**Professional/clinician**

But certainly the ones also that are willing to sort of look outside the box and look for other ways of doing things, not just seeing exactly what’s in front of you, look at the….well yeah I guess just look at is as a whole and look for other things, like if the radio was blaring, or if this could be upsetting, or if this could be an environment that could be distressing somebody. You know people who take more time to look at those things.

**Family member**

A Her approach. It’s just the way she approaches, the way she talks, with communication. The way she gives time, she allows time, do you know what I mean? That’s the big difference between giving time and allowing time. If I give you my time, say you’ve got ??? if I give you my time and allow you time, do it in your own time. That’s what it means in my sense. And that’s what she does with our (Sister/patient-participant), she gives time and allows time. Even though she might be a busy woman, she might have a lot of things to do, she’s going above and beyond. Because that’s the difference between being good and great isn’t it?

**Family member – lives with patient-participant**

Q Do you see a lot of similarities between the parent’s care and the doctor’s care then?

A Yes. But doctors only will give what they can afford to give you, you know the care and the time or whatever they can give you. See a doctor 10/15 minutes, that means you’re finished. In that 10 or 15 minutes whatever they can offer you, they offer you, that’s it. But they always say “if you need anything always give us a call” or “call back” or “drop in” that kind of thing.

**Family member – lives with patient-participant**

**NB. A = Patient-participant’s family member ; B = patient-participant**

Q (Name of son/patient-participant) do you have any thoughts, any advice for doctors and nurses how they treat people like you and your brother?

B Besides co-operation, time is valuable things for many people you know. Everyone needs that time.

A It would be nice for nurses or doctors to realise that that patient is very sensitive that needs to be quickly dealt, or quickly seen and let them go off, you know that kind of thing would be nice. With a normal, “OK then this one that’s a normal, not a big issue, can wait another 5 or 10 minutes” you know.

**Patient-participant – person with learning disability and Family member – lives with patient-participant – person with learning disability**

NB. S = Patient-participant; B = Patient-participant’s family member

A Well (name of previous social worker) I weren’t very happy with her. Because every time I wanted to phone her “I’m sorry she’s in a meeting” or “she’s on holiday”.

B She used to say that with me, she’d say “oh sorry I’ve got to be in a meeting in a few hours” she was on the phone.

**Family member – lives with patient-participant – person with learning disability**

A Well they come in at 6 o’clock to help with the tablets. I think one lady come in at 6 o’clock in the morning and say 6 o’clock in the evening to... I said to (name of participant’s wife/patient-participant), I said instead of them coming in at 6 o’clock I said they could come at perhaps quarter to 7, like that in the morning. Anyway it was timing to have, but the rest I’m in bed.

**Carer**

She took her time with this gentleman, explained everything in the way that he needed it done, and if it wasn’t at the time she asked, you know “do you understand that”, you know making sure that he knew exactly what was going on and, you know basically explaining things in a way that could be understood well.

**Carer - lives with patient-participant**

Participant – Dr [name of psychiatrist] has been amazing. I think that has helped with three-monthly, six-monthly reviews with Dr [name of psychiatrist]. I think Dr [name of psychiatrist] has access to her counselling and the most amazing counsellor that [patient participant] had, she was absolutely amazing with her. It took her a while to grasp all of the complexities of [patient participant]’s nature. She was able to guide her in counselling in every way.

**Patient-participant – person with learning disability and Family member – lives with patient-participant – person with learning disability**

**NB. S = Patient-participant; B = Patient-participant’s family member**

A She is a good social worker.

Q What makes a good social worker? What makes her good?

A Well when you phone her she’s either….she’s gone to see other people and… Or she wants to come and see us some time.

B I’d say when she’s got the time to come and see us like.

Q Is it important to you that people come and see you?

A Yeah.

Q Why is that important to you?

A To see how we are and….

B And to see how we’re getting on and things like that.

A Yeah.

Q Does it make you feel a certain way?

A Happy and….

Q How about you, how do you feel when they come and see you?

B Well it sort of makes me feel pleasant. And, well basically I get overwhelmed.

Q Overwhelmed?

B Yeah, I do when they come and see us like.

