**Carer - lives with patient-participant**

Q So, what I’m really interested in is how you, as a carer, how you work out what that best thing is. How do you do that?

A I work it out by knowing the person. If you work as a community carer, you’re going in to see somebody, might be there for 15 minutes, you make them a cup of tea, you say hello, you fill in your book and you leave. You don’t know that person. With [patient participant] and the others, we know them, so we know how to do the best for them. We don’t always get it right, but we’re not superhuman, but we know the person and know responding to them in a certain way will give them the best care. You know when to not intrude, when to assist, to step back. That’s all care, that’s caring for the person. [patient participant] was eating the other day, and we could see she was struggling with her knife and fork, I just got up, got a spoon out from the drawer, popped it on the table next to her and sat down and continued my meal. I didn’t want to say, “I think you should use a spoon for that,” because I would feel that I’d be telling her how to eat her dinner. Having the option of… I’ve just put that spoon there for her… ooh! That’s easy! That’s caring, thinking one step beyond what [patient participant] needs sometimes before she needs it.

Q Sure. Yeah, thank you for that. Just going back to healthcare, could you tell me a story of the best healthcare professional you’ve met in relation to [patient participant]? Does anybody stand out as that person?

A I think it has to be the nurse at her GP practice that takes [patient participant]’s bloods. She’s know [patient participant] for a long time, I think she knows her family as well, she is always very personal to [patient participant]. Over the years, she knows [patient participant]’s life. She remembers things, she remembers… we went for her bloods around [date], and she remembered the time before we told her we were taking [patient participant] on holiday, she was very excited, “So! Tell me [patient participant], how was your holiday?” It was really important; she remembered something [patient participant] had told her. She is a continuous person, unless she is on holiday or sick, we always see this particular nurse for [patient participant]’s bloods. [patient participant] doesn’t particularly like having needles stuck in her, but she likes to see this lady. She has sort of got a bond with her and it is worth having a needle stuck in your arm to be able to go and see this particular nurse. I won’t say it is something she looks particularly forward to, but it doesn’t hold any fear for her. She’s always “Oh! We’ll see….” I think for me and for [patient participant] this is a really good experience because it’s taking something that isn’t very nice, but because of the continuity of that care and that person making an effort… I don’t think it’s an effort for her, she’s just a lovely person who now knows [patient participant], she has been seeing her even before she came to live with me, she’s been at the same surgery taking her bloods for a long time. So, it’s just a really positive experience and they have a laugh and a banter, she knows [patient participant] and she knows what she likes, so they can have a little joke about something. [patient participant] comes out feeling on top of the world, like she’s just seen her best friend.

**Professional/clinician**

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.

**Carer - lives with patient-participant**

look at their case history… this happens so often that nobody looks at previous case history. Nobody goes back in… you can go and see the doctor and they will go “how may I help you today?” Excuse me? I’ve just spent 20 minutes filling in a clinic form, and you have to detail everything that is wrong with a person, or yourself, before you submit it, and you’re asking me why I’m here? You know? Have you not read it? Do you not know why I need an appointment today? You’re not there for a jolly, you’re there for a specific reason, but people don’t seem to have the time to look back. Social work… when we get… if a social worker is involved in anything, they pull up a file that is maybe ten or fifteen years old and they’ll change just the relevant things you’re talking about on that day, then you get sent a copy… you know, as an example, the last time [patient participant] saw somebody it said [patient participant] lives with her [family]… and I’m like, she’s lived with me for the last seven years, so… they don’t change the data, they don’t update it. I suppose there is not enough time, there is not enough people, so therefore incorrect information is going to the next person. That paperwork hasn’t been updated for ten years. They need to be more aware of the person and look at what has been wrong with them, look at what they’re coming for on that day, but look back because there might be a connection. You know, you saw her two years ago about something, this is very similar. Have we not treated this in the right way? If they don’t go back in the history like doctors used to… you know, you knew your doctor, you saw the same doctor every time, and they knew you, so they didn’t necessarily have to look back because they knew you… If you were with a doctor practice, unless you moved away… I was with the same doctor for [decades], now you can’t even see the same doctor, so it’s very difficult. They just need to be more aware of the person they are seeing and know a little bit about them before they walk through the door.

**Professional/clinician**

Q …how do you apply like that holistic thinking to someone that you're working with a learning disability?

A I think the first thing that has come to mind is like what are they doing and what do they want to do? What more can they do, can we do to enrich their life to make their lives even better. Also then also thinking about what have they been through historically, what are the barriers that are kind of impacting somebody as to why they might not be able to achieve that and what can I do to help, what can I do to help if it's in my capacity to do so? Sometimes it's not unfortunately, but if it is, I would love to kind of give it a go.

**Professional/clinician**

A OK. I think some of the best learning disability nurses that I've worked with have again just really got to know the individual. Just one nurse I'm thinking about who really got to know the person that we were working with, really learned some of the things that they liked, some of the things that he really enjoyed. And they connected and spoke about the things, so like candles and like lots of sensory smells, they were able to really you know strike up a conversation and build a good relationship based on some of the likes that the individual had. Yeah that’s the person that comes to mind.

**Professional/clinician**

And as part of my learning experience and carrying a small caseload I was encouraged to sort of go out and spend some time getting to know (name of patient-participant) and obviously her husband and to develop a relationship with them. Yeah. So then when I came back into the team then as a qualified nurse in [redacted, past 5 years] (name of patient-participant), obviously because I’d had that relationship with her and the knowledge of her, and for continuity of care as much as possible, she was allocated then to my caseload. So yeah I’ve been involved with her for a year since. So I obviously go out to see her whenever I can, give her a call whenever I can, support her with anything that I can really around her healthcare.

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

Q The other thing you said is, you said knowing things about the patient. Your example was they know how long you’ve had epilepsy for.

