**Carer**

Researcher – What advice would you give them to make their work more humanising?

Participant – Be kind, I think just be kind is the best thing, understanding humanise people, just recognise that they have the same needs as everybody else but in a different way.

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

A Well I would suggest, people with a learning difficulty or whatever, they need their own small space and not with a crowd, with a big crowd you know. With a big crowd they get nervous, all these people coming in and out, in and out, you know.

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

Q So how can doctors be the best doctors for patients who are Muslim like you?

B It doesn’t matter if they’re perfect or not, they can still take the information and research in them to get an idea. That’s how I got with dumb doctors, the same advice. And I picked up in high school other methods and that. And here I am now talking to you.

**Carer**

A No it's fine, don't worry. He once told me when we were sat waiting, “I wish they'd make a cup of tea” because we were waiting. And again, my one thing, we only see it from our point of view I guess, waiting for anybody I think with… who tends to be anxious doesn't help them perform well if you like when they eventually get into the appointment. And on this particular day he'd waited quite a while and he was very fidgety and we actually…. I think you were there actually because I said, "I think (name of patient-participant) would like a cup of tea." Obviously he couldn't have one but that kind of touch would humanize it more.

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

A To be honest, I know time is very valuable, time is very valuable for normal people and the doctors. The doctors sometimes can keep you waiting for hours for them to be seen, you know. The doctors know the patient is in that….

B Waiting room.

A Yeah. Sometimes the patient could be so sensitive it would be nice if they would just call straightaway, do you know what I mean?

Q So (there’s a wait?) for patients.

A Yeah, especially sensitive people. Like if it was normal people, like I’m going to the GP I can wait hours in this time. But like for (Name of son/patient-participant) it’s too much for him. He is not…if he went to the doc he needs to be seen by a doc he wants to be seen straightaway, that kind of thing.

**Carer**

A Or the other thing might have been if somebody came out, anybody it didn't matter, “look we're going to be half an hour”.

Q “Go away, have a cup of tea”.

A Go and have a little walk round or….yeah, yeah. And I said, "Fab, come on (name of patient-participant) let's go and have a stroll”. And that way he's occupied, he's doing something.

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

Q Tense, mmm. Does the dentist or the nurse do anything to make you feel more comfortable?

A Mmm.

Q What do they do?

A Er…

Q No?

A They look after me.

Q Yeah they look after you.

A They take good care of me.

Q Do you have any examples (name of patient-participant) of things they do to take care of you? What is it that makes someone…. I don’t know imagine you want to tell a doctor or a dentist how they can help you most, what can they do?

A Talk to me.

Q Yeah?

A Yes.

**Carer**

A It's funny they should call your research humanizing healthcare. It's hard to explain, but it's just like this lack of awareness, lack of…I'd love to get them in a room and say…..do you see what I mean, just for a couple of hours and say, "Come on, you can do this, if you understood the difference that when you meet someone who has a learning difficulty you can make”. And you know it's a great feeling, a very selfish feeling I think. Because when I've managed….so some days I go home and I think ‘I've made a difference today, I made a difference to someone’s life, or so-and-so made a difference to their life. And I tell the staff that, “you made a difference today. I don't know if you realize it but you did”. And I think we underestimate that and it's okay to feel good about it. I'm not ashamed or embarrassed to feel that ‘I got that right today, I made a difference to that particular person just for half an hour’. And it's a great feeling because it can be the difference between them having a crap day and them having a great day, feeling worthy again. And we all need to feel that.

**Carer**

A First of all the security man, he's not part of a medical team but he was helpful, he was accepting he was kind, and I keep saying that.

But that sequence of events that made such a difference to this person and what her clinical outcome was. And I think if I had one message it would be that all of these little people, I shouldn't say that, but all these….

Q Well those small jobs only…. you know.

