[0:00:00]

Interviewer: Hello again. Alright, [Name 1], so the idea now is that we have an informal conversation, okay, and then, you know, if you need breaks throughout let me know. I expect this will take about an hour or a bit less. If you need to finish sooner just let me know. Okay, so can you start by telling me a bit about your work, please?

Respondent: Well I’m an advisor for the Huntington's Disease Association. I’m the only advisor in this county, we have large areas to cover, and in fact I cover two counties, I cover [Location 1] as well, so it’s a large geographical area. And obviously I work for a charity rather than for the statutory sector. I used to work in [redacted] but I retired and then after a couple of years of being retired I took this job working for the Huntington's charity. And I suppose the role -

Interviewer: And is that a full-time role, [Name 1]?

Respondent: Sorry?

Interviewer: Is it a full-time job?

Respondent: It’s part-time but it’s four days a week. And my experience with them jobs that are four days a week are basically that you’re doing five days’ work but you’re squashing it into four days. It certainly doesn’t feel like a part-time job. And I suppose the role is to get to know the families that want to have contact with the Huntington's Disease Association on my area and to support them in whatever way I can. A lot of the role is about accessing services for people. So we run a support group and we can, you know, do home visits and offer support to families that way but when you work for a charity it’s very different from working in the statutory sector, you don’t have much authority to actually do things so what you’re often doing is getting the families that you support in contact with social workers so a social care assessment can be done or liaising with the neuropsychiatry team to arrange for a neuropsychiatry appointment, accessing OT, speech and language therapy. You know, a lot of the role is kind of helping families to access help and then providing support and being involved with a support group, which we’ve got one that meets every two months in [Location 2].

I also delivery training as well, so that can involve going to nursing homes or day care centres where they maybe have people with HD attending and they want some training for staff about Huntington's Disease. There is no specialist care home for Huntington's Disease in [Location 3] so quite a lot of people with the condition in [Location 3] who go into a care home or a nursing home, they’re often the only person in that home with Huntington's Disease so quite often when the home have someone go to live there who has Huntington's the manager will ask me to go and do some training to the staff about the condition. So I think that –

Interviewer: And then is this like a one-time… You go there one day or is this like a more sustained training, or…?

Respondent: It would be a one… It’s a pre-prepared training session that takes about an hour and usually they… And I’ve got a portable projector that I take with me and usually they let me use the staffroom or a small meeting room and I project it onto the wall and go through the presentation and I answer any questions from the staff. The number of people attending has varied from three to about twelve so they tend to be small sessions.

Interviewer: I can imagine that they’re supposed to be providing care and attend the training. I imagine that like at that point when they’re at the nursing home they’re doing their shift, I guess, and they need to… Yeah.

Respondent: Yeah, so it’s difficult for the care home managers to arrange for large numbers of their staff to be available at any one time because of covering a shift pattern and so on. So I’m quite happy to go back to places and deliver more than one training session. I did deliver two training sessions on one day at one nursing home, one in the morning and one in the afternoon, and that covered staff that were available at both of those times. But also through the Huntington's Disease Association the same training can be offered through a webinar as well, so what I’ll do is share the links to the webinar with the nursing home so that any staff that can’t attend face to face training can attend it through a national webinar that one of my colleagues runs.

[00:06:21]

Interviewer: Is this free for the nursing homes, [Name 1], or what happens?

Respondent: Yeah, I mean, generally what happens… If we call it ‘training’ we are supposed to charge a fee and then people would get a certificate and, you know, things like that, but if we call it an ‘information session’ then that’s delivered for free. It’s the same training but obviously people don’t get a certificate or anything at the end of it. And I’ve found what most nursing homes say is “Oh just call it an information session” and I’m fine. The fee the HDA charges is only something like £50 or something for the training session, not per person.

Interviewer: Not per person. Okay.

Respondent: So it’s not a big issue. The important thing is that people get the training rather than anything else, yeah.

Interviewer: What’s the feedback you get after that hour of training, I mean, do people give you…?

Respondent: The feedback I’ve had has always been positive. There is some feedback that goes to Head Office which I don’t get to see and obviously all the other advisors throughout the UK are also delivering similar training in their areas but I don’t know what the national feedback is. I’ve only been in post since August last year so I’m relatively new to it really.