B Yes.

Q What other things should a doctor know about you?

B So it’s like what I do and….sometimes people get stressed and….who knows?

Q Should they know how to help you not get stressed?

B Yes. Like therapy is one way that I know. And I have my own personal instrument of this above us.

Q What do you play?

B Guitar.

Q Oh nice.

B A bass guitar.

Q A bass guitar. That’s really cool. Do you enjoy that?

B I play whenever I’m able to.

Q And you mentioned that in relation to sort of helping you calm down. Is that something that you find relaxing?

B I usually make my own music on my own bass guitar.

Q That’s really cool. You’re a very creative person aren’t you?

B You can see my drawing!

Q I like your drawing, I think your drawing is great.

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

Q Yeah, care for someone, what does that mean to you?

A Care for someone is like looking after a baby, a newborn baby, that’s the care. What a baby needs every hour, every two hours you know you have to know as a mother ‘my baby needs this’ you know.

Q What about for someone (Name of son/patient-participant) age, someone like (Name of son/patient-participant), what does it mean for you to care for him? What does it mean for a doctor to care for him?

A Ah, for (Name of son/patient-participant) to care from a doctor, again the doctor has to be like a mother or father who knows the child, who knows their patient, and willing to help with whatever they need, you know. As a parent I know when my child needs what. Or he’ll come to me and say “mum I need this” or “mum this is happening to me”. This is just me as a mum he will say it to me. But with a GP or a doctor you have to know your patients more and the patient has to know more about the doctor, is it a reliable doctor, yeah.

Q Yeah.

A You can’t just say that the patient just can’t treat the doctor straightaway “you are my mother” or “you are my father”, it will take time to get to know that relationship.

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

You’re happy with the staff. Yeah do you want to tell me about any of the staff that help you?

A Well I know some of them. Like some of them say to me “hello (name of patient-participant), what are you doing here again”.

Q Yes, so they’re kind of familiar, they know you a little bit?

A Yeah. And they say “what are you doing here, why are you…” why are you here and everything, and they’re talking to me.

Q Yeah. And so when they’re talking to you do they sound….do you think that they’re friendly, do you think they’re angry, do you think they’re….

A No they’re friendly.

Q Yeah. How do you know they’re friendly?

A They’re talking nicely to me.

Q Yeah? What does that look like?

A They’re talking and they want to know how….they speak to (name of patient-participant’s husband) and they want to know how I’m getting on and….

Q Yeah, so they’re asking you questions. So they want to know more. They already know your name.

A Yeah.

Q They’re using your name, which I suppose is important as well, they’re remembering your name?

A They say “(name of patient-participant)”

Q How does it make you feel when they remember you?

A Very happy actually.

Q You’ve got this big smile as you’re talking about actually the staff.

**Family member**

A When we originally arrived at the scene at the respite home they were on the floor trying to get their usual responses from somebody. So as I said, we said “excuse me, can you just step back”. And they were like “no, no, we know how to deal with it”. I was like “I completely appreciate you need to do what you do but we know how to bring (name of sister-in-law/patient-participant) round when she’s normally like this”. So again, soft gentle touches, “(name of sister-in-law/patient-participant), (name of participant/patient-participant's sister in law) come to see you”. And again (name of partner/patient-participant's brother) would be…(name of partner/patient-participant's brother) has quite a deep voice so (name of partner/patient-participant's brother) would be “(name of sister-in-law/patient-participant), (name of partner/patient-participant's brother) has come to bring you something”. And whether it would be “we’re going shopping, (name of sister-in-law/patient-participant) tell (name of participant/patient-participant’s sister in law) what you like on your shopping list” there’s certain things that bring (name of sister-in-law/patient-participant) round, caravan conversation, “(name of participant/patient-participant's sister in law) has come down to talk to you about the caravan”.

Q Yeah. I suppose it’s like those are all examples of things where she’d be really motivated to respond.

A Yes.

Q And then if you are just saying her name that’s probably not enough for her to respond in most situations.

A Yeah, yes just saying her name. And again the familiarity of my voice saying her name to a stranger saying her name is two different things. Because in that situation, again respite service do really well and they do have a continued staff, she does know the ladies down there and the gentlemen down there, so she would know their voices. But again, family is something different. When you are stepping in, you know the voice, and she would hear that voice. So I think they were a little bit stand-offish sometimes when we would just say “hang on, just give us a second, we might be able to help here”.

So we give our advice. The gentleman was trying to hold (name of sister-in-law/patient-participant) hand to take a reading. (name of partner/patient-participant's brother) felt that he was holding her hand a little rough, and especially where (name of sister-in-law/patient-participant) is a little weaker on that side. Where (name of partner/patient-participant's brother) was more aware, (name of partner/patient-participant's brother) got a little bit upset, which understandably if someone is holding his sister’s hand. So he did say to the ambulance man like “please don’t”. The ambulance man got quite abrupt and almost asked him to leave the room.

So I think that understanding, of where (name of partner/patient-participant's brother) had more understanding of where he[r] weakness was, and he was just trying to say “listen I’m doing my job”, I just think there could have been more communication between understanding the family aspect of that over the health and a mix between the two would have made the situation a little bit better. But eventually by the time we got out to the ambulance it had completely changed and I think the situation had calmed itself down, that she had come around a little bit more, that everyone was a little bit more calmer. So it could have been both parts. And again, seeing his sister in that situation again isn’t easy to (name of partner/patient-participant's brother), or uneasy to anybody really it doesn’t matter who that is.

