I'm not trying to sell surgery because I do hope there is an alternative one day. It did work for me when nothing else did. I'm no longer on antidepressants. I do still take um anti-anxiety medication mainly for night-time anxiety and flying (I'm a horrible aeroplane flyer. I need to be drugged severely um [laughter] to fly). But yeah. So I mean, it's definitely had a positive impact in all areas of my life. Having the surgery, but I don't feel like (.) it (.). It sucks that it had to be the case, but it is what it is. I'll get to an attitude of gratitude. I'm sure. **Interviewer:** And so for you, it did also vary with the concentration of oestrogen? **Helen:** Yeah. **Interviewer:** Or the way in which you were receiving oestrogen that they had to get that right afterwards (.) **Helen:** Yeah. Yeah. You distilled that very well. So I had no HRT after surgery, which honestly I wouldn't recommend to someone else. I feel like my doctor (.) as most gynaecologists are like I don't really know what I'm working with here, but I'm gonna believe you. You seem like you know what you're talking about. You know, I've done my research as a gynaecologist. So she gave me the surgery. But even (.) post-surgery she was like, "I don't know". You know, she's just like, I don't know. We're just kind of (.) like I was almost a case study. You know, for her in a way. **Interviewer:** Oh right! **Helen:** So I felt really good for a while. And when I stopped feeling good, I would go to her in a panic. And she really had no answers. So then I started kind of a new process of bouncing from doctor to doctor, trying to figure out what to try. And I think that (.) and this is why IAPMD is working on a surgical menopause program, because, you know, it's the last line treatment option for PMDD. And then we're now put in the bucket of 'all women' who have had oophorectomies, no matter the cause. And then we're all also, again, being treated the same way. So there, you know, I was put on one milligram. I don't know what that translates to in the UK, but it was one milligram of oestrogen gel. And I was like I went from hating myself to hating everyone else. And I wanted to, like, flip a car. I couldn't walk out my front door. It was awful. So I went off of it. But that's what they prescribe 'most women' post-surgery. They give them start them at 1 milligram. Well, as for me, who is hormone sensitive. That was extremely too high. So then I went on zero nothing for two years. But that causes other issues. You know, vaginal atrophy and dryness and insomnia and so many things. So I did great emotionally. But then my body physically started to suffer um and I guess it just (.) just like PMDD [referring to how she finally got a PMDD diagnosis] I went to somebody that had been through the same experience. You know, "here's my problem. I feel like I'm cycling again almost". She's like, "oh, here's what I did". So I follow her steps. I mean, it just seems to be the whole life cycle of PMDD from start to finish. Seems to be, you know, rely on your peers more than your doctor. Um Sadly, but it works [laughter] immediately (.) because she got, you know. So I started out point two five patch (.) worked my way up to point seven five where I'm at now. And now it's great. Now it's you know, I feel really, really good on this dose. So (.) but that's five years! That is five years post-surgery of getting to where I am today. **Interviewer:** And your insurance was okay, about all of these because you'd had the hysterectomy (.) and so they kind of had to? **Helen:** Right [overlapping] Yeah, because I was in surgical menopause. Yes, they cover it. **Interviewer:** It's quite different here because um we have free healthcare, obviously. But when we see a general practitioner first. And then you have to get referred. And then it's I guess it's 50/50 whether you get referred to a psychiatrist or a gynaecologist. **Helen:** Oh wow! **Interviewer:** And they will have their different ways of wanting to treat you. And then eventually they probably will both do the GNHR agonist tests and then you might get surgery. But they definitely always give you HRT, like all the guidelines are like 'you must do add back'. And then there can be um (.) adjustment issues (.) so a bit like when you start a contraceptive pill, it takes a while to kind of whatever it is doing for your body to adjust and then things tend to settle down. But there's no way they wouldn't give you a HRT. Like that's quite shocking for me to hear. **Helen:** Oh, yeah? **Interviewer:** There's just these differences depending on where you live. **Helen:** Oh totally. And they don't do testosterone here at all. I can't get it. Like I'd have to go to a compounding pharmacy like off label by myself out of pocket. I mean, I have no testosterone inside. That's one thing I will say sucks. Like I (.) I really (.) Oestrogen helps a little bit with libido. But I mean, I just did a lab probably six months ago. And now in the US we have (.) I know. And I think this is different in The UK, like we have access to everything. Like all of our medical records. Lab results. Do you guys have that? **Interviewer:**] In theory, we can yeah **Helen:** In theory? **Interviewer:** [Overlapping] in reality we quite often never see it (.) **Helen:** What's that? **Interviewer:** Sometimes (.) so you can ask. I've asked and I've still not seen it (.) So (.) um but in theory, we should be able to access it. But I think they lose a lot of our notes. It's a wonderful system, but it's also a bit rubbish in terms of admin. **Helen:** Yeah. It's not an exact science yeah. But like we have an app on our phone through our provider (.) my (.) my (.) my provider does and I can go see all my lab results all my different appointments and stuff. It would've been great when I was younger, but it's like a new thing. But I went in there and I was like, oh, there's my testosterone [laugh]. It's like at the very bottom of the scale. Yeah. The U.S. is just. Well. **Interviewer:** You know what I think (.) I think people are prescribing it here, but I think it's off prescription. **Helen:** Oh, is that it? **Interviewer:** Yeah. I don't think in the EU they have (.) I haven't seen a trial of the correct size to be able (.) for doctors to formally prescribe it. So I think it's something that people do (.) particularly if you talk about libido. I mean, I must admit my libido is terrible. And I (.) I still have a menstrual cycle and I only feel randy during menstruation, which is great because I don't want to get (.) I don't wanna get pregnant! [Laugh] But, you know, I don't fit this idea that you get randy around ovulation. I never have. **Helen:** I did before I had a kid now I'm just tired [laughter] **Interviewer:** Yeah and I think (.) I think the tiredness is actually (.) and I think men are similar, their libido goes right down, even at our age and their testosterone hasn't gone. So, I think life has quite a big (.) part to play (.) in some of these symptoms (.) **Helen:** Yeah, I think you're so right! I know. I tell people I'm (.). They ask, "how are you doing post-surgery? Do you have a libido?" And I'm like, "honestly, no. But I also have two kids, a full time job, a partner, you know, a twelve year marriage (.) like my father passed away last year". I'm like there's (.) just 'life happens'. Like, you know, you forget to (.) you live so long. You know, with your diagnosis defining you. It's like you forget to drop a diagnosis. And also remember, we're human and life still happens with and without ovaries, with and without PMDD. And um yeah, so I tell people, "like, did the surgery work for me? Absolutely. And I'm glad I did it. Yes. Because they had no other options. But also to have realistic expectations because life will still happen. You know, you're cutting out your ovaries, not your heart" [laughter].

### E25- Integrating different perspectives? Rate my chances?

**Anne:** Go for it! I think that would be really good. I know how much hard work these things have (.) hard work is involved. But if you're passionate enough about it. Yeah. I think that would be really good. I do think nowadays not that I’m an I.T. person at all. But I do think the apps are probably the way forward. And we've target (.) because of what I've said about the need to make this diagnosis much earlier on. We're looking at ways of targeting the adolescents. You know, often the condition is just put down to adolescent behaviour, you know (.) But again, in a lot of (.) lot of people. You know, some people that will be the case. But in some girls, just to look at their menstrual cycle and treat that, could actually make a big difference in the whole thing. So (.) and so what I'm saying is that how do you target the teenagers of today? And I think it's got to be social media, hasn't it? It's got to be the apps and things. So I think that would just be one thing that, you know, I feel is the way forward. So to develop an app would be good. I think look at the ones I mean, the ones that your (.) [name of app] seems to be quite a good one. And I don't know what the range of symptoms on that is? (.) And the other one was the one developed by [colleague name] and one of his research fellows has done a thesis around it. **Interviewer:** I've read about the app, but I haven't downloaded it, so I haven't yet seen it in practice (.) but I have the information about it. I actually work with [name of app previously mentioned]. You know I run Menstrual Matters? And initially this research was going to hopefully use some of their data because they've got millions of users. But very unfortunately and it's actually a language thing in Scandinavia where the app developers are from (.) the word PMS, they use PMS like the English word directly equates to low mood (.) or angry mood (.) at the top of their list of symptoms. They just have PMS and what they mean is low or angry mood. And so that just means I can't use that data. **Anne:** Oh what a shame! **Interviewer:** And also there are other issues in the way that they prioritize certain symptoms over others, you know, like all of us do. But it was quite marked. And so, again, you're priming people to notice certain problems. But, I know that they are open to feedback on this issue and so again (.) if we could get a big app like that to change the way they present their symptoms that would be very helpful. **Anne:** Yes **Interviewer:** And also, as you probably know, as a GP, people feel very empowered once they have the data to talk to their GP, I think a lot of patients worry that they're going to be dismissed. And told that 'it's normal'. **Anne:** Mm hmm. **Interviewer:** And so I found that people, whether or not they end up showing the data to their GP, they just sort of feel empowered to ask, to be referred or to ask for a different (.) for a different treatment. **Anne:** Yeah. **Interviewer:** Because they know that it's cyclical. Like they've got that. They know it. **Anne:** Yeah it's very (.) it's very powerful. isn't it?And I think, you know, if I had to say one thing that could in terms of awareness, just to get that message across, if you were, you know, and PMS and (.) and I don't know whether, you know, anything about this new curriculum that's coming into school, they're going to do more teaching around menstrual health. We're just really keen to get in there and try and provide some sort of learning tool that (.) well for teachers really to put across to their pupils. But doesn't that what you've said just give you, you know, support your work? Because it needs to change. **Interviewer:** Yeah **Anne:** It could actually, you know, could become a lot more simple, a lot more simple, but not (.) it is very complex at the moment, isn't it? Because of the range of (.) of information that's out there. So you almost want to make it easier for people so that they can be diagnosed more readily? **Interviewer:** Yeah, I actually don't think it's (.) this is a complex job. I think what's got in the way are different disciplinary perspectives that have actually quite different (.) views about the whole thing. The aetiology, the treatment, the types of things we're talking about, the symptoms we're talking about. But actually, it's not particularly the most common symptoms. I think it's actually we are all kind of (.) all agreed what the most common let's not say top 10, but the most common (.) fifteen? I think everybody would have all of their symptoms in there that the different disciplines are mainly talking about. And it's kind of just persuading people that that it's possible. You know, I and I think really a lot of the work's already been done by the Montreal Consensus. And then I'm just kind of dealing with the tensions that remain. **Anne:** Yes, yes (.) yes. **Interviewer:** You know, there are a few I think. And as you say, people are just now talking about periods, talking about menopause more. So these issues will (.) people will spot them [laugh]. You know, it's not just people like me who are interested in this as a research thing. It's patients who can see that there's a mismatch between what's being (.) so sometimes on tracking tools. They don't mention pain at all. And you know, everyone knows that period pain is very common and that it will affect your mood. **Anne:** Yes **Interviewer:** You know, like this is kind of human stuff that people know. So I think there is appetite and I wouldn't be doing this if I didn't think it's possible. I think. Although it is a complex biological system that is you know that is happening or a process and it's complex. You know, there are external factors and all the rest of it doesn't mean it has to be a complex kind of diagnostic (.) **Anne:** Yes, and, if you can make a difference for the sufferers, then that's good to be very rewarding, isn't that? **Interviewer:** Myself included, that's why I got started (.) **Anne:** [01:21:15] Right OK. Well, often people are passionate, but, you know, that's where their passion comes from, if you've got that experience. Yeah.

**Barbara:** It already exists in the literature if it is sorted out to examine well-designed, placebo-controlled studies where symptoms are charted.

**Andrew:** [Laughter] Ha-ha. Erm, medium! [Laughter]. I think I (.) as I said, I have tried the same in my humble capacity in various consensus groups where there have been a lot of people and I have tried to do the same and have been very modestly successful. I think that is a very (.) I (.) and this is my personal opinion. The others will not agree, but I think there is a good scientific argument to divide these different conditions into different (.) different conditions. And it's a very strong tradition among gynaecologists not to do that. So what one would have to do then is to convince the gynaecologists of doing this. I don't think you would have any problem with psychiatrists to (.) to separate (.) to skip the Eleventh item of the DSM, for example, and regard it as merely a mood condition. But I think it would be very difficult to convince the so-called opinion leaders I don't like that word, but the people are sometimes called that opinion leader key opinion leaders. I don't (.) I think it would be difficult to convince those in gynaecology of abandoning the concept that that all premenstrual symptoms are part of the same syndrome. **Interviewer:** Yeah (.) so (.) **Andrew:** Good luck with that! [Laugh].

**Debbie:** [Laughter] Alone? Not very good. Networked into the world of, you know. I mean, this is for any of us, right? I think (.) I rate you (.) I would say I rate your chances of impacting this (.) this conversation in a positive way. Ten out of ten, I would say. It's like what tends to happen is that (.) and this is what you're doing is so brilliant is like we all get into our little silo's and like have our own answers and whatever. But I think as long as we can sort of have some sort of basis for agreement, like the scientific method or at least some integration of the scientific method and rational discourse. But I (.) I (.) I think (.) your chances of (.) of making a strong case and (.) and working with the, you know, community to improve things are very, very high.

**Celia:** [Pause] Yes, I think. I think it probably could. I think you probably need to study large numbers of women with prospective recording to see what we're dealing with out there now. And then come together with some sort of a Delphi group. Need not just include experts could include patients in separate meetings, you know, focus groups and that sort of thing? I don't know how these forums or these things are derived nowadays, but I think it's certainly an important process.

**Sarah:** [Pause] [audible exhalation] Well, I think that's what we attempted to do with all our studies over the years and I mean, I always worked in multidisciplinary clinics so psychiatry, you know, we had other people, gynaecologists, psychologists all working together. I think that's the best way; all informing each other and the same with the research it's got to be multi-disciplinary and trying to bring all those things together. I mean, I think there's been, you know, there's now large cohorts of people in different countries where that sort of literature is available and could be brought together and for analysis it's much larger datasets than we ever had. I think that's true and there's a lot of interest in different countries. I know in Australia there's a national women's health study that looked at this like women in reproductive age groups as well as women before that in adolescence or whatever. So I think that if all, if a search was made of those, large databases and a collaborative project, I think you could then you could analyse that. I think that would be fascinating. That would be good. But I think there's probably enough data out there already published you really (.) you know you'd be able to look at it.

**Thomas:** [01:02:32] Well, I mean as a medic or as a (.) a (.) let's say health care giver (.) of course, everything which causes problem for the patient should be investigated and treated and (.) and helped. So whatever it is I mean, I think that's (.) that's the (.) my view. On the other hand, I mean, one has to prioritize because the amount of money available is limited and that perhaps one could say yes, well. I'm surprised that you have got grants to be able to do this research?! [Laughter] **Interviewer:** Well, it's maybe back in? We're in a new era. It's fashionable again. Periods are (.) **Thomas:** Yeah, OK. That's nice. Anyhow, anyhow, that's (.) that's something which is so (.) so I think that first (.) first thing first and then the second thing. And what (.) whatever (.) I mean the most common things I think would be good to be able to treat it properly. **Interviewer:** Mm hmm. **Thomas:** I can also say that we are not or I am not completely unbiased (.) in that way that I am (.) I have discovered that there are possibilities to actually antagonize this provocateur, as I believe allopregnanolone provocateur with a medication, with a compound that we are developing as a medication. And we have in fact made a preliminary first study where it was very positive and in (.) in patients with PMDD (.) and we are now doing a major study.

**Susan:** No. Because I think (.) well, what's implicit in your question is the notion of, you know, pathology and normal as if there's a dividing line (.) and pathology is something which is a construction. Um if you look across the history of psychiatry and if you're doing your PhD within medical sociology, there's great writers within that discipline. If you look across the history of psychiatry and what we pathologize, it changes across culture. It changes across history. And PMS is a construction of 20th and 21st century Western biomedical and arguably psychological thought and practice. So the idea of (.) your question implies some sort of realist (.) Um, conceptualisation of PMS and PMDD as if it is a thing and you can find this absolute criteria that if you tick these magic boxes, then you have got it and someone else hasn't got it. So I think you're chasing a kind of (.) I dunno what the proper metaphor is (.) a red herring, really? Maybe I can think of a better one when I come off the call (.) But it's (.) it's (.) it's (.) it's I don't think that's the thing to be chasing. I think it's (.) what I would say and I think your intention is really good about getting awareness of cyclical changes. So I think what you're trying to do in your question is what you need is, in a sense, your answer. I think what we need is greater awareness of women's cyclical changes if they're causing distress. And I think that's one of the posi (.) one of the onl (.) one of a few positive things about the DSM across the board in terms of diagnostic categories is, it's about symptomatology. But if that symptomatology is causing distress [only], so that's you know. So I do a lot of work in the area of sexuality as you probably know and you can have changes in terms of sexual functioning, but if it's not causing distress, it's not a pathology. If you've got no libido or if you're a man and you've got no erectile functioning, it's not causing (.) If it's not problematic, to you, then it's not a pathology. And so I think that's what we need to be doing about PMS, is having greater awareness that many women or some (.) some women (.) some women experience cyclical changes that cause distress. So it's important for GPs to be aware of those and how they impact on women. And as you said in a previous question, if that's interacting with other underlying conditions or chronic conditions to have awareness of that and not be looking for some magic formula, that's (.) so a GP can say, "ha ha!, you've actually got it!" 'cos it's about that individual woman and her symptomatology and the level of distress and then understanding why it's causing distress, what's actually going on. That's what I'd say as a psychologist, it's not simply giving a pill to get rid of it. **Interviewer:** Yeah, I (.) I think that (.) [interrupted]. **Susan:** I always say that if there was a magic pill that could get rid of it. I'd be all for it. But there isn't and SSRIs are not the answer.

**Geraldine:** [Laugh] yeah, I was going to say, how are you doing with that? [Laughter] Well, I think that (.) I don't know, I wouldn't say it's impossible, but (.) it would have to be embedded in something that says that changes in physical and psychological and cognitive experiences are normal. And if a change is severe or impacts a person's daily life, then they should seek some kind of help. You know, it would have to have those elements in it, I think. So that it's not so broad as to say that everybody experiences it (.) but not so narrow that women can't make their own evaluation of what's normal for them.

**Chris:** Well, you see you've got to distinguish. No, I don't. Yeah, in the States. If it's private, they're fighting for ownership- in the UK. They're hoping that somebody else will take you away. You know, unless they're interested in the subject. So that's the reality. Gynaecologists are in (.) tend to do surgery earlier. Oh, well psychiatrists aren't going to do surgery. But they’re more (.) and you know more (.) you're going to more likely get [emphasis] surgery. With a psychiatrist, you are more likely to get labelled as non-hormonal bipolar disorder, which in (.) that's the reality. That's my experience. **Interviewer:** I'm quite interested in this because I came from (.) I used to evaluate social projects in international development which are very complex, it's very difficult to know who did what. When I came into medical research, I thought it would be really scientific. **Chris:** Oh, [laugh] well, it is. Well, well, well, anything you read about me is very scientific. There's nothing wishy washy in there at all. But to say (.) to do it scientifically, work out whether they should go to a psychiatrist or gynaecologist is not a scientific question. That's the trouble. **Interviewer:** But I suppose I thought medicine was a bit more um (.) **Chris:** No, well it's not! **Interviewer:** You know, ‘scientific’ is the best word I can come up with. Sort of (.) or at least (.) **Chris:** A bit more organized. Even? **Interviewer:** Or just get (.) you'd get guaranteed (.) you know, that people would follow the guidelines and you would do this (.) But it isn't. It seems to be very (well not quite haphazard), but it really depends who you get referred to. **Chris:** Yeah. **Interviewer:** As to what treatment you'll receive. **Chris:** Yeah, yeah. I mean, maybe there should be (.) I mean I would say that (.) gynaecologists should (.) I have said this somewhere (.) it’s possibly better if a gynaecologist sees patients when the GP hasn't got anywhere and the psychiatrist hasn't got anywhere. Then they should be seen by a gynaecologist. That's almost what I really think. But (.) um that said, if you're trying to do research on it, you want them to come, in private practice, you want them to come. So it's not quite as straightforward as that. And the GPs don't want to see them at all. Because they don't know how to manage it. Because it's really complicated (.) because I haven't told them how to do it well enough. Maybe? **Interviewer:** Yeah, well, there's also this pressure on GPs. They have ten minutes. **Chris:** [Overlapping] Yeah. You can't (.) you can't (.) diagnose PMS in ten minutes! **Interviewer:** You can't expect people to monitor (.) It's getting easier with apps and lots of smartphones and whatever **Chris:** Yeah **Interviewer:** But still I think patients don't take time off work lightly in order to see their GP and would almost prefer (.) There's definitely a feeling that people want treatment. Right now. **Chris:** Yeah. **Interviewer:** Rather than taking 2 months. But I don't think that's a good enough excuse for GPs to not (.) um (.) Because they (.) I don't actually have anything against GPs because they (.) they do deal with this quite often. They're the front line, they have to rule out anything that could be serious. You know, first particularly for gynaecological things, but (.) **Chris:** And particularly for (.) particularly for suicidal. **Interviewer:** Yeah. And if somebody's suicidal. They have to follow certain guidelines on that of course. And then they may not see that person again. You know, it is (.) **Chris:** I don't think (.) I don't think it can be dealt with in general practice, to be quite honest. I think that's my real view. And then it should only be seen by psychiatrists who understand (.). Have you spoken to the guy in [named university]? **Interviewer:** [Name of colleague]? Yeah. **Chris:** Yeah, yeah, yeah. Well, someone like (.) well he's done gynaecology and psychiatry, hasn't he? **Interviewer:** Yeah. That's why I was keen to speak to him (.) **Chris:** And he's on our guideline. Yeah? **Interviewer:** Yeah. I thought that'd be interesting because in one person he's got both of these (.) **Chris:** In theory! [Laugh] **Interviewer:** But he (.) I think he comes (.) I think he came down slightly on the 'psychiatry side', if there's a psychiatry side? **Chris:** Yeah. **Interviewer:** But, you know, part of my thesis is really looking at how your discipline, how your resourcing of that discipline does make some of these decisions regardless of (.) **Chris:** Oh, absolutely. Yeah. Yeah. **Interviewer:** Well, if he runs a clinic in, you know, his situation- then like your situation is different. So (.) this is what I find very interesting (.) **Chris:** Well, let's (.) let's see(.) in my situation I will treat with SSRIs. I'll (.) I won't treat with lithium. I'll treat with hormones and I'll treat with surgery- in his situation. He is not likely to use hormones. He's only likely to use SSRIs. And in fact, if you look at anything written by the psychiatrists in the states. Where PMDD exists, they really (.) everything is designed around SSRIs, if SSRIs don't work. I don't know what they do because they object to anything surgical? They object to hormones (.) Not object, but they're very, very unhappy with them. So I think you need someone (.) I think you need to be able to do everything, including the surgery. You can refer for the surgery, of course, yeah (.) **Interviewer:** I'm also interested just (.) earlier you said some gynaecologists want to avoid it. **Chris:** [Overlapping] Yeah, because they don't understand it, either! **Interviewer:** Because it's not their interest or, you know, they're not comfortable with it? Or is it that they prefer to do surgery? **Chris:** They prefer (.) they prefer not to deal with it because it's a very difficult subject. You know, if you're a gynaecologist without interest in PMS/ PMDD um (.) You (.) try to avoid this topic coming up (.). You know, if you've got a quarter of an hour (.) for a follow up appointment. You really don't want to (.) It's you (.) you want to avoid it, if you can.

### E26- Reflections, comments

**Anne:** Okay. Yeah. No, it's been good to chat it through. It's always nice to speak to people who are as passionate as I am about this (.) [laugh] about this condition and just really encouraging. That work is being done because I think in today's climate it's just so difficult. I mean, I (.) when I was doing research, it was so difficult to get funding. And I'm sure it's no easier. It's probably a lot harder now. So it's just really refreshing to (.) to hear about projects such as yours and (.) just saying about NAPS that we are a very small organization, all voluntary don't really get much funding. It definitely is difficult. But I would say we're all have similar passion about trying to increase awareness and want to improve the education of both health (.) I mean our main aims are information for health professionals and supporting sufferers. And so, you know, to be (.) to know about this work and to contribute to it, this is what we want to do. It all helps.

**Barbara:** Best wishes for a good report.

**Fran:** What do you plan to do with the data once you collect it? **Interviewer:** I’m speaking to a range of different experts from different clinical backgrounds and I’m speaking to patients, as well (.) and I’m doing a sort of (.) it’s called a Critical Discourse Analysis of what people have said. The idea is that it will help, improve specifically in regard to ‘PMS’ rather than ‘PMDD’- improve the quality of the (.) the way that it’s diagnosed. So, at the moment the lack of any listed symptoms is not very helpful for clinical diagnosis purposes, but also in regard to research- each trial will be selecting and using people with different symptoms and experiences, which has been a problem in the past with not being able to compare studies. So, the idea is to try and come up with a shortlist that perhaps everybody can agree on. **Fran:** Are you familiar with the (.) um, [name of university] and their daily rating form? **Interviewer:** I’m sorry- I’m not catching any of that? **Fran:** Have you, in your literature search seen the daily rating form from [name of university]? **Interviewer:** Is that the DRSP? **Fran:** No, it isn’t (.) it’s something I would suggest looking at because it is in the [name of journal]- by [colleague’s name] **Interviewer**: Oh, yeah! **Fran:** So you’ve seen that? It’s called [tool name]? That has a lot more symptoms (.) **Interviewer:** Yes (.) **Fran:** Oh so you are familiar with that? **Interviewer:** Yes, and in fact I’m speaking with [tool author’s name] next week! **Fran:** OK. Because that’s an attempt to be a little bit more comprehensive in terms of rating premenstrual symptoms but you were aware of that (.) **Interviewer:** Yep. **Fran:** OK well I’m happy to look at a transcribed script of what we’ve been talking about.

**Andrew:** It was a pleasure. And I think the questions were all very relevant. Absolutely. I think one should not (.) should not underestimate first the controversy around this diagnosis that you mentioned briefly, that there really is such a controversy. And in some ways, it's quite understandable, a condition that pictures women are (.) as angry and unpleasant. Of course, it should be controversial. On the other hand, if you have seen men and women with severe symptom, which I (.) I could tell you also that (.) that when he first approached me, this gynaecologist that many decades ago, and said that should we do work together on PMS, I said PMS is that really something to do research on? We were working with schizophrenia and severe depression. Bipolar. Is that really a real condition? I asked. But then in our clinical trials, I mean, I interviewed a lot of patients that I got a tremendous respect of the really serious consequences this may have. So but I think, you know, I think you (.) you (.) you at least briefly mentioned that aspect and you (.) also, the questions to (.) have me expose the (.) the (.) the differences in opinion, I think. Yeah. I think it was a good interview. You used the right questions. I don't know if the answers were right, but the questions were right. **Interviewer:** I'm not testing anyone [laugh]. I really am interested in, for instance, how a gynaecologist expert is going to answer these same questions. You know, I might get different (.) well, there'll be similarities. You know, I find it interesting, the different discourses we draw on when we're talking about these experiences. **Andrew:** If you would like the extreme gynaecologist position, I think you should ask [colleague's name], he has been a strong advocate for the (.) he's not very (.) he doesn't like the DSM and he doesn't like the SSRIs. He's very much a guy who wants a hormonal approach. But then, of course, [colleague's name] has had a lot of impact on these consensus documents you refer to. He had a key role, of course, there. So he would be one to interview. Yeah. No, I think you will, by and large hear the similar story from (.) from the different people. But I don't know.

**Debbie:** Oh, great. I think it's great. I'm so impressed. You know, I'm so entertained and (.) and um you know. It's been thought provoking to sort of pull at all the little edges. You know, I mean, I do this on my own anyway, but actually in a lot of different ways than what you did. And I think this is because I spent all my time thinking about different biologies and like ways in which within PMDD there are differences [laughter]. And so I think this has been good. Yeah, I think it's great. Well done. I'm very (.) I'm really excited about (.) what you're doing. Wonderful. I can't wait to read it!

**Celia:** No. I'd like to see what you come up with [laugh]. I'm very interested in that and I'd be glad to do whatever I can to help you if you need anything. But I appreciate the opportunity to be sampled on this and whatever I can do. I appreciate it.

**Sarah:** Oh, no, not really. I mean, you are taking me back in years because I haven't done this sort of work now for some time. I was a bit worried about whether I'd be able to actually tell you anything useful, at all. **Interviewer:** No, I knew you would. It's not like (.) a lot of people have been a bit anxious because I'm framing you as 'experts' and they're thinking I haven't actually worked in this for a while, but it's more about how do you describe these things? And then I'll look at how other people describe it. So it's not a kind of test or (.) yeah, it's all about kind of the way in which we talk about these experiences (.) that I'm interested in. So everything you said has been really fantastic. As I said at the beginning, in your work in particular. I mean, really, for me, it's I think (.) I understand why the PMDD diagnosis was made and how that's very helpful for the severe mood symptoms but I think something has been lost about possible aetiology of some of the physiological effects, like blood pressure or anaemia, or even pain and you know, extreme pain as having a role in low mood that can be a bit lost. Certainly in the literature there's less literature on that kind of crossover between the physical side of things. So yeah, your work was very useful. Because it just (.) you started with a kind of an open mind and asked people what they're experiencing, whereas I think a lot of studies start with a list of symptoms and then they ask you to record them (.) **Sarah:** The same thing happened in menopause research (.) you know we had this list of symptoms come up for menopausal symptoms. And they were from a gynaecologist who said "right, well it's this, this and this" but no one had actually gone and asked women for a start what they thought the symptoms were. When you asked them you got a very different list (.) and they left out (.) they managed to leave out some important changes by not asking women, you know if you don't ask the right questions and they're not in your symptom list, well then you'll never see it when we studied what happened to women when they went through the menopausal transition? So that's from active menstrual cycles to becoming very irregular. That symptom of breast tenderness was, you know, came up as so important, you know that because what happened, of course, was that you're getting high levels of oestrogen, as the ovaries sort of being (.) kicking in to try and respond to what's happening. And so it's (.) it's varying and you're getting some high levels of oestrogen with unopposed progesterone because, you know they're not (.) and so that was actually quite an important symptom that was happening in the transition into menopause. That was left out of all these scales from the early researchers where they hadn't asked women? You know, not thought was important or it would have been included. **Interviewer:** Yeah. Well, something I find a lot (.) is that a lot of people get nausea and vomiting with their periods before or with their period. And quite often that's missed off, symptom tools and things. And that can be quite disturbing. You know, it's difficult to go to work if you're vomiting. It's quite debilitating symptom if you get it. So, yeah, it's quite interesting. There are these gaps and I understand why, but it's sort of (.) it's quite interesting how it happens. **Sarah:** Yes. But it all (.) I mean, it's part of the new you know, well not new now, but some years ago NIH decreed that rating scales had to be developed from the people up, rather than [laughter] from the experts down. But until then, that was a normal way to do it. It just wasn't a good way of doing it. Basically.