Interviewer: Well I didn’t mean it from your perspective of delivering it, as in being you, my thoughts are more it’s a one-hour training to people that potentially have never cared for Huntington's, so do they feel it was, you know, enough or, you know, do they ask for like a monthly session? That’s more like –

Respondent: Yeah. No, I’ve not been asked to go back to any of the nursing homes I’ve been to to deliver more training as yet but I guess I’ve been in post six months so it may be that homes will have new staff start and might ask me to go again at that point. What the national feedback is I don’t know. Someone at Head Office would have all that information.

Interviewer: Okay, that’s fine.

Respondent: And there are other courses that are run through webinars as well. So, for example, there’s a course on PEG feeding, for example, you know, and there’s some others as well. So if anyone at any of the homes that we have contact with want any of the more specific training courses there are some other courses that they can access through the Huntington's Disease Association as well.

Interviewer: So, [Name 1], you’ve been in post, yeah, since last year so did you have prior knowledge of Huntington's Disease, like professionally, or…?

Respondent: Yeah, so up until the beginning of 2022, so basically two years ago more or less, I was working as a [redacted] in the [Location 4] Genetics Clinic and I had a specialist role in neurogenetics [redacted] So I had some experience of HD from being a mental health nurse and then once I was in the genetics clinic the focus of my role really was taking people through predictive testing and the pre-test counselling and then taking a blood sample, seeing people to tell them the result of the predictive test and then supporting them through that period after they’d found out their test result. So I wasn’t really working with people who were severely affected in the later stages of Huntington's Disease but I was experienced with working with families.

Interviewer: The symptomatic and… mm.

Respondent: It’s just the people that I was seeing tended to be people who either had no symptoms or maybe some early symptoms and they were at that point of wanting to have the genetic test to clarify if they were going to develop Huntington's Disease or not.

[00:11:14]

Interviewer: Wow, [Name 1], you’re like the most competent like qualified advisor. Wow. (Laughs) You’re, you know, like a diamond, you know, because you have mental health experience, genetics, so HDA has like found their diamond. So when you came to post at the HDA was there training for you like when you started your role or what happened?

Respondent: Yeah, so I retired from the [redacted] and I didn’t expect to return to this kind of work. I actually could retire on the [redacted] pension scheme that I was on at the age of 55 so I retired and I actually got a job working behind the bar in a [redacted] pub near where I live and I thought, “Well that’s me done”.

Interviewer: “That will do,” yeah. (Laughs)

Respondent: But then after, you know, 18 months or so of being retired I felt that I wanted to be doing more and it was just at that time that this job with the Huntington's Disease Association came up, so it was perfect timing really. And then when I did start there was an induction period, so the first month was lots of meeting the various teams that work at the Huntington's Disease Association and doing all the various mandatory training and things like that. And then there was a three-day course which I think everyone who starts to work for the Huntington's Disease Association does which covers all the different aspects of Huntington's Disease. Yeah, so new advisors are given training, yeah.

Interviewer: So you’re covering two counties?

Respondent: Hmm hmm.

Interviewer: Do you know like roughly how many people are you supporting?

Respondent: I kind of know that for [Location 1] because I had a proper handover from [Location 1] and I think it was that there were 179 contacts, I think was the figure. Now, that doesn’t mean there’s 179 people in [Location 1] that I’m in regular contact with because some of those will be family members and some of those will be people who just phoned once for some advice and they’d have been given a file number so that the advice that was given is recorded and they’re on our system, but then they might have never called back, you know? So, you know, some of those people will be people I may never have contact with because they just phoned once for some advice and then they’re happy with the advice they got and that was it. And then there’s other people I’m much more involved with. And I guess I’m more involved with some families when they reach a certain point. You know, some people want support through predictive testing, some people it’s because looking after someone with Huntington's Disease is reaching that point where they need to get help in, you know, OTs or speech and language therapists and so on, or they might need to apply for PIP and they might want me to do a supporting letter because someone’s becoming more and more affected. And then at the other end of the kind of condition really is the people who are reaching the point where they are talking to me about their relative going into a nursing home and what are the nursing homes that are around and things like that, so… So it’s difficult to put a number on the people that I’m actively doing quite a lot of work with and how many of that number are people who are just there and I may at some point get a phone call from them.

