[0:00:00]

Interviewer: Alright. So, can you start by telling me a bit about your work?

Respondent: Okay. So, I’m a Consultant in Neuropsychiatry in [location 1] in Huntington’s disease, sleep disorders and general neuropsychiatry.

Interviewer: Okay. And how long have you been working with patients with Huntington’s?

Respondent: [redacted]

Interviewer: Alright, okay. Alright. And what happens at your centre currently is that you have clinics running or…

Respondent: Yeah.

Interviewer: Do you visit them in the wards?

Respondent: So, we provide outpatient services, so if the person needs to be admitted to the hospital, so if it’s physical health issues they would go to general hospital, if it’s something more to do with mental health, they would go either to general adult psychiatry ward or old-age psychiatry ward. And then obviously we do weekly clinics, a follow-up, and also we’ve got a clinic for new patients suffering from Huntington’s disease, that’s run by [name 2], follow-up clinics run by me, and then obviously we’ve got a nurse who does care home visits and liaises with the care homes. And then obviously some of the liaison work is done also with our specialist occupational therapist and dietitian and SALT. But we sort of run it very strictly as a tertiary centre because we cover all [location 3] region except for [location 2], so obviously we rely on local services to deal with emergencies. So, we kind of see regularly, and if we need to adjust medications or have a look at correct movements or something a bit more complicated, we would do here within our clinic or schedule time outside the clinic. If local services need some guidance and support, we would be available for that as well and we would, you know, do joint meetings together and all that sort of stuff. But at the same time, if somebody needs intense support, emergency support, such as home treatment team, for example, because they are in crisis or they’re manic or severely depressed, then we would arrange the referral via GP usually or A&E to local mental health services, so depending where they are. So, usually crisis team, home treatment team and kind of take it from there.

[0:04:22]

Interviewer: Okay. When you mentioned earlier your outpatient services, was this the clinic or at the patient’s houses as well, the community

Respondent: So, we do home visits if necessary. But we also do outpatient clinics. So, as consultants, we don’t do a lot of home visits. We only do if everything fails and the situation is really difficult, otherwise we sort of… we often have a registrar in our team so they can do a bit more home visits, and obviously we… if need be, thee are other professionals, so OTs or dietitian would do home visits, but we try to do as much as possible within the clinic, and patients can choose whether they want telephone or face to face. And sometimes obviously there are occasions when we have to say, “That patient needs to come as face to face because it’s going to be difficult to address those particular issues over the phone”.

Interviewer: Do you have… I don’t know if you have this issue, but at [location 4], for example, our more advanced patients would decline many times coming to the outpatient appointments.

Respondent: Yeah, yeah.

Interviewer: Do you have that experience as well?

Respondent: What we do, so usually the patients are advanced, so either they would be visited at home or they would have a telephone consultation with their carer. So, obviously we can’t expect somebody very impaired and with advanced disease to come to the clinic, so we still offer telephone consultation for the carer or family member or the video as well. So, in our experience, patients and families are not too keen on video consultations.

Interviewer: Okay. They’d rather telephone?

Respondent: Yeah, yeah, they’d rather telephone, yeah, which is interesting.

Interviewer: Okay, okay. Do you have any specific video call system that you use?

Respondent: Yeah, there is a programme that can be accessed and when I worked in other teams in the trust, not in neuropsychiatry, it was successful. But I guess it’s a personal choice.

Interviewer: Yeah, yeah. I mean it must be maybe age-related as well. Maybe our future patients will prefer more video calls. Okay. And so really with Huntington’s disease training, of course you were being exposed to your patients while in the job, but did you have any further training specifically for Huntington’s or was it on-the-job very much?

Respondent: So, obviously I did a sort of higher training within the [location 3] deanery, so as part of the postgraduate training, so I did a placement in neuropsychiatry of two years. So, there is sort of competences you’re expected to obtain and to gain. And also neuropsychiatry is a branch of general adult psychiatry, so there are very specific competences that you need to obtain, work-based assessments, paperwork, exams, etc., so we’ve done all that. In addition to that, I’m doing a part-time master’s in clinical neuropsychiatry and also, it’s not direct… and the other thing I’ve got, which is not directly related to Huntington’s disease but it’s helpful, I’m expert in sleep medicine, expert somnologist.

Interviewer: Oh, that’s very good.

Respondent: Yeah, awarded by European Sleep Research Society. So, when patients do have sleep difficulties with Huntington’s disease, I kind of touch on that as well because that’s a common problem.