Q Tell me more about that feeling, about feeling overwhelmed.

B Well like I’m more happy and joyful in myself when they come and see you. Like I like to think oh I wish she could come like say more often, which I know they get busy.

Q So you feel like overwhelmed with positive feelings when they come?

B Yeah.

**Family member – lives with patient-participant – person with learning disability**

A When we used to be at (old address) I think they used to come at quarter to 7 when we were up there. But since we’ve been here now they seem to come at 6 o’clock.

**Professional/clinician**

Because some people will be happy with this kind of explanation and that will work for them, but other people will need something different, other people might need more time to process.

**Professional/clinician**

A Ah, thank you. No I love it. I wouldn’t do anything different. It’s hard, it’s challenging but I wouldn’t want to be anywhere else working, no.

Q That’s great to hear. I don’t think you have an easy job so I think it’s great to hear that you love it.

A Yeah, I do. And it’s because I work with great people. My team is great but I work with really great patients you know. And it’s just lovely to take the time and have a chat to them, because people don’t get that I don’t think so much in hospitals. But certainly on community, you know I can go and I can sit and have half an hour with (name of patient-participant) and just chat about what she’s been doing at day centre, and what she’s been making, and what they’re having for dinner, or what’s happening on [patient-participant's favourite television programme] you know. And sometimes those conversations, you get a lot more out of somebody than if you’re bombarding them with questions. You know little things will slip in, or you’ll hear something and you’ll think “oh, I’m not quite sure about that”. You know it is really nice in this job that we are encouraged to get to know people, it’s fab, it’s great, yeah.

**Professional/clinician**

A Yeah. Block out a bit of time if (name of patient-participant) were to be there because respectfully it naturally gets drawn back to (name of patient-participant) and to their lovely relationship. So it takes a little bit of work trying to draw it back over to (name of patient-participant's husband).

**Patient-participant – person with learning disability**

Researcher – so she told you to put your arms out

Participant – then she’s already done and put the bandage and plaster on it

Researcher – so she did it very quickly

**Family member – lives with patient-participant**

The one doctor talks very, very slow and quite quiet and he’s very caring, the one doctor, very, very caring and he doesn’t rush you, you know and he does find time to talk to (name of daughter/patient-participant).

**Carer**

Q And what about the way that she communicated was humanising for you?

A How…I suppose it’s how it was put, how it was explained. It was soft touch with, you know the voice. It was not rushed, it was slow, it was done at a well paced talking. It wasn’t like trying to rush the appointment, it wasn’t trying to, like “right OK, OK we’ve seen you sort of thing, now we can move on” sort of thing. It was taking into account what the appointment was for and why this gentleman wanted the appointment, which was basically to improve his life, get the most out of his life. So that was the best part of it.

**Carer**

Q Anything else you want to say about that kind of good story? Like what would you want our doctors and nurses to take away from that story about how they treat people with learning disabilities?

A Take your time.

Q Yeah.

A Take your time. Be clear. You know be calm, be respectful, don’t just try to treat the appointment as a five minute slot just to fill, you know. And to treat them like a human being, taking the time and all that, yeah.

Q What about a bad story, have you got one that sort of stands out or is it all gloom?

A They’re very average to be honest. Like you said it’s very procedural, you know it’s just…not like the good one. So they would be the bad one in my eyes is the fact that it’s all just taken as a five minute slot, just a quick thing, nothing is really explained well to them. Nothing is…. I can’t say it’s not fully investigated or looked at and that because I’m not a doctor, but the way that it’s done is not like the lady I was just speaking about you know, with that soft touch and explaining the communication. Just goes that level beyond, yeah.

Q And by soft touch you mean like gentleness?

A Yeah just….you know just your tone and, you know…got to be like, I suppose “oh another day as a doctor”, you know it’s another day, so like a feeling of you don’t want to be there sort of thing and that then outputting to everybody around you. And rather be, you know happy, high spirited or whatever you know to make the appointment easier I suppose. Because people with learning difficulties can I suppose have high anxieties as it is without, you know worrying about if the doctor’s going to be nice or not and hear my out and stuff.