[Location 3]’s a bit different because the previous advisor left a few years ago and then there was a period where the county was really covered by people temporarily helping out to cover the country until I was appointed, so I didn’t get a proper handover in terms of the figures and the numbers of people. But [Location 3] and [Location 1] are very similar counties, they’re both large rural areas with kind of market towns and one county town, so I would imagine the figures would be similar for the two counties.

[00:16:05]

Interviewer: Do you get contacted by people living in [Location 3] or not so much?

Respondent: Sorry?

Interviewer: Do you get contacted by people living in [Location 3] or not so much?

Respondent: I do, yes. In fact, I’m spending more of my time working in [Location 3] with families in [Location 3] than in [Location 1] and I’m referring more people for help, particularly to the community neuro rehab team which I mentioned to you in an email. And I suspect it’s because in [Location 1] there was a proper handover from someone who was handing the area over to me and a lot of the families in [Location 1] were already plugged into all of those services, whereas in [Location 3] I’m speaking to people who when I say, “Have you seen an OT, have you seen a speech and language therapist?” they’ll say, “Oh no, we don’t know anything about that”. So I suspect the difference is that [Location 3] hasn’t been properly covered for a while because of not having a permanent advisor in the area. So I’m spending more of my time actually working with families in [Location 3] than in [Location 1] but I suspect that’s because there’s a process of catching up going on.

Interviewer: I can see you’re building those connections because they just probably fell apart a bit in this interim period so you’re getting people into the right pipelines.

Respondent: That’s right, yeah. And the community neuro team are very, very helpful. So they’re a multidisciplinary team and when I was doing my networking I went to one of their team meetings to meet them all, and they include a speech and language therapist, a physiotherapist and an occupational therapist. There is neuropsychology but I think the post is vacant at the moment and they’re looking to recruit. They’ve basically got all the people that you need to be involved with someone with Huntington's Disease and they very much see Huntington's Disease as part of their remit. The one thing they’ve not got is a consultant neurologist; there isn’t one of those really in the area. Consultant level is provided from [Location 5].

Interviewer: [Location 5]?

Respondent: Yeah.

Interviewer: That’s where the consultant is? Okay.

Respondent: Yeah. Yeah, so the community neuro team, they’re everything that you would need for therapeutic involvement with someone with Huntington's Disease apart from the consultant level, so anyone who needs a consultant review, they would be involving the consultants who come over from [Location 5] to cover [Location 3]. I think a few years ago [Location 3]’s neurology services went through a very difficult patch.

Interviewer: I’m just looking at my map, that’s what I’m doing. (Laughing) I’m clearly not English so, you know, sometimes I’m a bit like, “Where’s [Location 5]?” (Laughs)

Respondent: [Location 5] is just north of [Location 6] and it kind of borders on [Location 3] really.

Interviewer: Okay, alright. I thought they were going to [Location 7]. (Overspeaking). That was just me thinking. I got some emails to say, you know, perhaps they’re being cared for by the clinical teams in [Location 7] because –

[00:19:39]

Respondent: Yeah, in terms of neuropsychiatry rather than just neurology there is someone in [Location 8], a Dr Alberto in [Location 8], who sees some people, particularly who live in the north of the county. People who live in the south of the county tend to go and see Dr [Name 2] and his team at the [Hospital] in [Location 6].

Interviewer: In [Location 6], yeah.

Respondent: Yeah. But that’s neuropsychiatry. Neurology itself, you know, there’s a good community neurology team that the consultants cover. It is a bit absent really, I mean, they must struggle to recruit to the neurology team or something and then brought the service in from outside. So the neurologists from [Location 1] cover [Location 3].

Interviewer: Okay. So, [Name 1], is it like by…? How do you connect with these different professionals, is there like an MDT that you go and join or like a clinic that you go and join or is it by phone an email or…?