A Yeah, I'm just trying to think of a better way of putting it. Right to the staff nurse who was helpful and accommodating and she was very busy, but she listened. She listened. And in the past we've had it where “oh they have to wait their turn whoever they are”. And I think at that point then I become antagonistic. And it's sort of I'm thinking to myself, “ well you won't be saying that in about 20 minutes when this person is wrecking your A & E.

**Carer**

A Somebody who listens, who just listens, who considers what's being said to make a difference for that particular person and not just be based on tick boxes and their job or my job but to have the person - which I always thought is supposed to be the focus of attention. But we can only all do that if we all work together. And I think the NHS, some staff looked down on social care.

**Carer**

Q (Name of participant) what could make things better?

A I suppose the majority of people would say money. I don't think it's all about resources and money. I don't think it matters, if somebody come along, waved a magic wand and suddenly you've got all the perfect hospitals built and everything else. I think it would make it easier but I don't think money can change making the health service more humanized in particular. First of all the people have got to change. In fact I'll give you an example.

**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.

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

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

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

**Carer**

Q What advice do you have for healthcare workers to make their work more humanising for people with learning disabilities?

A My advice is to, like I would say again, is to picture themselves that they can be in that position. So if they picture themselves that they can be in that position I believe they can do better or they would do better. Because if someone is in that position, like the example I stated earlier, you would not want to be treated badly. So once you put yourself in that position, like the other lady that came in ??? it’s not here doing. It was during that time, like the ??? she has epilepsy, and from there had two years from then, seizures. So from then she was able to not talk. So that’s not her fault that she’s that way. She was not given birth to be that way, she was speaking in Year 1 and when she was a year plus. So it was when she had a seizure in [2-5 years] that she has the issues. So it could be anyone. The fact that, I call us favourable, the fact that we have been favoured or we are lucky I’ll say, does not mean we should treat people unfair. So if they can see themselves that nature can happen to then, it can be anyone, so they will be able to ??? So that’s my advice for them is to always put yourself in their shoes. When they see a disabled person the first thing is to put yourself in their shoes that “this could be me”. So I feel when you’re having the mentality of “this could be me”, you’ll want to do better. So that’s my advice for them.

**Carer - lives with patient participant**

Researcher – Sure. What advice would you give healthcare professionals to make their work more humanising?

Participant – I think one of the most basic things they can do is to be kind, with kindness comes an interest in what is wrong, how to put it right, how to make the personal feel like they’re not a nuisance or they’re not being listened to, or they are faking it even. I think kindness is a good route to start with to humanise kindness, and just being nice to them because they are treated badly everything, especially in the health service, which is awful.

**Carer - lives with patient participant**

Participant – I think it is a start, and with that kindness it provides a starting point for providing a good service for people with learning difficulties to use. Patience is another one. I can’t think of anything else; I think most things stem from kindness. I think if you are a kind person, you would treat a person with a problem to the best of your ability, whereas somebody who is not so kind probably would not be so keen to resolve things.

Researcher – Do you have any advice to professionals on how to cultivate kindness?

Participant – Put yourself in their shoes. Imagine how you would feel if you had difficulty in expressing yourself and somebody wasn’t interested enough to find out what the problem was, just because they are not interested in being kind enough to get to the root of the problem. If you put some health professionals in that position, they would learn to be kind very, very quickly.

**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**

And my advice to this 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.

**Professional/clinician**

A Yeah. And (name of ward sister) was very much - and I tried to take that on board – “never ask anybody to do what you wouldn’t do yourself. Never expect anybody to do more than what you would do yourself. And be prepared to roll up your sleeves and get on with it”. You know we’re all here to do a job of work and let’s do it to the best of our abilities. And that’s what I try to say to the staff, we haven’t got the knowledge of it all. If we don’t know, ask if we don’t know. But always be prepared to take advice and learn. You know if you think you know it all then I don’t think you should be in this job, because we’ll never, ever know it all. And always just give all what you can as the best you can. But I’m also aware that you can’t do that without support. You know there’s no “I” in “team”, and you need a team and you need to be willing to be approachable but also to have the opportunity to talk and discuss and reflect on practice, and what is good and what does work, what doesn’t work.