**Family member – lives with patient-participant**

But we did always manage to get through and (Name of consultant) gave us her other… her non-NHS email, her personal email address so that if we had a problem and we were worried about something we could send her an email and she would communicate with us and book a….she would see us at the end of one of her clinics or something. And we would go happily and sit there for an hour and a half before we saw anybody but we would…. So we always knew she was there if we needed her. And (Name of daughter/patient-participant) had total trust in (Name of consultant). If (Name of consultant) asked her any questions she would always answer them, and whatever (Name of consultant) said she should do, she believed it was right.

**Carer**

Q And this word ‘respect’, you’ve mentioned that a lot today and you know it’s something that (name of patient-participant) wasn’t sure about as well, what does it mean to you to be treated respectfully by doctors and nurses, and is it something that you see a lot with your interactions with your service users and doctors and patients?

A Yeah they respect them, I can’t say that they don’t, but like I previously said some do try to rush you. And I think that comes down to a bit of respect. I don’t know what their behind the scenes dealings are with how their targets are and whatever, but that’s for them to know. But yeah it’s….the respect….yeah I just think respect is being kind, it comes down to as well being kind, nice. You know it’s all about…that’s respect, being nice, kind and listened to and all of that really. Which I suppose they’re listened to, but it’s the being kind part I suppose is missed then, you know quite a lot in appointments with a lot of doctors, you know.

**Carer**

A Their demeanour, you know it all comes back to I suppose the communication. It’s being high spirited, happy, and then being kind as in fulfilling the way that you want the appointment to be. You know just being kind about it, offering….you know “would you like this to be done”, you know if there’s a need for blood tests or whatever you know, rather than just saying “this is going to happen, right we are going to do this”. Give the option of asking “do you feel that you need something else from this appointment” rather than just assuming that what I’m telling you is the way it’s going to be.

Q Right.

A And then it comes down to the time and stuff that they have to do that you know I suppose.

**Carer - lives with patient-participant**

Researcher – So, as you are someone who knows [patient participant] well and attends appointments with [name of psychologist] and Dr [name of psychiatrist] what is it that he does that makes them such a great practitioner?

Participant – She listens to [patient participant]. After a few sessions she was able to… because [patient participant] jumped from one moment of thought to another… became good at guiding [patient participant] to the crux of what she was saying. She just got to know her really well. But I think it was the fact that [patient participant] had ongoing counselling, she was able to get through the layers of her complexities and anxieties. I think it was really, really important that she had ongoing counselling for well over a year to get to the layers of perhaps the best way reach, and for her to understand triggers that caused anxieties within her and things to do where she was in control of her life and mood swings, to the point now that I would say that [patient-participant] life has become enrichened where she is not as distressed as she used to be, and in a way that ongoing care has paid off because her life is so smooth she hopefully doesn’t need long going, intense NHS care because, myself and [participant’s partner] can support her to have a good life and avoid the anxieties and triggers that she was constantly feeling before. That was longwinded, sorry.

**Carer - lives with patient-participant**

She was patient and very respectful.

**Family member – lives with patient-participant**

Q So compassionate is another one of those words that we use to describe humanising healthcare. So how do they show that they’re compassionate?

A Touching, looking into her face, holding her just gently at the back of the shoulder. I mean just finding time to talk to her. And I know they’re very busy all the time but they always found some time out of every day to pop in to talk to her and to see how she was getting on.

**Family member – lives with patient-participant**

Q Community nurse, urology nurse (name of nurse). Has she experienced being sort of touched by doctors or nurses that are male? Have you noticed that? How do you think that would affect things? I think (name of daughter/patient-participant) grabbed the psychologist up by the hand, but that was her touching and dragging him up rather than vice versa.

A Yeah. I mean the psychologist made a lot of home visits and he was very kind to (name of daughter/patient-participant) and always speaking to (name of daughter/patient-participant) finding time to speak to (name of daughter/patient-participant). And he’s always get up, come over to (name of daughter/patient-participant) to her table to see what she’s doing. And he’s always held her hands, you know.

**Family member – lives with patient-participant**

Q Can you talk to me a bit more about (name of psychiatrist) and his care and those home visits.