**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.

So when I went away then and went back the next day, I’d come back the next day and she was walking, she was having breakfast. The liaison officer had spoken to the nurses and expressed to the nurses how (name of person participant supported at work A) likes to be spoken to. She uses phrases; what particular breakfast is her favourite; motivations; loves ITV2, loved all her detective programmes. So they managed to find a TV at the hospital, took it into her bedroom so she could watch her afternoon TV which had cheered her up, which had then got her motivation lifted, which would then make her want to go to the toilet and walk to the toilet. So they worked that into a plan where she would watch some afternoon TV to cheer her up, all her programmes, then would have her favourite lunch, and then would be up moving. So the communication between us all then, from supported living home to hospital to liaison officer was wonderful.

**Family member**

I’ve watched (name of sister-in-law/patient-participant) pull a lock of…twist a lock of hair round her head and just pull it out. Quite a thick lock, without flinching, without…and just pass it to me as if like “you can have that now and I’m going to find another piece to start”. It’s a sensory thing of overload for (name of sister-in-law/patient-participant). But again, without the flinching she wouldn’t. So we know if she flinches she is in real bad pain. But the NHS, again if the doctor would ask me “is she in severe pain”, all I would say is “well she’s wincing”.

Q Yeah OK.

A But that wouldn’t seem much to somebody else, but we know (name of sister-in-law/patient-participant) enough to know that (name of sister-in-law/patient-participant) doesn’t wince unless she’s in real pain. So I think some of the questions could sometimes be close-ended where they could be a little bit more open to perception.

**Family member**

Speaking to the support staff who deal with them, sometimes their opinion I find – and as a support staff, I’ve been deputy manager, manager – as a support staff sometimes your word isn’t as valued and it’s like “OK don’t worry”. So we’re trying to explain.

And we deal with them day in and day out, I know her words, I know her mannerisms, and I know what she’s trying to explain to you. And sometimes it’s more brushed off. So the respect sometimes of the support worker standing with her trying to explain the situation isn’t valued as much, and the respect of the individual in the bed trying to tell me and trying to tell the doctors what she’s trying to tell you. It’s just taking back sometimes and thinking outside of the box.

**Family member**

A Again, our hospital passports that we send in, we have these little phrases, we put these in our hospital passports. So we do like a mini breakdown. So “if I’m thirsty or if I’ve got a dry mouth or my mouth is stinging I would like a cup of tea”. If “I’ve had a cold for 20 years my nose is playing up” and we’ve got like a little ??? purifier which seems to help, or she just likes her nasal spray or a really hot honey and lemon tea, so it says “please offer me a honey and lemon tea or use my nasal spray”. So we’ve got these little short breakdowns, but sometimes these hospital passports get lost in translation. I think maybe these could be put on a board in her room, so a cleaner coming in, if she said “oh do you know what, I’ve got a really…” another one is a salty mouth. A salty mouth means she wants a cup of tea. But you wouldn’t know that.

Again with (name of sister-in-law/patient-participant), if she’s got pins and needles in her feet (name of sister-in-law/patient-participant) would tell you she’s got glass in her feet. If she’s on her monthly period she’ll tell you she’s got glass down there, because in theory if you cut yourself with glass you bleed. No, sand in her feet for (name of sister-in-law/patient-participant) if she’s got pins and needles, she’ll tell you she’s got sand in her shoes – not glass, sand, “I’ve got sand in my shoes” and she’ll tap her foot and just continue to tell you “I’ve got sand in my shoes”.

Q It makes a lot of sense, it’s like it’s a feeling of discomfort in that spot.

A Yeah. Well you’ve got pins and needles, so you imagine sand in your shoe it would feel that sensation.

Q Yeah, yeah, yeah it’s a good….all these examples you are giving me are like, that’s really good communication from the person that you are talking about. And I’m feeling a bit confused as to how someone wouldn’t know what they were on about. But I think that’s because people are in a rush aren’t they and they are not listening.

A Yeah. And some people “oh you’ve got a salty mouth, OK what do you want”. Their answer is “OK, I don’t understand, why is your mouth salty”. So they potentially would go to a doctor and say “she’s got a salty mouth” and the doctor would say “oh well I don’t know what a salty mouth means”.

Q Yeah. But think about it, if you have just eaten something salty and you have a salty mouth you would want a big glass of water. Like that’s just….

A Yeah. But if you break it down to a small point you can understand, right OK salt, what would you want if your mouth was salty, you would want a drink.

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

Q What do you think makes the best like doctor or nurse?

B In training or….

Q In, you know the ones that you meet in the world, what’s important do you think for a doctor or a nurse to be? How do you think they should treat patients with learning disabilities?

B Understanding of them and knowing how long they’ve had it. And…well to try your best to respect how much you’ve got to respect the people who’ve got it and they don’t.

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

Q Yeah, where we can’t expect these people’s workloads to lighten, what advice would you give to a healthcare worker working with a patient like your daughter?

A Observe and listen and take in, take in. Simple. Just take in what’s happening in front of you, you know. Don’t go in there with your blinkers on, keep it open so you can see it. You don’t have to go looking, you can see it. And that’s what I don’t get with these professional people, it’s staring them in the eye. We’ve been going for two years “it’s the drug that’s suppressing her appetite”. 2 years down the road we’ve had a camera – can’t find nothing. So please fucking listen, take in, take in.

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

Q Do you want to talk to me about your pharmacist and how they’ve helped your family.

A My pharmacist is quite good. They’re just literally round the corner where I live. We know them from years you know and they know (Name of son/patient-participant) because he had all these bad illness, they’ve got records of all his medication. So they knew, when I walk in they know who am I and my son (Name of son/patient-participant), especially in charge of the pharmacy, he knows that my son is (Name of son/patient-participant) you know he’s got a lot of problems. They’ve been quite good, the pharmacist has been good. They just get in the medication when they order it. Sometimes they have to order it again for it to come, otherwise it’s not here.