Respondent: Lots of contact by phone and email. If I want to refer someone to the community neuro-rehab team in [Location 3] it’s an emailed referral form, so there’s a template for me to fill out and then email to them. That system seems to work very well. The community neuro team in [Location 1], it’s similar but I’ve not had need to refer anyone to them as yet because everyone I’ve met has already been involved with the community neuro team in [Location 1]. So I think my predecessor had already involved that service for them. In terms of attending team meetings, it’s a bit patchy. So the consultant neuropsychiatrist, for example, in [Location 8] was quite happy for me to go and sit through an entire clinic even though some of the people coming to that clinic lived in [Location 7] and didn’t live in my patch. Whereas if I go to [Name 3]’s clinic in [Location 6] they’re really kind of tightening up on who sits in on clinic appointments and not because of the confidentiality side of things. So that’s kind of shifted from me being able to sit in with the clinic to now only being able to attend appointments with people who I’m involved with from my patch, which makes it more difficult really because I have to make that decision is it worth me traveling 30 miles there and 30 miles back into [Location 6] if there’s only one patient who lives in [Location 3] or [Location 1] that’s attending that clinic, and that one person may be someone who’s very stable and who’s just going for a review appointment and I’m not really having much involvement with them. So I’m having to kind of weigh up whether it’s worth me going to a team meeting or not and, you know, judge that with how busy I am actually out in the (overspeaking).

Interviewer: Well yeah, for just one person as well, yeah. So, I mean, you know, I understand the confidentiality point but has there been no discussion about giving you access, like a proper contract, like (overspeaking)?

Respondent: Well when I started I asked if I could have an NHS.net email address, which obviously I used to have when I worked in the genetics clinic because that made it much easier to communicate about patients. Because at the moment –

Interviewer: (Overspeaking).

Respondent: Because if I email the neuropsychiatry team I can’t put any patient identifiable information in the email because the Huntington's Disease Association’s email system isn’t part of NHS.net. So that’s ben something that took a bit of adjusting to really because I used to work in the [redacted] and I used to just email people and it was secure from one end to the other. And what they said to me was that I’d need an honorary contract to be given an NHS.net email address and then it’s kind of not progressed any further from that. I emailed the relevant person and then I’ve not heard anything. The impression I get is that there’s a bit of reluctance there and that they’re looking at their clinics and it’s probably coming from management level and they’re thinking there’s too many people who don’t work for the service who are coming and sitting in on clinics and things like that. Yeah, it’s a strange one, yeah.

[00:25:04]

Interviewer: So does it work the other way around then that they would ring you and say, “Well, [Name 1], we have this person here, could you start following this family closer up?”? So would the other way around (overspeaking)?

Respondent: Yeah. And there’s no problem with me referring people to them. Well, actually, if it’s a completely new referral I have to get the person’s GP to make the referral so it’s different from… I don’t really understand why the community neuro teams will say, “Oh no, you can refer to us” but when it comes to referring someone to the specialist HD clinic it’s -

Interviewer: It’s to go through the GP.

Respondent: - it’s got to be a GP referral. I don’t know whether that’s to do with funding contracts and things like that but I have to ask the GP to refer them. But once someone’s then on their books I can then attend virtual team meetings at which I can discuss the patients that I’m involved with with the consultant and the rest of the team. So the only issue is really that initial referral having to come from the GP rather than being able to make the referral myself. Which is frustrating because I used to work in the [redacted] and if I wanted to refer someone to the specialist HD clinic when I was working as a genetic counsellor I’d just write a referral letter and send it off and that was it, they accepted it as a referral, but I think now that I work for a charity it’s more like “Can we accept a referral or not?” and (overspeaking) –

Interviewer: It doesn’t seem to have the same weight?

Respondent: No. But I don’t know whether it’s because it’s a regional clinic as well, whether it’s to do with whether they’ve got contracts with that GP practice or… I don’t know. But it’s not an issue with the clinicians, it’s an administrative management kind of thing, I think, rather than the clinicians, you know. So, yes, I have to –

Interviewer: So do you get contacts, say, from the clinic that, for example, email you and say, “Oh, [Name 1], we’ve got this family”? So that was my point, like, okay, you can’t sit through but would they connect with you, should they have like –

Respondent: Yes, they do, yeah, regularly.

Interviewer: Okay. So you can’t… Okay, yeah.