**Thomas:** I can also say that we are not or, I am not completely unbiased (.) in that way that I am. I have discovered that there are possibilities to actually antagonize this provocateur, as I believe allopregnanolone provocateur with a medication, with a compound that we are developing as a medication. And we have in fact made a preliminary first study where it was very positive and in in patients with PMDD. And we are now doing a major study. And I'm sure you have talked to [colleague's name] I suppose? **Interviewer:** I hope to. I'm finding him difficult to contact because he's retired from his clinical (.) from his university position. Yeah. I hope, to (.) I know people who know him very well (.) so I'm hoping to be able to contact him (.) **Thomas:** Yeah, he was (.) a he was the chairman of this group. **Interviewer:** Yeah (.) yeah. **Thomas:** There is also a person, [colleague's name], do you know her? **Interviewer:** Yeah. **Thomas:** She's now one of the most active persons in in these studies, which we are doing [pause]. So (.) and this this study is published. It's a gynaecologist [colleague's name], who is the first author? I'm sure you have seen that paper. It's a quite recent one. **Interviewer:** Yeah [pause]. And just finally. How do you feel about this interview? And do you have any questions or comments you'd like to add at this point? **Thomas:** Well, I would like to see the script. **Interviewer:** Oh Yeah? **Thomas:** And I would like to be able to to change it. If I want to (.) if I feel that something is in error or that I would like to omit something which I have said I got enthusiastic at the beginning telling you about this [retracted story]. Because that made an impression, certainly. **Interviewer:** Ok, yeah that's fine. And I'll send you the consent form again. So just tick the ones that you're happy with. And the thing is, because I'm doing a discourse analysis, when you see the transcript, you'll see that it'll include all of your 'um' 'er' pauses (.) It's a detailed transcription. So if you do want to make changes (.) don't feel like you have to tidy things up. I'm looking at speech and the way that people speak. So obviously, feel free to change any ideas that you want to change. But don't feel like you have to correct the grammar (.) because basically I transcribe it differently. It won't be in correct grammar. It's about pauses and the way that you use speech. But that's fine! **Thomas:** I'm not good at grammar. So I will not be helpful [laugh]. **Interviewer:** Well, somebody else asked for this (.) and then when it came back to me, it had one hundred and thirty changes! And there were a lot of like corrections where they just deleted the word 'um' or 'er'. But actually, I need that. It's important for me for (.) the analysis I'm doing. **Thomas:** What kind of analysis are you going to do? **Interviewer:** It's a type of discourse analysis, which is (.) **Thomas:** Discourse analysis (.) I have done some kind of (.) of the, let's say, qualitative research, but I'm not aware of that method? **Interviewer:** So (.) and the one I'm doing, the theory underneath it is critical realism, which in plain English (.) it means, I don't know if you know, in sociology there is a whole movement in the 1980s and 90s that a lot of things are socially constructed, so illnesses as a social construct. And that it's something that we create as humans rather than necessarily being a biological fact or truth. And then on the other side, science sometimes implies that there is a biological truth when in fact (.) so sometimes some medical stuff has implied causation when in fact there's just been correlation. And that was this kind of tension then between (.) positive scientists and social constructionists. And for me (.) so what Critical Realism is, it says, well, yes, we agree that things are socially constructed terms and definitions and the way that we categorize things are social constructs. But that doesn't mean that there isn't something real (.) biological or physical that is happening that we can better describe through time and through experiments and all the rest of it. So it's a kind of middle position. And so the analysis is kind of looking at the way (.) the discourses that different people use. So you as a medical person, you've used a medical discourse most of the time. And then I look at the way that. So, for instance, a long pause indicates that somebody is thinking or laughter indicates either that something is funny or that there's a kind of slight awkwardness. So sometimes when I speak to patients, they laugh quite a lot because they are (.) they're uncomfortable talking about constipation or words like that. So it's also getting at why people (.) choose certain discourses at certain times when, you know [pause]. So I purposefully asked two questions in a certain way to see how you would respond. And as easy as you know, a lot of this is (.) you could answer it in different ways and obviously, people with different disciplinary backgrounds do answer in slightly different ways. So I'm just comparing those. And the idea is, is that from that you get a kind of (.) a richer insight into how we've come to this, where we are with the clinical definitions. And I believe there is a slight mismatch with people's experiences and the way that PMS is currently clinically defined. Just in that (.) as you say, it doesn't clearly delineate what's normal and not pathological, but also some of the symptoms I think have become (.) because of the focus on the mood changes have become slightly overlooked. And actually behind all of this is the fact that we're not educated well enough about our own menstrual cycles. So the fact that patients don't know enough about what's normal is part of the problem. But then medicine shouldn't have to sort it out. But in reality, quite often it is doctors that are making those decisions in the end. I hope that makes some sort of sense? **Thomas:** Oh, yes, yes. It makes sense. Sounds like it's realistic. I like that. **Interviewer:** You (.) I'm trying (.) my background was in human rights work. So you're always trying to get consensus or to integrate things rather than (.) you have these false dichotomies of like, you know, it's (.) ‘psychiatrists versus gynaecologists’, or ‘feminists vs. biomedical people’ and it's not true. Everyone is trying to help people and they're just coming at it from different angles. And so I see my role as somebody who could maybe (.) help better define what are these problems, why are we arguing or why are these tensions? And to sort of basically integrate them? That's the plan anyway. **Thomas:** Oh, good. Good luck [laugh]! **Interviewer:** And so, yeah, I can do that, so it will take me a while to do this transcription. I've got four interviews today. So it might not be next week. It might be the following week that I can share the transcript with you. And I'll send a follow up email with the consent form. All you have to do if you don't want to bother scanning it is just reply to the e-mail saying that you consent to and to which numbers you consent to. And then the final thing is that I'm going to send you a link. It's just a two minute survey. It's because I'm anonymizing. Your answers it's to give some demographic information. So age, gender and disciplinary backgrounds, that kind of thing. Because in my thesis, I'm not going to say who you are. It'll just be (.) your pseudonym and this information. **Thomas:** Everyone will know who I am anyhow, so (.) **Interviewer:** Well I did think about that, because there's not many people working on this topic, you know. **Thomas:** This is a small community, you know, within (.) within the community. I mean, everyone will know each other. So, yeah, well, I know most of the people which are sort of in the community, even though they didn't participate in the consensus meeting. On the other hand, which would be nice if you could help us, if there are some persons in Germany and France, especially in France, that are interested and you have found out. I would like to know the names? **Interviewer:** So no. Yeah, no, I haven't. Um (.) because this is qualitative and I'm only speaking to about 20 to 25 people in total. **Thomas:** Okay. **Interviewer:** And including patients. So I'm only speaking to a select group. And it's obviously been easier for me to speak to English speaking or just as you're saying, just to find lists of people. I agree that there is research going on in France, but then I don't have connections there, although I do have a friend who she's (.) she's an academic in social science and she's very interested in it and moving into this area. And she's French and based in Paris. **Thomas:** So if you if you can share the name. That would be nice because she could point to (.) because we are going to do a bigger study that we would like to include France. But France is difficult because no one there seemed to know anything about PMDD or PMS? **Interviewer:** Yeah. Have you ever read the paper by Knaapen & Weiz? Probably 2012 (.) something like that? **Thomas:** Knaapen, I know. Quite well. But Weiz, there are several Weiz (.)? **Interviewer:** They compared France, the UK and America and the kind of history of PMS research. And it is quite different in France. Again, that's interesting for me as a sociologist is the way because it relates to gender as well. A lot about (.) what (.) what's seen as normal, what's seen as a medical issue and the way that women are seen and France seems to be a bit different. Also, their treatments have been different. So they were big on diuretics and in Italy as well. They were big on diuretics. And it's partly because some of the research happened in those countries but there might be other reasons why they prefer a different way of doing things. So yeah I'll look into that for you. **Thomas:** Oh that would be nice.

**Susan:** No.. I don't (.) I don't think so. I think the only thing I'd say is (.) I suppose my view of PMS has changed over my own life. Partly to do with my experience of my body and premenstrual change. And also my own academic journey in terms of different ways of thinking. And I think academically, I moved from a (.) you know, very positivist, you know, experimental view point to a social constructionist let's dismiss it, let's deny it. You know a much more political position to where I am now which I've talked to you about, so I won't repeat that. Where, I do acknowledge the embodied aspects of it and the hormonal aspects of it. I mean, I don't know if it's hormonal. I'm not a biomedical person. And I think in terms of my own experience, not menstruating anymore, it's actually really interesting. And I haven't you know, I've been so busy in the last year when I haven't been menstruating. That I haven't had time to (.) to really sit and think about it and think about what that means in terms of how I would be (.) how I am as a menstrual cycle researcher. [Pause- change in tone] but I'm really amazed by the difference in not having those cyclical changes. You know, it's (.) it's (.) and it really (.) I wouldn't have ever denied hormones anyway. I think earlier on in my career I would have done, like I really did. I went through a phase in my 20s and 30s when I really was you know 'anything hormonal is terrible' kind of thing, of people who took hormonal positions. It's really interesting from a personal perspective, even that like academically I am (.) I always acknowledged them anyway. But it's really interesting personally to stop menstruating and actually see that those cyclical changes are not happening. So yeah (.) **Interviewer:** I have (.) like loads of weird things have happened to me. Like I started experiencing some symptoms that I never used to get and I started experiencing the exact things that some interviewees had told me about. And I don't know if it's psychosomat (.) You know, I don't know if it's (.) that I’ve been primed or it's coincidence. It could be either. It could just be a (.) kind of that I'm noticing things that I didn't notice before. Things I always had, but it's been quite weird and there's no kind of um (.) it would be impossible to tell anyway, because I'm just one person. And this is my experience and I have quite variable experiences. It's weird when it happens to you, and you think "Ah! Okaaay (.)" [laugh] **Susan:** Yeah. Well there is that a positivist symptom complex that exists in any culture and that we express our feelings of distress through that symptom complex. And I think, PMS is one of those for women today. And it's (.) it's a (.) it's a way that we give meaning to our experiences of distress and we can articulate our experiences of distress. So it's not surprising that you are becoming aware of more symptoms from talking to people that you might then tune into them in yourself, and you might have had them before but not noticed them. So it might be (.) so that's another argument, you know, with increased awareness. You could say "Oh my god, you're going to get everyone to self-diagnose" but most women having awareness and then actually (.) awareness that you can cope with them and change. I mean, I suppose that's the other thing I'd say and you probably know this, hopefully you know it, anyway? Is that in the research that I've done both with [colleague's name] and the research that we've done here in [country] is that psychological approaches to (.) to premenstrual distress can actually really work. And they are as effective as Prozac, as SSRIs, and that they don't get rid of the symptoms, but they alleviate them and they help women feel that they can cope with them and they reduce the level of distress massively. **Interviewer:** Yeah. **Susan:** So, I suppose that's really important to acknowledge, but it's not getting rid of the change. Women still get changes, but they don't feel distressed by them. And that to me is also you've got to really look at that physical, psychological and then the sociocultural and the meaning-making. And I'm going to have to go because I've got a meeting in five minutes (.) **Interviewer:** Of course! Thank you so much. And, I’ll send you this email, very quickly. And that'll be it. And I'll keep you posted with how this is going (.) **Susan:** Yeah, that's good. Yeah, good. It's important research. I'll be really interested to see what you (.) what you do with it!

**Marta:** No, I think I've said pretty much everything I wanted to say. And one of the things I really wanted to point out was (.) was about suicidal ideation, which I think hasn't really been (.) been that well known. And it also seems (.) to me is (.) is one of the reasons I say that this is actually a relatively severe mood disorder and not just a mood disorder. I think it's severe for many women. And I think it should be emphasized for the sake of the women so that people can understand that this is far more (.) more severe than most people think about. I also think what we have (.) I also dislike the way that people are using PMS to categorize a number of symptoms. That seems to be more like menstrual symptoms. You were talking about dysmenorrhea (.) I think that's also important that we shouldn't mix (.) mix these (.) these symptoms up for many reasons. So those were really the two major points I wanted to make today. And one (.) and you asked about it! But I mean, I like the interview. I like (.) I like what you're doing. And I think that there's not really sufficient research ongoing at the moment. And I can certainly say from the (.) from the interest we've had in the study we did that there are many women out there. And they really want to be (.) they really want us to do more research about this and provide them with more treatment options. Because even though I say that anti-depressants are really, really good. Doesn't mean that the women think that it's really, really good, and that they want to continue taking them. It's absolutely clear from (.) from the trial that we've done there's an interest in participating (.) that women want alternatives. So I think what you're saying about lifestyle interventions and other alternative treatments, that that area should also be developed. **Interviewer:** Yeah and just (.) um just out of interest (.) are you finding more patients are using apps to track their cycles anyway? **Marta:** Er (.) not yet, but I think maybe it has to do with the (.) I mean, most women who come to me in the clinic, they're (.) they're 30 to 40 years of age. I think when (.) when the next generation is coming into the PMDD age, they will probably be more used to using apps to monitor their health than (.) than the women I've been seeing over the past 20 years. Er (.) occasionally it happens. And if I get questions from patients on my e-mail, for instance, that's usually what I tell them. Find an app that you really like and (.) and monitor the symptoms and bring the app and then and the output from the app to your doctor. Occasionally I've had patients with apps.

**John:** [Pause] er (.) I don't think so. I suppose I'm just listening to the way that the questions have been developed, which is very much one of (.) um (.) a heightened concern about how DSM 5 has described PMDD? At least that's my reading of it. That's kind of (.) it has that kind of feeling about it. And um (.) I don't think any diagnostic classification of a condition is gonna be perfect, and I think it's probably helpful to have something to sort of work around (.) that (.) provides a framework. I don't think most clinicians are that literal in terms of how they use these things (.) whatever the condition is. **Interviewer:** Actually my bias, or whatever, in all this is that I had symptoms, mine were nausea, and vomiting, and it took two years of being really quite severely ill with those symptoms before any kind of inference was made to the menstrual cycle. And that's not because [pause]. So right at the start, my GP did say, is this a monthly thing? So implying, you know, is this a menstrual related thing but I had wrongly assumed and I think they did, too, that that would be limited to the few days before menstruation only. And actually it was at ovulation, premenstrually, and menstrually. And so for me it's this kind of (.) I think, the PMDD criteria (.) there are some issues I have with it, but it's what's left with the PMS diagnosis that I think is missing (.) um, some of these physical symptoms and for instance. I think a lot of people are given the diagnosis of anxiety, generalized anxiety or depression, and it could be a cyclical thing, which if they had recorded those symptoms over time, they could have different treatment options. So it's this kind of trying to tease out. The role of the menstrual cycle really in a whole range of things. And to not overlook it as a potential trigger. **John:** Yeah, but that's the menstrual exacerbation of other conditions, isn't it, which I think is appropriate for any doctor to be aware of (.) but that's different from PMDD or PMS, isn't it? **Interviewer:** Well, I don't think people check. So I don't think people are asked to do their daily rating symptoms, very often at all (.) **John:** For other conditions? **Interviewer:** For other conditions but even for PMS and PMDD I think, sometimes, people aren't actually (.) **John:** I think I mean, as far as the PMS and PMDD area goes, I think one of the more controversial things which I've strayed away from that I think is of some interest is the appropriateness at the moment of that falling far more in the gynaecology than the psychiatry camp [pause] and I think there's a couple of good reasons for that. One is psychiatry is completely overwhelmed with mental health problems that it can't manage already. It certainly does not want to have another condition in there to have people coming to (.) and the other one is that people with PMS symptoms will sometimes fear that if it's categorized within mental health (.) the stigma associated is one that will not lead them to searching for treatment. But in fact, I think that gynaecologists (.) certainly in (.) for a lot of things that I see, are gonna be out of their depth and (.) are probably misdiagnosing people. Now there's a gynaecologist out there. Who you, I'm sure have read who suggests that that's what psychiatrists do. That we're misdiagnosing people with PMS with bipolar disorder. And I'm sure that there are cases of that. And as much as the ment(.) the mind is (.) it's complicated and as a psychiatrist. You always have a differential diagnosis, which you don't seem to have quite so much in gynaecology. It's much more black and white. So we're kind of used to existing in a world where we're not sure (.) we've got a bunch of differential things that we're thinking about. I'm going for one and testing it, and thinking about the other options. At least that's how we're trained. And I think, you know, for a gynaecologist to work out, for example, what a personality disorder looks like and feels like when it walks into the room. And how that might be impacting on some of these things, I just don't think it's going to be something that is going to be done well. Um (.) and I think teasing out what's bipolar and what's borderline and what's ADHD and what's (.) is very, very hard. I think psychiatrists find it hard and I think a lot (.) if I look at the people that come into this clinic. They're complicated in terms of the pathology. And it's a case of having to tease those things out. And I personally think that it's something in an ideal world you'd have (.) You'd have psychiatrists more trained up in, as opposed to gynaecologists more trained up in (.) **Interviewer:** yeah **John:** But um (.) I don't think I'd get many of my psychiatry colleagues sort of cheering that on because they're (.) they’re fire-fighting (.) suicidal, psychotic patients with a resource that's limited. They don't want to have 5 percent of the female population who have got the severe condition that they're not currently having to treat. I don't think they want them. **Interviewer:** Yeah. **John:** And then if it's bigger than 5 percent because we're actually going to treat everyone that doesn't fulfil the strict criteria. That's a big burden for a speciality to take. And at the moment, it falls onto GPs predominantly. And I think they probably are well-placed for the kind of lower level patients. But anyway, that's something that you know (.) if I were doing what you were doing, I would also be interested to tease apart in terms of, you know, who is it, that's managing it? And is it the right speciality? **Interviewer:** Yeah. **John:** And if it's not, why isn't it? **Interviewer:** And if I could just ask you, do you think psychiatrists would be happy to prescribe hormonal (.) **John:** I think with a bit of training (.) I mean, at the end of the day there's a bit of stuff to learn. But we've all had our medical training and errr (.) it's (.) it's not a biggie. **Interviewer:** And then vice versa. I suppose gynaecologists aren't allowed to prescribe or (.)? **John:** Well, I think that, as you say, with gynaecol (.) it's not just the prescribing, it's the diagnosing and working out what's going on and managing that risk. And gynaecologists would need a huge amount of training to be able to do that. Whereas psychiatrists would need a relatively small amount [pause] so (.) I believe in the States because it's a commercial system. There's also a (.) I mean, it's been suggested by this particular person who thinks that the psychiatrists get it wrong, that the reason why it exist within the mental health system in the states is financially driven. Er (.) which I think is a pretty cynical (.) observation. I mean I'm sure there are financial (.) ramifications, but I also think that (.) **Interviewer:** Well one pharmaceutical company in particular did behave slightly cynically, but as to whether or not that's why psychiatry in general got behind the PMDD diagnosis (.) it's probably for different reasons (.)? **John:** Yeah, I don't know which drug company, which drug this is? **Interviewer:** Eli Lily. So they rebranded Prozac, as Serafem, specifically for PMDD. To extend the patent. So, the patent was coming to an end for Prozac (.) **John:** Right. **Interviewer:** And so it was rebranded. Which means you can extend (.) basically you can have a new patent. So it is the same chemical compound made pink (.) ‘for women’, and called Serafem to make it clear that it was for women and they were er (.) held (.) they were sue (.) sued, or I don't know (.) the FDA had to get involved because they also then included a self-diagnosis tool, which was essentially menstrual changes, fairly er, you know normal menstrual changes? And then they did talk about mood but they were kind of pathologising low level mood changes like all people experience for whatever reason. So they did have a kind of (.) financial reason. But then also in the States, you couldn't get any treatment covered for what we call PMDD or severe PMS because it wasn't listed as a (.) diagnosis under insurance policies. And so getting PMDD in the DSM was important for those patients who needed treatment and up until that point kind of fell through the gaps. If they didn't meet the criteria for bi-polar or (.) **John:** Yeah **Interviewer:** So it's complicated (.) **John:** But then that's a (.) that's a pragmatic reason isn't it? **Interviewer:** Yeah. **John:** Erm (.) **Interviewer:** Sorry I've used up plenty of your time. **John:** That's all right. I've found it quite interesting. **Interviewer:** Yeah. I mean, I find it fascinating! **John:** Yeah. I suppose yeah, I don't really get asked these things very often.

**Interviewer:** So that's it. We've managed to get all of the questions done. So that's really helpful. Thank you very much. Do you have any questions or comments you'd like to add at this point? **Laura:** No **Interviewer:** Thank you so much for your time.

**Zoe:** Um (.) No. No. No questions or comments on the interview itself. No. I did (.) it did feel a little bit like an interrogation [laugh]? **Interviewer:** Oh! I'm sorry- I was trying to keep to time. But actually we were fine in the end [laugh] **Zoe:** Yeah. It's just it's interesting (.) and this is, you know, not (.) you can stop the tape if you want to or keep the tape running, I don't mind? It is just interesting that (.) it's probably because I'm not someone who experiences PMS, it was an interview with me as (.) as a researcher and a clinician in a (.) you know, an informed sort of a stakeholder. And it reminds me of the interviews we do when we do interviews with health professionals. And they tend to take this much more sort of question/ answer (.) a question answer approach. It's very different to when we do interviews with women who experience P (.) premenstrual stress. And we'll just start with one sentence, which is "tell me about your PMS". and they literally will just have the rest of the conversation going for forty five minutes, to an hour or so. It's interesting because this was (.) you were asking me more about my knowledge and my opinions rather than my experiences. And so I just found it quite interesting that I'm used to doing more of the experiential interviewing than this um opinion based interviewing so (.) but that's not a (.) that's not a comment about the interview. It's just that it was a different form of interview for me. **Interviewer:** Well, I'm being quite sneaky, really. I'm actually doing a discourse analysis. But I wanted to see which discourses people use under which circumstances. So sometimes we'll choose, let's say, a more feminist discourse for some answers and then the biom(.) more biomedical one for others. And then I'm also analysing when people laugh or the pauses or the kinds of hesitations in speech which indicate, you know, that you're thinking or there's some sort of a conflict or sometimes laughter for uneasiness. Particularly when I've spoken to patients, I have a different set of questions for patients but laughter is quite common. And it's (.) it's usually to cover something slightly shameful or awkward or just, that they don't know something. And so it's been quite useful to (.) and for me, I wanted to compare (.) you know, a whole range of different people on quite similar questions, so it really is a mix between almost like traditional quantitative surveying - although, if I'd have sent this out, as a survey, I (.) I wouldn't have got the answers that I'm getting from asking (.) them **Zoe:** Well no (.) **Interviewer:** And also I can respond, you know, because I'm here. But also, it is (.) there are these parallels. And it's interesting, to then (.) so for example, I think I've spoken to 15 different experts from a range of different disciplines. And so far I've had 15 different answers for what (.) for what causes premenstrual symptoms. I mean, some of them are more closely related to each other than others. But there's this huge range. And for me that's very interesting that (.) the way that we try and explain something that basically isn't quite known. We don't really know exactly. But then (.) then (.) then it's quite interesting. So then which discourses do we go for and why? And so really this (.) my whole thesis is, I think to begin with, I thought I was going to make this huge impact on the world of PMS, but I think it's going to be a much more interesting look into the way that we have practical responses and want to help individuals. And then how do you do that like you were saying within bureaucracies and how do you get that support for them? And then depending on your clinical background or academic background, how you think the best way to do that is (.) **Zoe:** Hmmm Ok. Interesting. And yeah, as always, you know, we like to catch up with you when we see you at the [menstrual health] conferences to see what's happening next. So, yeah, we might (.) we might see and hear ourselves in a de-identified way. **Interviewer:** You shouldn't be able to hear yourself [quiet laugh]- I'll have slipped up on my interview process if you ever get to hear yourself. But yeah, you'll probably recognize your words. Yeah, I know it's quite a small world, so I think some of the experts might work out who each other are. But it's nothing too controversial. **Zoe:** No, no, exactly. Nothing (.) nothing that people actually wouldn't be happy to be identified with.

**Geraldine:** No, I think it's fine. I'm always happy to talk about this. It's a very interesting topic. **Interviewer:** Yeah. I mean, I really appreciate all of your work and I largely agree with every word you've ever written. **Geraldine:** Oh, that's very kind of you, Thank you! [Laugh]

**Chris:** You're obviously, I don't know how you were with your first few interviews because you've obviously got a lot of the knowledge, now? And I don't think you can get the knowledge just from all (.) because of all the different views or just from reading the papers. But you obviously got it (.) I think you've got a fairly narrow personal experience because you don't fit all that well for the (.) for the generality. And (.) and uh (.) but you've obviously got a great knowledge now. So, yes. It's an easy interview. That's all I know about that, I've forgotten everything else.

**Jo:** Nope, no, it be really interesting to see the outcome of your research (.) and I think (.) I've got another (.) I'm supporting somebody else with a Masters. I think she's doing who (.) erm, that whole thing about definition came up in her thesis. And I (.) I think it's really important. I think if nothing else, if we could just have some clarity about that would be very helpful to women.

### P31- Reflections

**Alice:** Yeah, yeah. Well you’re the first person who has (.) well obviously I have spoken to my friends and family and they've witnessed it first hand. And I've got the pressure from them to go and do something about it, which must mean that I am to them (.) that this is not normal. There's a problem (.) but I feel much more relaxed about my physical symptoms than they do. But I think they see it as alarming. But I think you're the first person who's wanted to listen to the actual my thoughts and knowledge and understanding and the journey of the symptoms that I've experienced. What I mean by that is when you do go and see a health professional, you don't expect necessarily an outcome. But, I mean if they had just said to me, this is normal (.) that's fine, but no one tells you anything. They look at you like you are an absolute nutcase because. This (.) or, you're making it up because they have never witnessed this. And actually, when I did have the worst one ever, which was when I was having a miscarriage, which is different (.) then the bloke told my mom on the phone, she was panicking so much that he needed (.) that she needed to call an ambulance (.) and now I said, 'no, this will pass'. I know myself more than anybody. But actually people don’t have time to listen to these stories and they don't want to know. And I think talking about it can make you feel more normal than alien [laugh].

**Beth:** Yeah. Definitely (.) I think it's (.) it's made me think about (.) how (.) how PMS and periods are discussed a lot more. I don't (.) I don't think we think about it enough. When you asked me about how I'd explain periods to a child (.) that was so challenging. You know, it's really highlighted to me that, you know, we probably don't explain menstruation (.) well, enough to children in a way that they would understand. You know, me as a parent and a doctor really struggled to do that, then I guess a lot of other people would struggle. To have that discussion as well. So it's really useful to have that flagged up. Yeah.

**Dani:** I think I hadn't really thought about why we get PMS of before, which is something I will want to know now. But you know, I think about periods all the time. So it's not that [laugh] unusual for me [pause] yeah. Not (.) not massively, but I think that's because of my job rather than attitude. If you know what I mean? Initial attitude I mean.

**Emma:** I've really enjoyed it. So thank you. You've asked some really thought provoking questions, and I'm surprised that (.) I've struggled quite a lot to articulate what I thought I knew, which is really weird considering (.) um (.) I’m presenting on this [for work]. So, yeah, it was challenging to actually think about opinions and what I think about things. So that's a lot of food for thought. And I'm super curious to read your paper and see what the themes are that (.) come out.

**Gemma:** It was a really good conversation. I think it's maybe like opened my eyes to make me feel normal [laugh]. I didn't know people dealt with the constipation and diarrhoea thing, so that's made me (.) and the contractions. Cause I know that (.) I know that (.) I know that when I have a baby and I'm in labour (.) that is going to be what it feels like. I just know because my belly goes in (.) the breathing is very (.) it comes natural. It's so crazy. So I'm just glad that other women have the same experience. And I'm not weird.

**Faith:** And I feel like (.) I feel like suing my doctor [laughter] but (.) so I'm a bit annoyed about that but also, there were points that I felt quite emotional (.) and like there were certain things that made me feel quite emotional. And I can't say exactly why. **Gemma:** Yeah. **Faith:** Maybe it's just to do with my experiences over the past few years? **Gemma:** When you were talking, I was getting emotional when you talked about the whole um, your experience with doctors because I feel like a lot of it could have been prevented. So, yeah, not the fibroids, of course, but the way it was managed. **Interviewer:** Yeah, me too. To be honest. I am feeling a bit emotional at the moment anyway (.) but it's just this sort of (.) um (.) you know, it's 2020 and this isn't rocket science (.) like I've taught myself (.) all of this. It's very easy to understand. And um (.) just this is very frustrating. And I think particularly for fibroids, cos they're really common, particularly common in young black women. And yet those are the very people that don't get the help that they need. **Faith:** And I think that links as well (.) so to the "get on with it culture" that we spoke about, with our older black elders. So, like our aunts and our grandmothers. Our mums and stuff (.) **Gemma:** Yeah **Faith:** They had the issues. Cos, a lot of women in my family, have fibroids. But they just dealt with it. **Gemma:** Yes. **Faith:** So I feel like maybe it's new that people are voicing their pains and issues. And also the variety and the extent of what people experience with (.) changes and changes, I guess, along with that. I think maybe there wasn't enough pressure (.) in like (.) learning about it! **Interviewer:** It's like another thing that you might (.) it is the same with sexism as well. It's like a weakness (.) **Both F&G:** Yeah (.) **Interviewer:** Like you are showing an inferior body because you're more prone to get these things. It's probably a good sign that we're now more able to talk about inequalities because before, like my mom's the same, my mom never takes medicine for anything. She's really stoic. And it's got to the point where she had like a really bad kidney infection and she hadn't told me that there was blood in her urine. And I'm like [sigh] it's ridiculous! **Faith:** So she was just getting on with it? **Interviewer:** Yeah (.) and I was like, you like you can die from these things? You need to ask for help. And she just totally internalized that. Like “it will get better. You just gotta (.) like, tough it out”. And so, I mean, I get it and I understand it, but at the same time (.) **Gemma:** It's sort of not doing yourself any favours. **Interviewer:** No. And for me, it's thinking about children. Like because children get periods like I think we as women can cope with (.) **Gemma:** Yeah (.) **Interviewer:** We can cope with these things. It's not great, but it's up to us. You know, we're adults. We've decided (.) but when it's children, I just think ‘no actually’. **Both F&G:** Yeah (.) **Interviewer:** It's not good enough. **Gemma:** It's not good enough. Actually. But thank you for the conversation **Interviewer:** Thank you so much.

**Helen:** Honestly, I appreciate this conversation very much. I mentioned earlier about vulnerability hangovers. And er (.) just (.) just to get this off my chest: 'Giving Tuesday' [US social activism day after Thanksgiving holiday], there was you know, I've shared my story so many times over the years in media news articles online, in my (.) my community. You know, and I had shared for Giving Tuesday my story and I had just moved to a new area, met new people. New people who are friends with me on Facebook. And I posted it and I regretted it (.) and I just (.) like was angry almost and embarrassed. And I never had that feeling before. And I realized I'm like, I moved to a new place. I think I was finally ready to give it up. And then I felt a bit like (.) I went back to square one where I had become so confident and, you know, empowered by being able to share my story. I felt like I was being a stigma basher all these years. And then I went right back to square one. And I just (.). So I appreciate this conversation because it reminds me of why I share my story, why this matters, to talk to other people that are like, "oh, I get it. I've been there. This is my field". So I appreciate this interview today. Quite honestly. Yeah. I don't know if that all made sense? **Interviewer:** Well, I'm just going to ask if it's okay. **Helen:** Yeah. **Interviewer:** To clarify something about that? So you felt angry at yourself. For going back to this kind of earlier identity or what? **Helen:** Right. Yeah (.) yeah. **Interviewer:** So it's more like you want to move on and leave it behind? **Helen:** Yeah. Like, I just (.) I think it has defined me for so much (.) I think, you know, like earlier I shared a story and I became weepy (.) it's like (.) it's defined me for soooo looong, you know, like I don't want to ignore that it ever happened because, you know, we have this organization now because of this experience I went through. And all these people are big advocates all over the world. And people (.) like I think, you know, the collective experience, my experience, all this really matters. And people are being helped and a lot of progress has been made. But also as a hu (.) an individual, you know, I think I'm, you know, feeling like, OK, now that that was this first half of my life, what's the second half? **Interviewer:** Yeah, I understand that. I mean, I get that just sometimes I wish I wasn't working on menstrual health because it's just never-ending. **Helen:** Yeah, right. **Interviewer:** It's like. There's so much research to be done, which is great but also (.) I sort of would like to be able to switch it off sometimes. **Helen:** Totally. **Interviewer:** Because everyone and I mean, you'll be the same when you tell them what you do. You get their menstrual history, you get their friends'. And again, I don't mind getting that information and I get asked for advice and that's fine. But I sort of feel like I need some other interest in some other things to be able to talk about! [Laughter]. **Helen:** Totally, yes (.) [laughter] oh, my gosh! But I think that's a danger to anybody in any profession like (.) you know, my husband's in medical sales and he gets (.) he gets like wrapped up in it. And I'm like, you need a hobby [laugh] you like (.) you need something else or go rediscover what made you you (.) before you became all this job, you know? But yeah, I mean, I think being, you know, having a period, talking about periods like you do become this like person for menstrual conversation and you're like, can we just talk about something else for five seconds [laughter] I feel you. I feel you very much! [Laughter] **Interviewer:** Ahh, This has been so good. Thank you.