Interviewer: Yeah, that’s great. I mean that’s really useful. And I imagine you do an assessment of the patients, but does that include the carers as well or… so one of the things when I did my literature review, one of the things that came out was that we tend to focus on the patients and then we don’t… in terms of research, not clinical, so in terms of the research that had been done, that we tended to oversight a bit the carers. So, I’m asking is there any specific carers’ assessments you do or…?

[0:09:15]

Respondent: So, that sort of… usually, so if we see that the carer doesn’t cope or needs some additional support, we do ask, obviously, the carer how they’re coping, if they need more support, and if they do, we usually, I think, signpost for that. And obviously our team, so it wouldn’t be myself directly but would be other team members that would help out with that.

Interviewer: Okay. So, this bridges well in terms of how do you link with other support, like outside the clinic?

Respondent: Yeah.

Interviewer: So, what… I mean do you know… you’re saying it’s not you directly so I don’t want to reinvent the wheel right now on the call, but you mentioned earlier like the crisis teams, for example, that you would connect if there’s, well, if there’s a crisis out of hours, and community services, is that the sort of teams you tend to connect more with or what sort of teams or resources do you connect with outside the hospital?

Respondent: So, what happens, what we say to our patients, so the appointments, usually a follow-up is every 6 to 12 months, unless it’s clinically indicated, for whatever reason it needs to be brought forward. But if they struggle in the meantime, they can ring our team secretary. And then depending on an issue, if we feel that it’s very much HD-specific then we would try and see them earlier. Sometimes I could give a call on the same day to the patient and carers if I have capacity, or bring the appointment forward. Or if, for example, it’s more to do with an issue that the dietitian would be better to deal with or SALT or occupational therapist, then those professionals would contact them or we’d sometimes bring the appointment forward. If, for example, if we kind of based on that phone call, we can think, okay, well somebody’s manic or has severe depression and is at extreme risk of suicide, and I know I’m talking extremes, but these things do happen.

Interviewer: Well, yeah, I mean yeah, that’s…

Respondent: Then we would direct them and say, depending on the family, depending on the patient, because Huntington’s disease is very difficult to say one size fits all, because each patient is unique, circumstances are unique. And also it depends a little bit which area they are as well, so we kind of tend to say, well, you know, this is an emergency so then we advise to contact the crisis team, which is home treatment team, and then we sort of… home treatment team and leave it with them, but then if they struggle then they can get back to us. We often liaise with home treatment team or community mental health team and say, “”Well, you know, this patient is in crisis. They need to be picked up,” because we don’t provide crisis management because we’re just too thin on the ground to do it. So, we liaise with them, and then what we usually say, “If you want us to attend any meetings or any advice about the patient, just let us know,” and we’ll take it form there.

Interviewer: As you’re saying, [name 1], I’m quite impressed because you’re basically having to really expand. You’re saying you’re thin on the ground because also the ground is quite vast. I mean you’re saying you’re seeing patients from different counties, then [location 5] as well.

Respondent: Yeah.

Interviewer: So, I’m quite impressed with how well would you know the services available in those counties outside your own that allow you to activate or link with the right teams. Is this like on protocols or…?

Respondent: No, so it varies. So, with [location 5], obviously, if somebody’s in [location 5], it’s a little bit easier for us because we know [location 5] services a bit better. But if, for example, [location 6], [location 7] or [location 8], so it varies, so sometimes we try to reach out to GPs to do it, sometimes we contact [location 8] ourselves. Sometimes our professionals, OTs, registrars, end up spending an entire day trying to get hold of somebody, so it’s not always straightforward. And there are times where because… particularly, you know, it doesn’t come to that very often but if it does come to that, somebody needs a mental health assessment, we do offer somebody from our team to come and participate in that as well just to give that support to the services if we can. And I participate in mental health assessments, even in [location 8]. So, it does vary. Yes, it is a little bit easier to work with [location 5] I have to say that, and requires sometimes a bit more work to get hold of services in [location 8] or [location 6], which are different trusts. But we sort of, you know, we’re trying our best and because, as a team, we’re a very close team so we all of us try to… sometimes occupational therapists will do a bit of coordination, sometimes it will be a nurse, so it just depends on the case because the patient sometimes can have a very close relationship with one professional from the team just because they’ve just had a bit more involvement than the others, so that person might be taking the lead in pushing things through a little bit. Yeah, so it’s very individual. It does depend.