Respondent: Yeah, so they might, say, have someone who goes to a clinic appointment and they say they feel that they need a bit of support and then I might get a message saying, “We saw this person in clinic today, they live in [Location 3], would you mind making contact with them and discuss what support the HDA can offer?” What’s also happened is when someone has not attended an appointment and is finding it difficult to attend an appointment - to travel from [Location 3] into [Location 6] is quite a journey - and they’ve said, “We should have seen this person in clinic but they didn’t attend and they’ve not attended a couple of times, would you mind making contact with them?” I’ll go round and do a home visit and see how they are and then I feed back to the team at the team meeting, so yeah.

Interviewer: Okay. So, [Name 1], what happens with…? Because you mentioned earlier linking up with services and you also mentioned the social workers, what happens with linking with social workers? Can you tell me a bit about your experience with social care?

Respondent: Yes, I mean, I have involved social services a couple of times since I’ve been in post. That seems to be relatively easy to access in terms of that I can just phone social services and say, “Could we have a social care assessment for this person because they look like they need some support at home” or whatever. And it seems to be a very easy referral process, you know, there’s no barriers there, no one tells me, “Oh no, you can’t make the referral” or “It’s got to be a written referral,” they’re quite happy for me to phone up and request a care assessment. The only thing I would say about social services is I don’t seem to get feedback from social services as to what the result of that care assessment was so I’m then… You know, I’ll find out that there was a care assessment but trying to find out what exactly the outcome of that was I’m often talking to the family themselves and they’re trying to explain it to me or I then have to phone social services and try and find out what the outcome of the assessment was. If I have a safeguarding issue then I think social services are very good at being involved with you. As soon as you mentioned the word ‘safeguarding’ then it all works a lot better and they’re keeping you informed and you’re keeping them informed, but when you’ve just said, “Oh this person’s looked after by his wife, they’re struggling, they might need a bit of help going in, could we have a social care basement?” you don’t necessarily get the feedback and you end up having to chase them for the feedback and what was decided and what’s going to happen, you know.

[00:31:43]

Interviewer: And who was even there, I guess. Do you even know who’s gone in or…?

Respondent: So I would say the referral is easy for social services, there’s no real barriers to making a referral, and certainly as soon as you mention safeguarding they take you very, very seriously, but what’s a bit lacking is the feedback once they’ve done their assessment. You often have to chase that feedback up yourself rather than it coming back to you naturally, you know.

Interviewer: So with safeguarding… I mean, again, it seems to work better. When there’s a safeguarding issue would they have a social care worker allocated, like would it be that person dealing with that issue, like an appointed person?

Respondent: (Overspeaking) an issue with safeguarding that’s arisen was someone who was affected with Huntington's Disease being looked after by his elderly mother and him having, because of his condition, outburst of anger and aggression and that potentially being a risk to his mum, you know, if he was to push her and she fell over or something like that, so… And then as soon as a social worker from the safeguarding adults team was involved it’s been excellent really. I’m on first name terms with that social worker and I can phone her very easily. She keeps me informed of what’s going on as well. It’s been very good, yeah.

Interviewer: Okay. I guess it’s just… Well, trying to avoid a crisis doesn’t seem… So once the situation is more acute it seems to be easier to deal with multiple teams than in terms of prevention or like making an earlier plan, is that what happens?

Respondent: Yeah, once you escalate it up to being a safeguarding issue, that gets something done, or if someone phones the police, that gets something done, but that’s probably because the police then escalate it to a safeguarding issue. They probably then get in touch with the Council and say, “We’ve been called out by this family because they can’t cope with the aggressive behaviour of the person that they’re looking after” or whatever. So yeah, I think there’s some truth in that, that when a situation is rumbling along and everyone who knows the family is thinking, “This is gradually getting worse and at some point it’s going to reach a crisis point” it’s difficult to get people involved at that point, but then once it reaches a crisis point then it’s much easier to get people involved then.

Interviewer: It’s almost ironic.

Respondent: It’s frustrating because you would ideally want to get those services involved to prevent it reaching that crisis point and that seems to be a bit more difficult to achieve, yeah.

Interviewer: Yeah. Okay. So in your opinion, [Name 1], what do you think needs to be improved for people with Huntington's?