**Kathleen:** [Long pause] Yeah, I mean, I think it's been good to talk about what's happening in my own body 'cos I haven't really talked about it, I've just processed it in my own mind. You know, I think about my own symptoms. Um, what was really helpful actually (.) because you (.) after your talk [interviewer's presentation at fibroids support group] I've thought a lot about how I view periods and the shame aspect of it. You know? Yeah. You know what (.) I've been thinking about what if someone sees the blood then why is it such a big deal? When it is a natural part of (.) So, I'm still thinking through that. And just talking today as well (.) has made me (.) um (.) think about just owning the experience or feeling ok in our bodies and kind of naturally owning that a bit more but I don’t know what that would look like? For me. Um (.) it's made me (.) thinking back again about just how grateful I am to have my periods. And I have (.) when I (.) when I got my first period after my surgery, I did thank God. Cos I just (.) I don't know what you've experienced, but with fibroids, especially like because I'm (.) I'm older [early 40s] er, and I want to have children. But there is this whole thing that you know, you might not have children you know, they put me on this medication. I have to take medication to stop my fibroids for a little while. And so there is like this thing at the back of your mind that (.) you may never get your period again! And so that's why I'm so grateful now to God that I still have my periods. And so I have a more of an appreciation for them now than I ever have. I see them as a really kind of, not quite beautiful but a way that it tells you that my body's functioning properly. Naturally. I wish it wasn't. You know, I just wish the (.) the discomfort obviously, I don't like. But generally, my experience is quite positive. Um the only thing that I'm not so sure about. Is because I do have the heavier periods and I don't know if that's (.) it's so difficult 'cos once you get to know your body to such a (.) for a long time. You're fine (.) and then if there is a change um, you know, you don't know whether to worry or not? Once again, I don't know whether that's to do with my surgery? So that is something I am going to be looking at (.) looking into more properly after. Yeah, and it's a long way of saying that it's been a good conversation! **Interviewer:** Just thinking about the heavy bleeding again. So are you slightly afraid that you might have fibroids? **Kathleen:** Yeah. **Interviewer:** So, you sort of (.) you don't really want to know? **Kathleen:** Yeah, but I think just (.) I mean, the reason why I will get checked out (.) because I (.) I know the danger the last time of waiting and waiting. So (.) yeah. So I mean I've been to the doctors and stuff I'm just trusting the process of doing that. Yeah. Then again, that's the thing, like, as women, well I suppose men do as well in a way. But definitely for women given the (.) when you have fibroids and I'm sure other conditions as well (.) people with endometriosis, for example, a lot of these things just never go away. They just manage it. So I think for me, I had a good few years when I was fine and the bleeding was fine and then it got a bit heavier and then started thinking, "oh, I'm going to have to go down that path again", you know? But I'm hoping and praying that it's not there. But if it is, I would definitely report them earlier than the first time when I went for ages before I even sought help. At least now I'm thinking actually, yeah, it could be that my body's changing. But actually it could also be that (.) um, there are some fibroids there and that's what's making the bleed a bit heavier. **Interviewer:** Yeah. This is (.) the thing is (.) it's the link with fertility. And obviously, then the fear and I've spoken to people even who've had children, and they know they don't (.) they're not planning to have any more. They still (.) it's such a big part of our identity. And in some cases, your future plans. That it's not like you don't want to know, it's that you're hoping it will resolve [laugh] **Kathleen:** Yeaah! **Interviewer:** And things do change, so (.)! **Kathleen:** Yeahh. No, I think (.) I think you're right. It is attached to so much. [Long pause] yeah, it is attached to (.) say (.) if you haven't had children, like myself and er you do want to have children (.) it's not just about a check-up, you know [short laugh]. It's about (.) it is your kind of dreams that are linked to these hospital check-ups, you know. So I saw the doctor a little, two weeks ago. And I talked to him about it (.) and he was very [pause] he didn't really understand my worries. He was very professional (.) and what was good was that he knew a lot about fibroids, which is very rare. So I was quite happy about that. But he was (.) he was very, very kind of like "Oh, don't worry!" [Appeasing tone] you know "Now now!" you know. **Interviewer:** Yeah, like it's an inconsequential thing to be worrying about. But it isn't (.) **Kathleen:** He was trying to be sympathetic yeah. But he (.) yes. I think he's trying to be sympathetic, but he er (.) I don't know if he understood just how worried I was (.). And I've seen another doctor previously, a lady doctor, and she's the one who sent me for the tests. And she's very sympathetic. I don't know if that's because she's a woman or because she's experienced it herself. I don't know. But it was (.) I just (.) I just loved it because I went in and I just explained what was happening. I explained my previous history. And before I knew it, she got out her pen and said, "OK. I'll send you for this, I'll send you for that". It was all very straightforward. There weren't any questions, you know, or (.) she just believed what I said. And it was really good. So it was interesting. And again I dunno if it's a gender thing because there's so many things at play, isn't it? This male doctor knew lots about fibroids, he's drawing pictures and doing lots of explanations to me but um (.) he was (.) he was a little bit about (.) kind of "Don't worry. Oh, you'll be fine. It will be okay". And, you know, and I realized the other day that he sent me for a scan, but he put it as a normal scan. But in my mind, I was like "that should have been urgent because I need to know as soon as possible!". You know, so it's that kind of thing. And so obviously, it takes a lot longer to get the non-urgent scan. So, yeah, that was an interesting experience. But I didn't (.) I'm not (.) to be honest, the only (.) I would have been very critical of him had he not, because I went there prepared because of all the knowledge I have about fibroids. I'm just not going to take any nonsense. So in one sense I was happy that he knew all the lingo and understood it from a medical point of view, but on the other hand. [Smiling] He's trying to encourage me, I think. but I don't know he quite grasped how I was feeling about it, especially because I lived through it before so um (.) that (.) I think that would be I don't know what training doctors get on these kind of things, but I think it's just sensitivity to why someone might be more (.) anxious about something when they've been through the journey, might help them. I'm not (.) I might even be being overanxious? Everything might be fine? **Interviewer:** No. Well, I mean, I think you should get it checked out just because I think heavy bleeding shouldn't be (.) it's not (.) it's nothing to be sniffed at (.) like you don't want to get anaemic again. It's just such a hard road getting the iron levels back up. **Kathleen:** Yeah **Interviewer:** And (.) it might be (.) it could totally be nothing (.) **Kathleen:** Yeah. I don't think he (.) I think he meant well. I think he meant well (.) **Interviewer:** I won't keep you any longer. Thank you so much for your time.

**Aisha:** It's made me feel more that I need to (.) um when I'm having that PMS to be able to manage it a bit more, to be able to go to the doctor and talk to them about it a bit more. And it has made me feel better talking about the period because I hardly speak about it. [Laugh] It's usually a conversation with me and my brain. **Interviewer:** Yeah. **Aisha:** So, yeah, it does feel good speaking about it (.) **Interviewer:** Ahhh. Thanks very much for speaking to me. I really appreciate it. This is very helpful. **Aisha:** No problem. And thank you for coming to talk to me!

**Mala:** I actually enjoyed this conversation (.) um, maybe some of the things I (.) like, maybe I can speak to my family more about it. So they are more aware of what PMS actually is. And also, maybe the way I'm feeling like when I'm very irritated it's not really (.) I can go to the doctors, and actually see what they can say about it because I've never actually been (.) to see if I could actually get help because it can get really (.) hard on yourself at times. Um, yeah. **Interviewer:** That's brilliant. Thank you so much. **Mala:** No problem! You know, I have never actually spoken about it [before] (.)

**Noor:** [00:20:53] I think I need to do more research on it! [Laugh] **Interviewer:** So this has been very interesting for me because (.) also because having spoken to your sister, it's really interesting to compare (.) **Noor:** Uhuh. **Interviewer:** So obviously because of her experiences, she's got much more into like technical. **Noor:** Yeah. **Interviewer:** Like the clinical side of defining it and things. So it's really great to get this comparison because, you know, you have the same family, same parent (.) but different (.) **Noor:** Different yeah **Interviewer:** But different experiences and different point of view. So it's been really great for me.

**Ria:** Yeah, well, I feel great about it again. I'm so excited and think it's so important that you're doing this research and talking to people and sharing knowledge. One thing that we didn't touch on is the piece around (.) like a piece around addictions and how I think that all humans are addicts and we just have our own things that we use to cope with trauma, whether that's food or exercise or plant medicines or whatever, smartphones, et cetera. And so during the PMS season, the autumn season, people might experience higher amounts of cravings for their various coping mechanisms. And at the same time, research shows that if you, for example, alcohol is a big one that people do research on. If people drink more during the autumn season, it increases the amount of pain. And I'm not sure about the flow of blood, but for sure pain. And I personally have experienced that as well, where like, yeah, it was just very bizarre as soon as I had (.) it just took one drink and just a severe amount of pain that I haven't experienced before. And it's based on the timing (.) and so in supporting people who have higher (.) accounts of feeling a lot of the symptoms of PMS or even identify with PMDD, and (.) thinking about how they can, you know, just become more aware of it or maybe mitigate some of the effects that they're feeling. I encourage people to engage more heavily if they want in their various coping mechanisms during the spring season. So basically any time after your period until you ovulate because the body can just handle it a lot more. Based on the oestrogen (.) oestrogen is a form of (.) it helps us metabolize a lot more, etc. And so that's one piece that I'd like to have on the record because I don't think people talk about. There's a lot of talk about the connection between caffeine and alcohol and menstrual cycles or periods in general. However, I find it to be quite negative and not honouring the fact that some people just are (.) not some people. Literally every single human is coping with their trauma through various addictions and on the spectrum of being high to sober. And so I think opening up that conversation a little bit more to get people the support that they need in terms of how they can dose whatever it is that they're using in a way that supports their menstrual health, especially as more and more federal governments and provincial governments are legalizing or making legal more plant medicines that have been (.) you know, banned basically by the patriarchy for however many years. Yeah. I don't know. Did that come up at all in your interviews? Like did people talk about? **Interviewer:** Yeah. You know, people notice alcohol, the effects of alcohol as being different at different times of the cycle and having worse hangovers, but also it effecting pain. That is quite common. I think most people realize that through their twenties when they're perhaps drinking more on certain days (.) Friday nights Saturday nights, so they notice it. Something that's interesting is about food cravings. Is that the people I've spoken to who list food cravings as their most (.) as one of their main changes (.) quite often say that they give into it (.) so (.) so they'll eat loads of crap food. And obviously I get that, I have the same cravings and whatever for sugary foods. But medically speaking, that's not the thing to do. It's actually, it's like you're saying, to try and refrain at that time and you can knock yourself out at other times. But at that time, it is actually going to make pain worse. And I think also probably like breast swelling and the other things that it will have an impact on just because it's basically sugars (.) either carbs or normal sugar (.). And I think that's very interesting (.) that because we all have this idea that sometimes your body is trying to tell you something, and particularly with the menstrual cycle, it's a really positive thing to listen to your body and to not overdo it and not ignore it and suppress it. But at the same time, in this one thing about cravings, it's kind of a bit counterintuitive. But I do think, I mean I've worked with people that if you do reduce it and I've noticed it myself. And for me, I have to reduce sugar the whole time, I can't trust myself to go mad at any point (.) that actually the cravings aren't as bad then (.) **Ria:** Yeah. **Interviewer:** So you can actually bring it down. **Ria:** Yes. That piece. Yeah. So how do we use the menstrual cycle sort of as a way to build our willpower? In a way, because we are in my research in the realm of what is commonly understood as mental health and addictions like on a whole as a society are, because we're like as the years goes on, we're all becoming more and more traumatized. It gets passed down to our children, et cetera. And there's, you know, countless doctors. Gabor Maté [famous psychotherapist] comes to mind who talks about the link between trauma and addiction. And yeah. And then being menstruators. And I am a teacher in a university, so I work with undergrad students who are around anywhere from 18 to about twenty four, twenty five. And because I'm (.) at the [Name of institute] there are a lot of menstruators in my class. I would say like 85 to 90 percent of the class people who identify as women for the most part. And it's shown that things like eating disorders and body image struggles are extremely prevalent in that demo. And so there's the piece of like you should look exactly like this. And this is what you should eat. And like, we are just exposed to so many fitness magazines. And one idea of what beauty should look like and then prepared on top of that is the cravings that come. And so I imagine people have this (.) it almost like is a double impact where they have a craving, they eat because they're fucking hungry and then they feel guilty for eating because then they don't (.) it's like "bad! Sugar is bad! I shouldn't be doing this. I should look like this. I should be going to the gym, etc.." And so I think opening up that conversation about how do we dose? How do we dose well? How do we dose according to our self-defined needs and not just physical needs, but mental, emotional, spiritual needs as well. Because I worry (.) the one thing I worry about is menstrual cycle research and activism becoming co-opted and then and also influenced by mainstream understandings of what a healthy body should look like. And that healthy body image is basically created by advertisers who want to sell us stuff. And I'm just worried about those two coming aligned where we're telling people to, you know, do all these things that they should be doing with their bodies so that they can be healthy instead of honouring that. You know, some people like if they even think about doing a diet or cutting something out of their meal plan, it just immediately triggers disordered eating like within a day. And so I'm very cautious in talking about that aspect of it with people and just figuring out where they're at first before having the conversation. I guess I went on a tangent, but what you were saying was kind of sounding like (.) **Interviewer:** I'm not saying that. You know it's very easy to accidentally reinforce something that's problematic about society and particularly around sugars (.) and the menstrual cycle because you know, you don't want to body shame anyone or shame them about their diet. But there are links between sugar and people's experiences, but you can (.) I find that basically it's about informed choice. So it's not saying anything about 'fat' because fat doesn't really have much to do with it. It's to do with explaining what the craving probably is. It's low blood sugar (.) that you can have a bit of sugar. That's fine, but it might have an impact on pain. So it's best to not go like too mad, to not (.) because there is this (.) I mean, I've met several people recently who see it as a green light to just eat a lot. And then they feel bad. And I'm not saying that, in fact, I wouldn't say they have an eating disorder. It's just that you're saying that we're socialized to believe that that's a negative. **Ria:** Yes. **Interviewer**: But with a lot of these things. It's kind of a fine line between (.) providing advice and not accidentally reinforcing something that will shame (.) like particularly around, shame. **Ria:** Yeah, very tricky. And even in our research and even the word like disordered eating or eating disorder comes, for example, from the DSM, which is like a whole thing. It's just been on my mind. I bring it up because it's been on my mind. And there are a few students in my class who are doing their final projects around their relationship to food. And it just made me as somebody who's always interested in periods I'm like, "Ooh (.) I wonder what your menstrual cycle situation is like?" And just thinking about that link between them (.) yeah.

### P1- Family talk about periods?

**Alice:** Erm, so how do they regard them? Well, mom was always very open to trying to educate us about (.) what they were and what to expect at an earlier age than most. I was (.) because I'm the middle child. I think I probably was the second experience of (.) so, I'm one of three girls (.) she probably (.) she for her, it was the second person going through puberty, so she probably had more experience. And when my older sister went through it, so she started when I thought it was quite early (.) to sort of tell me about it. And actually, erm maybe this is a bit graphic (.) but as a young girl, I remember her taking me into the cubicle with her so she would go to the loo and I'd go to the loo and she might have her period and I would ask what was going on. So she might use like a tampon or sanitary. And I would say, 'oh, mom, what's going on?' And she (.) and that's what she started the education. And actually, I asked her when I was probably older, not old, but, you know, 17, 18. What (.) what her experience was (.) and she said, well, right from the off, she wanted to make us aware of what to expect. And it was more actually not necessarily about the symptoms at all. It was more that expectedly once a month. And this is how you manage it. Yeah, that was it, really. But that was because she had a very shocking experience where she suddenly bled as quite a young girl. So you'd say she (.) I think she was maybe twelve or thirteen and no one had told her anything. So she didn't want that to happen. But I mean, well, in terms of the family really open erm (.) lots of conversation about managing that (.) and how to manage that because we were very sporty. Now when you went swimming, when you're at school and all that kind of thing, so it was something that had to constantly be talked about.

**Beth:** [Laugh] Okay. Erm (.) to be honest, I don't remember (.) the first conversation about periods. (.) I have vague memories when I was pre-pubertal of my mum having quite heavy periods and talking about flooding and stuff, and I kind of knew what (.) vaguely what periods were, but I don't remember having any conversations about how I should prepare for having periods or anything like that. I do remember my mum calling (.) referring to periods as the curse [laugh]. Erm, and I didn't really know why [laugh]. And then in what would now be called year seven at secondary school, we had some sort of biology lesson about menstruation. And I remember we got given like a free sample of Tampax, which were in a little plastic container to keep your tampax in that would fit like inside your blazer pocket. And, erm, now I'm thinking that's really weird to give tampons as a first sanitary protection to like ten, eleven year old girls. But I guess it was because the talk was probably sponsored by Tampax or something. And we were given some very sort of biological information about periods with sort of diagrams of adult women inserting tampons into vaginas and that kind of thing. And I remember (.) not feeling like (.) I couldn't talk to my parents or my mum in particular about the fact that we had to talk about periods at school. And I was really embarrassed when she found the Tampax in my blazer pocket. And I don't even know why I was embarrassed about it? I just was (.) I was deeply embarrassed. **Interviewer:** Do you remember? Did she say something or did you just notice that she had found it? **Beth:** She was really surprised that I hadn't told her. And she said, why didn't you give me a free sample? I could have done with that. [Laugh] 'Cos I hadn't started my periods at that stage. I started my periods, I guess, a couple of months before I turned 13. So by that stage, I think I felt a bit more comfortable (.) with (.) and less embarrassed about them (.) but at the stage that we had the talk at school. I just remember feeling almost automatically embarrassed about discussing them at all and I can't (.) I can't figure out where that sense of embarrassment came from?

**Dani:** Erm, It was (.) so I have three sisters. I'm the second. So it was pretty much just something that er (.) I think I probably just learned about it when my older sister started. It wasn't like a massive (.) deal. But equally, it wasn't something hushed. It was just sort of. "That's what happens to girls when they get to about teenage (.) teenage age", basically. So, yeah. So my mom, I was aware of like tampons around in my mom's bathroom. So that wasn't like (.) it wasn't like a hidden thing. I remember seeing them quite a lot. Not quite understanding what they were, but (.) but yeah, definitely wasn't hidden.

**Emma:** Iiii (.) used to talk openly with my mam about periods. and she was always very open. She has struggled with her period. And so was very empathetic and offered lots of support and advice and would answer any questions. So I was really lucky to have had that when I was growing up. Erm, my (.) Dad, I never (.) I never spoke about periods with him [laugh]. It just (.) yeah (.) and in fact, it was really embarrassing, if I needed any kind of period products, I wouldn't even put them on the weekly shopping list! [Laugh] because I was too embarrassed. So it was never something that was discussed in front of him or with him. Er, it was a very private conversation with me and my mom. I remember having a book as well that that my mom bought for me. I think I must've been maybe nine or ten. And it was all about puberty and the bodily changes that happen. And I remember just (.) I think that was the kind of (.) way in to the conversation about periods and puberty and what happens and all of the lovely fun and shenanigans [laugh] and changes that occur. Yeah. So that's (.) that's what I remember about family and conversations.

**Faith:** When I first came on, my mom said (.) (actually, this looks horrifying that she said) "that this means that if you have sex, you'll get pregnant". And that's the only conversation we ever had [laugh]. **Interviewer:** Oof! [laugh] **Faith:** Everything else. I think I learnt from school and through conversations with my friends. **Interviewer:** And can you remember what age at school. What was it like at Primary, or (.)? **Faith:** Erm, my period pains started in year five, which is interesting, but I think my period came (.) Year seven? I would say (.) so, for two years (.) I kept having pains every month. And it got to the point when the school thought I was lying. But then after a while, they were like "this is happening every month. Are you sure you're not on your period?" And I'm like "I don't know, I don't think so?" [Puts on child's voice] and then to be fair, it was just before secondary so it was maybe during that summer break when secondary school started? So the symptoms came before the actual periods. **Interviewer:** So you didn't know it was anything to do with periods? **Faith:** [Overlapping] No, I had no idea. **Interviewer:** You just had a sore tummy? **Faith:** Yeah (.) I'd like vomit all the time, and like really bad like debilitating pains. I had very regularly and just didn't know why [voice breaking- sadness] **Interviewer:** Ahhh. [Sympathetic sound]. And you told your family and you told the teachers? **Faith:** Yeah. So like in the beginning. Well, my family was always sympathetic, but with the school in the beginning, they were sympathetic. But, you know, if you're always going there every month and "Ow, my belly hurts", then eventually they were like "Oh, she's just trying to get out of let's say PE or something (.)" that sort of approach (.)

**Gemma:** My mom was away. She was a police officer so she was training at the time. I can remember it because my Aunty Mary was (.) was at my house and she was really good about it. She'd like she sat me down and she was like, you know, "this just means that you are transitioning into a woman". So they related to like my womanhood kind of thing. So I had a good experience in that way. But when (.) my mom was always really (.) my mum's quite 'tough love', but on my periods, I can remember her being very caring like I would get really (.) do you remember [to Faith] (.) like I got really bad cramps in the beginning, but she would really baby me like get me a hot water bottle and she kind of really took care of me when she knew I was in pain because of my period? So I knew that like it was (.) I (.) I knew that it was okay. Like I said, I knew that it was something that we go through. And I had the support. So yeah, I had a bit of a different experience. And we're cousins, so that's a bit weird (.) [Laughter] **Faith:** I think my mum was just petrified. **Gemma:** Yeah **Faith:** So, I think this just goes to show her train of thinking (.) like 'sex' [laugh]

**Helen:** I will be honest. I don't think they did [laughter] I don't think we did. I don't think it was really explained to me until the day I got it. Maybe? I feel like my education was based on what I learned in school. Not (.) not in the home.

**Kathleen:** My family didn't really talk about periods (.) Um, from what I can remember (.) um, certainly not when I was little. I think that (.) probably um [pause] as I (.) I think it was probably around even primary school or just around starting secondary school, that um (.) my mom may have talked to (.) to me about what might happen or what would happen (.) at some point. But definitely not until kind of, around nine or ten. I don't remember conversations about periods. **Interviewer:** And what about at school, did you get anything at primary school? **Kathleen:** Um [long pause] I mean, there must be a session, but I don't remember it, to be honest? Um (.) yeah. There must have been? Yeah.

**Aisha:** We never spoke about it at all. Literally, I started and that's when we spoke about it. Like you have to do this. End of story. Like erm, yeah (.) you have to put your pad on. You have to change it every hour or whatever and (.) yeah. And you have to have a bath and shower after you've finished (.) and (.) yeah. And because it is the (.) obviously, I'm Muslim and when you're on your period you're not allowed to pray. So it was explained you can't pray and et cetera. And that was it. To be fair. **Interviewer:** So you didn't know about them before you started? **Aisha:** No, but my mom knew that (.) it's kind of taught to us in school. So she let them do it.

**Mala:** I think because I'm from an ethnic minority, it wasn't really um [pause] we didn't really speak about it openly. Well, the male in our family didn't anyway. But the people that I went to, were my aunts and my (.) my mom, actually, is really good at explaining things. But I initially went to my aunt and then told my mom and my mom sent me to my aunt again [laugh]. So they told me what I needed to do, but I kind of knew what to do because of my educational background. Like when I learnt it in school. **Interviewer:** Can you remember when you when you had that lesson at school was it at primary school? **Mala:** It was in primary school, yeah. **Interviewer:** And what age, can you remember? **Mala:** I think that was in year six (.) so, I was eleven. I believe? Yeah. **Interviewer:** So you had the lesson before you started? **Mala:** Yeah. **Interviewer:** You knew what it was? **Mala:** Yeah.

**Noor:** We didn't. **Interviewer:** OK and do you sort of know why or (.)? **Noor:** [Pause] No idea. It just never came up, if that makes sense? And then it's only in school when you (.) when your friends actually start. **Interviewer:** Yeah. **Noor:** The topic came up. **Interviewer:** So was it a lesson in school or was it literally your friend [overlapping speech] started? **Noor:** No, one of my friends started. **Interviewer:** And was that at primary school? **Noor:** Primary school yeah. **Interviewer:** So one of your friends started and did she know what it was? **Noor:** She did, roughly. So she was a bit nervous. And then obviously she told us, and we told the teacher and obviously, I came home, told my mom and she was like, "oh yeah, that's just normal". And that was it.

### P2- First period?

**Alice:** Well, actually, it was erm, something that I kind of thought wasn't ever going to happen because I was quite old (.) as in when I say old, all my peers it had happened to. Whereas I didn't get mine until I was 16. So I just thought. 'Oh, it will appear at some point'. And it appeared when I was on holiday with a friend in Scotland. And unfortunately, I didn't expect it to appear. And I was sleeping in a bed like full of white sheets. And then I embarrassingly had to go and speak to her mum. And it was away from home to say, this is what had happened. And I don't (.) I don't think I had anything with me because I was away from home. **Interviewer:** So you felt embarrassed? **Alice:** I felt a bit embarrassed. Yeah, I felt very embarrassed because I'd messed their bed up. But she was amazing. She was just like, 'don't even worry about it'. But I think she may have thought 'that's odd for a 16 year old. Not to be prepared', but I don't think I said, 'this is my first one'. **Interviewer:** Yeah **Alice:** So it was still very mortifying. So I was embarrassed that I was older, but it had happened to everyone else already. **Interviewer:** And were you kind of worried about that? **Alice:** a bit. I think my mom was a bit worried because with my older sister, it happened much younger. And for her, it happened much younger, so I think for a while they were like, this is strange, but we never sort of did anything about it. We just waited for it to arrive. And I was quite sporty. You know, I was, you know, doing an early morning swimming and training like twice a week and running and cycling. And actually, if you look at pictures of me, I didn't sort of develop at all until I hit 16. And then suddenly I got boobs and hips and everything. So I was just a later developer.

**Beth:** Erm, I just noticed it as some blood in my pants when I went to the toilet at school one day. And, erm, it wasn't painful. It wasn't particularly heavy. And that was it, really. I mean (.) I don't remember much else apart from that about the first period, and I remember sort of whispering to one of my best friends in the playground that I'd started. And (.) I don't even remember what I did (.) Because I was at school (.) about sanitary protection, whether I just used some toilet roll. Or, I can't even remember if I went to the school nurse and asked for a sanitary towel or something, I (.) I honestly can't remember, but I remember my mom picking me up after school and I was sort of feeling quite nervous thinking I've got to tell her I've started my period. But because we went to a shop before going home, I sort of had to take her aside while we were in public and like, really whisper to her. 'I started my period', you know, and there was all these sort of hugs and like, oh, 'you're (.) you're a woman now'. Which felt, ridiculous when, you know, I was like 12 (.) but erm, and then, yeah (.) she took me to buy some sanitary towels. And that's all I remember about it, really. I remember the few subsequent periods after that. Feeling really utterly fatigued on the first day (.) or two, they would tend to be quite heavy for four days and then stop for a day and then carry on for another four days. So it was a bit of a drag that my periods seemed to last eight or nine days. And yeah, I do remember feeling as though I was sort of going down with a virus or something on the first day. Erm, for the first few periods after they started I remember having to cancel a music lesson because I just felt too rough to go. I think on my second or third period I ever had (.) but that's about all I remember about them, really.

**Dani:** Like it was very small [interviewer laughs] it was! [Laugh] it was a small (.) like a very small amount. And I had bad pains the night before (.) but apart from that, it was pretty uneventful. Like it was just, you know, I think I just wore a pad, like it was just (.) just quite like a (.) I was relieved that it arrived because I was desperate to start. So that was more that's more I remember rather than the actual period. **Interviewer:** So what kind of age? Where are you then? **Dani:** I think I was twelve or thirteen. **Interviewer:** And do you remember telling anyone and like telling your mom or telling people at school? **Dani:** Yeah. Yeah. I literally yelled (.) yelled to my mom [laugh] I remember. And then I told all my friends. Yeah. It was quite like. It was quite like a big deal. At that time, you know, as I'm sure you can imagine. So I told everybody that I knew. But (.) but then my mom told my grandparents, which I was hugely embarrassed about. I did not want (.) I did not (.) I didn't want other adults to know. D'you know what I mean, but like I (.) I was (.) I was very happy for my friends to know.

**Emma:** I have absolutely no idea. I can't remember it. I've asked my mom because I couldn't even remember how old I was. I was eleven. She said that I'd been complaining of cramp and then (.) told her that I thought my period had arrived and that was it! But I literally can't remember it. So it yeah, it wasn't, ironically, for all of the problems it's caused, that first one was obviously insignificant. I don't know where I was. I don't remember how I felt. Nothing. Sorry. It's not very helpful. **Interviewer:** No, It's good. It might be because (.) eleven is quite young, so (.)? **Emma:** I think maybe I was expecting it as well because I'd been talking about it and because I had my book [laugh] and it was (.) it was more expected and just normal, like a normal occurrence.

**Faith:** I had been away at some summer school sort of thing. There's a thing called [name of scheme], where they'll take you away for a couple of days. So funny enough, a few girls had started, so we had kind of had a conversation about it. So when it came I was like 'I'm part of the crew, now!' [Laugh] I mean, that was what's happening. So, I don't think I had pain that day. So it was a mixture of surprise and 'oh, it's finally here' and all of that. But in terms of physically, I don't think on that day I had any pain. It was just like, OK. "What I do now, OK. Mum gets me a pad and then I start kind of processing that “OK this is now (.) I'm part of the 'woman's club'” [laugh] You know? But physically, I was fine.

**Gemma:** And for me. Yeah. The first period was fine. Didn't even know (.) I was shocked a little because 'Oh my god, there's blood'. And I don't think I was aware. I don't think I knew about periods before I had one. I heard other people speak about it so I knew it happened (.) but it still came as a shock (.) but I had no pain and the first one it was a complete surprise.

**Helen:** I want to say I was twelve. **Interviewer:** Um and can you remember what age you would have been when you got the school, the first school thing? Was that when you're at junior school? **Helen:** So here it would be grade school. I want to say like fifth grade maybe. How old would I be? I was twelve (.) I'm trying to think what grade I would be in at twelve? **Interviewer:** Seven or eight? **Helen:** Yeah. I must have been in seventh grade. I was always the youngest in my class. I think it's was in seventh. **Interviewer:** Can you remember? Sorry, carry on (.)[overlapping] **Helen:** Oh, no, no, no. I was just kind of doing the dates my head. I want to say that we learned about (.) menstruation in school, like around fifth grade, fifth or sixth grade? Yeah, it's a good 20 plus years ago [laughter]. **Interviewer:** A few of these questions you might not be able to remember, but I'm just sort of getting a sense because some people are much older when they find out about it. And can you remember what your first period was like? **Helen:** Um (.) Yeees, I remember being at my aunt's house. This is so gross. It's (.) so much information! But I remember I think I had a yeast infection right before that. So It was like a double whammy of like "what is happening" [put on high pitched confused voice], you know, "to my body!" [gentle laugh]. But I remember being in my aunt's house using the bath (.) I remember the bathroom. I was there. I remember all of it, like just that moment. But it was very like, you know, I told my mom and my Aunt and they were, like, "oh, you got your Period". Like, I don't remember it being like a big (.) like it was celebrated in a small way. I think I got a box of candy or something? [Laughter] but again, it's like thirty years ago, I can't remember! [Laugh]. **Interviewer:** That's a result! I didn't get anything for mine. **Helen:** I feel like I did, but I might be making that up. I don't remember, to be honest. I'll make sure my daughter gets like a cake and like something like I'll really remember it so she can remember [laughter]

**Kathleen:** Er (.) I don't remember what it was like in terms of the look and feel, but I do remember (.) er, I did physical (.) physically feel but I do remember feeling a little bit anxious, you know, er (.) I didn't quite know what to expect. I think my mom had talked to me. So I knew what to do. So that was fine. Um (.) but it was yeah. I think I was feeling a little bit anxious about it. **Interviewer:** And, do you know what age approximately you were? **Kathleen:** I think I probably was around twelve. Could have been 13?