**Professional/clinician**

So we all take sort of a comprehensive history and information about the patient who has come in to decide the best way forward, whether it is for the team, which person in the team, if we all joint work. So that’s sort of very much my team.

**Professional/clinician**

And as I think you are aware, obviously (name of consultant 1) then felt that there was a link with this and (name of patient-participant) getting up early. And you know I’d spoken to her quite a few times, and I know (name of social worker) had and (name of consultant 2) had about not needing to get up so early. But that was something that (name of patient-participant) wanted to do and something that, you know she wasn’t comfortable them coming in and finding her still in bed in her pyjamas, you know that was important to her that she wanted to be up and ready.

**Professional/clinician**

Obviously for (name of patient-participant) it’s really important for her to sort of be as independent as possible, you know she’s got a really good social life. Her and (name of patient-participant's husband) are really sociable, they love going out, and we want her to continue to be able to do that and to manage everything else as much as possible. So you know rather than having to go and live somewhere with staff there all the time, because (name of patient-participant) wouldn’t want that. One of the big things that always sticks with me is, she’ll say “I’m [in her 60s], not 6”. (name of patient-participant) is very much aware that she’s an adult and she wants to make her own decisions and live in the way that she wants to. So yeah. So obviously what we’re trying to get in place for her is a way for her to do that and be safe at home for as long as possible, yeah, with (name of patient-participant's husband).

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

Q So your doctor in (name of town 2) you’re mentioning, that doctor, did you see the same doctor when you were a little kid also?

A Yeah

Q Wow that’s amazing, so they’ve seen you basically grow up

A Yeah, its really helpful, mum rang up ages ago about my tonsilitis they saw me the same day cos they know me and they used to be really helpful cos I ring up

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

Q What about staff. What makes them….

A Well the familiarity for a start. You know they know (name of daughter/patient-participant), they get to know (name of daughter/patient-participant). They’re just lovely people.

**Carer**

A When [patient-participant] has been to appointments, I don’t always know that the doctor is aware that she has a learning disability. Sometimes you have to sort of step in a little bit, even when you’re sitting there with your badge. They were very few and far between in the beginning when she would be ok with us going to her appointments with her. I think now she prefers to go on her own because she can say what she wants… which she could do anyway. Yeah, I don’t always know if the doctors know she has a learning disability.

Q That’s really interesting.

A Yeah, I don’t always know because it’s not like you go in to an appointment and go, “do you know that this person has got a learning disability?” before you start. I don’t know sometimes when she makes appointments with doctors, do all those doctors know… because you don’t always go and see the same doctor. Is it written? I don’t know if it says on her notes that she has a learning disability. It’s the same for all of them, I don’t know because I’m not within that service.

Q Whether it’s written in her notes or not, are you saying you sometimes have the feeling that the doctor doesn’t realise she has a learning disability? Actually… can you tell me what the doctor does that makes you think this?

A Well, actually it has just come to me… we had a… she came back after having a conversation with a doctor and we questioned the conversation… it didn’t sound right. So, we phoned the doctor surgery and said this doesn’t sound right, and she is telling us this, is this what has been said? And obviously we get a doctor phone up in a bit of a… a bit like “no, that is not what I said!” So, I think that’s where we were like… we’ve asked for communication between us, and nothing is happening. Sometimes she comes back with a story that she wants… if that makes sense. I can’t remember what it was about… it was about her doing something or not doing something and it was totally the opposite to what the doctor had said.

**Carer - lives with patient-participant**

…you’ve got to understand the person, you’ve got to try and relate to them as well… it’s not just understanding, you’ve got to put yourself in their shoes. I think you’ve got to listen, always listen, constantly listen. Don’t make harsh judgements about people, because I think that can be a really negative thing.

**Carer**

A That's how I feel. I could be totally wrong and you could ask (name of patient-participant) if he trusts (name of carer 1) and he might say no. But I think I'm pretty sure he trusts me. So it's like this morning I had to talk to him on the telephone because I'm working in the other house and he was telling me that he bumped his head last night turning off his fan you know. And he gets quite forceful. He'll say “no, no, I do not want to see a doctor. I'm OK”. So, you know it's obviously with staff and everything. But it's just better, I get a feel for it if I talk to him as well. But yeah, I don't know, there's just a mutual… but that's [more than two decades] worth.

**Carer**

Q You used the word ‘respect’ to talk about how the psychiatrists treat (name of patient-participant), “they always treat him with respect”, his doctors do.

A Yes.

Q So my first question about that respect thing is, how do they treat him with respect? What does that look like to you?

A I think that they always address him as (name of patient-participant). He likes to be addressed as (name of patient-participant), and I think he immediately gets that. I think sometimes doctors being doctors they use sort of big words let's call them that….or in (name of patient-participant) presence when they're talking across the table to other professionals who understand, and at which point (name of patient-participant) puts his head down. And I always know that he… (name of carer 1) attends these appointments more than me with him these days. But in the past, I've always known that's when he's kind of shutting down a bit, means nothing to him.

**Carer**

A Yeah. I'm there because I need help from them because they know more than me about that particular problem. They need me there if you like, because I know that person and I know what will keep her or him calm and safe, happy to a degree even though they're unwell, and familiarity. So working together. In other instances we've had nurses say to us, "God, you're amazing. nobody else leaves their staff here all the time." Or, “we're so grateful because we don't really know what we're doing, other than the clinical side of stuff and the nursing part, how do you feel about working together” you know that kind of thing.

**Carer**

Q Do you ever….how do you feel about initiating hugs and touching someone's shoulder if they're upset or something like that? Are you happy initiating that or is it something….