A He’s always come out…well not always come out, we’ve always gone to him as well, but it’s been a mixture of both. But he always finds time. He always sits on that seat there, always finds time to talk to (name of daughter/patient-participant). And he speaks very clearly and very well. And (name of daughter/patient-participant) has always got to flick him and shock him, that is her greeting ‘welcome to my home’. But she will talk to him. Now (name of psychiatrist) is very, very tall but he is….

**Family member – lives with patient-participant**

A Yeah. But he always speaks lovely to (name of daughter/patient-participant) and always finds time to speak to (name of daughter/patient-participant) And always came a little bit earlier than the community nurse or whoever else was coming and always had a chat. And I never once felt phased by a professional person coming into our home, which was nice, I felt comfortable you know.

**Professional/clinician**

I know I can be a little bit more available than I should be in that I will answer the phone when I’m not in work if I know the family is genuine, which most of them are. You know they only ring if they are desperate or they’re stuck or don’t know where to go, and if I can help them I will do that.

**Family member – lives with patient-participant**

Q And do they all make you feel as comfortable having them over as (name of psychiatrist) does?

A Erm…yeah, most of them. Obviously if there’s a new face, you know somebody new in the position, I mean they always greet….you know they always greet themselves “I’m so and so” and I invite them in. We’ll have a quick sort of chat and then we get down to what we need to talk about, you know. But yeah a lot of people come out and we also meet a lot of people, you know annually or every quarter with the health professions, you know usually up in the (name of hospital) (name of house). But yeah we’ve had a lot of visitors out regarding (name of daughter/patient-participant)’s health problems, which sometimes is easier for (name of daughter/patient-participant) and for myself. Obviously as well when (name of daughter/patient-participant) started with (name of care provider), the support out in the community, the manager came out a couple of times with one of the carers and she sat for about 4 or 5 hours assessing (name of daughter/patient-participant) what her needs are, what she likes to do, activities and different things like that. So they done that for a lengthy time as well before his staff were about to take (name of daughter/patient-participant) out and about into the community. And it made me feel comfortable that she was in safe hands. And they got to know her quite a bit before they actually took her out on her own, you know without me being there as a parent.

**Family member – lives with patient-participant**

You know if they’re going to talk to somebody I mean and you know there’s something wrong, be understanding and respectful of that person. I mean don’t judge a book by its covers. I mean you need to take time out and listen to them. And you could sum it up, you know in the first couple of words, you know. I mean just be caring to the fact that it could be a child or a relative to that person. I mean whether they like it or not or they feel a bit embarrassed trying to talk to that person with the learning difs or what, or have got a disablement, I mean they need to stop and think, those young people you know or those adults have got feelings and they can see, they can hear and they can feel. I mean they need to step back and take into consideration of that person who they’re talking to and treat them like a human being by way of giving them time and giving them enough time to understand what you are trying to tell them. And if you feel that they don’t understand obviously speak to the person that they are with, but also looking at that person, talking to them, but also talking to their carer or their parent, whoever is with them, addressing them as you would do with any other person. You know include them, don’t….I can’t think of the word….exclude them is the right word, is it?

**Family member – lives with patient-participant**

Q What makes her [learning disability nurse] knowledge more powerful than the doctor’s knowledge?

A Because she takes the time to explain it all to us, it’s not rushed. She’ll sit down and have a cup of tea and explain it to you “this does this, this does that, this is why this is doing that and this is why this is happening”. She’s just repeating what they have said but with a bit more detail and information for us. And it helps us understand what’s going on. Just simple things, simple things. With the professors, it all seems a bit rushed for me. No sooner are you in you’re back out. And there’s not enough time to get them to see the picture. Very hard to get them to see the picture. And that’s where (name of LD community nurse) has given us a bit of piece of mind, just explaining things to us.