**Aisha:** Erm, I think like (.) oh, my gosh, it was [pause] I think it was a shock, like I was probably havin' symptoms before I started and (.) you know like as in (.) er (.) I don't know. I knew I was gonna (.). I didn't know I was gonna start but erm, my first period. It just came. If that makes sense? I hadn't er (.) can't really remember it, can I? I just remember I was crying when it (.) when I started. And that was about it. And it was really heavy. I remember. It usually is. **Interviewer:** Oh Right. Your first one was heavy (.) **Aisha:** Yeah [softly]. **Interviewer:** Can you remember what age you were? **Aisha:** Maybe 14 or 15, one or the other? **Interviewer:** So, at Secondary School? **Aisha:** Yeah yeah (.) **Interviewer:** And so at school can you remember when you had the lesson, did you have anything at primary? **Aisha:** Not in primary (.) it's more secondary school. **Interviewer:** Secondary school. And that was just like a lesson about puberty? **Aisha:** Oh sorry (.) primary school was the lesson, but it was about more about sex education and I don't remember being fully taught about periods, if that makes sense? We knew it was coming because other people were gettin it, but we wasn't taught a lot about it, if that makes sense?

**Mala:** Um, my first period was a bit bizarre because (.) um most of my year group (.) so, I started in year eight. So I was fort (.) 13, 14, and most of the girls in my year group had already started. So I felt like I was a bit of a late bloomer. And I was wondering "when I'm going to start?" And when I did start, it wasn't really how I expected it to be because it wasn't like a lot (.) How you (.) Like they taught you lots of blood flow (.) It was more like, should I describe it? **Interviewer:** Yeah **Mala:** Brown, and it was dry and then nothing happened for the next three months. So I questioned was it even my period or not? And then after three months, then it started comin' regularly. **Interviewer:** Aha, mine was the same. It's called spotting, but nobody told me about that (.) **Mala:** Yeah, I never understood. I just thought it was going to be blood and blood and blood that's all!

**Noor:** So I actually started in year 9, so everyone started and then I was later. So I was aware of it, if that makes sense? **Interviewer:** Yeah. And how did you feel? Sort of did you want it to happen at that point? **Noor:** I didn't realize like, d'you know, it's one of those things because you don't talk about it, you just know of it, but you don't want it. Does that make sense? So when I started I was like "Oh, okay". And then I show (.) came home and told my mom. It was (.) I think it was at home, actually. And I told my mom. And then she just gave me a pad and she was like "whenever you start wear this". That was it.

### P3- Changes before, during, after period?

**Alice:** Erm, so, yes. So I have only learned that probably in the last couple of years. So I feel (.) and also my periods have never been the same. So when they did arrive, they arrived. And then I never knew where they were going to come. So completely irregular for maybe three years. And the only solution when I reached 18 was to put me on the pill to make them regular. That's what I did. But I then found that I got loads of breakthrough bleeding and it made it worse. So I eventually came off after being on the pill for a while. And this was [overseas]. So it was then a pill that you couldn't get when I came to the UK to go to university, which was quite traumatic in itself, but (.). erm, what was the question again? **Interviewer:** Do you feel different like at certain times before or after? **Alice:** Yeah. So before I was saying I know my body a lot more and what to expect before I know it's coming because I might feel a bit low. So for a few days before, even up to a week before, I might feel a bit emotional and I don't know why (.) or it might be something ridiculous [laughter] and I will feel tearful and I'll have like some flat time (.) not (.) not for a long time. Maybe for a day or two days. And actually, my mom who I'm very close to, will say now 'is your period coming'? And I say, 'Oh, no, not yet'. But it will arrive in the next week and she'll say, 'well, that's why you're feeling emotional because it's on its way'. She's like 'I know that about you, now'. Yeah. You know, so she might have prompted that, but I can recognize when it's coming. So that's one mood. It's not like how the media says [sigh], you know, 'you lose it and you can be a bitch'. **Interviewer**: Yeah. **Alice:** It's not that at all. It's actually quite inward. It's quite (.) erm (.) it's quite emotive and I feel a bit low. So that's one sign. The other physical thing is I start to feel a bit heavier. So I feel that, erm, you know, you read scientifically, it's like water retention and stuff like that (.) but I definitely start just for a little while, but before, not during. I feel a bit heavier (.) and my boobs got a bit bigger (.) and they get a bit tender. So I'm quite sporty, so I’ll know because I put my sports bra on and it will feel a bit tighter and a bit more painful. Erm (.) what else? Probably other things, but erm, that's the main symptoms before and then during erm, so I know normally like the day that is going to or about to start because I won't feel great. I feel a bit sick. Erm, and when it does start mine are quite variable, but maybe, [pause] maybe like every other or every other other. So like one in three, they're horrendous. So I get (.) er, it arrives on the first day and the first day's light. But by the time it's sort of the second day on, sometimes is actually even hours, so it might have arrived in the morning and it's light. But I know that it's going to be horrendous on the horrendous day and I start to get sort of a little bit of pain. And if I can catch it on time when I'm in the right place, I will take like a kind of high dosage of ibuprofen or ibuprofen and paracetamol to sort of nip it in the bud before. And I'll try to eat some food so that I don't have it on an empty stomach so that makes it worse. But if I'm having one of those one in every three and it's very erm (.) it's completely immobilizing, so I will (.) you know, I've been out in public when this has happened, so I will vomit (.) er, I can pass out. I'll be on (.) I'll have (.) I'll have everything at both ends. So it's very grim. So I'll have complete (.) the vomit will be pain relief because I'll be er 10 out of 10 more pain. I mean, over-the-counter medication doesn't touch it. I'm not somebody that would want to take loads of that anyway. But it doesn't touch it. So I will vomit in relief because the pain and then my stomach will just go to shit, literally. And I will just sometimes need a bath and the toilet because it's so awful. **Interviewer:** yeah **Alice:** And that will go on only for that (.) the afternoon of the first period, or it will be day two see the first day is very light. It's not always exactly the same pattern as I said, I sometimes know it's coming so I can try and hold off and take the right medication. Sometimes I can't. And the pain is, is the cramping. So it's, you know, really lower abdominal, absolutely excruciating, can't communicate with anyone. Have to sort of zone out. **Interviewer:** Yeah **Alice:** Into myself to try and just (.) deal with it. And that will last [sigh] maybe for a minimum of two hours and maybe maximum of three or four. And after that episode. Gone. I normally (.) well, I might have (.) as well as (.) I'll pass some real thick blood. And so like some clots. But not you know, I've spoken to medical professionals about this and they'll describe it as a massive clot, it isn't it's just clots, you know, like we all get clots and sometimes just a lot of blood that comes out. **Interviewer:** Yeah. **Alice:** And then I have a normal period once that's passed. And so that might be like day two or it might be day three, whatever. It's always slightly different. And that will mean that for me I'll have two or three days of heavy and then I'll have like day four, five and six, which will be really light.

**Beth:** [Pause] Definitely over the last several years since erm, my mid-30s, I've really noticed that a lot more (.) probably when I was younger, I (.) whether it didn't happen that I didn't get the symptoms or I was just less aware of it. I don't know? But yeah, over recent years I have noticed definite premenstrual symptoms and symptoms around the time of ovulation as well. Yeah, there's a definite pattern.

**Dani:** Yeah, I feel really tired before my period and like just a bit. I get quite grumpy and my boobs hurt. It's not the same every month. But it is pretty much or they're a bit sensitive. Yeah, pretty much. I just feel a bit low. I think I would say not like and it is (.) not depressed of any sort. But just a bit low.

**Emma:** Before my period I feel absolutely horrendous. I have erm severe premenstrual syndrome, premenstrual dysphoric disorder. Erm, so I have some really awful symptoms that are debilitating. So I really struggle with fatigue (.) and low mood (.) and erm, negative thoughts that can be intrusive. And I get very down about things and question everything and over analyse. Er, I find it difficult to be organized, and to be productive. So work becomes very difficult. I don't want to talk to anyone. I tend to become completely introverted (.) and I just want to shut myself away. I become very irritated erm by random things, from noise to just people and movement. And so going somewhere like Central London, when I'm premenstrual is a nightmare. And it's really anxiety inducing. It just (.) it yeah, it's just really hard. But being around people in particular and having to talk to people, that's really difficult. I also have a lot of self-loathing and (.) just a real drop in confidence (.) and feelin' gross. Feelin' absolutely gross and rotten on the inside and that lasts (.) so that starts after ovulation. So about three two/ three days after I've ovulated. And then I get a few days respite where I'm okay. Then the week leading up to my period, that's when things become really difficult. So I have to take anti-depressants to try and stabilize my mood. And that has really helped (.) But I've actually got an appointment next week because I've noticed a drop recently and a change (.) So I'm gonna go and get that checked out. When my period arrives. I am usually a write off for two days because I get really painful period cramp. I usually have very heavy periods. Again, the (.) the fatigue really hits me and I just have no energy. So even getting up out of bed some months can be really, really difficult. If I can (.) I tend to be at home with a hot water bowl bowl? Hot water bowl? [Laugh] **Interviewer:** A hot water bottle? [Laughter]. **Emma:** And just (.) I literally can't do anything. I'm just useless for day one and day two of my cycle. That being said, last month I went and presented and pushed through it (.) like we do (.) and I'm not quite sure how I got through that, but I did. And then after usually around day four of my cycle, day 4/5, I feel the benefits of oestrogen increase in oestrogen and I usually feel a turnaround in my mood and an uplift in my energy. But again, this month I'm on day nine today and I'm still waiting for that to happen. It hasn't quite happened this month. So I feel a bit short-changed. And that's the cycle that I tend to go through every month with my cycle. I'm not on any kind of birth control either, because I've had really awful experiences with different contraceptive pills. And so I try and manage as best I can with erm, a very low dose of anti-depressants and painkillers and trying to lead a healthy lifestyle. So exercise and diet help. But it's very hard to stick to that when PMDD kicks in.

**Faith:** Emotionally and, yeah in terms of cravings, so (.) I've become like quite 'short'. Like things frustrate me and (.) I can cry a lot easier [laugh] and I'll be really thirsty all the time and I'll just have like an awful sweet tooth (.) and like, I wake up in the middle of the night and if I don't have water (.) I have to have water by me when (.) when I'm going through PMS, if not, then I'll go downstairs like twice in the middle of the night because I'm always dehydrated and craving sweet things. And I guess yeah, the emotional side is just being emotional and also being short. And then during (.) first few days are always awful like (.) walking is a struggle. It used to be (.) it's a shame (.) because it used to be the first day then now, the first two days, sometimes it'll be three days, so it seems like it's getting longer and longer with time. **Interviewer:** And is that because of the pain? **Faith:** Yeah, yeah. During (.) well, when my period's started emotionally and mentally, I'm fine again. But physically, that's when it's like this one through three days. It's like awful (.)[short laugh] **Interviewer:** And is that like a cramping feeling like on and off? Or is it more like a general (.) cos there's like two types. There's that heavy (.) **Faith:** Yeah (.) **Interviewer:** All day feeling. And then there's that sharp. Cramping pain (.) **Faith:** Yeah. It's like (.) it's that you know that dull feeling across you whole (.) I don't know what this line is called? **Interviewer:** Lower abdomen? **Faith:** Oh yeah. Yeah. And then like on top of that you've got like the scrunch like it all kind of [laughs] comes crunching in, sort of thing.

**Gemma:** My periods, so like before I am a wreck, like I cry over anything, which is just crazy. And I know it's (.) I'm so happy because I know it's 'your period's come and you're cryin' for no reason! I think I'm horrible looking (.) and that's just not me (I know that I'm very beautiful) [laugh]. But I actually look at myself and like 'urgh'. Like, it's really bad. I look at myself in the mirror, I'm like, 'you're, you're really unattractive'. It's so strange. It's the weirdest thing. **Faith:** I concur! Ooh, sorry [to interviewer for speaking at same time] **Interviewer:** Yeah. It's fine. I have it as well, I have 'ugly day' **Faith:** But do you like know that this is because you are on your period? **Gemma:** Yeah. **Faith:** Or is it kind of sometimes you think (.) **Gemma:** No, I tell myself 'you're on your period' like it's OK. Like feel like this. Because honestly I'll wake up in the mirror and I 'll be like 'ergh' (.) like you're (.) just you're fat. You're not pretty. Like it's so bad. I mean it's gotten worse as I've gotten older because it was a little bit before, but it is getting worse. It's really bad. So I think I get really (.) erm, insecure before I start my period and I'm much more emotional. And then when I'm on it, I'm fine. I swear to you, this is gonna sound so crazy cos' I've never been pregnant. But I think I get contractions. Like, I literally go [breathing noise] through the pain. And then this is a bit explicit (.) but I need to go number two. Very strange. And then it closes again. And then I'm like. I breathe through it like [breath out] and I get hot. I take all my clothes off. Yep. And then I go on the toilet. Then it happens again. And it's a cycle. It actually happened three (.) I was in [European city] for work and I had to go upstairs for like an hour because I had to just do it. And after it's done, my body is very exhausted. So, I have to lay down for about 10 minutes. Then I'm fine. I'm (.) I'm absolutely fine. After (.) It's like one day of that for about an hour and a half or an hour or two hours. Then my period is absolutely fine. No pains. It happens very early in the cycle so it's like day, two. **Faith:** Yeah. **Gemma:** Then the other three days I have, short periods as well. They're like 4-5 days max. So not the next few days are a breeze. No problems. I'm very light. Everything's fine. But that's the cycle and I know it. So I'm kind of. It's really weird. I kind of look forward to it because I know, OK, this is gonna happen. This is gonna happen. And then you're gonna be okay. **Faith:** Yeah. Cause (.) why (.) why I was asking if you know, and that it's okay. **Gemma:** Yeah, I do! **Faith:** Is 'cos sometimes I don't! Which is weird like it happens every month but sometimes I don't (.) you're in that hole so you kind of (.) you can't (.) I don't really tell myself 'oh this could be because of my period' I'm just like (.) **Gemma:** You still feel it though, isn't it? **Faith:** And afterwards, it's like 'Oh that was why!' **Gemma:** Oh, okay. That was why (.) I think I (.) I've got the tracker. So I (.) it's the moment I start feeling off. I look at it and I'm like, okay, this is okay. If it (.) if it isn't like sometimes you might be having a bad day. And if it isn't, then I'm like 'Gemma, please (.) get it together' [Laughter]. But if it is because of my period (.) then I'm like, it's okay to feel this way because you always feel this way and this is your cycle. So, yeah. But I swear I have contractions. I literally go [birthing breathing]. It's really strange. Yeah. And I naturally do it. It's not something that I told myself to do. I literally (.) no one told me (.) I go [birth breathing] I breathe in. Breathe out. Breathe in. Breathe out. So strange (.) very strange.

**Interviewer:** Um, Are you still menstruating? Or not? **Helen:** No, not anymore. I had an oophorectomy and hysterectomy in 2015. [Suddenly serious] **Interviewer:** Ok, so. I might come back to that in a minute. But for some of these questions, it's just a matter of whether I ask you about the past or the present (.) **Helen:** Yeah, absolutely. **Interviewer:** And so when you were menstruating, did you feel different before, during or after your periods? **Helen:** Um (.) yes (.) so all through my adolescence, I was always regarded as hyper emotional before my period to the point where my mom took me to the gynaecologist and they put me on birth control even before I was sexually active to try to help with those emotional swings. And I don't know that my sister or friends had that same experience. It was just (.) I think I thought that was normal. But I look (.) you know, looking back, that wasn't normal. I think that was for me, early indication of the road to come. **Interviewer:** And when you say emotional, do you mean like low mood or irritability too? **Helen:** Oh low mood! Yeah. Low mood for sure. I would be very, you know, defensive and weepy and I'd feel very um (.) ah what's the word I'm looking for? Probably insecure. There's another word I'm looking for and I can't think of it right now. But just, you know, kind of (.) what's that word when you feel like threatened in a way you feel (.) **Interviewer:** Paranoid? **Helen:** Yeah. Paranoid! Thank you. I felt very paranoid, like about my friendships, my family. I felt very like, you know, I remember feeling like, oh, everyone's mad at me. You know, no one likes me.

**Kathleen:** [Long pause] Um [pause] so before my periods, no. But saying that I do tend to get (.) I don't know how. But I do have a knowing that I'm just about to come on without always seeing any blood. I don't (.) I don't know what that is, but I just know. And then I'll just put a pad on, and the next morning, it'll be there. Um, during my period, are we talking about now or historically as well? **Interviewer:** It can be either because one of the questions is have things changed over time so we can go back to that. So, it's however you want to describe it (.) **Kathleen:** Yeah. So (.) so just if we talk about now. So yeah I just tend to know now. During my period (.) you know, I went for many, many years just not experiencing any particular change in mood or (.) um or just kind of carried on functioning really. But more recently I would say within the last year, I don't know if it's got to do with age or if it's got to do with, my fibroids journey, I'm not quite sure? But I definitely notice a change in my moods now. Um, it (.) I tend to feel (.) just a little bit more down than I would normally or I just feel, maybe a little bit more on edge. But it's not in a major way but I notice it now, but I went for decades without really experiencing that at all. Um, the reason I remember that is because my friends always used to talk about how they felt. And so we had conversations about it. And I just knew that I just generally what (.) what was (.) was okay. But more recently, I tend to notice a change in my moods a bit more. And I try to (.) not (.) um I try to just carry on as normal as much as possible, really? Um, and then, after my periods [pause] the other thing that happens as well during my period is maybe a bit of bloating. Yeah, and then afterwards that goes down. And then I'm fine. Back to normal.

**Aisha:** Oh, yeah, definitely. So before my period and after my period. Definitely during my period. I'm a lot better. **Interviewer:** Yeah, so how (.) how exactly do you feel before? **Aisha:** Before, I am constantly craving for food. My mood is like, you know, I've got patience for anything. But when I'm PMS, like, I believe I have PMS erm (.) I'm constantly just being a cow and snappy, snappy. And also my anxiety flares up. Um, definitely I have an increase of anxiety and feeling low and I either go through a crazy cleaning spree or I can't be bothered to do anything. **Interviewer:** And then what about afterwards, then what's happened afterwards? **Aisha:** Afterwards, I tend to feel very low and I don't like to socialize. Very low, definitely, and erm, it more plays on my mood, my low mood side of things. **Interviewer:** And during what's that? **Aisha:** [Noticable change in tone- to happier] During, I'm uplifted, I'm me. Um, I don't really get pains or anything, but I'm a lot more energetic. That's when I get my goals done. I'm a lot more productive. Definitely.

**Mala:** I feel different before my period. I'm very (.) I have two moods. So the first mood is I'm always hungry. Like I want to eat anything and everything. Um, and I'm always having cravings. And if I don't get it, I get really like "I need (.)" I'll go out of my way to go and get it [laugh]. And the other mood that I have is just agitated by people. I mean, mainly people I'm really close with, not people that I'm distant with. I'm okay with everybody like that but people who I'm really close to I'm very agitated and angry and everything they say just annoys me. **Interviewer:** When you say food cravings is that for particular types of food? **Mala:** Yeah. Korean food. Yeah. I just want like bibimbap and all that stuff. **Interviewer:** So, that's kind of a bit spicy and (.) **Mala:** Yeah. I love the (.). Yeah. I like the sticky rice.

**Noor:** Yeah. So I'd say about three or four days before I start (.) I want to eat everything in the world [laugh] I feel a bit moody, not myself. I just want to be left alone if that makes sense? **Interviewer:** And then during or after- any differences? **Noor:** Mmmm, I'm back to normal. As soon as I start, I'm back to normal.

### P4- Refrain or do something special for period?

**Alice:** So the traumatic periods which happen like one in three is just one in three. Sometimes it's like one in six. Sometimes it might just be twice a year. So do I have to do anything differently when it's a traumatic one? Well, yes. Only (.) do I do anything differently? I try and I never know when that's going to come. And some people who I've spoken to about this (.) although, to be fair, I no longer speak to any health professionals about it because my experience has been 'it's normal. Get on with it'. So I just deal with it myself. Um, I have tried, as was saying, to (.) to try and (.) you know, because I'm a health professional myself, so I know about medication, so I try and look at the symptoms. Am I gonna have one of those explosive days? So I try and take the medication to sort of get in there before it happens. So that's one thing that I might try and do, but that depends on context and circumstances. Often I get these in the middle of the night or sometimes when I'm (.) er (.) one time (.) it happened when I was cycling and I thought I was going to blackout and pass out and it was happening. I was in the road and luckily I was in the local area. So I just cycled straight to my parents' house, managed to ring the doorbell and then passed out on the doorstep. My dad had to carry me in and put me on the toilet and then put me in the bath. He has experienced that and my partner has experienced it. And I think for other people, it's really quite frightening to see you in that state. They think 'this can't be right'. **Interviewer:** Yeah **Alice:** So do I do anything differently? The medication I try I don't know whether it makes any difference, but I'm very active. So I find when I have got my period (.) that I get a lot of relief through exercise. So saying that, exercise (.) actually, I will run if It's about to happen. But sometimes that can go one way or the other. So it isn't always that great. But I swim and run and that. And I will do that throughout my period and beforehand. So I think that probably helps. **Interviewer:** Yeah **Alice:** (.) And I think diet definitely makes a difference. So, for example, if I've drunk (.) not hungover or a lot, I've had a glass of wine the day before my period is due, it’s a hundred times worse. Which is probably something to do with not enough fluid in your body?

**Beth:** [Pause] I don't think so. No.(.) Erm, [pause] I mean (.) I (.) saying that I've done something today. I mean, I've got here a plaster on my neck which I haven't (.) actually [laugh] it looks like I've deliberately done it for the purposes of the video, but (.) but it's just a coincidence that this sort of issue has flared up. I've got (.) erm a condition, a psychological condition called compulsive skin picking or dematolamania that's linked to anxiety. And I also have anxiety and this really does flare up in the couple of days before my period that I'm a lot more likely to pick my skin. **Interviewer:** Aha. **Beth:** Because I'm trying really hard to self-manage it at the moment and not pick. I'm down to my sort of last self-inflicted scab that had almost healed but because I'm premenstrual right now. My period's due imminently (.) last night I had a bit of a relapse. I've just had a bit of a pick, at this almost healed scab on my neck and I know I'm going to pick more (.) erm, until my period starts (.) erm, because that tends to be how it goes and how it's been over the last several years, really. So I've covered up the area so I don't pick it further. So, yeah, I guess from the point from (.) the point of view of that particular condition. I am more aware before my period that I'm more likely to pick because recently I've started to make a real effort to manage it. I (.) I am more aware that I need to make a bigger effort before my period to try and stop picking.

**Dani:** I don't like refrain from exercise, but I would if I feel too tired to go to the gym, I wouldn't make myself go (.) basically but like I wouldn't be like, "oh, I won't go to the gym because I'm on my period". But I would I would possibly just be like "Oh, I'm not. I'm not really up for it. Yeah, that's fine".

**Emma:** I (.) try to plan ahead. So I have a calendar, a desktop calendar, which is colour coded around my cycle. So I use that as well as an app on my phone to (.) [inhale] to consciously try and schedule things to fit around either my good days or my (.) my bad days. And I will try and keep day one at least day one and day two of my cycle completely free if I can. It doesn't always (.) In fact, most of the time it's not possible to do that. Or I work from home to avoid traveling. But certainly anything that requires a lot of energy that I know I'd really struggle with, I try where possible to avoid that during my period. Maybe because I know that I won't be able to give it my best. And I just won't be in (.) physically. I won't have the energy or even the mental capacity to engage with anything that (.) requires much thought or energy or positivity. Erm, yes, so I'm much, much more aware of planning and scheduling and avoiding travel and meeting people and socializing and anything that's going to need me to be with other humans, really? Yeah, that's (.) that's kind of what I do. **Interviewer:** Can I ask you a bit about that? Because obviously the menstrual cycle changes in length a little bit for most people each time. So do you have to kind of plan quite a few days like, you know, roughly when it ought to be, or do you just kind of wait until, you know, do you note ovulation and then you've got more of a clear idea? How do you do that? **Emma:** That's a really great question. So my (.) I'm really lucky in that my cycle is relatively predictable. Give or take one or two days. So, yes, I'll give perhaps three days where I'll put black stickers on (.) they are my 'flow' stickers [laugh]. And then I've got red stickers, which are my PMDD symptoms. So they are bad days where I know, um, I'm probably gonna struggle. Erm, but ovulation (.) Yeah. I'm also (.) also very conscious of when I'm ovulating again, I'm really lucky because some people don't really know when it's happening, but my body does get lots of signals. And yes, I use that because I know that my period will arrive about, oh, God, I can't do the math (.) twelve days after that, because I have relatively short cycles?

**Faith:** Like Physically? Or, like (.) **Interviewer:** Anything (.) like some people um (.) might not go swimming or might not (.) it doesn't have to be exercise but like anything (.) **Faith:** Drinking. If I drink before my period, then I'd like (.) just like pass out, vomit, that sort of thing. And it took me a while to realize that whenever I drink. If I get in a really bad state, then the next day, or then two days later, my period comes. I know that during my PMS my body can't take alcohol. So I've kind of come away from spirits anyway. But before that, I realized that drinking when I'm coming on to my period, is really bad for me. **Interviewer:** Yeah. So you wouldn't get more drunk or anything. It was just the hangover? **Faith:** Yeah. And I guess I thought it was that and I used to tell everyone 'Oh it's the oxygen!' [Laughter]. I was tryin' to figure out like, what was it? [Laugh] but then I realized that my period would always come next. Straight after (.) So, it was that. **Interviewer:** That's quite common. **Faith:** Really? **Interviewer:** Uh-huh.

**Gemma:** Do I do anything (.) or do I stop myself from doing anything? Not really, no, no. I tried to make sure because I tried to make sure I'm in a hou (.) it's weird your body, because somehow I always (.) It's like when that day comes, with the contractions. I'm always at home. I'm never really at work when it happens. Only because I was in [European city] that time [for work]. But it's always that late at night or whatever where it’s like I can manage it. I never get that thing. Rarely have I ever (.) I can count how many times in my life I've got it at work and I've had to go (.) I've never had to go home. But I've got it at work and I can kind of hold it. But it's always like towards end of the day. It's weird how my body kind of knows this is when you're gonna go crazy now. So I've never had to stop myself from doing anything. Erm, with drink I feel like I get more (.) more drunk definitely if I'm on my period and I'm drinking. It hits me much quicker. Um, that's about it. I don't really stop myself. I don't really swim anyway. So (.) and yeah (.) I wouldn't (.) I'd actually gym more. Which is weird. I actually feel more inclined to get out and do something when I'm on my period. [To Faith] Do you get that? **Faith:** Yeah. I second that, actually. I'm a lot more um (.) **Gemma:** Active! **Faith:** Yeah. **Gemma:** Which is weird, right? Cos your body is supposed to be in all this pain? But I actually want to be more active when I'm actually (.) during that time of the month.

**Helen:** Well, gosh, let's see. I'm about (.) I'm gonna say no. I don't think I really did (.) not until I realized like we (.) got a formal diagnosis of PMDD and really understood what it was. Did I try kind of controlling the situation (.) But growing up, you know, as an adolescent through my 20s (.) not knowing that I had PMDD. I don't (.) nothing was really done to (.) other than trying birth control and anti-depressants. As far as treatment. But I didn't change any lifestyle behaviours to minimize it.

**Kathleen:** I (.) probably [pause] wouldn't go to the sauna if I was on my (.) my period. Um [pause] I've been to the gym on my period, but not on my heaviest days, yeah [nodding] I tend to avoid that. Um, anything else? Yeah (.) yeah. I probably wouldn't go running on my period. Just bec (.) or on the (.) on the heavier days just because I feel a bit sluggish sometimes. Yeah. **Interviewer:** And with the sauna, is that because you feel too hot? Or is it because you don't want to leak? What's the thing with the sauna? **Kathleen:** I think with the sauna (.) I think it's more about discomfort, to be honest, really. Yeah. Because the thing about being in a sauna is you know, the less you have on the better, and just for comfort, I think. I think it's more to do with comfort. But, yeah. You know, I definitely wouldn't want to leak as well. I think I'd feel really conscious about that. Yeah.

**Aisha:** So obviously, like I don't pray during my periods (.) um neither (.) if I was to fast, I wouldn't fast. But before my period, what I do is (.) um is a long bath. So, I definitely increase that because it really helps, um anything special? Oh, and I just let myself loose. If I want to go crazy eating out, I'll eat out. **Interviewer:** Yeah, so you're kind of kind to yourself? **Aisha:** Yeah yeah yeah (.) **Interviewer:** And the baths (.) is that for period pain or just relaxation? **Aisha:** Just relaxation [long pause]. And I feel as if before my period I stop sleeping there's one day that I don't sleep.

**Mala:** No, I don't do anything. I just. Let me let myself feel (.) or, I just (.) if I've got the craving? I eat (.) that's the only thing and I do get cravings for spicy food as well.

**Noor:** Do you know what? My body tells me like d'you know obviously you try and do healthy eating etc. But when I (.) because I've got the calendar when I know it's three days. If I wanna eat, I just eat whatever and I just do my own thing.

### P5- Does your period affect you at home, work or socially?

**Beth:** [Pause] Erm (.) I wouldn't say so much the period itself as in, the menstruation side of it, I don't have particularly problematic erm, blood flow or pain or anything like that. But the premenstrual symptoms (.) do affect things. I mean, I've got a teenage daughter. I guess I become a little more impatient and short tempered and irritable with her if, you know, we're having an argument or (.) erm, I'm sort of having issues with her behaviour or some things (.). So, yeah, in the few days before my period, I find it a lot harder to (.) be patient [laugh]. So, Parenting! [Laugh] If you see what I mean? So, yeah, it does affect me at home from that point of view. Also, I just get tireder (.) **Interviewer:** yeah **Beth:** And (.) and that affects how much I can get done (.) erm, because (.) I get worse anxiety, I guess. Around ovulation, I get quite a sudden spike in anxiety, which seems to time with ovulation like bang on mid-cycle. And then that subsides and then again a week before my period. It sort of gradually escalates again to about the level (.) erm, it was ovulation in the one or two days before my period starts and the anxiety has a knock-on effect on my concentration. So again, I feel that affects my ability to get stuff done and focus on work (.). Erm, It affects my sleep a bit (.)? Yeah (.).

**Dani:** It (.) it depends. and now, I've got (.) for the past couple of months I've had the implant, so it's not (.) you know in the arm. So I don't think (.) it's not like a proper period anymore. Is that right? I don't really know. **Interviewer:** It depends. I think it stops ovulation in most people (.) **Dani:** Yeah. But for some reason I still got the withdrawal bleedin', which is nice. But what was the question? Does it.? **Interviewer:** Does it affect you at work, or just like socially? Yeah (.) like not really socially, but at work, I sort of find it a bit harder to concentrate. Just because I feel a bit tired. But it's not (.) some like (.) occasional months. It really affects me (.) but in general. It's like I just get on with it. But it's. Yeah. I haven't had pain in a while. But you know, when I get that then sometimes you just need to go home or just sort of lie down. But aside from that, like it doesn't affect me too much. It's more that post period (.) I do feel much more energetic so I sort of use that, you know, I mean, rather than worry about the bit before.