A God yeah. No. no, definitely. Definitely. I think that’s human, just to put a hand on somebody's shoulder. I'll tell you something interesting if you can bear it. The lady I support who's profoundly deaf and uses BSL, deaf people are very tactile because they have to be you know, so there's a standard way of, you know tapping her on the shoulder so she turns around to look at you and things like that. And all her communication is extremely visual. So if you weren't demonstrative or you know visual with her learning difficulties she wouldn't understand you anyway even signing in BSL.

Q Do you think….sorry I interrupted what you were saying.

A No, no that was it really. So it's just another important part of it. And I just think there are people that would say it's inappropriate. I disagree. Yes it would be inappropriate of me to come up and hug you. It would be inappropriate of me to be in a hospital and just start hugging another patient or something. But if it gives comfort to somebody you've known for [more than two decades], what's wrong with that?

[CONTINUED]

Q And that made me think about what you just said about your person that uses BSL that the touch is necessary because, yeah. It makes me wonder whether touch becomes more important when….more important but also more risky with someone with a learning disability.

A Yeah, I think it's more risky and I think you're sensible to know some background, because it's not always appropriate. You know we're in a blessed position, we know history, we've got risk assessments, so you tread wearily at first but it's…. Another lady who lives here. I won't use her name, but she hates too much touch stuff. And she don't know how to hug, it would be impossible and she'll kind of back off you know. But then you don’t do it.

[CONTINUED]

Q Yeah. There are some people that are really averse to it, right.

A Oh definitely.

Q Really averse to it.

A Yeah definitely. And that’s about respect isn't it, respect that? That's fine. Don't just go around hugging everybody because they've got learning difficulties, you know. But I think that's the very essence of treating people as individuals. And that's why the healthcare professionals, whoever they might be, need to respect care workers because they're the people who know that person as individuals, and be guided by them in that nobody's asking them to be guided by that with any clinical outcome, just “oh, she won't like that”. “He’ll be scared if you do that”. “Perhaps you could try….” You know that kind of thing.

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

A Yes. But she’s on maternity leave. She has been there a while. But before that we had a lot of changes. I think it was (name of psychiatrist) as well, so we had a lot of zoom calls. And it was quite difficult because nobody ever got to know (name of daughter/patient-participant), whereas (name of another psychiatrist) has met, come to the house and met (name of daughter/patient-participant) so she does know (name of daughter/patient-participant) so that’s good. So I think she could see and thought – and I had said about we thought (name of daughter/patient-participant) problems were down to the seizures activities. So if we can get that under control I think (name of daughter/patient-participant) would be better.

**Carer**

A Because when you firstly go to (name of resident 2) she will tell you what’s wrong with her. So if you go to her and she’s pointing on that thing, if you haven’t, check it, she will have a behaviour? or she will like call you impatient? to it for you to check it. So the way we were able to know that she’s trying to copy someone is, for example we are in with her and we are….like you cough, you sneeze, she too will go and try to cough. Which you know is not a cough, and she’ll be like (coughs).

Q So you know how to ???

A So you know when she’s in pain or she’s coughing, and when she’s trying to copy someone. Because basically you are working for her for a month or two so you know what she wants, how she is, and I could tell a few things, if not pretty all about her.

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

I’ve been registered with the community nurse now for a number of years and she knows us really well and she knows (name of daughter/patient-participant) really well.

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

A Yeah and I know because lockdown they changed everything but its not fair on people that need to see their own doctor, and not see any doctors, any doctors don’t know you and you’ve got to explain

Q And do you think that for people with learning disabilities it’s more important to see their own doctor

A Yeah cos otherwise they understand the person, not someone that doesn’t understand.

**Carer - lives with patient-participant**

A 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.

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

Q So you know your other doctor Dr (name of psychologist), because I met her and I was in the meeting, how do find, because she is a different service, she’s the LD service-

A No she’s alright cos she’s in a different place

Q So what do you think about the LD service, is that better? The healthcare you get there?

A Yeah, cos they know me

Q So tell me a little more about that, because I wonder if we can learn something from the LD service, do you think your GP should be like the LD service?

A Yeah

Q Right, tell me about that

A Needs to be like that, because they need to know people with special needs, they need to know how to handle somebody’s needs, so many doctors ?? not a clue. Somebody who I know goes in there and they have a difficult time because they don’t understand them, ?????

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

Q …so there is an LD team there at (name of hospital)and they are there when you have your injections in your hip, which sounds like a big thing

A They’re there if anything happens, they’re there, I know most of them anyway and they know me

Q So when you say they are there, what does that mean to you?

A I mean they’re there like if I need help understanding something, they’re there

Q And they’re there literally in the room with you?

A Yeah

Q Oh that’s so good

Carer (?) - We book them

Q Oh okay

Carer (?) - to any procedure or appointment

Q I see, so the doctor or nurse, whoever does the injection, is just a bog standard doctor / nurse

Carer (?) - yes

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

Fortunately the lady that comes in on a [day of the week redacted] is a staff member at (name of day centre) where (name of daughter/patient-participant) goes in the daytime, so she’s very familiar. So that helps because then she’s very pleased to see her. We have a lady that comes in on a [day of the week redacted] who we’ve had for quite a while now and (name of daughter/patient-participant) has accepted and she knows. So on that score, that is OK.

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

But like I said, it helps that the carer on that [day if the week redacted] actually works at (name of day centre), so that to us is a lot of peace of mind.

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

Q And then, it’s really important that people know you

A Yeah, if you don’t know the person they don’t know how to treat you

Q Oh yeah and actually when you are with someone who knows you, do you feel different?

A Sometimes, depends on who they are

Q Of course yeah, but if there is somebody, when you see a doctor in (name of town 2), how do you feel when you see them?

A Fine because they know me, they know me when mum used to come with me, and mum explained and yeah they know me quite well over there

Q And how does that make you feel?