**Professional/clinician**

You know I’ve just been talking to another mother that I haven’t got a role that I’ve got to discharge, his epilepsy is now well-controlled, and I’ve said “look, I’m on the end of the phone if you need to run anything by me”. But unfortunately I can’t stay involved because there isn’t a role for me, our time is pressured as well and I can pick somebody else up instead. But I know that their needs are no less now than when I started with them, it’s just things have settled in one area. But their son’s needs are still high – and how little they have and how little support that they have. And they are [profession redacted - requires a degree and has cultural and social capital] that have retired but they can’t enjoy their retirement because they have to, you know continue to care for their son or put him in care – that’s the cracks of what they’ve got, you know. And I just think it’s hard and if I can help in any way then, you know I’ve said “just ring me, I’ve got no problem, just ring me, if I can help or pass you on to the right person I’m more than willing to do that”.

**Professional/clinician**

But like I said, I campaign for get through to the GP because sometimes you can be on the phone for hours. Mum hasn’t got the option of doing that because she’s so ??? So I say “right, I’ll ring them, I’ll pass that information on”. And GPs are better, they are more open now, and sometimes we’ve got an email that we can email that query to, whereas families can’t, so doing things like that just to lessen the stress on them if that’s at all possible.

**Professional/clinician**

Because it is only a timeframe, it might be a 20 minute to half hour appointment you know because everybody is so pressured and so busy, so let’s get the best we can in that option for all concerned.

**Professional/clinician**

Now I’ve always worked in that he wouldn’t go anywhere, wouldn’t go out, wouldn’t do anything, but slowly I gained his trust by visiting and saying “come for a ride with me”. “No, no I don’t want to go anywhere, no, no”. I said “come on, tell you what we’ll just go for a ride, we’ll pull up to a….” oh God, a thing on the side of the road and have a cup of tea, you know so we don’t have to go in, we don’t have to do anything. We’ll just go and have a cup of tea. He came. We went walking in his local community, called in a couple of shops, that worked. Taken me 10 years mind, it’s taken me a long time. Then it would be “right, do you want to come with me to the café” – no problem.

**Professional/clinician**

And that, I would have loved to have been able to have done that more regularly, but obviously with constraints I couldn’t. So it will be once every 6 weeks, once every 2 months I was able to offer that.

**Family member**

She spent around half an hour, 45 minutes just chatting with (name of person participant supported at work A) and myself getting to know (name of person participant supported at work A) before we went into that professional, and like I said the mar charts and everything else. We did manage in the end to get (name of person participant supported at work A) up walking to the bathroom and how best to do that.

**Family member**

Q So you know how we keep talking about this idea of sort of the word humanising and I wondered what that meant to you and what it means to be treated like a human being.

A I think for me it’s dignity and respect is the first two. And again sometimes with the NHS, and I don’t think it’s personal, you’ve got your job to do like you say or you’ve got your box to tick, you’ve got your script to follow. And sometimes that script can take away the human aspect of it, just “how are you feeling today”, “oh right I understand”. Sometimes you find there’s not much time to listen. And I think a big part of that is being heard and listened. And rather than feeling like you’re just that number, you’re going in and someone’s listening and someone’s actually able to help, or try to help.

**Family member**

Q Do you have any sort of advice for how healthcare professionals can make their work more humanising?

A Again I know it’s really difficult but I think it boils down to time. The time you are willing to spend with that person and actually listen. I think listening is the key. Listening and taking that away and thinking, as I said, outside the box. Where she would say “I’ve got sand in my feet”, think of that, look at that, and think right well what would that mean to me if I had sand in my shoes, how would that feel? And try and break down those conversations rather than just thinking “oh well I don’t know what she’s saying”, have that broader aspect around it as thinking outside the box when you are speaking to somebody with learning disabilities what that could possibly mean.

**Family member – lives with patient-participant**

…and takes your time, I wouldn’t want to be rushed because that would make you feel a bit uncomfortable.

**Family member**

A Well if (granddaughter/patient-participant) goes and says “I’m not sleeping”, instead of saying “put your phone down”. And I can understand very well because my sleep lately has gone out of the window. But I won’t go to the doctor. They should be saying to her “well why, what has changed?” Do they ever ask that question? No. Nothing has changed, you’re just not sleeping. So why aren’t you sleeping? But they’re not even asking these questions to find out. So again it all comes down to communication. And I think that’s the biggest part of it. They just want to get you in and out and that’s it. They don’t want to know the background of why this is happening or…. and to me that’s what it is. And that’s what I think they should be doing. They just seem to have lost that caring side.