**Emma:** Okay (.) so at home, I can give an example (.) erm, I find it difficult to keep on top of house stuff when I'm premenstrual. So things like cleaning can be left for at least a week. Until after my periods when I've got the energy to actually care about it and do it. Things like cooking just basic life stuff cooking, going to the shops when I'm pre-menstrual or when (.) day one and day two of my cycle. Those things are difficult and my (.) my boyfriend works crazy hours so he isn't always able to help. Which can be (.) which can be tricky. And that again it just saps (.) saps some energy that sometimes I would rather not use. **Interviewer:** And at work? **Emma:** Definitely. I'm lucky in that I freelance so and I study so I have flexibility, which allows me to plan around my cycle, but previously when I was a secondary school teacher. I would find things like. Oh, being in a classroom and being on my period was actually horrendous because I would have so much anxiety about having a leak or being caught out without any kind of products or just the physical pain of cramp and not having the energy to deliver a really engagin' series of lessons. Sometimes (.) this sounds awful now, but sometimes having to say to the kids, we're going to do it like an independent study lesson where you're going to do this. And I would feel really guilty about that. And that was a (.) strategy of, I guess, coping with (.) coping at work. Yeah and what else? And socially. So this overlaps with home as well. So this (.) this December, I've noticed that my period is due on the twenty ninth of December, [laugh] so that not only is that before New Year's Eve, my birthday is on the 30th of December and that means I'm going to be pre-menstrual at Christmas when I'm at home. And so that is really going to (.) [exhale sigh] I think I'll just be an emotional wreck over Christmas and being at home and around the family. I don't get to see them that much, them being up in [home town]. And I'm already thinking about 'Oh shit'. Like I hope I don't spoil it? I hope I'm not there being all down and irritable and in a crappy mood for the whole time. And what can I do? Shall I give them a heads up or should I warn them that I'm not potentially going to be in a good place. I'm not going to be on form. I might need to take myself off and, just have some alone time and again. They are really understanding. And I know that if I said to them that I'm pre-menstrual, they'd be absolutely fine. And Christmas is fairly relaxed in our house anyway. But the thing that I'm really frustrated about is for (.) for my birthday, my boyfriend and I usually go to Ronnie Scott's the Jazz Club in London and have a (.) have a nice night. There we go for some dinner and then enjoy some live music. And I've had to say to him this year, it's pointless doing that because I won't be able to enjoy it. So we (.) we've actually got no plans for that night or for New Year's. Because the chances are I'll (.) I'll not be in any place to do anything, which is really crap. And he's now missing out as a result of that, which I feel again, really (.) it sucks for him (.) he says it's okay, but it erm (.) I just feel bad that it's not a normal [pause] yeah, a lot of partners wouldn't have to deal with that. Yeah, so. So that's how it impacts (.) home, work, social life.

**Faith:** Um (.) all of the above! [Nervous laugh] So just because like (.) like those first like one to three days I'm not able to move, I'll just be kind of wallowing and just lying in bed. Like if I'm at home then I'll be in bed. If I'm at work, then I'll find a couch somewhere. And I'll literally spend my whole work day on that couch. Um, I wouldn't really be out (.). Luckily I haven't (.) yeah, I think my periods don’t come at a time when I have to be out (.). One time it came when I was on a plane, which was awful [laughter]. When we went to America (.) **Gemma:** Yeah. **Faith:** But um typically I'm just like shut off and just like going through the motions.

**Gemma:** Again, with me; second day, it's like the first day's fine. (.) pain, yeah, but it's manage (.) it's very manageable. Second day is awful again, it tends to be the end of the day. So it tends to be (.) it yeah it tends to be the end of the day; really late at night. Or like I'll be woken up because I'm in so much pain (.) and I need to do that thing [referring to defecation] or when I've just come back from work. So it hasn't really stopped me socially in doing anything. Like I would say it doesn't really affect me.

**Helen:** Yes. Yes. From grade school (.)well from schooling all the way through jobs, college, relationships. Every (.) every facet of my life. **Interviewer:** Can you tell me a bit more about that? **Helen:** [Pause] Oh, I'm so sorry it skipped out. Say that again? **Interviewer:** I'm sorry. Could you tell me a bit more? In what way? What was the impact? Or the main impact. **Helen:** Oh, gosh. So many ways. I haven't had to think about this in a while! [Laugh] [pause] just everything (.) like I feel like (.) just [exhale sigh] all my emotional well-being, just I couldn't show up for anything, I'd just (.) end relationships, I'd quit jobs just suddenly (.) just so much instability. I just always (.) you know, I think my (.) my sense of self took such a big hit. **Interviewer:** Mmmm **Helen:** [Visibly distressed] Sorry, this is hard to talk about. Oh, my gosh. I do this every day [surprised laughter] and just having to think back. Really sucks (.) [wipes tears from eyes while laughing] **Interviewer:** You're not the first person I've spoken to (.) a lot of people who are activists and have experienced it themselves. And it's interesting. We're used to speaking about certain things and then not other parts. **Helen:** Right. **Interviewer:** And there's no right or wrong answer obviously, I'm just trying to hear a bit more about your experiences (.) **Helen:** No I know, I think I just get like angry having to think about it, like how much time was lost. **Interviewer:** Yeah **Helen:** And, you know. But um (.) yeah. And one thing I did not say is, you know, I was definitely suicidal. I think I started attempting suicide in high school as early as fifteen sixteen. I think I was fifteen. I first attempted and [pause] yeah, it just sucked (.) every aspect [laughter while wiping tears].

**Kathleen:** Um (.) not so much (.) now. But definitely during (.) should I talk about my fibroids? During fibroids. Absolutely. I mean, my periods were very, very, very heavy for a long time. And before I had my myomectomy and during that time um it dictated a lot of my life. So I'd wear black pretty much all the time during my period. When I was at work. I was continually very conscious about when I changed my last pad (.) because I wear pads. You know, and sometimes I'd go and look and I was fine. But I just felt like (.) because it's (.) the flow of blood, was just it just felt like you were (.) like it's just flowing out of you [laugh] you know! It just feels more. But you get to the toilet and you're OK. So during that time, I would say it dictated a lot about my life. And if when I got home as well, I probably couldn't sleep a whole night without getting up and changing. And if I did leak then there's this whole thing about getting up and changing all the bed clothes and, um (.) yeah, changing clothes, all of that happened for quite a long period, it was definitely maybe a matter of years before I had the um myomectomy, even (.) even once (.) my fibroids was diagnosed, I think I waited about a year and a half, before I had the surgery. Um (.) so, yeah, it dictated it then. Obviously not so much now. Although my periods are a little bit heavier now than they were before. I had the myomectomy. **Interviewer:** Oh really? **Kathleen:** Yeah. Yeah, I don't know why. **Interviewer:** It can be age, mine are heavier now (.) I'm currently a bit anaemic, um and I used to be fine. **Kathleen:** Yeah **Interviewer:** Just thinking about your experiences there. Did you ever tell anyone at work about this kind of fear of leaking (.) and (.) **Kathleen:** No (.) no. **Interviewer:** It was just your private anxiety? **Kathleen:** Yes, it was (.) it was terrible, actually. And also, the thing is (.) like when I knew I had it was fine but for quite a lot of that period, I didn't actually know what was going on. Um (.) but I was leading quite a very, very busy life at the time. And I just did not take the time to investigate it. So, I was managing it for a while. So no I didn't tell anyone. Um, I had some incidents actually where, you know, you've got those blue chairs at work? And so one day you know, I bled (,) and I (.) you know I leaked onto the chair. And so I used to (.) I used to pretty much work very long hours. And so I think when I got up and realized I don't know if there was anyone else in the office, but they weren't on my side. And so I had to kind of discreetly try and find a way to clean the chair (.) then I had to change, you know, change and er (.) Yeah. It was really quite [pause] I think that happened more than once, I think that happened a couple of times. **Interviewer:** Yeah, it's interesting, it's the sort of (.) fear of being discovered, even though obviously periods are really common [laugh]. **Kathleen:** I know! **Interviewer:** And like it (.) It's something that shouldn't be seen and it shouldn't be discussed. I mean, hopefully things are changing. But (.) **Kathleen:** I hope so, I hope so (.) I mean, I feel more confident about talking about it now, but I think still I would (.) I would still feel [pause] a bit conscious about it. I do remember actually one time I was (.) I had a (.) some family round (.) like some cousins and we were having a bit of a get together. And this must've been quite (.) this must have been in the early days when my periods really weren't heavy and I didn't even know there was a problem. Um, and I used to (.) I haven't really had painful periods the last few years at all, when I was younger, I used to have them. Um, and I remember I bled so much but I didn't feel it as much? I don't know why? And when I (.) I was sitting on the corner of the couch of a cream couch. My cream couch. And my cousin yeah (.) my cousin was sitting next to me and I just got up. But I had no idea and kind of looked back and there was all this blood on the couch? It was a leather couch. So um (.) so she saw it, looked to me. But she (.) you know she kind of was like "Oh my god!" but she didn't say anything. I (.) she kind of cut in talking, and I just discreetly wiped this (.) But I think that was probably one of the first times I realised "OK. Something's wrong here." Yeah. But I still (.) I think as much as I do talk about periods a lot more. I think there is still a little bit (.) there is still a little bit of me that (.) I don't want to be the person that gets up and there's a red mark, you know [laugh]? **Interviewer:** Yeah, well it's shame and it's very hard to you know, this is my whole life and I still carry a lot of embodied shame, like a lot of shame about my body that, you know, my head doesn't agree with but my emotions are still there. **Kathleen:** Yeah

**Aisha:** Definitely, like my relationships (.) erm, with my mom and my sisters. Obviously, I go to the extent (.) my anger goes crazy, so I'm constantly arguing. At work (.) my manager's actually picked it up like (.) he'll be like, "Oh, you're so good at your job". Like they love me and they love what I do, too. But that week I go downhill and he's still trying to figure it out and that week I'll have arguments with him for no reason as well. So it's like he's saying "you're amazing. You're amazing". But (.) suddenly I become a different person, he says. **Interviewer:** Uhuh. And have you spoken to him about that it might be to do with your periods (.) **Aisha:** Well, I did tell him "oh I'm PMSing", but he just nods his head like he thinks he knows what PMS is. But I really don't think (.) **Interviewer:** like it's not a serious thing? **Aisha:** Yeah yeah yeah [pause] he doesn't understand what PMS is, I think. **Interviewer:** But at least he's kind of (.) **Aisha:** Or he's got it wrong (.) [overlapping speech] **Interviewer:** (.) talking to you and has noticed it (.) you know, like (.) **Aisha:** But that's because of a long whole crazy (.). It had to come to that point, like [laugh] Because my mental health can be really low and obviously I've had to have a lot of time off and then they were not understanding and constantly telling me off, constantly picking on me. And then I had to go to occupational health (.) explained it to occupational health. "This is the situation. Blah, blah, blah. He just doesn't understand because they feel it's not a mental health condition". So then from then, my doct(.) that doctor had to get him in who was just being really nasty and then explain to him that it will go under the Equality Act and he does come under the Equality Act and um etc. And ever since then he's really (.) trying to understand. So it (.) **Interviewer:** Oh good! **Aisha:** Finally. **Interviewer:** Yeah, it's tricky.

**Mala:** It does affect me at home (.) and socially (.) work, not so much. I feel like I can regulate myself at work. But at home and social, more relaxed settings. It does affect me because I'm very, very agitated and I can (.) my mood will change. Like by the second one minute I'll be OK. And the other minute I'm not okay. Yeah. **Interviewer:** So by agitated. Would you say that's like more like you feel anxious about things or irritable? Or both? **Mala:** Irritable. Or Both!? Sometimes I'm anxious. It depends. Every month is different for me. It's either a food craving or emotional. But when I get emotional it's either I'm very anxious about something or I'm agitated by someone. Like they are really annoying me or anything they do is annoying.

**Noor:** No. **Interviewer:** So you think you (.) you just carry on with (.) **Noor:** yeah (.)[overlapping] **Interviewer:**  Your normal daily stuff? OK.

### P6- Describe periods to child?

**Alice:** Ok. [Pause] so you, er (.) as a woman, when you reach a certain age or a teenager and that can vary depending on your, you know, it’s individual to each person, depending on where you get to that stage, you will start (.) your body will start to change. And men will have different changes as well. But as a woman (.) you are the one that may eventually carry a baby. And so you have ovaries and in these ovaries, you have eggs and you will release that egg, which will then travel to a certain destination. And if that egg is not fertilized with sperm, which is what a man will start to produce, you know, early or older, but through an intimate relationship, the sperm might come up these tubes. And if the egg comes down at the right time, it will fertilize. And if you're lucky and everything matches up, but it doesn't necessarily always work that way (.) you may have a baby. So that will take nine months. But if that doesn't meet the sperm, the egg will not be fertilized. And so what then has to happen is that it will pass through the lining of where the baby will be housed. And that whole area will break down to prepare for the cycle again. And that breakdown is when you bleed. So maybe that was probably a bit too scientific, but it's basically about the female sort of sex hormones and (.) the different processes for new life?

**Beth:** Oh, gosh (.) I'm trying to remember now how I talked about it (.) with my daughter. Erm [long pause] it's a really hard question, actually, because at the time I think I just sort of went with what I felt was right and try to make it sound normal and not scary and not embarrassing. Erm, so (.) I guess I'd say it's (.) it's something that [pause] happens to [pause] all girls when (.) erm (.) Oh, God! I dunno, why I'm finding this so hard, actually? **Interviewer:** It isn't like a test (.) it's just kind of (.) how would you describe the whole thing? **Beth:** I know it's not a test but at the time I didn't find it difficult to describe it. But now (.) being put on the spot, I feel, 'oh, gosh, what would I say? What did I say?' Erm, I guess I'd describe it as a normal thing that starts to happen to girls. And (.) it can be (.) erm, when you were as young as 8, so sometimes girls in primary school start getting it, or it might not be until you're (.) you're 15, 16, but (.) erm, but both (.) both can be normal. So (.) erm, yeah. And it's part of growing up and (.) usually a few changes happen to your body before you get periods, so erm, it's (.) it's all part of that process of erm, changing from a child into an adult. Erm, if you were to describe what happens when you get a period. I guess you have to tie it in with making the child aware of sex and where babies come from. So you've (.) you've got to explain that, you know, women have (.) have a womb and that's where babies grow. And every month the body prepares the womb to get ready for a baby growing there. You know, obviously, most of the time that doesn't happen. So (.) so then the womb gets rid of (.) all the lining that's built up to prepare for the baby and that comes away and it comes out of your vagina as bleeding and that can go on for a few days (.) There's actually (.) a lot to explain! And it's a lot of information for a kid to take in. **Interviewer:** Yeah **Beth:** Yeaah, and it doesn't sound normal at all really, to, you know, potentially (.) you're explaining it to a sort of 8 year old who potentially could be starting their period quite soon? Erm, Yeah. There's (.) there's loads of information that sounds quite weird for a kid to take in. Erm, It's a bit of a challenge to explain it in a way that they're going to understand and not (.) be sort of scared of, I guess, because, yeah, it is (.) it is quite hard to explain to a kid that, you know (.) every month, blood's going to come out of you, but 'that's normal'[laugh]! And, it's because your body is preparing to have a baby and then you don't have a baby. But of course, you're not gonna have a baby, you're 8!! [Laugh]. So, yeah, it is quite, quite a challenging thing to explain, I suppose? I don't know what the right way to do it is, I do remember having a conversation with my daughter about it. That was very matter of fact. And she just went. 'OK, cool' [laugh]. **Beth:** But, I don't know how other parents do it or how it's done in primary schools. Because my (.) my daughter wasn't at school. At that age, she was home educated so (.) yeah, I don't know! I don't know if that's answered your question but (.) **Interviewer:** Yeah, I think that's brilliant. **Beth:** [Laugh] it's just really complicated for kids to try and get their heads around periods! Gosh.

**Dani:** So, I mean, I have had to do this! Erm, but basically, I think I would describe them as 'if you have a vagina. You've probably got a womb, which means that every month or so your womb gets ready to have a baby and (.) it sort of gets all ready. It puts all the lining up. And then if it doesn't (.) if it doesn't, (what would I say) if it doesn't (.) if it doesn't (.) it doesn't decide to have a baby [interviewer laugh] then the lining just all comes out and that basically looks like (.) it looks like the blood that comes out your finger, except it comes out your vagina. But you haven't cut yourself. You've just had your period. And that happens every month or so. That's what I would say.

**Emma:** That it's a natural part of being female? And it is something that we experience [pause] every month. Erm (.) and it gives us the opportunity to have children if we want [pause]. It can be (.) it shouldn't be, er, painful or debilitating an experience [pause]. Yeah, that's a (.) I've never thought about how I would explain (.) that's really interesting!

**Faith: [**Pause] Ok. I'm trying to think (.) What would I start with? I think I'll start with [long pause]. Ok. Yeah, I think I'll start with puberty. So, I'd say men and women or boys and girls go through puberty when they're becoming men and women and for girls (.) we begin to (.) Ach, how do I explain ovulation, 'cos that's a strange kind of concept (.)? **Interviewer:** Yeah, It doesn't have to be technical. It's just sort of in general. **Faith:** OK. So um for girls. We (.) our bodies start preparing for the possibility of childbirth and through that (.) We have eggs that are released (.) every (.) (You told us it's not every month now!) [Laughter] [referring to public talk interviewer gave- about variable cycle length] so, every cycle [smiling] we all have (.) our eggs are released. And I guess if they're not fertilised, then (.) they (.) they (.) What can I say? It's not that (.) I don't (.) see that's where I'd get lost (.) Er, when they're not fertilised (.) then you'll begin to bleed or blood will come through (.) and that will be your period and (.) you (.) manage that by using tampons or using pads. And for some of us, there'll be a lot of pain. So you might have additional needs such as medication or the needs of contraception and (.) For that I would definitely (.) like try to put in like stuff about the sort of complications that they might have (.) So things like Polycystic um ovaries and fibroids and that sort of thing. But that's more technical, so yeah just for the basic period, I'd say pads, tampons and you can expect to go through some emotional (.) um changes (.) a week or two before you see the blood, and that could include cravings, that could include feeling a bit low. That could include being short with people. And that's all fine because it's your body that's adapting to what's about to come. And then after (.) when you're on your periods (.) be receptive to how often you're changing your pads and how (.). Yeah, I think, yeah, something about their health and you know change your pads and your tampons and just when to do so. And to share it with (.) your parents and somebody at school that you trust or can confide in?

**Gemma:** That's much better than mine! [Laughter] I would say you have (.) your body goes through a cycle and most of us experience that through the form of a period. And what will happen is that your vagina will bleed and erm, that's (.) that's OK. I' would definitely reaffirm to them. That is very normal. It's okay. And that we all experience periods very differently. So you may experience pain. You may not experience pain, but whichever (.) whatever way you experience it, it's okay, because I think a lot of that (.) as a child, you're scared. So it would be more so around re-assurance, because to be honest, I don't really understand periods myself, which (.) and I'm 28. So I think the way you explained it, because you've had to go through more of an understanding of what this is and what this means (.) for me is it's like I know that we're bleeding because we're releasing the um eggs that didn't fertilize. So, I would say that. But even that I just feel like my vagina is bleeding for three days, three to four days. And for me, I think it's a cleansing. Very strange. I just feel like my body's cleansing itself because honestly. Because the way that I experience it, because I do the number two a lot [laugh] during that time, I honestly feel like my body's being washed out. And it's just after (.) because I honestly feel after I've come off of it [phew- sigh] like a release. So I would explain it that your body is just cleansing itself out, not that you're not pure because you're having your period, but it's just like getting rid of like (.) um the things that didn't fertilise and you're just bleeding that through. And I'd also say to them that (.) this is a very powerful thing. I'd say to them that your period is very powerful. The fact that you're going to live with that and you manage it is very powerful and it's very unique. And I'd make them feel like (.) it's special. Even if it doesn't always feel like that [quiet laugh]. **Faith:** For me. I'd especially want it to be explained to boys and girls together. **Gemma:** Yes!. **Faith:** Because up till now, I feel kind of taboo when I tell a guy I'm on my period (.) **Gemma:** Yeaaah! **Faith:** But why should I? **Gemma:** Yeah. **Faith:** It's normal. **Gemma:** And that's why I would definitely say like I would want to explain it with a boy and a girl there and tell the guy. This is a powerful thing that women go through. These girls go through this and guys don't necessarily go through this. It's difficult now, though, in this day and age, isn't it? With like different people changing different genders at much younger age. Like you have to be kind of like, I don't want to say this is something that a 'girl' experiences because. It's complicated, more complicated now, right? So I would just say that like the female? Maybe female isn't the right word? But 'owning a vagina' I don't know. I think that would make it more difficult. I wouldn't wanna say only 'women' but 'someone with a vagina', or if you have a vagina, then this is what happens. Because even if you don't make the change, you might not have a period, isn't it? I don't think you can get periods. I say if you have a vagina. This is likely to happen. I think that's what I would say. And I wouldn't just put it to a girl or a woman because that could (.) cause what if I'm talking to a boy, and he wants to be or associate himself as a woman. Or he feels that way, then he might feel secluded? So you know 'Oh now I can't be a girl because I don't (.) I'm not gonna have any periods. So, very basic. [Laughter]. **Interviewer:** Oh! I was just gonna say that it's not basic, and I think that was really inclusive and wonderful! **Faith:** Yeah absolutely! **Gemma:** That's how I'd explain it.

**Helen:** Oh, God [still wiping eyes and laughter] (.) that's a really good question. Since I have an eight year old daughter [laughter] I think about this all the time. I'm like "when do I start talking about this?" Um (.) so (.) how do I describe a period? Your body gets ready to (.) I don't know, this one is really uncomfortable. [Laugh] I don't know! [Laugh] My god! I'm failing at my job. [still wiping eyes but smiling] **Interviewer:** Oh, honestly, this one has been very, very tough. I've spoken to doctors and people who have lots of daughters and they've struggled with it (.) **Helen:** Yeah, right. Like I could talk to anybody else, but you know, thinking about my own daughter. Um. You know, I mean, she understands that, you know, moms, we have an egg and da (.) Dad has a seed and we're born with all the eggs we're ever gonna have. But we're not ready (.) our body isn't ready to have a baby or make a baby until we're of certain age. But honestly, I have not talked to her about what that whole thing means. So I don't know how to explain that? [Incredulous] Yeah. God, that's horrible!? [Pained look on face and laughter]. **Interviewer:** Right, so this might be tricky (.) [laugh] please don't feel bad, you're giving me very interesting data so (.) **Helen:** [Laughing] but who gets to read this report?! "Activists don't know how to explain periods to their own children" [laughter]. **Interviewer:** Yeah. Like if I was a tabloid writer. Yeah, That would be right (.) but don't worry about it. And I have er several nieces. And so far, I haven't been allowed to give them the talk. Even though I'm like bursting, to (.) but I think I would get very technical. I think that would be my issue is I would go straight to like the science. And really, they don't need all of that? **Helen:** I think that's what it would be (.) I think because it crosses the line of, you know, being a parent, you do it on the fly. Most of the time, you know, we're just learning as we go and then talking to a (.) someone else in the field or someone else that's a peer. Like talking to a peer is highly different than like how do I explain this to a child that's age appropriate, you know, when it was never one explained to me (.) age appropriately. There is a need for a class for moms to explain this to their daughter! [Laughter]

**Kathleen:** Hmmmm. [long pause] I would say [pause] periods are [pause] something that happens to women and (.) part of their natural (.) erm [long pause] just part of the natural way that their body works. Um, it can happen monthly, but it doesn't always happen monthly. Some women have them, some women don't, um but it's just part of our natural way of um (trying to think of the right word) er (.) natural way of allowing eggs or cells to leave the body. Um, yeah. And I'm sure there'd be follow-on questions after that! "But what do you mean? Why do you have eggs?" [In child-like voice] [laughter]. **Interviewer:** Yeah, you might have to talk about sex, but (.) **Kathleen:** Exactly! But yeah, something like that.

**Aisha:** Oh my God. I'll like (.) I'll make them understand that it is something (.) it is a major thing of your life and it does affect you and definitely to be always tracking your moods, regardless, every single day. And um, also, like, understand, like it's OK. It happens to (.) like. It won't necessarily (.) you won't have pain or whatnot. But you know, the mood side of things. I'll explain that to them because we was not explained that at all.

**Mala:** I would say that it's a monthly cycle that (.) that every woman has. It's something that cleanse (.) I feel like it cleanses our body. And so it's very natural, a natural thing to happen. I'm quite open with (.) I feel like in my family now it's quite open. Like the men (.) and men know it's okay. We don't openly speak about it but we know that this is happening. That's why she's acting like that [laugh].

**Noor:** Oh, that's a difficult one! [Laugh] **Interviewer:** Yeah it's a tricky one (.) **Noor:** Um [pause] periods. I'd say it's something that every woman (.) has. I actually don't know! I'd probably do my research and then find the scientific stuff about it. **Interviewer:** So this isn't a (.) a test. This is more like (.) **Noor:** Just what you would say. **Interviewer:** Yeah. What is it that you (.) think I suppose, within yourself, even, about periods? **Noor:** Yeah, it's (.) just that women that bleeds every month.

### P7- Why do periods occur?

**Ria:** Hmmmm (.). So spiritually, I think that it's the way that the Cosmos has literally given us (.) a time to take breaks to care for ourselves [laugh], because it seems like in this humanity that we live in, that menstruators are time and time again the primary caretakers of the world (.) of humanity [laugh]. And as a biologist, I can say the same in pretty much every mammal. Um, it's been well documented that the ones who bleed are the caretakers. And so it's like this cosmic balance between masculine and feminine. And, you know, all the things that femininity embodies and all of that. And then physically, I think a lot of people would probably say it's to bear children and like continue on and all of that stuff. So that would be one thing. But for me, physically, it's a way (.) it's a detox process. So the period is a form of our body detoxing. So in the other seasons, you know, we're exposed to all these toxins, toxic people, toxic chemicals, toxic, et cetera, et cetera, in the modern world. And then we ovulate. And ovulation has been shown to not only promote really good bone health for (.) in the long term, but, you know, like it's so good for our bodies. Our bodies love ovulating. So, yes. And then the period comes and it's a way of detoxing, everything we've been exposed to. And then mentally, I think the period again is a time of quietude in a world where our minds are just constantly stimulated and we spend a lot of time like up here in our 'feels' (?), not as much grounding to the ground. So the period is again a reminder to just allow yourself to quiet the mind in whatever form people do that. And then emotionally it's also a form of release and detox because that autumn season PMS, as people call it, is so intense, like 'leaves are literally being like pulled from the body'. It's very (.) there's a lot of compost and movement and huge drops in um the temperature change, for example, even going up. And so the period is a way for that emotional release to also happen. I know there are days when I have a bit longer cycles where I'm just like, "Gah! Period, like come already!" I'm literally like vibrating. I need (.) I need that release to come and happen. And then the physicality of it all.

**Beth:** [Long pause] Erm, well they occur because human women are basically (.) after they reach a certain age. Erm, unlike other creatures, fertile all the time, so in the event of not becoming pregnant until (.) what sort of preparation and building up of the womb lining to prepare for pregnancy (.) has to (.) come away (.) erm, and whether (.) whether it's because we've evolved to sort of be well enough nourished to get pregnant throughout the year and we've got enough food supplies for that to happen, it means that periods are a regular thing in our species as opposed to us just having one time of year when we're on heat [laugh] like other animals (.)? So I guess from an evolutionary perspective, that's why we get regular (.) or most of us get regular periods. Erm (.)

**Dani:** Yeah, basically the above. Erm, Yeah. To get your womb ready for a baby and then it doesn't come and so the lining basically sheds and gets ready for the next month. **Interviewer:** Right. **Dani:** Is that right? **Interviewer:** So what I'm doing is (.) it's kind of the words and way that people describe this is what I'm comparing so there aren't any like right or wrong answers (.) so (.) I'm not testing (.) **Dani:** I know but still I feel that I should get it right [laughter] OK, cool.

**Emma:** [Long pause] We need the menstrual cycle or the ovulatory cycle to have children, so biologically it (.) it allows us to [pause] to (.) procreate. Er, yeah, in a very basic simple form! [Laugh]

**Faith:** Um. Theeeee preparation for childbirth. So the egg fertilised or whatever or expecting to be fertilised and then it's not [pause] and released? [Laugh]

**Gemma:** Preparation for childbirth is the only thing I was told, the only thing I know. Still don't understand, fully. Honestly, it's really weird but I just don't. But yeah, your body is preparing to have a baby and it's not having a baby. So you bleed. And that's why when you're on (.) when you're pregnant (.) for the most part, you don't get your period (.) so.

**Helen:** What is my understanding of why periods occur? Well, every 28 days or so on average. For me, it was thirty nine [laugh]. Your body releases an egg to be prepared to be impregnated and carry a baby. Your body releases an egg. And actually let me back up (.) before your body releases the egg (.) the wall of your uterus starts thickening to prepare to have a baby. So a place for the egg to go. So at the time when you release the egg if it's not fertilized, then your body says, "well, I don't need this lining" and it sheds it out into a menstrual period and if it is fertilized, the egg, will, ideally attach to the uterus lining and stay there for nine to 10 months until it's ready to come out.

**Kathleen:** [Pause] Um [long pause] periods occur (.) I should know this better but (.) um (.) **Interviewer:** By the way, this isn't a test! Everyone always feels like I'm testing, but what I'm doing is comparing what words people use (.) **Kathleen:** Yeah [overlapping] **Interviewer:** And how people talk about these things (.) **Kathleen:** Yeah, I know. But (.) um (.) I think periods occur as part of a natural cycle. To um, (.) yeah, a natural way to allow our eggs to leave the body. Um, because if they stayed in there they would (.) probably cause harm [laugh]. And, obviously it's part of um (.) yeah, we have our eggs so that at some point we can have children, but I um (.) yeah, that's probably what I'd say.

**Aisha:** [Pause] I guess it's for [pause] um, it's just the way our body kind of (.) I don't know? [Pause] It's like (.) It's preparing us for birth type of thing, more. I think?

**Mala:** Like I said, I believe that um (.) it's because it's trying to cleanse our body. So it's the [long pause] so the cycle, the wall that we have in our womb is trying to (.) it's just releasing it, taking out the blood, the bad toxins and bad blood out of your body, so you can re-start your cycle. And I think it's the (.) I feel like it's like a release of hormones as well. So when I do start my period, I'm back to normal. I'm my happy self. So I feel (.) it's like a relief for me.

**Noor:** Er (.) I understand it, but to explain it, I don't think I'll be so great? [Laugh] **Interviewer:** [Pause] so to do with (.) er, like having children or? **Noor:** Yes, so I know, it's the body um (.) What's that word? Every month. **Interviewer:** Yeah so just kind of cycling? **Noor:** Yeah. That's it. **Interviewer:** It's kind of like rejuvenating? **Noor:** That's the word yeah- rejuvenating every month, just to make sure that your body is normal, and it can have babies and stuff like that.