A Better there because there’s more space there and your always, always, not always see your doctor but you’ll see somebody who’s similar to your doctor but you’ll always see somebody and they know me because they’ve read my notes before

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

A But that’s the best part of (name of LD community nurse), (name of LD community nurse) has really shone amongst all of this. And all the way through. She’s been with (Name of daughter/patient-participant) for a lot of years. So she knows (Name of daughter/patient-participant) well as well you know.

Q Yeah. Roughly how long do you think she’s been with you?

A [Redacted - over a decade].

Q Oh ages.

A Yeah, yeah, yeah a long time, yeah. And she’s ??? at the [redacted] ??? which is, if you go over the mountain it’s [redacted] away, if you go round it’s [redacted] away.

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

People like myself who are caring for someone like my daughter, living it day in day out, surely we’ve got a little bit of experience by way of ‘this is what this drug is doing’, this is what this drug is doing. Because every time you introduce this you see an immediate effect, immediate it is, within 48hours it’s happening. And this is what they don’t see, the destruction. (Name of daughter/patient-participant) self-harming. I mean she peeled her toenail off, her big toenail off, she didn’t flinch, she did not flinch. It was sensitive when she come around. I mean she was pulling, I mean locks, I mean locks out of her hair with the distress.

Q With her hands.

A Yeah, the distress and anxiety level is up on the roof. But sense we dropped this by [redacted dose], which was a long time coming, the anxiety has lifted a bit off her, she’s come around a little bit. Like not loads but you can see, you can see, you know. And my advice to these people is, just take in what’s being said to you, even if you just have a window for 5 minutes it will help them, it will help them. It’s just like reading a book isn’t it, you read a book, you’re there, not so much educating yourself but you’re widening that score of understanding – in my head. But….they must have so much on their fucking plates that they just can’t think straight, that’s all I can come up with you know without being rude and offensive to these people.

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

A Which Doctor Who! And we always used to…but we can’t do that now, it’s just ‘a doctor’, and I don’t think that’s very good. But that’s another subject. I think the doctor/patient relationship is important to the patient and I think it helps the doctor understand. Because if it’s the same doctor, the doctor will remember and notice differences in a person, but you see one doctor, the next time you go a month or two later you see somebody else. And it’s not very good. So the fact that we saw the same person with (Name of consultant) each time I think built up a relationship. And she was able….she would hold (Name of daughter/patient-participant) hand and look at her and talk to her, and look at her eyes, you know she would be examining her without (Name of daughter/patient-participant) thinking she was examining her. It’s clever. It’s an in-borne skill that she’s got I think. Certainly she was able to be close….(Name of daughter/patient-participant) felt comfortable with her, she was always happy to see her, always liked to see her.

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

A Cor yeah. And that would be like mid-day. She was having them in her sleep, which sometimes she still does. There’s no break from them, you know? So like I say I can understand where they’re going with all of this, but their approach was all wrong and when it was staring them in the face like, you know. Look at her man, you can see. But they never got to see the destruction these meds were doing to her, they never got to see that. You know a 20 minute visit you’re not going to get a lot done in 20 minutes, no. I think they’ve got blinded, clouded, amongst all of this and the workload that they’ve got. They are good people and I’m not…I’m not going to slag them off in any way, but for everybody not just us to move forward, take in what’s being said to you. Because that will help people like me and (name of wife/patient-participant's mum) and (Name of daughter/patient-participant) as parents and daughter, and it will help them in the decisions they make.

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

And like when you said the [redacted]? will….they can’t do it because they just haven’t got the time, but a ??? visit off them, come and see them at their worst time so you can take in and think “fucking hell”, you know what I mean “this ain’t working”. But being told it and seeing it for yourself are two different things. Because seeing it in my head will stick with you, you know.

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

A Its just annoying cos like, its really annoying because I want to see my own doctor because my own doctor knows me, the one person I know in there is (name of learning disability nurse) but I don’t normally see her hardly

Q Is (name of learning disability nurse) a doctor?

A No a nurse but like a special needs lady, I saw her once to talk about my contraception but since then I haven’t seen her, its all gone downhill

**Carer**

Q How much overlap is there with care and that kind of understanding in healthcare? Do you think it’s….

A What, the understanding between the two?

Q Yeah.

A I suppose I would assume that they go sort of hand in hand to a certain degree with the part of that you’ve got rules, regulations, legislations to follow, like the Health and Social Care? Act 2015 and stuff which governs I believe not all just hospitals, so doctors and everybody like that you know. So that’s the overlap there I suppose. But we have a more personal approach with them where other healthcare professionals don’t I suppose. They have documentation and words written on a page rather than actually knowing the people. So that’s the two different sides and a bit of overlap there.

**Family member**

The ambulance service were really good to a point as we were trying to explain – I suppose it’s a good story and a bad. The ambulance service, as we were trying to explain a little bit more about (name of sister-in-law/patient-participant) and what (name of sister-in-law/patient-participant) responses are, they were sort of looking for the typical response. And so we are trying to say, “well no” because (name of sister-in-law/patient-participant) wouldn’t respond in that way anyway. So as I said, the usual, she’s got quite a high pain threshold, so if you were trying to respond or get a response in a certain way it would have to be a slightly harder response for (name of sister-in-law/patient-participant) to register that then.

Q Yeah OK.

A So we’re trying to explain that. (name of sister-in-law/patient-participant) sometimes, coming out of a seizure can be quite negative, or sometimes can be quite quiet, and she was at this point quite quiet, which you can imagine is her second seizure of the day. She’d already had quite a lot of medication so we were then explaining that, which I think was only half listened to. But we did go to hospital. We waited in the ambulance rather than take her into the hospital, which would again, more in and out, more exposure to light which would have been more uncomfortable for (name of sister-in-law/patient-participant). They brought the doctors to her in the ambulance, the nurses came, they were all wonderful. And as I said, we knew (name of sister-in-law/patient-participant) better so it was safer for her to come home to us and if she needed medication we could take her straight back in because we couldn’t give any more, but the hospital could, rather than her sat in bed in the hospital, again over exposure to sensitivity with the lights, people.