I know when you go into hospital the nurses do the bulk of the work, but they’re run off their feet and they try and try. But again they can only take so much. I mean last time I was in hospital you’re lucky if you saw a nurse coming and forth the ward because they’re so rushed off their feet. So maybe again, maybe the government ought to treat staff better so they came ??? instead of a conveyor belt sort of type thing, get them in, get them out.

**Family member – lives with patient-participant**

A I feel like even if she doesn’t respond you should ask, like “oh I’m going to do this now, is that OK”, something like that. I think it’s just respectful to do that, even though she probably doesn’t know. But yeah.

Q I think that’s a good example though isn’t it of like not worrying about the awkwardness of someone not responding but still engaging.

A Yeah, because my mum would probably step in and be like “oh that’s fine isn’t it (Name of sister/patient-participant), or like everyone to say something. Because I feel like people don’t realise how long it takes (Name of sister/patient-participant) to respond, because she’ll just be thinking about it for a while and I think they could not give her chance to respond if she didn’t. So yeah.

Q That’s interesting though isn’t it, do we need to give (Name of sister/patient-participant) more time then if we’re going to get an answer as well?

A I feel like that. I’ll come in from work, or if I’ve been out and I’m like “OK (Name of sister/patient-participant)” and then you wait there, and then I say “oh God I should go now”. You wait there, and then she’ll respond. It will be like a one word, it will be like “yeah”. It just takes her a bit longer.

**Patient-participant – person with learning disability**

Researcher – What is Doctor [name of psychiatrist] saying?

Participant – He’s saying thank you. He had a coffee with us

Researcher – Do you want to draw it here?

Participant – That’s a coffee

Researcher – Lovely. Do you want to draw yourself in there too? Otherwise, it looks like Doctor [name of psychiatrist] is drinking coffee on his own

Participant – I had squash that day, orange one

**Patient-participant – person with learning disability**

Q What does this word mean to you? What do you think it means to be treated like a human being?

A Being on your level and talking to me how….like how you want to be treated to each other. So instead of treating me like just another patient that you just can’t wait to get rid of, sort of treating me like I’m on my own and there’s nobody else there, trying all these different strategies, exploring these routes. I just think it’s that to be honest. To not rush everything even though you’ve got these other hundred odd patients that you need to see as well. But taking that time out to get to know your patient, get to know how to….get to see what’s wrong, what makes them better. Just doing stuff like that every day, or maybe appointments that would help improve them with their health. I think that’s what it would be like to be a human being.

**Family member – lives with patient-participant**

A Yeah. Why would somebody make something up about somebody? Like as a parent of a young child then, why would I make something up that they’re…especially if I’ve got video evidence to prove that they are doing it as well. But they’re so negative. And when a parent speaks openly about a child - it’s not so much… obviously we’re not talking about (Daughter/patient-participant) now but another child, when a parent speaks negative about a child, or an adult or whatever, don’t take it as they’re being negative because they want to be, it’s because they are trying to portray the image of said child, adult or person with a disability. They’re trying to portray, to give you the story in such a short time. Because everybody knows when you go into an appointment you’ve got 20 minutes max basically. And like I said, if you go in somewhere and you’re telling them “oh yeah everything’s great”, you can’t expect no results if you’re telling them ??? you’ve got to be the Negative Nancy to tell them “no it’s not great”. But then you’re seen as a bad person then, or a bad parent, so it’s like “mmm, OK you’re not very helpful”. Yeah I am, I’m trying to get the support that they need. It’s weird isn’t it when you look at it.

**Family member – lives with patient-participant**

A So we never minded that. And I think that was part of it. You see often we have seen consultants, you know you’ve got so many minutes with them really. You know with other things I’ve seen consultants and you don’t get the feeling that….with (Name of consultant) you had the feeling that you were important. I think that’s why she would spend a long time with anybody because it made them feel that their case was important and that she knew about you. I think that gave us confidence I think that the advice we got was going to be good, because she wasn’t in a hurry. I think particularly with neurological things, it can’t be like looking at a broken arm or something, you’re looking at something you can’t see. You’re trying to….the consultant is trying to get inside you, and that is never going to be as quick as looking at a broken arm or whatever. I understand that it’s a slow process and the longer that somebody like (Name of consultant) has with a patient the more likely it is that she’s going to give the right advice.