And I guess not be dictated to. You know because quite often managers say “well we are doing it this way”. And I’m like “well why? We tried it before and it doesn’t work”. “Well tough, you’ve still got to do it”. And I’m like but that’s not how things should be, they should be a bit more fluid, they should be a bit more two-way. Yes I know we’ve all got restraints and we’ve all targets unfortunately that we have to meet, but we’re not numbers either you know, we’re not a number that needs a tick box. And quite often that’s what I feel some of the work can resemble, you know it’s filling a form in and ticking a box so that there’s a statistic to say that that’s been done. But you know we’re not are we, you know we’re not, you know it, it’s more about being validated and more about being listened to and people having the opportunity to express their emotions and offload.

And I just try to do that, like I said with the youngsters as well. You know listen to them and the difficulties that they may have and support in whatever way I can. And equally they’re supportive to me, you know especially with “what have I don’t now, please come and help”. And they do you know, so yeah. And humour, you know I use a lot of humour in there. I pulled my drawer apart yesterday, they were hysterical, it’s just like “argh…” I’ve got a little 3-drawer like filing cabinet, but I got something rammed in it so I had to pull the drawer out, couldn’t get the drawer back in then. Well they were all hysterical because I’m always doing stupid things like that. So that’s where I need support, it’s like “ooooh”.

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

Participant – Yeah ???? puppets, like to show people with LD, the doctors hold puppets they can do it on puppets and then do it themselves

Researcher - Brilliant idea

Participant – The only way work ???

Researcher - That’s a really brilliant idea because people say they want the doctor to really explain things to me, but explaining with words, not everyone likes that

Participant – But with puppets, and they do it to a puppet, and you see it on a puppet and then do it to you and then they can see it

Researcher - That’s such a good idea

Participant – Anyway would work

**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.

And again, sometimes we’re never right. Sometimes I’ll never know what that gentleman is trying to tell me, but I will never stop….as I said, I’m a support worker so it’s a little different, I do spend more time with them but I’ll never stop trying to work out what that is and how he can potentially communicate that better to me. Whether that would be through somebody who is non-verbal you can use PECS, you can use pictures, so maybe that’s something that they could use. Communication. If somebody is non-verbal it doesn’t mean that they’re not still able to communicate. I can communicate through pictures. Again we used to use eye gazers, I know eye gazers is quite expensive, I’m not expecting any ??? to be put in eye gazers on all the beds, but there are things outside the box that we could look at to help. Again PECS is a nice easy one. PECS is a picture of “I want” and what I want is sticking pictures.

Q Yeah.

A And having those on wards may potentially help with communication. “I want”, “I need”. Sometimes routine for somebody in hospital, they’ve lost all aspects of routine. So if the hospital created some sort of routine plan “this is what’s happening now, the doctor will be round at this time”, but I suppose it’s really difficult to say times isn’t it? If the doctor will be around in the evening so you could put an evening clock between 6 and 7, between 7 and 9. Just again different ways of communicating that I think would help. And these hospital passports I think would really help and the aspect of handing them down through daily shifts, monthly shifts. Because I think sometimes if someone has been there a few months that can be lost in translation, there’s a lot of agency staff in and out. And again we can’t help agency, I know exactly where we are. Sometimes someone phones in sick, sometimes you have to have the agency, it is part and parcel of the job unfortunately.