### P8- Religious, spiritual, or other symbolic significance?

**Ria:** Yes. And so I'm very excited to be working on a project that will be trying to uncover more of the positive aspects of periods around the world as it pertains to spirituality and spiritual health and I guess religion. I won't go into the definitions of spirituality and religion, but there's lots out there to talk about it. So for me, I religiously identify as a practitioner of Sikhism and Sikh, and primarily I follow a Sikh feminist interpretation of the scriptures and my practice of it. And so what I have found and please tell me if I'm repeating myself, I don't remember what I (.) if I had shared this in the last interview, but basically (.) so my ancestors, Sikhism was born in about the sixteen hundreds in modern day India and Pakistan in the Punjab region, which in 1947 before it was like one region. And then borders were drawn, blahblahblah, partition happened. And so prior to partition happening for those three four hundred five hundred years it was a very volatile and tense, um violent space. It wasn't always like that. It's just that like this anger and frustration in (.) at literally every human living there got so intense and at the same time, like the and the Muslim empire and the Vedic, Hindu empire and the males and their hetero patriarchal interpretations of the Koran and the Vedas which. For the record, nowhere in those does it say menstruation is pollution, menstruation is bad, any of that stuff. It's not written there. It's just people using them to get power for themselves and they happen to be male. And so there was a lot of conflict. And so out of that, Sikhism was born, which the original founders were like. "OK. Everybody is dressing the same. All genders are equal. We're all going to make food together. We're all going to sit together in circles and we're all going to do service and sumgut, savar and lunger; service, community and food are the three tenets of Sikhism. And so part of gender equality being a piece of that as the person that I mostly follow, Nikki Gunnendenkar Singh who's based actually in the UK. She wrote this great book called The Birth of the Khalsa, a feminist re-memory of Sikh Identity. And in it, she talks about how the Khalsa was basically like a process of childbirth that this had been gestating. And she talks about how the first proponents of it believed in the process of menstruation and the life giving power. And it was very much honoured as opposed to the way that it was being interpreted by these like huge patriarchs, basically. And then they were telling everybody to not go into temples if you're bleeding and from (.) and I didn't understand why. And so then I in my research on Coast Salish Territory shows that indigenous folks there, they also do 'quote un quote' in English language do not let people who menstruate go into sweat lodges. And so I was then got curious about why that was. And according to their knowledge and wisdom, it's because they (.) we're too powerful on our periods [laugh]. And so our energy on our period just ends up affecting everybody around us. And so that's why period is a time of solitude. So those people to do their spiritual work, they would (.) when they're in the winter season of their cycle, they would go and do a solitary activity. So whatever brought them joy and pleasure at that time. However, because of hetero patriarchy, one- people were barred from these spiritual sites. This is my interpretation from periods because they were too powerful and because the men presumably wanted to be in control, which is like we can't argue against that because if we look at every head of state in the current iteration of nations, you know, whatever percent are males. So that's a commonly understood form of power and democracy. And so we can say that (.) that men (.) we live in a patriarchal society right now. And so, yeah, so that's one aspect. And then the other aspect is like, I guess over time it's (.) blood has become this thing that's now. GROSS. As opposed to, I don't know, I'm pretty sure human (.) like ancestors from a million years ago [laugh] didn't think blood was gross because it's literally like how we survive. And people even if we think about people who survive off like seals and still just eat raw seal with blood and it's like beautiful. And that's an example of people living more in alignment with our (.) like the more than human world around us and blood being a connection to all of that. So those would be (.) that would be my answer to the religious aspect is I think in every scripture and every oral history of what we understand as religion, it's seen as a positive thing. However, over time, due to I don't know why it's like written in the Cosmos, that hetero patriarchy [laugh] is just going to be a thing that we live through. Over time you see it in pretty much every religious scripture. Like same thing happened with the Quran. Same thing happened with the Vedic scriptures. Sikhism is interesting because it's one of the newest. It was only started in about the 1600s. And still we can see like literally [laugh] they said "we're gonna do gender equality" 400 years later. Is that happening? In my opinion, not as much. People are trying and becoming more aware of it, which is great. Like in the UK, for example, there is the Shepherds (.) a guardwara in Shepherd's Bush, and they implemented a period policy where they're giving out free period products. They're doing workshops about it. They're hopefully talking more about it. And I hope that will also translate to more spiritual leaders who are menstruators. And a removal of this, I don't know where this belief came from that periods (.) for some reason people should not engage in spiritual activities on their period. It's more so we need to understand that it's based on those four cycl (.) four seasons our spiritual activities will look different and to accommodate and respect those different changes, just like we do the physical emotional changes and also the spiritual aspects of it. So yeah.

**Alice:** No [gentle laugh] **Interviewer:** So, not at all? **Alice:** So also (.) the only thing I would say as somebody who has now gone through the other experience [pregnancy/ conception], because I was told that it was always very likely that you would get pregnant very easily. And actually it's not until you start that process that I think and I think there is a strong connection between periods and people who've gone through traumatic periods and then conception and fertilisation (.) for me. So I have always been quite anxious about carrying a child because I've always had, out of all three of us, we're very close sisters and family (.) I'm the only one that has experienced this so while they are very supportive (.) [sigh] I don't think (.) I think they look at me and think 'God that is so horrific and feel terrible that it's horrible to have to go through that (.)' And what I'm getting at here is actually (.) I've had some anxiety ever since I experienced this, which has been much later on in life, but my periods have been very much up and down, as I said. I mean, I could speak for days about my journey of having periods. But for me, there is a big connection between releasing an egg and what happens to your body and then how is it your body, who (.) who (.) then struggles with that kind of (.) then carrying a baby. And then I (.) also I'm pregnant at the moment, and I'm quite fearful of the end, you know. And some people have said, 'oh, you'll be fine because you've experienced all this trauma just through your periods'. But actually, could that could that contribute or maybe it would be extra worse. You know, maybe it's my experience in speaking to some professionals that they sort of see this as very scientific and that they often have said things like we'll do a scan and then we might have to do something invasive and you might have all these physical issues and actually I’ve had multiple scans and they’ve not found anything wrong at all (.). So no religious. No spiritual, no. But I think as I said to my mum, 'I felt a few things, which is I think the whole fertilization is much more spiritual'. And, you know, maybe spiritual isn't the right word, but it's more magical. **Interviewer:** Yeah? **Alice:** And you can’t just get pregnant like that. Which is what you're taught in school. And we haven’t (.) so this is my third pregnancy, but my erm only successful one. So I've had miscarriages. My miscarriages have been like my traumatic experiences that I've told you about. But a hundred times worse. **Interviewer:** OK. **Alice:** So I would say not spiritual, or religious, but I think that's something (.) maybe that's a coping mechanism for me this time around. It's been like a miracle now. It's magical. And actually, you know, teaching children, you remember this is as an adult. Just that don't ever, ever sleep with anyone unless you have contraception because you you'll get pregnant instantly. Might be the case of you’re 16. Actually, that education needs to change (.) it is quite traumatizing for people when they've been trying. I've got friends who've been trying for three years now. You know, in one of them, the husband says, 'I've no idea why I've used contraception for 10 years because I clearly didn't need to'.

**Beth:** No, I mean, like I said before, I remember my mum calling periods 'the curse'. But I think (.) that was more of a generational thing than a religious thing. My family sort of went to church, but we weren't particularly religious. So I think she just called it 'the curse' because that's what her mum had called it and her mum had really bad periods. I don't hold any (.) Spiritual or religious significance with them, no (.) no (.)

**Dani:** Well, because (.) being Jewish, you sort of grow up with periods being (.) essentially dirty. They never really say it. But I grew up in in an orthodox synagogue, but wasn't really orthodox in practice with my family. But I remember my grandma. Um, she used to come and visit from Glasgow. She must have gone to (.) I think maybe she went to a bit of a different, more liberal schule? But every month, every month, every time she would visit, she would go to shake the hand of the rabbi. And it was quite like (.) she would always forget or I don't know if she forgot on purpose? But basically, like men aren't supposed to touch women because in case they're on their period, then they're impure. And so I remember like it was quite a big deal because our rabbi was like, oh he was a really nice man and never embarrassed her by not shaking her hand. But basically the implication was you don't (.) religious men especially, but just men shouldn't touch women, because if they're by any chance on their period, then they're impure. Which is like I mean, obviously, it's not something I believe intellectually, but I think that kind of thing must stick with you when you've basically grown up with that. Not in my family at all, but in your sort of community. And I think it's very much an understanding and there's, you know, religious practices concerned with it, such as the mikva. which is where you sort of cleanse yourself. That the period is dirty and therefore requires cleansing. So, yeah, nothing spiritual personally. To be honest, I don't find my period particularly spiritual. It just comes out it's (.) well it just shows me my body's working. But in terms of religious, even though I'm not religious, it has those connotations. I think sometimes without realizing.

**Emma:** So for me, no. but I have heard about the significance in other cultures. A lot (.) a lot of times that's negative. So things like (.) women being shunned from the community when they're on their period, and not being allowed to sit down on chairs and having to have (.) to go through a cleansing ritual after their period. Yeah, but for me personally, no, there's no kind of (.) spiritual [pause] I almost wish I did [pause] relate in (.) on a deep level, but for me, it is a very pragmatic thing of [pause] it's a biological process and that's it, but maybe that's because I have a very dysfunctional relationship with mine (.)? [Laugh]

**Faith:** Um. This isn't (.) this is just me being weird. So basically when I was younger, not younger, but I went I was like a teen, through my early 20s. I used to feel bad. I used to be like 'this could have been my child' [putting on sad voice] [laughter] but that was just me being (.) weird. [Laughter] **Gemma:** Really? [Incredulous] [Laughter] **Faith:** So when I saw the blood (.) it was 'Oh, this could have been the blood of my child'[laughter]. Seriously. I've never like (.) um, we're both Ugandan so that's quite interesting, so I'll ask (.) er, my Mum to see if Ugandans have any significance (.)? **Interviewer:** So do you mean you'd feel a bit sad? Like, that could have been a child, but it wasn't? **Faith:** Yeah! [laugh] Perhaps like a potential life [nervous laugh].

**Gemma:** For me, Spiritual. Yeah. Which is really weird. Just because I really do associate it with the cleansing because I think it's (.) I found my period very liberating. So I actually like the fact that I feel more (.) I think. I just think it's a beautiful thing. Like, I like the fact that I cry. I think it's so strange, like (.) and I think it's amazing as well. Like how our bodies are like, why am I crying and why is it uncontrollable? And I have no control over that. But I know it's going to happen and I can't stop it. So I just think I find it very liberating and very like spiritual, because I think, like, you don't have any control over this issue, your hormones, your body is kind of acting alone (.) and just allow it. But again, my (.) I think I think that way (.) because I don't go through as much pain as a lot of women go through, touch wood [idiom]. So because of that, I'm able to see (.) but like if I was not able to walk for three days, I'm not going to find it beautiful, you know? Yeah. [laughter] **Faith:** No way! [Laughter] **Gemma:** Because I get one day of like, you know, my contractions. Then it's not as bad for me. So I think that's why I'm able to see the more positive. **Faith:** Yeah.

**Helen:** Noooo (.) but I kind of wish it did. **Interviewer:** Mmmm **Helen:** Yeah, I think it would have been less like 'this is just a thing you live with' and more of how (.) why this matters to you [pause] I think it would have made a difference. You know, like as far as (.) because there's that you know, "Oh everyone has a period", you know, "you're just not (.) you're being mentally weak". "You're not (.) you know, everyone has a period and people don't act like you act, you know, before your period or during your period". So I think um ascribing a more, more or less what's the word, existential or more meaning to it, you know, as far as like (.) you know anything like applying anything less biological meaning to it, I think would have been helpful. But it wasn't my family experience (.) so [laughter] **Interviewer:** Yeah. That's interesting, you sort of feel that (.) having a kind of (.) probably more positive kind of outlook on it? **Helen:** Yeah [nodding] **Interviewer:** You know, that (.) that could have had um (.) I guess sort of made up in some way for some of the negative things that you were experiencing, that kind of thing? **Helen:** Yeah, like there's nothing good about it [serious]. It was horrible [laugh]. Like, I felt horrible, like it wasn't anything worth celebrating (.) it was something (.) you're like plagued with, you know, there wasn't anything great about it (.) [tone change] other than when I was trying to have children. It was a great way to know, "hey, I'm going to ovulate, let's make a baby!" [put on excited voice], you know? So that was exciting. Outside of that, not much positive about it.

**Kathleen:** Not to me, no, no. [pause] I (.) er I do know (.) yeah, I was brought up in a Christian faith. So I do know (.) in some instances, it can be but not for me.

**Aisha:** Um, not necessarily. But as a woman, I do feel as if um we are not allowed to pray, etc. And it does give that time (.) because as women, we are a little bit more sensitive emotionally. But this is just my view. The fact that I believe in my God and I believe he gives us that time when we are on our periods to be able to reflect on ourselves kind of thing and be easier on ourselves? **Interviewer:** [Pause] so you see it as sort of time off, or for time to (.) Yeah. Yeah. To take care of yourself? **Aisha:** So yeah, basically.

**Mala:** Not so much. It's like a (.) it's like a thing that a female goes through every month (.) that's it really [laugh].

**Noor:** Well, in my religion, we can't pray while we're in (.) on our period, but I see that as a positive thing. Cause it's kind of like a break. **Interviewer:** Yeah. **Noor:** And then (.) and I feel like our religion (.) religion knows that it's a tough time for women sometimes not for everyone, but some women. So it's that break. Just sort of 'do you'.

### P9- How do you feel about periods?

**Alice:** Yeah, well, [laugh] it's nice not to have for that not to happen at the moment. It's lovely (.) I mean, being pregnant, you get slightly different hormone influxes and definitely different circumstances, a different kind of journey (.) I think I just don't (.) I deal with it. You know, I've learned to deal with it. **Interviewer:** So you just will deal with it at the time? **Alice:** I do not let it overrule my life. You know, I will rarely (.) I mean, if I've had like a horrible one of those one in three periods and it's happened in the middle of the night and I've been up all night, then I might be late for work for three or four hours and I'll have to call in. And I won't tell the truth. You know, I'll say I've had (.) I'll just say 'I’ve had vomiting' and often then they'll be like 'don’t come in, if it’s something infectious or whatever'. So I don't (.) I do not let it ruin my life. I just get over it. Do I worry about each month? No (.) I have people around me said, you know, you really need to do something about it. Yes, but to be honest, I've got to the point of, just ignore it.

**Beth:** [Long pause] Erm, personally (.) it's just something I've accepted really (.) but I think I've been pretty lucky, though, because (.) over the whole course of (.) erm, my life since I started menstruating, I haven't had any major problems with them. I'd imagine for a woman who'd had really, really painful periods ever since she started or really heavy periods or other sort of major health problems associated with them. It would be a real drag and quite debilitating for her to look ahead and think, 'oh, god, I'm gonna have periods until I'm like in my mid-forties, mid-fifties'(.). But for me, it's just a thing, you know. It doesn't bother me that much. It's only been over the last, I guess, five years (.) that premenstrual symptoms have become more of a drag. And I sort of don't look forward to that every month. But (.) apart from that, the thought of having periods for many years doesn't bother me. And (.) you know, it's (.) enabled me to (.) the fact that I have periods is an indication of, you know, fertility, it's allowed me to have a child. Theoretically, it still gives me the option to have another child, although I think that's quite unlikely given personal circumstances. Erm, So I think, you know, that's the positive side of having periods for many years (.) is the sort of fertility side of things for women who actually want to carry on having children.

**Dani:** I mean, before I started working in periods, I just don't think I really cared. Like I just was like, it's just you can either be on the pill and it not be your period (.) and you could do that or you could have the coil and not have periods at all. Or you could just crack on which I was, but like I just didn't because they don't really affect me or they didn't (.) I didn't notice that they did because I wasn't tracking. I didn't really care. And I still don't actually quite (.) not enjoy (.) but I appreciate having my period now because it probably because of the work I do like because I kind of have to (.) but I think that it's always just been to me, it's just part of life. It's not like it's not a bad thing. It's not a good thing. It's (.) it's (.) it's just your body (.) it's just your body works basically by having a period. [Pause] Yeah. I mean, obviously, like I'm furious about all of the inequalities surrounding periods because, you know, we're made to feel like we're dirty, we're made to feel like we're like less capable, you know, all of this. But [pause intake] I just (.) I don't see it as being true. I think there's a lot of education to be done. But yeah, I think it just doesn't really feel (.) it often feels quite neutral to me having a period. That's just what it is. **Interviewer:** Okay. **Dani:** And it means (.) that means I'm not pregnant. And, you know, [laugh] that is a worry when you're trying to not be pregnant. Having your period is a relief. It shows that you're not. So, yeah.

**Emma:** [Pause] I fuckin' hate them! Excuse my language. [Pause] Erm, the thought of going through this for another however many years and then going through perimenopause and awww, and the fact that I (.) I don't want to have children either. So, the menstrual cycle to me is [pause] I lose two weeks a month every month. [Pause] That's how it feels. It feels like a half-life. It's annoying. It's a pain in the arse. It's (.) it's frustrating, it's exhaustin'. And I've (.) given the opportunity I would consider having everything whipped out just to have a better quality of life than what I've got now. But I'm keeping everything crossed that the drugs that are in development will hopefully be available within the next three to five years. But yeah (.) for me it just feels like such a (.) an unnecessary evil that I would rather not experience. And I feel really awful saying that because there are people who don't have periods, which means they can't have children and they want children. And so I feel very selfish when I say that in some respects (.). Yeah, but that's (.) it's (.) it's very difficult to feel any kind of positivity apart from the few days I get when oestrogen is dominant. Yeah, but it just (.) it has caused so much disruption to life and I feel like (.) I wish I'd know much more about periods and menstrual cycles and menstrual health and well-being and PMS and PMDD and Endo[metriosis] from such a young age to because I feel like at thirty three I'm only just beginning to take control. But it's more like my menstrual cycle controls me and my life, not the other way around.

**Faith:** Sad (.) No! [Laughter] And I think that the perspective that Gemma said it was really lovely, but I'll be honest, that on a personal level, on a general level I get the significance of it but on a personal level. I (.) **Gemma:** (.) Struggle [whisper] **Faith:** I really really, like, you know, when you're just exhausted at life? **Gemma:** Mmmmmmm **Faith:** And sometimes I've just felt like (.) 'Is this like is this really what I'm going to go through until menopause? I don't want to do this, sort of thing. And this is how it is, it's just been like really depressing (.) **Interviewer:** Aha **Faith:** Really depressing, really depressing just in terms of like the pain inside. There's no getting used to the pain. So, yeah, it's been really [Gemma providing various encouraging noises] **Gemma:** Every time is like the first time (.)? **Faith:** Yeah. [Pause] I haven't (.) taken well to it (.) [trailing off]

**Gemma:** [Interrupting] I'm not happy (.) I'm not happy about it but I'm not sad about it. I'm just I'm kind of like, it is what it is. Um (.) the thing that makes me happy about my period is because of the cleansing that I feel because I feel like it's like I don't cry for the whole month and I almost feel like it's a release (.) I'm looking at it more of the emotion, what it does for me emotionally as opposed to physical because I don't feel it as much physically. So the emotional part, I enjoy that part because I feel like, you know, in a month, things piss you off. Work pisses you off? But I don't cry. That's just not me. And I just like the fact that you're going to cry and you're not going to stop and you're going to release. So I look forward to it. I'll put on something, a stupid little M&S advert, and I'll start crying (.) [laugh] **Interviewer:** Yeah, it's always adverts! **Gemma:** I always cry, you know! [Laugh] Good old Mark's and Sparks just get the tears going [laugh]. And I will cry for like an hour non-stop. And I'm laughing because I'm just like, 'you're not even sad. You just you just need to let it out (.)'

**Helen:** Well, once my PMDD was in full bloom. It just felt like a life sentence. I felt extremely hopeless when, you know, I tried all the different treatment options. Nothing worked, at least nothing worked long term, um (.) you know. And then the next step was the Lupron, trying Lupron. And when my insurance denied it I remember just like, "well, that's the end. Never gonna make it to menopause". It was too far away. It felt too far away. I mean, now that I'm 40, it doesn't feel that far away. I mean, it's over now, but, you know, [laughter] But Yeah. It felt like a life sentence. It just I was like, I'm not going to make it. I'm going to kill myself before that happens [serious].

**Kathleen:** I've got to be honest, I [pause] when I (.) I had some really difficult years, with my period, when it was very painful? I think it was probably towards the end of my teenage years going in to my 20s and then they mellowed out. And during those years, I hated them, it was just like (.) I mean, it was so bad, sometimes (.) I think sometimes I had to take days off school and that kind of thing. Um, but as I got a bit older, they got more and more (.) It just became a natural part of life (.) um, until fibroids came. Um, but how I feel about them now? I do feel (.) I feel like they're a good thing. I feel quite blessed to have my periods. Uh (.) and I (.) it took on a greater meaning to me (.) um, after they stopped for a while because I had to take um (.) some medication, to stop them ahead of my surgery. And so I did panic a bit, like "What if they never came back?" You know. Um (.) and I think just going through that whole journey and then having them come back, I felt very blessed. You know? Like I (.) yeah. I feel quite grateful to still have them.

**Aisha:** Like um (.) I've accepted, it. And I believe, yes (.) it is the right thing because when I don't get my periods when I'm late (.) it really affects me as well. Like I'm really late at the moment and I'm not myself and I get a bit confused. Oh, my God. I’m meant to be PMSing. But I'm getting a late period and I like (.) I appreciate that (.) it does come every you know, for 40 years. It feels normal. If that makes sense?

**Mala:** I feel (.) I actually feel okay um (.) because when I do get my period, I'm actually really (.) I feel like (.) I do feel that relief. It's like these emotions that are built up inside me throughout the weeks and it is just like a relief for me so I do feel good about it.

**Noor:** A couple of years ago, I'd be like "eurgh", because I used to get so much pains, but now I'm used to it and I don't mind. It's just one of those things that happens. **Interviewer:** So has the pain got better? **Noor:** Yeah. Yeah. Much better.

### P10- Magic wand?

**Alice:** Well, I wouldn't want that necessarily because that would mean I can’t have children. I'm (.) actually I think releasing an egg and go through that process is something that a lot of people say, 'oh, God, I never want that to happen again'. But for me, it's more of a necessity for new life. And I think if you speak to women who go through the menopause, which is maybe another study you could do [laugh]. There's a real lack of evidence and research and that and a lot of people would say, 'I would give anything to go back to feeling the way that I felt when I did menstruate, even if I had terrible menstruation'. So, no, I wouldn't want that for the reasons that I said. And, you know, I am a bit more fearful as well of what happens to your body just physically and emotionally when you do go through the menopause. But if I could have a magic wand to take away my one in three only for those four hours, that would be great.

**Beth:** [Long pause] Ohhh! Probably not, because(.) Although I really don't like (.) some of the premenstrual symptoms I get. Erm, I don't know how I'm going to feel (.) I think it's a case of better the devil you know, from, you know, from a personal perspective. In that if my periods just stopped (.) I'd effectively be menopausal. So would I feel even worse if I wasn't having any periods at all [laugh]? I don't know if you mean is this just a magic thing where you could just stop your periods and there'd be no sort of menopause consequences of that? I think I'd rather be having periods than go into the uncertainty of an early menopause right now. And also it would also take away the option of having a child ever again. Even (.) which is silly, because rationally, I know that I'm, you know, ninety nine point nine nine nine percent sure I'm not going to have another kid, but just the fact of completely taking that option away, I'm thinking “not sure I'm quite ready to like say definitely no (.) 100 percent not just (.) stop my periods and that's it”. You know, it's not rational, but that's how I feel.

**Dani:** I really don't think I would, you know [pause] I really don't (.) I probably would have said like years ago. "Yeah, yeah, definitely". But there's just I dunno? I appreciate it. I like having it. It's not like (.) I like (.) I like the way that my cycle works. I like that (.) it sort of tells me where I am in the month, you know? Not in (.) you know, in a red tent way, [laugh] but just didn't (.) you know (.) but, you know, I do have different energy levels at different times of the month. And that is like my marker. And it does help me look after myself, basically. So, yeah, no, I don't think I would get rid of it, to be honest.

**Emma:** Yes! [Laugh] Yes! [Laugh] If I had a genie with a lamp and three wishes, that would be one. Yeah, I would definitely. Definitely.

**Faith:** Can I still give birth? **Interviewer:** Um Yeah (.) it's a magical thing. **Faith:** OK yeah. Hands down. **Interviewer:** So you want the fertility? **Faith:** (.)[Nervous laugh] yeah! **Interviewer:** (.) But you don't want anything else? **Faith:** Yeah. Unless I could have pain free periods? **Gemma:** Or limited pain because you get it on the next level? **Faith:** Yeah [pause- interviewer turns to Gemma] **Gemma:** No, I wouldn't [pause] I can manage it for now. Touch wood. It's horrible, but it's not as (.) I know (.) I've got friends who [names], like (.) I've got friends who experience it (.) next level, and I'm (.) because I'm around them so much and I see (.) I see (.) I hear the pain they go through (.) **Faith:** Even just like (.) the embarrassment of like leaking. And just like every time I get up I'm having to look at chairs to see like if anything is there, and all that stuff (.) **Gemma:** Because you're like really heavy as well, right? **Faith:** Yeaah **Gemma:** And I'm not (.) so, you know. So I feel like (.) it's not that serious for me. D'you know what I mean, I'm (.) I'm privileged. I'll keep it [laugh]!

**Helen:** So hindsight, I have the benefit of hindsight, and the fact, that I don't have ovaries anymore so I am now living that life. It's much better obviously! [Laughter] if I had a magic wand, I would have had an alternative. I would still (.) I would have (.) I actually miss having a period. I miss the opportunity to be a normal woman with a period. Does that (.) make sense? Like. I mean [pause] I don't know. Like, I guess there's some deep sadness about (.) this was (.) like if I had cancer, I guess I would feel the same way? Maybe if I had to have an oophorectomy for ovarian cancer (.) I still have that? You know, we didn't plan on more kids, but had I got accidentally pregnant it would've been great to have another baby, you know, or it would've been great just not to be (.) you know, and pardon my (.) this isn't P.C., but not to be a lunatic [laugh] on my period. If that was my wand, that would have been my (.) my magic not to have to have surgery, to just have the normal PMS. Yeah. Or no PMS?! [Sudden realisation]. You know what, why am I shorting myself? If I had a magic wand. I'd have no PMS. I just have wonderful, beautiful always pad version commercial, you know, commercial version periods! [Laughing]. **Interviewer:** Yeah, I mean, occasionally I meet people who don't get any. They don't get any symptoms. And their biggest complaint is that they don't know when they're gonna start. And it's like, well, that's not a bad thing, you know compared to what you can get (.) **Helen:** Yeah [laugh] you could track that! Mark it on a calendar! You're good [laughter].

**Kathleen:** No [shaking head]. No (.) I feel (.) you know, as I said, I just feel (.) um [pause] yeah I just (.) I just feel like it means that if I (.) you know I do want to have children. It means that I can have children. It's just a natural part of the way our bodies work (.) it's doing (.) I know it's doing something good for me. I mean, it's just part of the way that God (.) I think it's how God has made us. Um, I'm quite grateful to still have them.

**Aisha:** No. [Pause] **Interviewer:** Is that for any particular reason? **Aisha:** Because when I'm on my period, I am the most happiest. **Interviewer:** [Laugh] so, yeah, they're your good time (.) that's great! **Aisha:** If you wave your wand about the PMS (.) then definitely! Yeah, but you know, when I'm on, I'm happy I'm normal and (.) yeah, I'm balanced.

**Mala:** No, [laugh] I like (.) I don't mind my periods! [Pause] and I think it's also because a lot of females, they do go through a lot of pain when they're (.) and I don't really go for much pain. Mine was a twenty one week cycle. And only lasts five days, and it's not very heavy. **Interviewer:** Sorry, so how long is your cycle? **Mala:** 21 days (.) **Interviewer:** 21 days, so it's a relatively short one, and a (.) **Mala:** Yeah. **Interviewer:** And a short period as well (.) **Mala:** Yeah, a short period. So I don't really have it like (.) long periods and I don't have to wait for it. It is very on time. Very short. Not very heavy. I(.) it's bearable for me.

**Noor:** Yeah [laugh] definitely. **Interviewer:** Why is that? **Noor:** It's the bloatedness [pause] the mood swings, sometimes. **Interviewer:** So it's that you'd prefer (.) because they're uncomfortable? **Noor:** Yeah **Interviewer:** You'd rather not have them? **Noor:** Definitely.

### P17- Visited a doctor? If so, how did it go?

**Alice:** Yes. So once this happened (.) well, to be honest, a few times. So at the beginning when it wasn't regular, but it wasn't that I ever had painful periods when I was younger, they were when I when I hit my (.) late 20s. And that was just really “put me on the pill”, mean it really worked (.) and that was that. And then I had irregular periods for a long time, but I could cope with that. So there wasn't any sort of pain or anything like that. I can completely cope with the emotive stuff and the change in boob size and weight gain, whatever, you know. It is the pain for a couple of hours or a whole day or passing out and the fear of that happening while out. That terrifies me (.) I actually can't tell you how painful it is- that it's so awful. I want to stop it and make it go away. So it happened once when I was in [an East Asian country] and I was with my sister, my older sister and my dad (.) and I said to them, 'I really don't feel good'- we were in the big shopping mall. And they say, I said, 'leave me on this bench'. And so they went downstairs for a different floor (.) and when they came back up, I kind of knew it was about to happen, but I couldn't go anywhere. I had vomited and had diarrhoea all over the place and I passed out in the middle of a shopping mall. And about fifteen women were openly fanning me and one had run to the chemist and got tissues. And my dad and sister arrived to find me in this heap. It was hard and really embarrassing, and I think that they were quite shocked at what had happened. So they rushed me to see a Singaporean GP who was in the shopping mall somewhere and the health services are completely different there. And he just took my blood pressure. And did all the normal observations. And, you know, I said, 'I'm on my period and I get this. Sometimes it's stress. I was in the wrong place and I wasn't at home'. And he just said, oh, I said, 'yeah, you're fine now. Everything's fine. Go home and rest. I think you passed an ovarian cyst'. And I was like, 'Oka::y, right. OK.' But I knew that I didn't have any cysts. You know, maybe I did. I'm a bit sarcastic about it, to be honest, because I just sort of think that we get fobbed off. So anyway, I went home and after a bit of pressure from family members, I think I had actually already maybe (.) I can't really remember the details, but I'd previously gone and like asked (.) just had a bit of a consultation and they just said this was normal (.) but then I went back and eventually asked to be seen. So I went to a GP, who referred me to a gynaecologist and he was a man. Which is fine (.) but they took (.) they had an internal transvaginal scan where they look to see if they could find anything. And they couldn't find anything at all. They couldn't find any cysts (.) and he said it was unlikely that you'd passed a cyst. And he said. And he offered me. He said two things. He said, 'there aren’t any signs of endometriosis but It sounds like endometriosis' (.) so I thought, okay. He said, 'so we can't determine whether you have endometriosis. The only other option is to have an invasive (.)' I can’t remember what it is called (.) **Interviewer:** a laparoscopy? **Alice:** Yeah (.) and he then said, 'obviously, this is an infection risk. And if you have that and we find that you do, we can, you know. What's it called like surgically? Try and tidy it all up by sort of cutting it, etc.' But to be honest, for me that isn't a solution. I don't want to go and have an invasive surgery. And if I do have it, why don’t I have this traumatic experience every month? I only have it like once every four, once every three, or once every six months. And I don't have any of the other signs of endometriosis. So the jury is still out there. So after that, I just thought. Well, that’s less than useless for me. So I didn't go back. I continue to get pressure from family members to go back. But I have to say [sigh] I think it's a waste of my time. **Interviewer:** So there’s a sort of sense of not knowing. And managing anyway. Or, does it make you a bit anxious that you haven't had like a definitive (.)? **Alice:** Not really. I think it’s more anxious for other people. I think I just. I just have learned to live with that and deal with it. And certain strategies work, and I don't live in fear (.) thinking, is this month going to be one of those months? I just hope that it isn't going to be, and get on with my life. I think other people who have witnessed it find it pretty traumatic to watch (.). So I've had that (.) when I'm in public, it’s so much worse (.) when I'm at home, it's fine. So once in the [overseas] shopping mall in public, it's bloody awful. And then once on the doorstep of my parents’ house. But luckily my dad was in. I’ve had it at home lots of times. When I’m on my own, I find them quite scary because I always know I will pass out for a little while and just hope that I wake up. So when I had one of my miscarriages, I did pass out. And my parents found me on the floor. So I think it can be much scarier for other people than it is for me because I have just learned to deal with it. So then they push you to say that must be something that can be done. But I actually just found that I think this is just a period for some women, full stop. And yes, you can get people who have endometriosis. Yep, and you can get women that have polycystic ovary syndrome. Yep. I think it's just menstruation, slightly different physical makeup's, hormonal imbalances. I mean, I haven't looked into any of this apart from my own research and reading (.) certain things can trigger and induce it and make it worse. So I know how to cope with certain things and (.) then exercise works for a lot of women. And I think it's like probably having a period or PMS or whatever the certain categories that women may experience these symptoms or no symptoms. And I don't think we've done enough research to look into why there are the variations of (.) of physical and emotive symptoms (.) I think we just it's easier sometimes to say let's do an invasive test (.) to fix it or (.) it's normal – get on with it! (.) But I do think it shouldn't be that (.) you should (.) you shouldn’t have to be like that. I mean, when I say that I've I think I’ve learned to cope with it, but I don't think you should have to cope with the traumatic ones. I don't think you should ignore that (.) I think there should be something that can be done. But my experience has been that there isn't anything that can be done. So I just get on with it.