**Family member – lives with patient-participant**

So I think booking an appointment for quarter of an hour/20 minutes or whatever it is, that is wrong for people like her and I think that’s caused he a bit of grief in the past, and still does I think. (Details of personal stories the consultant shared with the participant; redacted)...And I think that all stems from the fact that if she’s got a patient she will spend as long as she needs to with that patient – and I think that didn’t always suit other people. I don’t know.

**Family member – lives with patient-participant**

A So I think she….that’s why she was never in a hurry. You never felt she’d got so many minutes. You were there and “how can I help?” You always felt that she wanted to help as opposed to “gosh it’s nearly time to go home”. So I don’t think you can teach it. But I think by observing it, by somebody observing it and seeing how she does it and then going home and thinking about “now what did she do?”, I think that’s the only way people would learn.

**Family member – lives with patient-participant**

I think the problem with healthcare at the moment is that people don’t have the time to humanise it. A doctor has so many minutes or something for you – well it might take longer than that. If I go with having cut myself badly, that’s easy; or you’ve broken something, that’s easy. But if you need somebody to try to understand what the problem is… And these days, if something’s wrong or something hurts you or something, right, send you off for an x-ray, that’s got rid of you – next patient please. As opposed to…

**Carer**

Researcher – So we are exploring the word humanising and are trying to define together with patients with learning difficulties and researcher with learning disabilities what that word might mean and we used the word initially because we felt it’s about being treated like a human, which is something you also said quite a bit in this interview so would you mind drilling a little bit into what being treated like a human means

Participant – I think, no matter our ability, our age, our background, religions whatever it may be we all have blood running through us and we should be treated how we would treat our family members, it shouldn’t matter what disability or whatever you have going on just being respected and spoken to appropriately and when I say appropriately I mean to the level of understanding for that person, taking time not rushing people, just being a person and understanding the person you are with is a person that’s kind of what it is, I think.

**Carer**

I think in personal experience, I think what doesn’t go so well is the time restraints and how long everything takes, when you get to it, it can be amazing but the waiting list is so many things, is just.

**Carer**

…patient’s, time, not being felt like you're a number…

**Carer**

Participant – I think, I have a service user up the top who has dementia, he can get quite upset around new people and I think some healthcare professionals have almost been a little bit weary of doing or saying certain things around him but he was having one particular day where he had gone back to being younger and he was doing his boxing and he was just dancing around pretending to box and getting quite agitated with the situation and this doctor put her bag down and started boxing with him, and in his room he has a punch bag and she said come on then I’ll give you a go and I think that stuck in my mind, as I thought you are just being human, it was nice just for you to take the time to get into his space where he’s at, at that particular time and wait for him to be ready to speak to you rather than saying I’ll come back another day. That did stick in my mind as I thought, that’s care, that’s someone that actually wants to see what the issues is with him when he is ready, they waited for him to be ready

Researcher – Really open to him.

Participant – Yeah and not just being like “oh I will have to come back”, I think they were probably here for a good hour but eventually he was happy to sit down and be looked over and checked and he was very open to that, where usually he not even when he is in best of places doesn’t particularly like to be touched and prodded, well nobody likes to be prodded, but it was just nice to see that, you know that she had actually taken that time to see where he was at and wait for him rather than in her time.

**Family member – lives with patient-participant**

And so we always believed that and (Name of daughter/patient-participant) always believed that and so when we went to see her, even if we had to wait a long, long time – we usually did have and the nurse would come round and say “I’m sorry”. But we’d say “no, (Name of consultant) is never in a hurry to get rid of us either, so the fact that we’ve got to wait a long time because she’s running behindhand is exactly what we know she does. She will spend as long as she needs to be with somebody and if that makes her unpopular, well tough. And we never complained, we never said “oh gosh we’ve been waiting for an hour and a half to see you” – she knew we had. But we were just pleased to see her. And I think she often saw us at the end of her clinic, so often when we came out the place was closed, they had to unlock the doors for us to let us out, you know.