Respondent: I think – and this is a conclusion I’ve come to through years of working in the [redacted] and the work I’m doing now – that the whole health and social care system in the UK needs a rethink and a complete overhaul. There isn’t a good enough link-up between health and social care. And I think there’s a lot of joint working that already goes on where statutory services involve people like myself who work for a charity or, you know, private sector nursing homes are involved and so on and so forth but I’d… I heard [Name 4] talking on the telly and he’s obviously the Shadow Health Minister, who if we have a Labour government after the next election will be the guy in charge of the NHS, and he seems to be talking very much about the NHS moving towards being, you know, where the different services, whether it be social care, voluntary sector, NHS, private sector, all working together a lot more, you know. And I think that the whole system probably needs an overhaul to bring that joint working between voluntary sectors, you know, statutory sector, health care, social care, to make it work better multidisciplinary-wise. Things like the issue that I could know an HD family better than anyone else because they live in my patch and I visit them and I get to know them and yet I can’t refer a member of that family to the neuropsychiatry service.

[00:37:25]

Interviewer: Unless you go through the GP, yeah.

Respondent: And then I speak to the family and say, “Well the referral letter needs to come from your GP” and they say, “But we don’t know our GP, we hardly ever see them,” you know, and the referral letter has to come from someone who doesn’t really know them as well as I do, you know. So I think in general more joint working between the different sectors and that I think is probably the way things need to go rather than, you know, health and social care being separate and the voluntary sector being separate and the government just throwing more and more money at the NHS and thinking that that might solve the problem. I think, you know, all the different sectors needs to be working together a lot more and a lot more fluidly without any barriers to, you know, referring or communicating with each other. You know, the issue of NHS.net email, for example, you know, I mean, that means that if I email someone in the NHS I can’t put anything in that email that’s patient-identifiable so I end up putting the patient’s initials in and hoping that they know who it is that I’m talking about. And sometimes they do but other times they don’t and then I end up having to phone them and then sometimes it takes a while to get hold of someone on the phone, because over the phone I can actually say what the person’s name is, what their date of birth is, NHS number or whatever. Whereas if the voluntary sector was part of the same system, you know, secure email system, I’d have just been able to send an email which included the patient-identifiable information and the communication would be much easier. So that’s kind of what I think, is that the whole system needs to work better together. It’s too fragmented, you know.

Interviewer: And if that would happen, ideally, what change do you think we would see at patient level? So what differences do you think people would feel? If I were to measure if things are working well how would I know that it was working well?

Respondent: Yeah, how would you measure it? I don’t know. I mean, it –

Interviewer: I don’t mean like, you know, which tools should I use or…. I mean, in their day to day life what difference do you think we would make if the systems are more joined up?

Respondent: Yeah, I mean, I think I was probably thinking of it more from the point of view of being a health professional or someone who’s working for a charity or whatever, I mean, it would certainly make our jobs easier if we could communicate more easily amongst the various sectors and things. In terms of how you would measure whether patient care had improved or not, I’ve not really thought of that but I would imagine you would expect it would be easier for people to be referred to the right place and less delays with referrals. I mean, I have found when I want to refer someone and I’ve got to get the GP to do a referral letter that there’s quite a delay there and I’m saying to the patient, “Well I can’t chase up when your appointment’s going to be yet because your GP still hasn’t done the referral letter,” you know. So I think it may improve that side of things.

I suppose from a patient point of view there could be a negative side of things. I think some of the people we see feel comfortable talking to us because we are a charity and it may be if we were working more as part of the system we’d lose a bit of that, you know. I mean, there are some people who wouldn’t want to go and see a doctor or, you know, a consultant but are quite happy to have a chat to people from the Huntington's Disease Association, so maybe there’s a benefit of being separate.

[00:42:14]

Interviewer: That’s why sometimes I guess there’s DNAs and then they ask you to come in and check with a person that just shows the approachability of the charity, I guess.

Respondent: Yeah. I think maybe some families see us as different, you know, we’re not kind of part of the system, we’re different. So maybe that would be the downside to the different sectors working more closely together, that we might lose a bit of that separate identity that we have as a charity that people maybe feel more comfortable talking to than talking to social workers or consultants or, you know, mental health nurses or whatever.