**Beth:** Erm, no. **Interviewer:** Do you think that's because you're a doctor or for any other reason? **Beth:** Probably (.) erm, I don't know. It could be because, I mean, probably the most significant premenstrual symptom I get is the anxiety, but (.) but I have generalized anxiety. Anyway, I don't think it's caused totally by my menstrual cycle. It's not (.) it gets (.) I've got pre-existing anxiety that's aggravated by changes in my menstrual cycle (.) but the menstrual cycle isn't the cause of the anxiety, you see what, I mean, so, yeah, I've consulted a doctor several times about my anxiety (.) but I haven't really brought up with my doctor that it gets worse (.) as a PMS thing, because to be honest, I don't really know what they're gonna do about it. I'm already on medication for anxiety (.) I have past experience of not getting on very well with hormonal contraceptives, which I guess a doctor might offer as a potential treatment for PMS. So I've kind of assumed that there's no point in me personally (.) raising my PMS symptoms with a doctor cause (.) I have kind of (.) I've found a way that's good enough for me to self-manage it and I dunno what they're going to add to that? That might be a bit pessimistic? And I wouldn't (.) I don't (.) I wouldn't want that to put other people off, you know, seeing their doctors about PMS symptoms. But for me, I don't think it (.) would help?

**Dani:** Only in terms of when I've gone on the pill. So I went on the pill when I was 17 because my periods were so irregular, which is I'm really annoyed about that now because I'd only been menstruating for like four years. Of course it was irregular! So that's really the only time that I've been to the doctors about anything to do with periods. So not to do with PMS or anything. It's just never been (.) it's never been repeatedly that bad. So I've had like a couple of months here in there where the pains the cramps have been quite bad or I've felt really shit, but it's never been repetitive. So I've never really needed to sort of get it checked out.

**Emma:** I was fortunate to be seen by a lovely GP when I was struggling with (.) well, I didn't know it was PMDD at the time, but I'd noticed these cyclical mood changes and realized it was linked to my periods and when and spoke to (.) yeah (.) my (.) my GP. Who was a female doctor (.) probably around a similar age as well and she (.) she listened and said well it sounds like severe PMS. She didn't use the term PMDD she said 'severe PMS’ and presented a couple of options which was birth control, contraceptive pills, and anti-depressants. At the time, I guess I didn't really understand (.) why I was being prescribed anti-depressants because I wasn't (.) depressed (.) but, that was (.) she was supportive and I certainly wasn't dismissed or not taken seriously, which I know is the case for a lot of people in that position. And she wanted to see me again for a follow up appointment, if I remember right. I did go back two or three times because I think we did try a few contraceptive pills and they just didn't help? In fact, it made things worse. Yeah. And then I moved away. So obviously, when you move away, you lose that (.) that support and that relationship that you got with (.) with the GP. But then I had done my own research and looked into managing symptoms and then treatment and things like that. So, yeah, I think the citalopram (.) worked enough so that I could self-manage. **Interviewer:** And just to clarify something, when you say that the contraceptives made it worse, do you mean the mood symptoms were worse? **Emma:** Yeah, Mood symptoms (.) and also, I just (.) I've always found this with contraceptive (.) the contraceptive pill, just this sense of being numb. Almost like a 'not in my body' type of feeling. **Interviewer:** Mm hmm. **Emma:** Which (.) yeah. I've tried lots of different kinds and have never (.) never felt right. Never felt like me. But again, for some people, it's a lifesaver. So it's just I think just for me, it hasn't either haven't found the right one or it it's just not the right treatment.

**Faith:** Um, Yeaah. Um, So I've had quite a few experiences. Shall I just stick to periods? Cos' I've had periods, and the cysts and the fibroids (.) **Interviewer:** Um, I think it probably all relates, so (.)? **Faith:** Yeah. OK. So with periods, again as a thing where when I was younger it was like "Oh, she's exaggerating, let's give her ibuprofen". And then as time went on and I'd always vomit and I was nauseous. And it was quite debilitating. And so then they put me on to trans (.) **Interviewer:** Tranexamic acid? **Faith:** Yeah [nervous laugh] and my body wasn't responding well to that either. So then they’re talking about contraception and then I was like, "I can't have contraception, I'm not having sex, so (.)" I always thought contraception meant sex, sort of thing (.) but that's only recent that I've needed it for that use. So I thought that for a long time and then I gave in. But then they had to do trials and see which contraception worked well with my body (.) so a lot of them were not working well with my body. Eventually, I found the Yasmin pill and stuck to that before going on to the Depo Provera injection. [Pause] Then with the cyst, that was the first issue that I knew I had (.) and the first (.) I was in Uni at the time in Birmingham, and the first time I went to the hospital um, they said it was food poisoning [nervous laugh] without even examining me, they were just like "Oh yeah it's food poisoning. Have a paracetamol and go home". Next time (.) **Interviewer:** Yikes! **Faith:** [Laugh] yeah. Next time, again, without examining me, he told me it was a UTI and then he said that if I come back and it's with the same pain. Then it's the (.) there's a possibility (.) that it could be something else. I can't remember what he said, but it was like this life-threatening disease. **Gemma:** Oh my god! [whispered] **Faith:** And I was like, "Examine me or something before you say all of these things!" Then this was the time when I said that every time that I had high-stress then I would like vomit until I'm vomiting black. So (.) there was a day when I was supposed to go back to London, and I literally collapsed at the train station and I couldn't like move or anything. So my friend took me to the hospital and then called my mom from London to come and get me. And that was when I think we were like "I'm gonna get you some serious help". So I went to [London] hospital and um, you know how fibroids and those issues are quite common for black women? **Interviewer:** Uhuh. **Faith:** So luckily I had a black woman doctor and she was like "OK, I'm going to do this examination because I think that this is what you have." And she was like "You need to have an emergency keyhole surgery" and at the time, my dissertation was due, so I was like "can I have it after my dissertation?" and she said "Do you want to be alive?" [Laugh] So, I always tell people she saved my life [laugh] "if you wait for that dissertation, you might not be coming back sort of thing". So then I had that (.) um keyhole surgery and that's when they found fibroids. But they hadn't made me aware (.) so like (.) two years later, I'm having the same sort of pains. So I go back to the doctor and then you go through the whole referral process again. You know, it's like you wait months (.) for just (.) the blood tests and then another few months for the scan. So eventually it came back that I had fibroids, but because (.) I can't remember how old I was, but I was early 20s. So he was like "you've already had surgery around that area. So it's too much trauma before childbirth to remove the (.) Fibroids, because you've already had the keyhole surgery", so he recommended that I don't do (.) anything about them and just stay with the fibroids, but now they've ended up growing. So in September, I had (.) so. this year they've been like really bad so I guess that's because they were growing. So this year I've had like a lot of hospital and doctor’s appointments. And in September, a gynae (.) he literally just stuck two fingers up me (.) and he was like, "You have to (.) have to get them removed, you have to have myomectomy because like, the size that they are at now (.) um, fertility will be (.) um, near impossible, sort of thing." Because there's (.) the one inside my womb is six centimetres or on top is like nine centimetres. So he was like "the size that they are at like you can't even (.)" **Interviewer:** It's a risk (.) **Faith:** If I lie down then my belly is like that [indicates pregnancy-like bump], like they are very prominent now, and I can't lie (.) it's like literally like having a pregnancy because I can't lie on my stomach, and I can't lie on my back because then it (.) it's like the way it goes onto whatever's underneath it sort of thing (.). So then it makes me feel gassy and I can't breathe. So just through all of that I've now had the myomectomy um scheduled **Gemma:** Do you know when it is? **Faith:** It was meant to be around April, but I (.) I wasn't (.) I don't know if you guys remember from the forum [a speaking event at which Interviewer had spoken about fibroids] when I was saying that I want to get a second opinion. So I asked for referral to Professor X [London-based fibroids expert surgeon] who is like the fibroid specialist. And that's going to be in January. **Gemma:** Amazing! **Faith:** But then it ended up being like there was no point because (.) after the forum, everyone was pretty much like "You're gonna end up having them out (.) anyway ['anyway' said in unison with Gemma]". So I'm just delaying the inevitable. But I still want to see him (.) **Gemma:** Yeah still see him and see what he says - he is the specialist. **Interviewer:** Can I just ask you. Um (.) when you switched from Yasmin to depo, was that because of the fibroids? Did somebody say that would be a good idea? **Faith:** No, actually, that was because I was er having sex. I haven't really had like (.) consistent sex. So that's when I started having consistent sex. And then we had um not used a condom once, and I got really panicky so I literally took the Yasmin (.) like this is really bad, but I took the Yasmin pill. I took the morning after pill and I was like I'm going to take (.) I want something more like concrete because what if I forget to take the pill or something so let me get um (.) I actually went to get the implant but she was like "You've got fibroids, right? Why don't you try this?" Because apparently it could have an effect on kind of reducing the size (.) **Interviewer:** Yeah **Faith:** And I was like ok! Without even like doing my own research into it and even with that I ended up bleeding for like a month. And then after that, like not bleeding at all. **Interviewer:** Yeah. **Faith:** And yeah. My body just went through like some bad reactions to that. But then it seems to be for the time being (.) it's adapted to it. **Interviewer:** I mean (.) I'm just going to (.) this isn't part of the study, but (.) 1. They should have told you that you had fibroids when you had the cyst removed because if you go on the pill (.) so Yasmin's got oestrogen in it, so it would be helping the fibroids to grow. **Faith:** Oh! **Interviewer:** So (.) so you should have been on depo or a progesterone only pill (.) **Faith:** Hmm. **Interviewer:** Right from the start, because if you've got fibroids, you should avoid oestrogens. **Faith:** [overlapping] oestrogens. That's why (.) **Interviewer:** So that's (.) them not telling you has had quite a big (.) or, potentially it's had a (.) big impact. **Gemma:** Impact **Interviewer:** I mean you have fibroids anyway and they will grow anyway and all the rest of it. But this is why you really need that information (.) **Faith:** Because I remember when we spoke at the forum and I was saying to you, I've seen this piece that's about like things to avoid which have oestrogen in. So now you're saying if (.) I hadn't even thought about the one thing that was taking every day that has oestrogen. **Interviewer:** Yeah **Faith:** But they knew! Like my GP knew! So, it's really strange that none of them (.) **Interviewer:** Well, yeah. That's the thing (.) is they (.) they're not trained on this kind of specific information about (.) well, they should be (.) **Faith:** Yeah **Interviewer:** And they should look it up (.) but um there is this gap in training, particularly for GPs and they have to know a lot about a lot of things and all the rest of it. But really every time you go on the pill, this is the kind of checks that they should do. **Faith:** Yeah. **Interviewer:** Is that pill right for you? **Faith:** Yeah. **Gemma:** Does it work? **Interviewer:** And one of them will be to look for fibroids [in your notes] (.) **Faith:** I feel a bit annoyed now. Like I could have avoided the size it's at (.) **Interviewer:** Well, [sigh] I'm annoyed because I hear this quite a lot. **Faith:** Yeah **Gemma:** Do you? **Interviewer:** I'm not a medical professional, but I just read this stuff and now I know it. And now I can tell you. You know, it's not rocket science (.) **Both F&G:** Yes. **Interviewer:** I just (.) I think particularly with fibroids. And I think sadly, it's because there's both sexism and racism going on (.) **Both F&G:** Yeah **Interviewer:** And that combination makes people not (.) **Gemma:** [interjects] care. **Interviewer:** [repeats] care (.) or dismiss (.) **Gemma:** Dismiss it! **Interviewer:** Like you said, like ‘it's food poisoning’. It's (.) and not examining you. Like, I've only really heard that (.) well, I've heard it from some white women about not being examined. And I've had it where I haven't been examined when I've had a lump, so that was interesting! But (.) it's more from black women and from young (.) like when people are girls still, for sure. It's as if you're just 'pretending'(.)

**Gemma:** So, it's because like they have (.) because they kind of internalize that you can handle the pain. Er, it's the attitude of like. You can (.) It's OK. Every time I talk (.), I've had really negative experiences with doctors. I don't go to the doctors, which is not good. I don't have (.) I don't have a lot of sex at all. So I don't really need to do that for check-ups and stuff because I'm not sexually active at all [laugh] which is very sad [laugh] which I guess is very sad. My depressing life [laugh]. I um (.) It's really sad. That's made me like quite upset. Oh, but the truth is, I did have at the doctors. I say I'm sick. "You're pregnant. Are you pregnant?" That was their attitude. All the time. Like always. Because I've always been overweight. So oh, you should lose some weight. And that's how they would talk to me. If I was having a bellyache or my feet hurt. Just weird things (.) that I used to go in there for. They'll just say to me, "it's because you're overweight, you should lose a bit of weight. Your BMI is too high". All these things are very generic and they would never sit me down and examine me. So I just have a very negative experience with the doctor, which isn't good because I'm going to need (.) God forbid. But (.) we will all need the doctors don't we? But it's just always been very negative. That's why I can't. And I think that has a lot to do (.) why I don't take medicine and stuff like that? I just have a neg (.) I have a very, very negative stance on doctors and how (.) how they treat black women. I know (.) there's a lot of research into it. Women in general, but then black women on top of that. It's hard. It's just awful. The things you care about, the rates of child, um mothers that die giving birth that are black. It's just crazy. And the treatment (.) [sigh] It is really sad. So I've never gone to doctors because of period pain ever. My mom has gone on my behalf because she's a bit more like."You you must do this (.)". **Faith:** She's a scaredy cat! **Gemma:** Yeah she's a scaredy cat! and she (.) she panics a lot. She's a bit of a worrier (.) so the times I have gone to the doctors is because she's called A & E for me or something like that. But I would never (.) yes, I just never have gone. [Pause] Not good.

**Helen:** Ergh [shaking head] (.) just the answer, transverses many peaks and valleys [laugh]. Just, you know, some did and some (.) most didn't. Most (.) I mean, I was told 'this is all in your head you've got (.)' I was told I had cystic ovaries (.) like just I mean, I was never given like a consistent, straight thing outside of "Go home, take a midol. Go shopping. You'll feel better", you know, until (.) I met a gynaecologist who actually diagnosed me with PMDD. And I had never heard of it. You know, I just was like, I feel terrible before my period. I feel so depressed. And she's like, have you ever heard of PMDD? I'm like, "Oh no (.)" I feel like that started it. But even after that diagnosis, even after finally being believed, I still had doctors being like, oh, like throughout the diagnosis, "Oh no no, you know, you're (.) you're bipolar" or, you know, like just I got painted with every brush by varied professionals. It just stinks [shakes head]. And I know that's true for so many. Like my experience is very similar to a lot. **Interviewer:** And did any of them before your PMDD diagnosis (.) ask you to track your symptoms to actually see whether it was cyclical or not? **Helen:** Never. Never once, not even after I was diagnosed. Was I ever asked to track my cycle? That was something I took upon myself after connecting with others with the disorder and (.) and learning more on my own independently (.) yeah.

**Kathleen:** Of PMS? **Interviewer:** Yeah. **Kathleen:** No. **Interviewer:** Um I'm gonna ask you about this, because I know this about you, about consulting your doctor, about your fibroids or, you know, the fact that you had heavy periods I guess was the (.) or just tell me about that. What was your reason for going to the doctor and how did that go? **Kathleen:** So the reason I went to the doctors was because I was feeling extremely fatigued. Um, for quite a few months and I couldn't work out why (.) it took me a long time to actually get to the doctor. I'll probably say four, five months um because I was very busy at the time. I had a quite active lifestyle and so I just thought I was just tired. It was only when I kind of stopped everything. It was over Christmas. Some years back. I slept really well. I ate really well. I was very rested. And I got up in New Year and still felt as tired as I had been. That's when I thought there's definitely a problem. But it was to do with fatigue. And in some (.) Yeah. It was then (.) my heavy periods started. I think I was having heavy periods but just didn't link the two? So, I didn't go to the doctor because of heavy periods. It was only um (.) when they started to talk about the fibroids. That I then started to share about heavy periods (.) but it was the fatigue that got me to the doctors and then once I had (.) once she had (.) um got the blood test back she basically, you know, she called me at home and said "you have to go to the hospital. Now!" So, yeah (.) **Interviewer:** That was because of anaemia? **Kathleen:** Yeah, yeah. **Interviewer:** Wow! **Kathleen:** She was she was just surprised I was (.) she said [puts on worried voice] "how are you? Are you feeling OK?" You know? I was at my friend's house actually babysitting [laugh] and I said, "I'm fine". She said "Are you sure?" And this was a Saturday night! Saturday night she called me. She said "are you sure because I've just seen your blood test results. Are you okay? Are you sure?" She said "you need to go to Á&E now!" And so I literally (.) I went to hospital and they took more tests and they wanted to keep me in (.) And then it kind of got really extreme. But it was a miracle that I was kind of (.) to them that I was functioning as I was, they just couldn't understand by looking at the numbers. They did a few tests. They expected me (.) you know, they wanted to put me on a drip, they wanted to give me iron in an injection. I kind of refused because I didn't really want to take them But, um (.) yeah. So, yeah, I didn't (.) I think I was yeah (.) it was a miracle, that I just didn't kind of faint or (.) they were kind of expecting me to kind of drop down, but I was functioning as normal. In a way (.) obviously, I was very fatigued. But um, yeah I was still just getting on with life. **Interviewer:** That is amazing because I'm only slightly anaemic and it kills me. I’m having to have, you know, the supplements every other day. I'm trying to build it back up, but I think (.) yeah, I think maybe age and there are other things going on, stress-wise as well. Just to ask you, why did you (.) why didn't you want the iron injections? Can you describe that? **Kathleen:** I [long pause] I'm one of these people that I kind of al (.) my default position is always the most natural solution. I know that's not possible, clearly I've had surgery so, er (.) but I just thought, I know my iron levels are very low. Um, so I kind of begged them to let me leave, taking I dunno, 6 iron tablets a day and promising that I'd eat lots of you know, iron-rich vegetable foods. And that's what I did, right (.) intensely for months and months. I think I had kale every day. Um (.) and these six iron tablets so that it slowly built up, so they were saying (.) they were encouraged every time they saw me that it was going up and up. Yeah, I just I mean, if it was you know, really (.) really bad. I probably would have said yes to the injections, but I just didn't want to start off with that. I just wanted to try another alternative (.) um because I felt like if I had a set of injections then, then they probably would've said "oh come back again", then I'd come back again. And I just. Nat (.) just my natural default position is what can I do myself before (.) before there's the medical intervention? **Interviewer:** Yeah. That's funny. I'm hearing this a lot from people (.) er, usually about pain rather than iron. **Kathleen:** Yeaaah. Okay. **Interviewer:** Um and I do the same. So I get bad pain and I still don't take painkillers. **Kathleen:** Yeah, I don't (.) **Interviewer:** Even though (.) well, sometimes I do because it's so bad I take it during (.) but you should really start before and I just very rarely bother [laugh] and I can't actually (.) I can't justify it because it's (.) it's irrational. It's not a logical position to have. I don't have any strong feeling about taking painkillers, and I think I probably should, but [shrugs] I don't bother? Anyway (.) **Kathleen:** Maybe we're too hard on ourselves? **Interviewer:** And I think it's interesting (.) it's interesting because I think there is something about gender there. I think there's something about the naturalization of pain and the naturalisation of suffering and that (.) that we have to just do it for some reason. **Kathleen:** I think to me as well. I just (.) I'm not [pause] generally, I try to do the most natural thing, if that makes sense as well? I think it's (.) it's (.) it's (.) that's what I believed it was. And I'm just (.) I'm quite conscious of what I put into my body. I'm not saying that, you know, I don't watch (.) you know, I'm not a kind of (.) yeah, I'm not like, you know, a lot of people who pay a lot of attention to what (.) to their food. I'm not like that, but I do (.) I am one of those people that I just prefer to cook. I like to cook my food and, you know, and just have more natural things. And that might've just been the way we were brought up. But um (.) so that's why I'm a bit like you. I don't (.) I will take painkillers if I absolutely need to. But it's more that I don't want to put something (.) chemicals into my body as opposed to (.) Does that make sense?

**Aisha:** Yeah. I have (.) but they don't suggest anything for it. I've never got anything for it (.) because I have PCOS as well. If anything, they just suggest the pill, but they don't (.) that's not necessarily for the PMS. **Interviewer:** So you feel like they do think you've got PMS (.) **Aisha:** Yeah (.) **Interviewer:** But they're not offering you any specific treatment? **Aisha:** No, no (.) **Interviewer:** And how about for the PCOS? Is that (.) do you feel like they're (.)? **Aisha:** No. There's no treatment for it. **Interviewer:** So other than the pill. You haven't been given any other options? **Aisha:** No. **Interviewer:** May I ask why you don't want to try the pill? **Aisha:** It's because I (.) I wouldn't (.) I'm trying hard to lose weight and I feel as if that will make me increase the weight. Does it? **Interviewer:** No. Well, it's a weird one because sometimes it's water retention, so you might put a little bit of weight on, but it will come off as soon as you start your period. So you have the little bleed in between your pill, but actually the newer pills. So there's (.) there's one called Yaz or Yasmin. And they don't affect your weight at all.

**Noor:** No.

### P18- Doctors’ training- is it adequate?

**Ria:** Hard No! [Laughter] we're talking about like medical doctors who are trained in that system? Yeah. Hard no. Hard no. I (.) yeah (.) I could go on and on. You know, my dissertation project is studying medical schools. And I worked in them and know what their syllabus is like and all of that? And so. Yeah. Hard no, from my end. And then I speculate that for many different reasons. Right now, part of it, I think, is just the sheer amount of information that they literally try to cram into four years of medical school. And then even beyond that, the way it works is the first two years of medical school to become an M.D. are lecture based. And then you have two years of clinical and then you go on to do a residency, which is a clinical placement with practicing doctors. And so in those first two years is where people get introduced to like a lot of new theoretical concepts, hopefully new depending on the age of the instructor and their research interests and all of that. So, it's very subjective and a lot of it is focussed on the biomedicine. So I imagine that's what they do. See (.) I'll certainly share that information when I get there. So, I can't comment on what's included, but that's my understanding is that it's very crowded, the curriculum. It's very hard to make space. And then once they get into the clinical sites, they're basically just learning from people who have been in the health care system for a very, very long time, particularly doctors. And so already like that just limits what they're learning. So a mentor of mine who's an endocrinologist [name], I don't know if you've heard of her work, but [she is] a doctor and she's like the only endocrinologist who studies menstruation and runs a group called the Centre for Menstrual Cycle and Population Research. And she is one of these people that is able to (.) has just been so amazing at the quantitative piece. Getting people to literally keep men (.) these intense menstrual diary logs for a very long time. She writes a lot about menopause and oestrogen as it goes on in the life and what she (.) her analysis of why it's not included is that the (.) is that the obstetrics and gynaecology department. So she's in endocrinology, obstetrics and gynaecology itself (.) she says that they're still using information and research from the nineteen eighties to teach OBGYN and you know, that's like 50 years ago now. And again, preview (.) my previous comment about how a lot of menstruators were not included in research back then. And so they're basing this knowledge just off of like maybe 10 people and then just building this whole curriculum off of it. And they really have not innovated since then. So that's troubling. It's very, very troubling. And I've been like on the caretaking side of many friends who have had experiences with OBGYNs, especially recently as a lot of people are getting pregnant and having babies. And it's like (.) totally confirms everything that she has been saying because it's honestly horrifying. So there's that piece. However, the exciting new movement is that we now have something, a new title called 'Nurse Practitioners', and it's a master's program and nurses (.) ninety eight percent of whom are menstruators compared to I dunno what the stats are on OBGYNs. But I think it's still pretty high that it's disproportionately people who identify as male. But yeah, so the nurse practitioners, they can now they have now the same scope of practice as a family doctor or GP, and that's a new program as of like three or four years ago. And so they get paid on a salary. They have 30 minute appointments as opposed to 10 minutes. And so all this to say that in their new curriculum, I think that they emphasize a lot more on (.) the menstrual cycle, however, again, based on my frontline experience working with MD's, a lot of them still do tend to prescribe the pill for anything [laughter] related to menstrual cycles (.) So, yeah, sorry. Long answer. **Interviewer**: No that was really brilliant, and that's really interesting. So we have nurse practitioners, but they wouldn't have that authority here. And they don't get 30 minute (.) appointments, which is really actually underlying a lot of problems here in the NHS, is the (.) it's 10 minute appointments. And it's not long enough for anything, really. **Ria:** No, you can't even like catch up and be like, Hey, how's it going? **Interviewer:** It's just enough to say "I want this test because I feel ill" [laugh]. **Ria:** Oh, it's that's like a whole other (.) like the actual health care system and how it's built in relation to the menstrual cycle. It's like a whole other thing. But in speaking about the education (.) that would be my answer.

**Beth:** No. **Interviewer:** [Laugh] **Beth:** [Laugh] Well, that was the brief answer. I don't think we do. I think we (.) we do get (.) our training (.) that's relevant to periods and menstruation is very focused on the menstruation part of it. And problems associated with that. So if women have very heavy periods, what treatments we can prescribe to try and reduce the blood flow and then what investigations we can refer for it, if that doesn't help. Or if they have very painful periods, then likewise what medications can be prescribed and then when we should refer to see if there's an underlying cause of very painful periods. And then if women are getting irregular cycles or, you know, bleeding in between periods, could that be a problem with the cervix? Could it be fibroids? Could it, you know, be polycystic ovarian syndrome? There's training for dealing with those conditions. But I think PMS is sort of given a bit of a (.) 'oh, by the way. Some women get PMS. What can you do type thing (.) it's probably a bit better than it used to be in that (.) you know, that there's a bit of it in GP training. There's a bit of a mention of, oh, sometimes the, you know, hormonal combined contraceptive pill can help with PMS symptoms or sometimes a low dose SSRI antidepressant can help (.) but (.) that's about it, really. Erm, there's (.) there's not much other mention of PMS in in GP training, apart from that, I don't think it's seen as a massively important thing to know how to manage.

**Dani:** No, definitely not. Because I think, like, you know, you hear about people taking so long to get diagnosed with endometriosis and then also just someone like me at 17 being put on the pill, which I was on for like 13 years. I just think, you know, I don't really know if there was anything like really terribly wrong with that. I also think we need to let a 17 year old just experience periods properly and just let them settle. So no, I don't think there's that (.) there's enough. I don't think there's like (.) at risk of sounding hippy (.) but I do think it's important (.) there's not really a holistic understanding like, of you know (.) and then like conversely, I do feel sometimes like I've been to the doctor and everything. It just gets related to my periods. And that really pisses me off because I don't feel like when they do that, they're taking it seriously. **Interviewer:** Could you give an example of that? **Dani:** Yeah. So I had vestibular migraines for a few years. Dizziness. Basically, I had really bad dizziness for two years. A few years ago. When I had to stay in bed for like two weeks at a time and I just (.) it was fucking horrible. And every time I went to the doctor, basically, I was a hundred percent sure it wasn't cycle related. But every time I went into the doctor's, that's all they wanted to know. And it just really (.) it really like [pause] It felt like when they were doing that, they were just brushing me off, basically being like "well it could it just be to do with your period?" And like I knew it was more serious and it was more serious. In the end, I ended up having a brain scan and (.) but you know, it was fine. It was to do with stress as well. But it was yeah. It really [pause] they had (.) they didn't seem to have a reason. I'm sure they did. But they didn't seem at times have a reason why they were relating to my period. It was just like, well it could be, but it was actually a really distressing time for me so I couldn't stand up. So yeah, it was horrid.

**Emma:** No, I don't. And (.) I think this extends beyond menstrual cycle symptoms to (.) to menopause and all female reproductive health, really if we bring endometriosis and polycystic ovary syndrome (.) and all of those things into the conversation. And it unfortunately, it's not just GP's, but it's (.) it's all health care practitioners. So psychiatrists and psychologists who are (.) who are seeing patients and don't ask the question, are you tracking your menstrual cycle and I dread to think how many women are (.) are in counselling and therapy. And it's linked to (.) to their menstrual cycle and nobody has asked them to track the cycle or (.) yeah. So I think to come back to your question, I think, you know, there's not enough awareness and there's not enough training and that for me would be a really positive step to (.) to improving things in terms of female reproductive health and well-being.

**Gemma:** Nope! [Laughter] **Faith:** Funnily enough, there's been a couple of times when I've been to my doctor and she's like (.) and not even just her, like a couple of doctors like, just like, they'll just like Google something. Or be like "Oh yeah. Must be that" Or Look up, they have this doctor's book (.) and she'll be like ok let me look for this or I'll say um, I went to this clinic, or this place, and they said to check out this and ensure that (.) and she'll look it up like she's never heard of what it is (.) **Gemma:** What?! [Whispered] **Faith:** So she'll just go to the book and go "OK. The textbook does this (.) says this so this should be our approach" Like you said, I empathize because they have to know about everything. But um it would be nice to (.) have at least like (.) just one person (.) per practice [laugh] who knows. OK (.) this is the person in our practice who will know about fibroids or will know about all of these um chronic hidden illnesses or that sort of thing, because like you just mentioned before, I feel like now the situation, that I'm in, possibly could have been avoidable. So, yeah, it's unfortunate [whispered last words] **Gemma:** No. **Interviewer:** Anything to add to that? [Laugh] **Gemma:** Just no.

**Helen:** I believe progress has been made for sure, but there's a long way to go.

**Kathleen:** No, I'm afraid [laugh]. Just my own experience and also from obviously, the group that I run [fibroids support group]. I hear it from women all the time. They're not listened to, or um (.) the doctors just don't take the time for them to explain symptoms (.) and I think I told you about um someone I know who went to the doctor. A female doctor, actually. And was explaining what was happening with her body and thought it might be fibroids and she explained that (.) and she was having a slightly heavier periods, than she was used to as well. Um (.\_) she explained that her mom had had fibroids, both her sisters had fibroids, and it was a bit of a fight just to do (.) to get the tests. So I'm sure maybe it's fine for some women, but um [pause] generally, I think there could be a lot more education on that. Um, my doctor, I think for me, my personal experience, my doctor was probably (.) she was a lot more sensitive because of the test result, because it was, teamed with the anaemia. I don't (.) I think if I'd just been for periods, I'm not quite sure what the response would have been. **Interviewer:** Yeah, I think that's probably right. I think that's the beauty of being able to do a test for something (.) **Kathleen:** Yeah

**Aisha:** No [very quietly][laugh] Is that really bad? Sometimes I feel like I'm teaching them and then they call me an 'expert patient' or whatever they call it. I think it's just seen too much as a norm.