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

A I don’t think it should be an option to discriminate against people because of disability. Like if a crisis happened again I don’t think it should even be thought about that because people have something wrong with them they should be given a Do Not Resuscitate or anything like that. Or like to be more humanising, I feel like things like A & E, I think rules need to be put in place more. Like my mum took (Name of sister/patient-participant) because she fainted, and they didn’t offer her a bed until they were leaving. But like she should have been offered that. Like she’s been in her chair, she needs to distract, I think needs need to be accommodated more. Because even like (Name of sister/patient-participant) behavioural thing, I think it needs to be taken into more consideration because it can be very distressing for her. It’s like she doesn’t want to be there anyway so if she’s not given like a comfortable environment she definitely doesn’t want to be there. Or want people to come here or like take bloods or something like that, it just makes the whole thing more difficult.

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

Q That’s a big question. What advice do you have for healthcare professionals to make their work more humanising?

A God!

Q That’s a question.

A I think just trying to put yourself in their shoes. Try to make everything simple, but not simple that you’re dull and you’re boring, but simple as in you’re not over-complicating it or over-explaining something that should be really simple to use. Maybe trying all these different other strategies before just chucking something out there and go “oh it’s this, you need to do this”. And then they’ve come back still with the same problem and then you still say the same suggestion, maybe try exploring all these different other routes that you could do, or refer them to these other people. Even if you spot something like….like I didn’t know I was dyslexic and I’ve only found that out when I was in uni, so maybe asking all these questions, getting them to all do these things, and maybe then just pointing them to the right routes. Because now I think I’ve got ADHD. So I’ve…

**Family member**

Q What do you want doctors and nurses that work with, and other healthcare workers that work with (granddaughter/patient-participant), what do you want them to know, what advice would you give them for working well with her?

A Listen to what she’s saying. And respect what she’s saying, not just shoving her under a carpet sort of thing. Because unfortunately one day her mum’s not going to be around. It happens to all of us. But I’m hoping by then (granddaughter/patient-participant) will have stood on her own two feet and be able to have that rapport with her doctors that they will listen and they will treat her with respect and not just say “it’s rubbish, you don’t know what you’re talking about”.

**Family member**

Q …what do you think doctors, nurses and healthcare workers, what advice would you have for them to have sort of more humanising practice when they’re working with disabled people and autistic people like (granddaughter/patient-participant)?

A Well show more kindness. And again I go back to my daughter and my own personal, her surgeon was out of this world. I’d said I had got experiences with hers.

**Carer - lives with patient-participant**

Researcher – What advice do you have for healthcare professionals to make their work more humanising?

Participant – Be more human. Remember that the person you’re dealing with is human… 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.

**Family member**

Q Can you get really specific about…you just imagine you are writing me a little training pamphlet for some student doctor or some student nurses, how should they be talking to patients, especially with patients like (granddaughter/patient-participant) who is autistic?

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**

Q …really care about your patients. What would you tell them, what would you advise them if you want to show that to their patient ???

A Listen I think, listen is the biggest one isn’t it? Because if you’re not listening to what the person’s talking about, or trying to understand and resolve the problems that the person is talking about, how can you help them? But also encourage that person to speak openly and clearly and say…because as much as I’m honest with (Name of consultant), I’ll tell her the negative sides of (Daughter/patient-participant) as well, if I wasn’t so honest with (Name of consultant) then maybe she wouldn’t have been able to pick up (Daughter/patient-participant) autism side of it as well. So like it’s hard to say isn’t it because like I said, they need to encourage people to be honest but they also need to listen to the people. But then…it’s hard then because like going back to pediatrics, I think they think you’re lying, you’re telling them stuff and they think you’re lying. Why would you make up stuff?

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

A Like I said they could split the [call in] system then couldn’t they, because at the end of the day the emails that are coming in are of people who need the Melatonin, the young ones who doesn’t like talking on the phones and leaving voicemails. But then that frees up the system then for the people who can talk on the phones and like talking on the phones.

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

So it’s difficult but I think if they’re going to be talking to people they need to be able to make them understand what they’re saying. Because I wasn’t being difficult, I just didn’t know. And the doctors knew I didn’t know, they had a job to understand. But they understood what he was going to be saying probably. So that’s the health service, that’s not a particular incident I expect, it’s the same everywhere.