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

A And I hope they take a bit of notice of this stomach examination that she had with the camera. Was she in here just now?

[redacted discussion about pet]

A I’ve forgot what I was talking about to be honest.

Q You were talking about how you hope that the examination of her stomach and them not finding anything they’ll pay attention to that.

A Oh yeah, I really do, I really do. Because as me and (name of wife/patient-participant's mum) said, they’re looking for something that’s not there. It’s staring you in the face mate, you know. And how they haven’t seen that I will never know. No. We’re not experts but it’s plain as the writing on that piece of paper there.

**Family member**

A I think they could be a little bit more detailed. I think it all depends on which company use them, I don’t think there’s a broad aspect of it. And maybe that’s the answer, the NHS creating their own hospital passports for the questions. And giving that space where are there key terms that this individual would use, are there key terms that we need to look out for. For example, (name of person participant supported B) will tell you she’s got a really upset stomach. If she’s got a really upset stomach what she’s telling you is, she’s hungry.

Q OK.

A But “I’ve just had a really funny turn and I’ve got a really upset stomach”. It’s either she’s hungry or she’s just had an epileptic seizure. So you just ask “are you hungry”, “no, no I’ve had a funny turn, my belly’s not well”. And you’re “right”. But her seizures are partials, so if you wouldn’t be sat with her you wouldn’t know that she would have one sometimes, it’s just sort of an absence, she would stare into a space, have this absent seizure lasting around 1 to 2 minutes. There’s no medication. And so again if you’re in there once every 3 hours, 2 hours, it’s going to be something that could be easily missed. But her answer would be to that “well I’ve got a bad stomach, I’ve had a funny turn”. You do offer food “no, no I don’t want food”. She may be a little confused with words and say it the other way round. So say for example “I’ve got a salty mouth” would be “I’ve mouth salty”, she wouldn’t quite be in the sentence until she’s eventually come around, which again her recovery time is only 2 minutes. So if you caught her in the midst of that you would see it, but otherwise you wouldn’t really realise unless she was telling you.

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

Q And what does having more time to go to the doctors mean to you?

A No I mean I will get to see my own doctor, I don’t get to see my own doctor, where I was before in (name of town 2) I always see my doctor always, here I don’t see my doctor, I see any doctor

Q I see right, so you make an appointment and-

A ??? someone else, I don’t see my own doctor ever when we’re in there, I should, cos yeah, I don’t see him

Q So why would you always like to see the same doctor?

A Because I know they know me and understand me, other doctors don’t really.

Q Right I understand, and is doctor (name redacted) somebody who works here but you never get to see them

A (name redacted) I don’t see them ??? in (name of town 2) used to have a doctor I know and he always helpful, they know me, over there they don’t really know me only my doctor but yeah

Q Yeah sure I can totally understand that how important it is to see the same doctor who knows you.

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

Q Why do you feel like you’ve taken the role as more of a “spectator” in those meetings?

A Because I don’t know enough. I don’t want to say something and be totally barking up the wrong tree, if you know what I mean. I’d rather….I mean (participant's wife/patient-participant's mother) does all the work, I mean she’s brilliant, she knows all the stuff. I don’t and I’ll admit that. I know her meds and stuff like that and things I can support, but I’m not up front there with any other sort of things. I can do like basics, like I can do her meds and I can listen to her, I know when she’s ill, I can be with her, I can stay there and look after her. But (participant's wife/patient-participant's mother) will stay up at night Googling things and, you know stuff like that.

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

Q What do you think it means to be treated like a human being?

A Well I don’t know, it seems to me it’s more of a quality. You know if you were talking to me, talk the same to (name of daughter/patient-participant) and be familiar as well, not just another person. Because a lot of people tend to bring sort of students with them, which I know they’ve got to learn and all that but sometimes it can be a bit disconcerting. I think that if (name of daughter/patient-participant) can be on first name terms with…and in most of the cases they are, it’s just this one, obviously one of them is off on the sick now and when she had a couple of those. But by and large they do know (name of daughter/patient-participant) but I don’t want to keep….I mean the worst one is the GP.

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

A Yeah. I mean if you came in and, I don’t know, “oh hello (name of daughter/patient-participant) do you like [popular cartoon]” and all of that, straightaway. But if you came in like “oh (name of daughter/patient-participant) have you done….” you know being officious, you wouldn’t get that sort of rapport that you would if you were human, you know if you were sort of like an everyday person. You get your facts and stuff but you get around it in a different way, do you know what I mean? If you came in, I don’t know if you had a bloody old ??? in your hand or something like that “oh”, (name of daughter/patient-participant) she would straightaway.

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

A I think they have like toys that (Name of sister/patient-participant) likes. And they talk about [popular cartoon character that patient-participant adores]. Or like her splints have like a [popular cartoon character] sign on it and I think she gets excited to see that. Or they’ll put music on that she likes. And yeah I just think she feels comfortable. And she goes swimming with them, I think she likes swimming, so I think it makes her feel more at ease doing things she enjoys, or music she likes, things like that, yeah.

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

Q And what about the GP surgery, if you could change it to the best GP surgery for your family what would they be doing differently?

A I think she needs to read her notes. I think she needs to read up or like maybe not be so rude.

**Family member**

But like I said at the end of the day I’ve never been one to shy away from saying….you know more so now as I get older because these men called professionals, they may know more than you and they may get paid more than you, but they’ve lived with them for 20 minutes in an appointment not for the other 23 hours and 30 minutes….