**Mala:** From other people that I've spoken to that have even severe PMS than me (.) I don't feel like they do. I think they dismiss it as just something got to do with hormones? It is got to do with (.) or partly because of it. But then what can we (.) What else can we do? Because some people (.) some people go through really, really bad stages of PMS where they can't (.) they can't control themselves at all. So what can they do about it? And there's no really an explanation or help for it?

**Noor:** Um, I actually don't know because I've never been to them, but through my sister, like I feel like when they... when... you have to mention it for them to say it... so it wouldn't come up. Generally, like if you go to the surgery and say, "Ah, I'm being moody dah dah dah" They wouldn't think PMS straight away, they'd think oh probably she's got a depression. de de de de dah. All of those options will come first before the PMS.

### P21- Do you track?

**Ria:** Yes, I do. **Interviewer:** And is that in like a phone app, or (.) How do you do that? **Ria:** I have a bit of a hybrid method where I note down my um (.) first day of my period and maybe like the next two days and then when I have like very high quality cervical mucus. So my peak day on a piece of paper, that's a little clipboard that's attached next to my toilet. So I don't forget to track. And then I (.) if I'm feeling like very, very nerdy that cycle, I'll use Kindara [Fertility awareness app] and take my temperature. However, yeah, I mostly just always know when those two days are? And then the rest of it, I'm learning how to be able to tell based on my body as opposed to the app. Um, however, when I first started charting two years ago yeah, I was like obsessively taking my temperature: didn't want to get pregnant. Every time that I got close to the end of my cycle, I was like, "Oh my god! Am I pregnant?!" Sort of freaking out [laughter]. So yes, now I'm a little bit more relaxed [laugh].

**Beth:** Not at the moment. I have done. Erm (.) over (.) probably not long enough, actually, because you should do it over three months, shouldn't you, to get a proper pattern of data? But I probably did it for two months at most (.) I think that (.) was (.) I don't at the moment. But, yeah, I did (.) but it was more with the purpose of tracking a specific set of symptoms to see if my menstrual cycle had any influence. Not to try to track my PMS symptoms. So I'll try and explain briefly, because I know I'm rambling on a bit (.) I've got possibly a condition that's being investigated at the moment called postural tachycardia. So I was tracking my pulse and blood pressure over the course of a couple of months and also tracking that alongside when my periods would occur (.) to see if it got any worse before a period or not, because I suspected it might. Alongside that because I was getting some random fevers, as well (.) I tracked my temperature, which didn't seem to tie in with my menstrual cycle? But I wasn't tracking all my PMS symptoms because I had already noticed that the anxiety and the bowels and everything got worse (.) at certain points. So I didn't feel the need to formally track those because it was so obvious to me when they were happening. But I think (.) tracking is definitely a useful thing to do if you get lots of symptoms. Well, if you got lots of them or if you get just one or two symptoms and you're not sure whether that's due to the menstrual cycle or something else, yeah.

**Dani:** I don't track as much as I did because I pretty much know now (.) for a good year and a half. I tracked everything and that's where I started to notice patterns. Like "Oh, That's why I'm really tired at this point". And, you know, that was blah blah blah (.) but I still put in just because I've (.) now I've got this implant (.) I'm trying to work out what's actually going on with my cycle with it (.) I just (.) just track the bleeding days. But I don't really tend to track everything else (.) but I did (.) I used to track everything like from energy to sex drive to like what I was eating. And I did find that really useful. But I just don't tend to need to as much anymore. But yeah, I still track the bleeding.

**Emma:** I do track my symptoms, but I think it's important to say I haven't always done so (.) and that has been quite a recent thing. Recent, as in the past five years or something like that? Well, yes, I track on paper. So my desktop calendar, which gives a visual reminder every day and just allows me to check in with where I'm at. And. I'd also use the Apple Health Menstrual Cycle Tracker and tool.

**Faith:** No, I should. But I had um (.) I had found that sometimes my periods will come every two weeks, every four weeks, every three weeks. So it wasn't until you kind of told us at your forum [fibroids talk], I thought there's no point tracking it if it's all (.) It's always gonna come when it pleases sort of thing. But then at the forum I learned that it's normal for it to have different (.) [pause] schedules [laugh] I guess, but yeah. So because of that, I hadn't and since the forum, I still have been on the injection so (.) [therefore, not bleeding].

**Gemma:** Yes, on that (.) period tracker [app] **Interviewer:** Do you find that useful? **Interviewer:** Very useful, very, very useful.

**Helen:** Yes. Once I became aware of PMDD and that I was (.) most likely had it. I started tracking all the time. **Interviewer:** And so you could see a clear premenstrual pattern to your symptoms? **Helen:** Absolutely. I could see it on paper. I could feel it in my body. I remember like two to three days after my periods started and I'd be singing in the car. I just felt like this huge weight had lifted from inside of me. And then it was right there as well on my (.) my tracking.

**Kathleen:** I do note when I start my period um but that's it, really. **Interviewer:** And did you ever track them or it wasn't something you did? **Kathleen:** In terms of like the mood changes and that kind of thing? **Interviewer:** Yeah, or anything? **Kathleen:** [Pause] No. I mean, I've always (.) I've always tracked when I'm on my period, but that's about it. Not (.) not kind of 'heaviness' although, looking back, I suppose I should have done that more. Yeah. **Interviewer:** Would you try and predict when you were maybe due or you just sort of reacted at that (.) each time? **Kathleen:** Yeah, no, I used to, I used to try to predict. I think sometimes. Yeah. Like I said, I used to just be very, very busy and I used to travel quite a bit as well. So I used to try to just to figure out would I be on, when I went away, or that kind of thing. Now not so much. I just I think I just continue to track out of habit, I think it's just good practice (.) for me to know. But it doesn't mean as much now when I come on, it's just 'I'm on'. And I'm not trying to prepare for anything I don't feel like (.) yeah (.) I need to know as much as before.

**Aisha:** Yeah. **Interviewer:** Menstrual cycle and symptoms? **Aisha:** I do have lazy times when I don't (.) **Interviewer:** Yeah yeah. And how do you do the tracking? **Aisha:** On their app (.) on the app. **Interviewer:** Which app do you use? **Aisha:** Um, P-dot tracker something like that. from Apple Store. What about yourself, what do you use? **Interviewer:** I don't track anymore. So I did, that's how I worked out that I had cyclical symptoms. I did it on excel! [Laugh]. **Aisha:** Wow. Fancy! Fancy! **Interviewer:** Yeah, I'm a geek. Actually, it was before any period apps. This was (.) er, eleven years ago. But I've downloaded various apps and I've looked at them. But I just find it a bit boring. And I kind of know. I know now. **Aisha:** OK. That's good. **Interviewer:** But more and more people are using them. And it's very useful for doctors. So like if you have that, you can show (.) when you go for your referral, you can say, look, I'm much worse at this time.

**Mala:** I do. **Interviewer:** Do you track all the different changes you go through or just sort of when you get the bleeding? **Mala:** I just (.) when (.) whenever I get my bleeding. **Interviewer:** And how do you track it? **Mala:** I've got a period tracker. **Interviewer:** Can I ask which one? **Mala:** I think it's called period tracker. It's on Samsung, Android (.) It's the P tracker. **Interviewer:** And why do you track that? **Mala**: Um, I initially first tracked it because it was a religious thing. Where, I was going to perform um (.) a pilgrimage. And so I needed to know when (.) because when we are on our period we're not allowed to pray um and it (.) doesn't hinder the whole pilgrimage but certain parts of it. Um, so I wanted to know when I was going to be on my period so I can (.) um take precautions beforehand so I can either take the pill to sort my period for that month or maybe book another ticket around my period (.) Yeah. **Interviewer:** And then you've just carried on? **Mala:** And then I just carried it on 'cos it's quite good (.) um, during Ramadan (.) um, when I know when I'm gonna be on my period so I can plan my Ramadan properly (.) yeah, around it.

**Noor:** I used to, but now I don't need to. **Interviewer:** Yeah. So you kind of know what's your normal? **Noor:** Yeah. **Interviewer:** And so you're tracking when your period starts. Basically? **Noor:** Yeah. **Interviewer:** And do you count cycle length or do you just (.) just note it each time it happens? **Noor:** Um, so if I feel like there's a change like I'm starting too soon or too late, then I'll track it.

### P27- Typical changes every cycle?

**Ria:** Yes. So I'll just list four for the Four Seasons. So period, I can always rely on flaking on the plans that I've made because I should learn to not make plans when I have my period. Like social plans (.) usually I want to stay in at home. Spring time I can usually count on my sex drive being a lot higher. Summertime. Around ovulation. I can count on (.) um really like huge, large creative ideas. And then PMS. I can usually count on preparing (.) having a well-stocked snack pantry [laugh] so that I can snack to my heart's desires.

**Beth:** Yes, constipation. And (.) well, look, we've already touched on the increased anxiety. I'm not sure if that's PMS for me (.) but definitely constipation is a PMS thing for me (.) increased bowel gas (.) and [laugh] at the risk of being a bit too graphic, more offensive bowel gas before a period. **Interviewer:** Yeah. **Beth:** And then going from being very constipated to being quite loose in my bowels. On the first day I start menstruating. Like a rapid relief from the constipation. That's a very consistent thing. **Interviewer:** Yeah. **Beth:** Also, weird (.) something I haven't touched on before. Weird dreams in the couple of days (.) before my period is quite a consistent thing too. **Interviewer:** Yeah. **Beth:** Yeah, That happens pretty much every month. But then other symptoms might only happen very rarely (.) I (.) I have had premenstrual breast swelling and tenderness but I could count on one hand the number of times that's happened. So (.) so that's a really inconsistent premenstrual symptom that I've had.

**Dani:** It's the tiredness and the feeling of like. Exhaustion, not exhaustion, that's a bit extreme, but I think (.) no actually I think one to two days I feel (.) I feel exhausted. So, yeah, that's every month without fail. And just a feeling of like just I dunno (.) It just stuff feels too much, maybe for like a day or two. But then then it sort of passes.

**Emma:** Yes, so (.) fatigue. Is one (.) and [pause] a headache which can sometimes turn into a migraine. Is one (.) ovulation pain and bloating happens every time. Er, mood changes happen every time [exhale] Yeah [long pause] Yeah, erm, I think just going back to what I talked about earlier. It happens, these things just happen every month. Insomnia happens every time. So I have [pause] days where it's either that I can't get to sleep or I have really disturbed sleep. And then hypersomnia where I'll sleep way more than usual, but I'm still tired. Um. Yeah. So there's this pattern just tends to be the same every month.

**Faith:** Yeah. I can definitely rely on dehydration. I can definitely rely on cravings (.) um I don't know if we mentioned. I don't know if we touched on this, but when the emotional thing that's been with age, so that hasn't always been as heightened…Yeah, I can't say what I'm actually like on my period. Again, those first two or three days. That's when my mental health is just not in check, sort of thing. I'm just like (.) but I think that's more associated with the pain and just feeling like i'm (.) sick of life! [Laughter] sort of thing.

**Gemma:** Um, with me, it would definitely be crying. I think every cycle now which again is age (.) that didn't used to happen when I was younger. That started to kick in when I was like twenty five actually, which is recent. Um, uncontrollable tears and definitely, definitely weight gain, every single period. It fluctuates between two to like six, seven pounds, but I will always put on weight during my period just before and it comes off like a week after?

**Helen:** Oh, yeah. So the emotional symptoms the (.) you know and as I got more severe, the suicidal thoughts (.) and ideation, those would be quite consistent. [Pause] panic attacks were very consistent. I'd have those quite often during ovulation and then right around the start of my period. **Interviewer:** Can I ask about the cramps, obviously were they severe the whole time? You know, from adolescence? **Helen:** No, I feel like it definitely got worse. They were I mean, they were bad like I remember as a bartender and I lost my job because (.) I couldn't leave the walk in cooler. I was just absolutely debilitated and doubled over in pain. And it's like, how do you explain that? But I don't (.) I can't remember (.) if it was like ovulation straight through? I think it was just a day here and there that it would happen. But I mean, it's difficult to (.) [remember].

**TANGENT!**

**Interviewer:** [00:38:41] It's just too much talking today. Um, but Thank you. That's really interesting about the pain. It's actually something I'm noticing. Really, everyone I've spoken to who has PMDD has had severe pain as well. **Helen:** [00:38:58] Really? **Interviewer:** [00:38:59] Anyway, I think that's kind of an area that might have been under looked. **Helen:** [00:39:02] That's really interesting. Like uterine cramps or all over pain or? **Interviewer:** [00:39:06] Fibroids are Big. Very common. And just I mean, I would say suspected fibroids for a lot of the others as well. Just... **Helen:** [00:39:14] Interesting! **Interviewer:** [00:39:16] You can't always tell if you've got fibroids from like, heavy bleeding and severe pain. So I think that's something I'd quite like to look into after this **Helen:** [00:39:25] Oh, my gosh... Please do! That's interesting to hear. Again, it's like even even six, seven years doing the work. I do, I'm like, I don't even hear this because you're just hearing pieces of people's experiences. You don't get to always sit down and have a conversation like this. Tell me about your pain. Tell me about where and when and how and the result. Yeah. So interesting. **Interviewer:** [00:39:50] Kind of relating to that. Did any of your typical symptoms change over time? Oh, Sorry. Somebody is at my door one second... **Helen:** [00:39:59] Go right ahead. I'm actually going to let the dog out. Thank you. Come on, buddy. [3 minute gap] **Helen:** [00:42:22] you watch the show [fleabag] or have you watched the show? You know, when she's talking with that gal who won the business award, they're at the bar. And she tried to kiss her, but she was talking about menopause. And she goes and then you go through menopause and you're free. And I'm like, what are you talking about? You. know... It was an interesting like, you know, bit of media. **Interviewer:** [00:42:43] I think, all of us. When you when you're an activist particularly, I lose my sense of humour so quickly, you know when someone gets something wrong. Like, yeah, at a stand up comedy show. I'm like, wow, that's not true.[laugh] **Helen:** [00:43:00] Well, it wasn't even that I disagreed with it. But it was just her assessment of going through menopause, like talking about how hard it was. And then she goes... then you go through menopause and then she goes and it's horrible and it's awful. And then you're free. And I think that's a pretty good assessment. Like I agreed with her, at least for myself as someone with PMDD. **Interviewer:** [00:43:23] Yeah, I mean, that might have been a good one, but normally it's wrong. I guess I'm so sensitive to anything that's not 100% correct. **Helen:** [00:43:34] Funny as we're talking and I won't take too long [laugh] I know you have to go for a run today! I'm sure you've seen it. There is a gal I think she is a psychologist. She did a TED talk about how p.\_m.\_s is a myth. And I'm like, that's the one that always just burns me up at 2:00 a.m.. I just think about it. I'm like, oh, that lady! **Interviewer:** [00:44:00] Well, she's, um [names PMS colleague]. **Helen:** [00:44:02] Yeah. **Interviewer:** [00:44:10] She's... She's really just being very precise in her language. all she's really saying is not that people don't experience severe cyclical symptoms, but that it's not a Premenstrual syndrome because really right from the start it should never. have been called a syndrome. **Helen:** [00:44:26] Yeah. **Interviewer:** [00:44:26] Because it implies something that it isn't. And then there's a lot of confusion now because PMDD is a you know, it's in the DSM. It's a mental health sorry, mental health disorder. And so that's controversial because obviously there's a biological it's just a physiological process involved in certain symptoms. So I think what she's really saying is that the term P.M.S is not a good term. And actually, it just isn't. But it's kind of the one that... it's very well known. **Helen:** [00:45:05] Yeah,. **Interviewer:** [00:45:07] And it's not as bad as Premenstrual tension, which is the original one, because that was really only talking about the tension bit. **Helen:** [00:45:15] Right. **Interviewer:** [00:45:16] Which is just a part of it. **Helen:** [00:45:20] I know, I think it's hard like people get so caught up on on the... and i'm sure it does matter. I'm really sure it matters. But like you know, people are upset that PMDD is in the DSM, that it's under, you know, a mental as a mental disorder when it's clearly both gynaecologic. I think it's just... it just speaks to the whole separation of the brain from the rest of the body. You know, when it's it's defined as one or the other. But I feel bad. When I see people getting really upset, they're like, I don't have a mental illness. And it's like, don't... you don't have to be ashamed about it. I mean, and I say this as somebody who has like vulnerability hangovers still. And I work, you know, and I do the work I do, but I don't want anyone.. It breaks my heart, my when even when I do it, that people get caught up in labelling themselves. You know what I mean in the label in the label in general. But I get why it's from a clinical standpoint. **Interviewer:** [00:46:29] Yeah, I know say the stigma all over the place because there's a mental health stigma. So nobody wants to be mad or whatever. And yet it actually doesn't help if you say it's a biological thing or a genetic thing. It's been proven that that's also stigmatized even it's known that let's say you're severe... Severe anxiety or something might be genetic or have a genetic component. It doesn't actually alleviate the stigma. **Helen:** [00:46:58] I know. **Interviewer:** [00:47:01] And there's the stigma attached to the menstrual cycle. You're not supposed to talk about it. And all these stereotypes about women being somehow inferior. So you're left with you know, I think it does contribute to this. Damned if you do, damned if you don't. **Helen:** [00:47:20] Exactly. Yeah. **Interviewer:** [00:47:22] Because know you're either... So I think that woman who you were talking about who did the TED talk. Well, it's partly because she went with that line as a click bait... **Helen:** [00:47:34] Right! [laugh] This is the wrong thing to lead on... **Interviewer:** [00:47:39] That isn't really what she's saying. **Helen:** [00:47:42] Yeah, I think it came across as invalidating. **Interviewer:** [00:47:46] Yeah **Helen:** [00:47:48] You know, and I think it's also where you are individually when you're watching it, because when I was watching it, I was in PMDD and I or just battling it and it's like, great, another person, even a woman invalidating my experience, you know. So I think that's where it was problematic as a. As a tool to like what she was trying to convey, you know, there's a lot of barriers there. **Interviewer:** [00:48:16] Yeah,. **Helen:** [00:48:17] Yeah, but the way you say it, it makes sense! [laughter] **Interviewer:** [00:48:19] Yeah, it's it's very nuanced. It's like a lot of research. It's actually very nuanced. And there isn't an easy way to shorten. Like you get it because you've been through everything. If I say you're damned if you do, damned if you don't. You know what I mean? It's like you can't win whether you are saying it's biological it's psychological. **Helen:** [00:48:39] Right. **Interviewer:** [00:48:39] Oh, whether you are really bad or virtually nothing... But in terms of communicating. Sometimes... and unfortunately, a lot of the feminist work, you know, and it's important that feminism talks about p.\_m.\_s because it's applied mainly to one gender. **Helen:** [00:48:58] Right. **Interviewer:** [00:48:59] But a lot of their work has been interpreted as like them saying that it's not real, but it's not that. They're saying we have to be careful about what we say and who we apply it to and to check that it's not applied to all women. **Helen:** [00:49:16] Right. Absolutely! Yeah. I think and again, just I won't harp on her Ted talk much longer. But yeah, I think the line she led with for ... and it must have been for clickbait. Was she explicitly says p.\_m.\_s as a myth and I'm like, why would you lead with that? other to get us all to click on your TED talk. But you've lost us at the beginning for being trying to be so, you know. I don't know. Again, it's... the viewer it relies on the viewer to. Who are they and their experience. But it was interesting. Now I'm gonna have to ... have to go back and watch it after having this conversation. I need to rewatch it. **Interviewer:** [00:49:58] Yeah. I find it frustrating. I'm going off topic massively here, but like I run a Website and I would get a lot more views if I was more clickbaity and I led with Provocative titles... but that Goes Against My Ethical Position, which is that people need to know about their bodies and what's normal and what's not normal, because that's I think that's the main problem, is that we're not taught about the menstrual cycle properly. If you had known about PMDD when you were 12, and then experiencing its symptoms and you would have known like you wouldn't have had all those years of wondering if you.... I mean, I know it's impossible because it wasn't a thing and people weren't talking about it. But with hindsight, if it had been around. That's really the problem, is that we're not educated. And then it falls to doctors and it's kind of up to them and their expertise to give it a name. and that's always gonna be a problem because we know... Doctors... They have their own disciplines and their own ideas about things that..., you know, it's just... the real problem. I think it's just ignorance and the taboo on menstruation, really... Well, I'm sorry. I'd better move on!I don't want to take up too much of your time! **Helen:** [00:51:32] No, it was a great conversation. Thank you so much. Yeah.

**Kathleen:** Er (.) not (.) so as I'm about to come up to my period there's nothing I can put my finger on. I think it's just we get to know our bodies. I don't know. Maybe there is some kind of physical, physical, physiological change that tells me that it's coming. But I definitely know it's coming. **Interviewer:** And you know in your mind or is it a feeling because there's this thing that previous people have called phantom discharge, which I've had as well, where you think you've started and you haven't? But you are just about to it's like an hour or so (.)? **Kathleen:** Yeah. That happens to me sometimes. Yeah. **Interviewer:** But are you talking about then a sort of just general awareness that it's impending? **Kathleen:** Yes. Yeah. That's what it is. Cause I can't put my finger on anything physical. But um yeah I just know it's (.) and literally by the next day. It's there.

**Aisha:** The food cravings [long pause] but it's (.) that's the food cravings really creep up. **Interviewer:** And that's like sugary food? **Aisha:** Meat, sugary foods, spicy food (.) bubble tea [laugh] sugary foods, yeah. **Interviewer:** So basically, you're hungrier? **Aisha:** Yeah. Yeah and I can, eat (.) even if it's healthy, even if it's not (.) I can eat like (.) constant and never get full.

**Mala:** Yeah. So that's the back pains and the thigh ache (.) and bloatedness. **Interviewer:** [Long pause] so then how common are the sort of mood changes? Is that like one in every three or like bit less common than those ones? **Mala:** What do you mean? **Interviewer:** Like when you get irritable or anxious, is that less common? **Mala:** No, that's all (.) that's every time. **Interviewer:** [Overlapping speech] that's every time? **Mala:** That's every (.) every (.) um, the week before, every month.

**Noor:** Yeah. Bloating. **Interviewer:** And just to ask you about your food cravings, are there particular foods or like does it change? **Noor:** It will be carbs and chocolate. So bread and stuff.

### P28- Changes over time?

**Ria:** Well, as I mentioned last time, I was on hormonal birth control for seven years. So during that time, I can't really comment because it just felt like a total shit show. And that corresponded obvious (.) and it also corresponded with like my typical point in human development at 18 where people leave their homes and all their childhood traumas and then go elsewhere or just evolve from that and are figuring out who they are as humans. And so, yeah, I wouldn't say that I was really paying attention then. However, in the last three years now since I've come off the pill, I would say that (.) in terms of changes, I think that I've just with more cycles and more knowledge of the cycles, I can now more predictably see the patterns. Whereas before I didn't, I think it was that I didn't understand what my patterns for emotional mental health were. I kind of only it understood the physical part of it.

**Alice:** Yes. So once this happened (.) well, to be honest, a few times. So at the beginning when it wasn't regular, but it wasn't that I ever had painful periods when I was younger, they were when I when I hit my (.) late 20s. And that was just really “put me on the pill”, mean it really worked (.) and that was that. And then I had irregular periods for a long time, but I could cope with that. So there wasn't any sort of pain or anything like that. I can completely cope with the emotive stuff and the change in boob size and weight gain, whatever, you know. It is the pain for a couple of hours or a whole day or passing out and the fear of that happening while out. That terrifies me (.) I actually can't tell you how painful it is- that it's so awful. I want to stop it and make it go away.

**Beth:** Yeah, definitely (.) probably I mean, I'm 39 now, and I would say since my mid 30s, the PMS symptoms have become a lot more pronounced. Although the bad ones have probably always been an issue, why (.) I think I've just become more self-aware of the pattern of these things happening. Whereas I probably was paying less attention to the timing of the symptoms when I was younger. So it's difficult to say whether I've only had the symptoms since my mid thirties or whether I've only become aware that it's PMS since then because I've been tracking it all.

**Dani:** Yeah. I don't get cramps like I used to. I used to get them every month. And sometimes I'd have to be picked up from school. And then I was on the pill. So it just sort of happened. It wasn't really particularly eventful. But yeah, no, I don't get as bad pain anymore and it's much, much, much more regular now. So I couldn't I don't think I would have known to track it as much before, but. Yeah. Now it's. Yeah. Yeah, I think it's just the lack of pain, no or not lack of just less.

**Emma:** That's a great question. So when I was younger, I (.) I don't remember happened. The psychological symptoms, actually, no, that's [long pause] I'm gonna (.) a recent realization was that (.) I didn't remember having any psychological symptoms. But, I used to have panic attacks, and on those days I would find it really difficult to go in assemblies (.) and because I felt really claustrophobic and it didn't happen all the time. It only happened sometimes. And now (.) now that I know what I know about PMDD and what I experience now as an adult, I'm almost convinced that that was happening in premenstrually. And I didn't realize because I didn't know about it and I didn't track my cycle. So the other differences were that I used to have incredibly painful periods to the point where I would almost faint and I missed school, had to be picked up from school because I was just crippled in pain. And that (.) that seemed to ease with age until fairly recently where the pain has come back. And the length (.) the actual length of my cycle has changed. Again, that's been quite a recent thing, so I've noticed a change. I think more significantly from my (.) mid 20s to now, so I'm 33 now, nearly 34, and I've got a much shorter cycle. I've got a much shorter [pause] bleed. But less pain and more mood related symptoms? Erm, so I don't know it (.) sorry for the complicated answer (.) in answer to your question, I (.) I don't know if the mood related symptoms have been there all the time (.) and it's just that I haven't been aware and haven't been tracking and haven't been conscious of them or whether they have come on from my late 20's?

**Faith:** Yes. So that (.) um yeah (.) so the emotions have grown. Everything else I've (.) yeah (.) I've always had.

**Gemma:** For me, it's just the emotions. Everything else is the same, but the emotions have gone crazy through the roof now. And I'm scared.

**Helen:** Yeah, the severity, the severity and regularity, I would think. And that might have been (.) the regularity might have been a result of (.) I was expecting it at that point in my life. But definitely the symptoms became more and more severe.

**Kathleen:** Yes. Yeah, definitely. As I said, I think more recently is when I would say I have PMS. Previously (.) if we'd spoken maybe a year or two ago. I probably wouldn't have said that.

**Aisha:** No (.) it's just that (.) sort of the same (.) but I manage it better now.

**Mala:** I think it's more, more now than before. Because I don't (.) I don't remember me being like this (.) um, when I was younger, but now I'm more like irritated with stuff, prior to my period.

**Noor:** Yeah, it's improved. **Interviewer:** So particularly the pain is (.)? **Noor:** Yeah the pain's gone. The restless leg syndrome doesn't happen anymore.

### Tangents:

**Faith:** I'll hear like (.) I watch (.)Or I can go to a show (.) I can watch someone singing and I'm like [indicates tears] it's just the power or the beauty of how they sang. **Interviewer:** Oh yeah, being moved, yeah. **Faith:** I feel like I can actually cry. **Interviewer:** I think (.) I think empathy is the best word because I think that's what music and particularly, choral voices, what they're doing is expressing an emotion. And then we're like, [indicates 'wow' moment] **Both F&G:** Yeahh **Gemma:** You're with me! **Interviewer:** Yeah. And like you, I enjoy it (.) because I'm not a very emotional person. **Gemma:** Yeah **Interviewer:** And so when I cry and I feel moved, I think 'yeah, I'm still working' **Gemma:** Yeah! [Loud] I always feel like that like in my day to day. I'm very emotional, but not sensitive. So things don't make me like that. These things don't make (.) when I'm supposed to cry. I can't cry. I'm just (.) I'm really like "what is wrong with you?" But when (.) you know when you cousins came to my house- I was on my period! **Faith:** Ooh! **Gemma:** Yeah, cos I kept cryin'. And I was like 'yes!' like we were talking about like really sad things and everyone was crying. And I cried and I was so (.) and I was like, you're on your period, this is why you're doin' this crap [laughter]. Otherwise I would not be crying. You know, what I mean? So I like it. I'm just like, yeah, you can cry on (.) at the right time (.) when everyone else is! [Laugh].

**Which is so crazy**

(P7)

**Gemma:** Oh my gosh! It's such a hard thing to navigate when your family are African. [laugh] I mean, "this is the way of life, you must (.) this is normal (.) like, what's your problem? We've all done it before (.)"

**Faith:** [Interjection] "Get up and get on with it!"

**Gemma:** [Repeats] "Get up and get on with it". Like, that's the attitude. "What makes you so special? Every woman has gone through it (.) and they were fine" my mom used to say to me, "you think that people haven't had periods before [laugh], are you crazy?" [Laugh] like when I say I want to be (.) I want to take a day of from work. She says "Are you mad? Do you think your Grandma's Grandma's Grandma's Grandma didn't have a period?" So it's very normalized. But again, it's very unique.

**Faith:** That reminds me of school (.) um again because my periods were so debilitating there were times when you have to do PE [Gahhhh from Gemma] Imagine that sort of pain and you have to run around and stuff.

**Gemma:** And they just don't understand!

**Faith:** And I'd tell her, like the PE teacher (.)

**Gemma:** Yeah

**Faith:** "I physically can't!" and she was like "So am I supposed to let every girl off every month?" sort of thing (.) and it's like [Interrupted]

**Gemma:** They're horrible!

**Faith:** And it's like you feel guilty for even asking, sort of thing.

**Gemma:** Yeah!

**Faith:** And it's because everyone goes through diff-

**Gemma:** [overlapping] Yeah

**Faith:** (.) like we've touched on, everyone goes through different, um, levels of pain.

**Gemma:** And they think you're playing up! And it's horrible when you're young, especially where we're from. So like, school's already [pause] 'resource scarce' so the teachers are tryin' their best, but then they don't have the resources and things are tight for them, so everything is an issue. Where was (.) we're not (.) we're not (.) we weren't brought up in the way that was privileged enough that these teachers could have more of a kinder (.) [laugh] a kinder approach to it, like " It's OK" (.) because I could (.) I spoke to kids who went to school in [richer neighbourhood] for example, if they said this (.) it's "no, it's ok, sit down, it is fine, oh my gosh! I'll get you a hot water bottle" [laugh in background]. Us! Are you crazy? Better get up! You could be bleeding, running at 13 and they don't care. So [pause] that's sad though, because it (.) it makes (.) it internalizes the way that you feel about your own periods-

**Faith:** Yeah, and then you-

**Gemma:** -and you see it as negative and-

**Faith:** Yeah. It was the internalisation that made me like 'OK let me stop complaining"

**Gemma:** YEAHH! And I'm dyin here-

**Faith:** They thought I was exaggerating (.) yeah-

**Gemma:** But let me (.) maybe it's okay?

**Faith:** Yeah.

**Gemma:** And let me not ask for help.

Interviewer: [00:42:35] Yeah, I know... I've heard that a lot. And it's sad. Particularly when you think back to the fact that you were a child.

Both F&G: [00:42:41] Yeah

Interviewer: [00:42:42] And It's just like, ooooh, I was a child in pain! [gentle laugh]

Gemma: [00:42:44] I was a child! It was all pain!

Faith: [00:42:48] And you're literally getting told off! [whisper][nervous laugh]

Gemma: [00:42:49] And I think it's nice now because we understand it so that when we have younger cousins and stuff and they come to us, we're like "Oh, my gosh, poor baby" Like We understand. Um because we... we don't have this whole... Even though we were treated that way, we don't have the approach of " get on with it!"... {overlapping]

Faith: [00:43:03] We don't...

Gemma: [00:43:03] Especially because of Faith, like because of her experiences of her sharing them so openly with me. I take it much more serious. Maybe I wouldn't have...