Interviewer: I don’t know, this politician when he speaks about having these different parts working together under the same umbrella, I’m not sure if they mean that you would stop being considered voluntary sector but perhaps in terms of funding there would be a shift on getting more support. I mean, you’re covering such a wide area and if you are going on leave or if you’ve fallen sick what happens?

Respondent: Well, I mean, what happens is that one of the other advisors would cover and there’s about 20 of us through England, Wales and Scotland. Sorry, Scotland have their separate Huntington's Disease Association. So there’s about 20 of us covering England and Wales. And I think if I was off sick for a short period of time my calls would just be dealt with through them being divvied out to whoever was covering the on-call system or whatever. If I was to be off and I was going to be off for several months then, you know, my patch would be covered by someone who covers one of the neighbouring patches, but that would probably involve covering in terms of talking to families over the phone or doing virtual appointments and only doing actual visits in really extreme situations because of the distance someone would have to travel from one of the neighbouring patches.

Interviewer: But I imagine they wouldn’t know… At least, you know, as a nurse if I moved from my ward to a different ward, I’m still a nurse and it’s still a ward but I don’t know the ward like my ward. So even if someone, you know, just tries to cover the more emergent I can’t imagine them being able to link up with… you know, because they don’t know with whom or, you know, “What’s the best person to ring in this team?” or “Who will answer me quickly for this issue?” (Overspeaking) –

Respondent: Yeah, that’s very true. And I think that might explain why I have noticed such a difference taking over in [Location 1] and taking over in [Location 3] because in [Location 1] there’d not been a period where it was being covered on a temporary basis by people from outside the area so [Location 1] was handed over to me by the person who’d been covering [Location 1]. And, you know, I think that shows that probably things in [Location 3] had slipped during the period when it was being covered temporarily, yeah.

Interviewer: Okay, alright. So, [Name 1], if I… So I would really like to improve, you know, the way the different parts are connected because I think, as you’re saying, it’s a problem. And you’re saying you think this is needed. You know, you don’t quite… We don’t quite know what it would look like, do we, (overspeaking), in practice.

Respondent: No, but I think it would be better. And there’s something [Name 3] said which I kind of agree with as well which is about people being able to self-refer. So, for example, in [Location 6] when I worked as a genetic counsellor we accepted self-referrals for people who wanted to come and talk to us about genetic testing. So people can just phone up and say, “I’m a member of a family that’s already known to your service and I’m thinking about having a predictive test, can I come in and talk to someone?” and that was fine and we’d set up an appointment. And we always got very, very positive feedback from people about being able to self-refer. If they’d had to go to their doctor and say, “I want to be referred to the genetics clinic to talk to someone about genetic counselling for Huntington's Disease,” that would’ve been a barrier, you know, they might not have wanted to talk to their GP about that. And also their GP might not have known where to refer them and may have referred them to the wrong place and so on. So self-referrals worked very well when I worked at the genetics clinic in [Location 6]. And I think in other parts of the country it’s different. I didn’t realise that other genetics clinics insist on a GP referral, and we’ve really held out against that and accepted self-referrals. But also when I was a mental health nurse I worked for quite a while in a community drug team so I was working with people with drug addiction problems, and that service was really set up to only accept self-referrals because you would only want to see someone who was motivated to change and they’d show their motivation to change by referring themselves. So we’d have people just walk in off the street and say, “I’ve got a problem with drugs, can I have some help?” and that was how accessible the service was. You can get in touch with their GP at a later date, you know, once they’re in contact with the service. So I think that kind of self-referral, I think the reason why [Name 4] was talking about it was that if certain areas of healthcare could work on a self-referral basis it reduces a GP’s workload because it… you know. And I do agree that that could be looked at. I mean, obviously there’s certain specialities where a GP referral would definitely be needed, you know, you couldn’t have someone who’s got a lump they’re worried about and then just refers themselves to a cancer clinic or whatever.

[00:49:24]

Interviewer: Yes, of course.