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

So we learned about her personal life and so on and I think that helped. I think that helped because we felt she wasn’t just a consultant, we like to think of her as a friend, and (Name of daughter/patient-participant) did too. I think that is important with a relationship, a medical relationship, if you actually think of somebody as a friend. We’ve never really had that with a GP. They seem they are not want to be…. At one time we felt we had a GP that we could ring up and ask for an appointment with Dr Who – not Doctor Who!

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

Q And how do you know it’s working? What does (name of daughter/patient-participant) look like and behave like when she’s doing well?

A Well exactly, there’s no….because she’ll tell you if she’s got a headache, she’ll tell you “my head hurts” and all that, she’ll definitely do that. That’s been very rare nowadays. You know you can tell by just looking at the colour in her face and all that. And her general sort of behaviour is, like when we go out in the shopping centre she’s alert, her head’s not down, she’s up, looking. Basically you can just tell.

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

And all this could have been avoided if they had just taken in what’s being said, you know. I totally understand where these guys are coming from, I do, I do and I understand the pressures they’re under. For them to help us the government has got to help the NHS, they’ve got to. You know they’re humans just like us you know, overall super educated. I’ve got a cousin who has got an IQ [redacted, very high IQ], it’s all brains and no common sense, a man who can’t even change a plug.

[Redacted further details about family member]. But that’s what I seem to think here. I think they’re blinded with so much information that they can’t see through it. It’s sort of like they’re clouded. I can only imagine the pressure they’re under, but that’s not helping people like my daughter you know. What have I got to do, cry to these people to get a bit of attention out of them to get them to fucking see like you know?

**Carer - lives with patient-participant**

Q So, when I interviewed [patient participant], it seemed to me that she is very fond of Dr . [name of psychiatrist] How do you think Dr [name of psychiatrist] managed to create that relationship with her?

A He’s very professional, asks a lot of questions to [patient participant] and asks myself and [participant’s partner] questions. I’m assuming Dr [name of psychiatrist] has spoken to our bosses in shared lives and just is a very good… Dr [name of psychiatrist] has formed a very kind and gentle relationship with [patient participant]… yeah, listening but also knowing when to talk as well.

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

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**

A I think it means that you as a person are being thought about as opposed to what the book says. That your actual….if you’re made to feel like a person and talked to as a person as opposed to a number I think that’s humanising it. Like knowing (Name of daughter/patient-participant) name and when is her birthday and things like that “oh it’s your birthday next month”. And then (Name of daughter/patient-participant) not “hello ” you know….

**Carer**

A I think that it is to do again with that relationship building so we have across (site 1) particular doctor that we would go to at the doctors surgery and she knows all our clients so well, so she knows their needs and they need it now whereas if you are Joe Bloggs phoning in, I don’t know about you but I think I have only met my doctor about once and I see hundreds of different doctors.

Q Same, same, I don’t know who my doctor is

A Exactly, and I think that is the difference because if you are a just a person phoning in the doctor, they are just looking at you on the screen and it’s bringing up your problems, your issues, your diagnosis etc is, whereas if it someone like we have Dr (name of doctor) who knows our clients so well, our clients aren’t just someone on a screen, she knows who they are and she knows that if we are saying we need something, she knows that that means they need it, I do think that works really really well, I know it’s a little bit different in hospital, I know that when I go and see my physician at the hospital I always go and see the same one. That’s better for someone who is not in a care home as such, so I hope that’s the same for everybody else. That’s my experience really.

**Carer**

A I think it’s the same, I think everyone should be treated the exactly the same in that respect, being polite, having things explained to your level of understanding, patient’s, time, not being felt like you're a number and that person having knowledge of what’s going on and knowing you well enough and to explain it in a way that you need to have it explained.

**Family member**

A Yeah she does have….I think it’s [company name] now is the company that she’s with now and they do go out sort of 3 days a week. It’s nothing like she used to do, 6 days a week with the previous company. But after COVID they couldn’t provide that care any more so she’s now with a different company. The girls are absolutely lovely, they really know (name of sister-in-law/patient-participant). She loves going out with them. It’s just due to health she can’t go out as often as she did, her seizures are a little bit worse at the moment, so she’s not physically able to do more.

**Family member**

And again it’s that aspect of communication where it would come across aggressive to anyone else, whereas somebody who would know him it’s just frustration of that anybody else would normally feel while visiting the hospital.

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

A It was the cause of the headaches. It was then. I think they were saying it was behavioural problems, we didn’t think it was, we thought it was a migraine or something going on with her head. Didn’t realise that the epilepsy could be connected. But they thought it was a behavioural problem I’m sure – I might be totally wrong with this. But in the end it turned out it was a migraine. I don’t know. (participant's wife/patient-participant's mother) will probably tell you a bit more than me because I’m sort of like I’m still working in those days so… But that was the thing. And we probably knew what….we knew, well (participant's wife/patient-participant's mother) knew.

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

A [name of female clinician]? But I’m not sure, I can’t remember. But they’ve changed again.

Q Oh have they?

A Yeah because one of them is on the sick.

Q Oh no.

A I don’t know. That’s what I’m saying, that particular person’s changed twice since.

Q OK, not ideal.

A Because at the end of the day they’ve been ringing (name of female) up saying “can we do anything”, but they don’t know (name of daughter/patient-participant). So we’ve said “look, if there’s something wrong we’ll ring you”, otherwise just don’t bother. Because it’s the resources like. Because they don’t know (name of daughter/patient-participant) as much as we do. Because that was the frustrating part of that that meeting. We knew what was wrong and what was causing it, but I don’t think…. they sort of disagreed with us. But (name of consultant - epilepsy) agreed with us. And then we got to the stage where we got this injection and it seems to be working.