Respondent: But I think there are some things like accessing genetic counselling because of a family history of a condition that means that you’re at risk and you want to speak to a genetic counsellor about genetic testing and I really don’t see why that shouldn’t be open to self-referral. Or if someone’s got Huntington's Disease and they want to refer themselves to the specialist Huntington's Disease clinic. I know what the kind of referral letters are that you get from GPs, they’re one sentence half the time, it’s, you know, “Can you please see this person, they’re worried about Huntington's Disease,” you know, and it’s probably took the patient a couple of weeks to get the appointment, then there’s a bit longer for the GP to write the referral letter, the referral letter, if it goes to the right place… And GPs sometimes refer people to completely the wrong place, they might refer someone to a neurologist when they want to talk about a predictive genetic test which needs to go to the genetics clinic. So even if the referral letter goes to the right place it then sits in someone’s in-tray, then gets registered on the system and then a genetic counsellor gives them a call, you know. I mean, why not just have a system where the person can just phone up and say, “I’m a member of a family with Huntington's Disease, you know my family, can I come in and have a chat about whether to have the predictive test or not”? Which is what we did in [Location 6] and I think it’s what they still do. But it shows how for certain areas of healthcare self-referral really does work, and insisting on a GP referral just adds to a GP’s workload and delays and causes stress for the patient as well and delays how long it’s taking for the patient to get to speak to the person they want to speak to, you know?

Interviewer: Do you think it would put people off from…? You know, because they know, “Oh, now I’m going to have to go through the GP and it takes ages” and like do you think it puts them off like from moving on in that position?

Respondent: Yeah. And also with Huntington's Disease sometimes people are worried about what’s on their medical records because I think it might affect them if they’re applying for health insurance or something like that. So their GP might not even know they’ve got a family history of Huntington's Disease, so to go to the GP and ask for a GP referral means them telling the GP, “I’ve got a family history of Huntington's Disease,” which, you know, if the GP hasn’t been the family doctor, you know, they might not be aware of it. So yeah, I think it can be something that puts some people off going and having a chat about predictive testing.

Interviewer: I mean, the GPs have these codes, isn’t it? You know, if a person has epilepsy it should have like a code for epilepsy and things like that. Or if a person’s father had Huntington's it doesn’t really show like an at risk sign, I’m assuming, on their medical records. There’s no signal of (overspeaking)?

[00:52:50]

Respondent: I don’t know. I mean, I suppose if someone’s registered at the same GP practice that their family’s been registered at for years then the GP might know about the family history of Huntington's Disease, but if someone’s left home, gone away to university, settled in a different part of the country, registered with a GP there, I don’t know whether there would be anything on their GP records or not. Well yeah, I think, you know, if someone decides to go ahead with the genetic test then you can discuss with them at that point “Really your GP should be aware of what’s going on” but it doesn’t need to be a referral from the GP in the first place. I think there are exceptions - when someone’s got a really long medical or psychiatric history it’s helpful to have in a referral letter - but most of the time I found GP referral letters when I worked as a genetic counsellor basically just said, “This person’s got a family history of Huntington's Disease and wants to have a chat to someone about getting tested” and would literally be the referral letter. (Laughing)

Interviewer: It doesn’t add much. Okay. Okay, [Name 1], I’m going to do you a couple of generic questions in terms of like just categorising my sample, which you might find a bit strange.

[redacted]

Interviewer: (Pause) Alright. Okay, and, [Name 1], is there anything… So we’ve been… You know, it was a really good chat for me and I can’t… Sometimes it’s hard for me not to introduce bias into the conversation and lead you into certain corners (laughs) but for me it was a really, really interesting chat and very helpful for the questions I’m trying to answer. Is there anything that we didn’t discuss that you would like to add?

Respondent: I don’t think so. I think we’ve covered a lot really, yeah.

Interviewer: You’ll need a nap after this. (Laughs) Thank you. Okay, so is there some feedback you would like to give me in terms of improving the next interviews I’ll be doing, you know, something could have worked better in the correspondence or on the call? Any suggestions?

Respondent: Not really but I was just wondering… So there are some families… and in particular what I’m thinking of doing is when I send out the invites for the next meeting of the [Location 3] support group, which is towards the end of [month], mentioning about this research for if anyone who comes to the group would want to take part in the research. Because I think you’ve probably got quite a few professionals involved and if you get in touch with the community neuro team I would imagine that they’d be willing to participate, I don’t know but I can’t see why they wouldn’t, but you might be short of carers and people who are affected themselves.

[redacted]

[End of transcript]