[0:15:22]

Unfortunately, it does happen sometimes because we are struggling that we don’t have an inpatient unit, so the patients sometimes can be moved back and forth a little bit if they need admission to hospital because [location 8], for example, sometimes they say, “Oh, we don’t take Huntington’s patients because this is a specialist bed”. So, [location 5], they would say, “Oh, well, we can manage with your advice. We’ll be okay”. So, it does sometimes happen that patients, even if they are under the Mental Health Act Section, they sometimes might be declined a bed. They sometimes might not get admitted as soon as we would like them to get admitted just because there’s this argument, so somebody’s, for example, neglecting themselves and they’re refusing care and they’re just a bit angry, but they’re not sort of actively running round in the streets and causing particular public disturbance, and then you can’t have a physical health hospital, general hospital, because it’s not exactly that, and then psychiatrists say, “Well, this is Huntington’s so it’s not mental health so we’re not getting involved”. So, there is sort of… sometimes we do get into situations where the patient finds it difficult to access help because of the lack of belonging, if you like.

Interviewer: They don’t fit.

Respondent: Yeah, so that can be tricky. So, [name 2] as well as myself sometimes spend a lot of time, really a lot of time, we’re talking about half a day or longer writing emails back and forth, making multiple phone calls trying to sort that out, and it is tricky. We’re hoping at the moment we’re sort of planting a seed, if you like, to establish inpatient links with [location 2] inpatient unit to see whether we could have a pathway to send out patients to get them well there, just purely because they’ve got a specialist psychiatry inpatient unit, there’s specialist OT, specialist physio. I know that unit extremely well because I worked there as a consultant for a year. And obviously geographically it’s not too bad, it’s only 45 miles away from central [location 5]. They do have beds and it obviously, you know, that pathway would help. But obviously, again, the challenges we would be facing is that we need to convince commissioners because that’s quite a radical way to change the pathway, and also different trusts have different commissioning groups.

So, at the moment what we are working on, but again it’s very early stages, we’ve just started having meetings and trying to get the costs, and then if we are successful then we’ll approach medical directors in the ward to try and push that through a little bit if we can, and we want to try that with [location 5] first because it’s a bit straightforward because that’s our trust. And then ideally, if that works, if we’re successful, hopefully maybe other trusts would buy in that too, but we’ll see. There’s just lots of challenges ahead, but it’s something if we look from purely clinical perspective, it would work better for the professionals and also for the patients as well because obviously with that issue, sometimes our patients end up in private sector really far away. We have somebody as far as [location 9]. And then obviously it’s very difficult for them to have any family visits and so… and it’s expensive as well, but it’s not the best deal for the patients because they’re moved quite far. So, yeah, so there are some challenges.

[0:20:12]

Interviewer: Yeah, I was going to ask what happens when psychiatry wouldn’t have the patients, what would happen to them? But it sounds like if they have money or if they find, yeah, if they can financially cope with it, they’ll go private, but then either way far, which isn’t ideal for anyone. And you’re saying you would spend hours trying to find a bed for the patient, like a team that will take them in terms of inpatient, and you’re doing like sort of a cost-effectiveness then to try and convince commissioners that, well, if it doesn’t spare, at least it comes out neutral, I guess.

Respondent: Yeah, so at the moment those who went private, the commissioners had to pay for it.

Interviewer: Oh, oh, that’s good. Well, for your case.

Respondent: Well, they had no choice because that particular case I have in mind had to go. They couldn’t stay, they wouldn’t accept, so they had to pay. And that was really expensive. The difficulty with funding we have, which we anticipate, because we did approach them before with that particular patient and it didn’t happen because the cost of a bed is tendered per bed. But if the patient is very disturbed or becomes very disturbed and needs two-to-one nursing obs, they would get paid only as a usual patient, but obviously it would be a lot more expensive for the department and for the trust because they would have to have an additional member of staff.

Interviewer: Yeah, one to one, yeah.

Respondent: And then the way they kind of invoice and cost, then they said they would lose the money, which is why there’s a little bit of resistance from it. But, as I say, we’re just at the stage, had some discussions, we’re going to have some more discussions and that’s where we’re at. So, it’s very early stages, but these are the challenges so far that we have identified. When these patients, at the moment they go to general adult wards or old-age wards. We have some examples of absolutely beautiful work done by old-age psychiatrists, and obviously, again, it does require a bit of convincing, a lot of ringing around to get HD patients into old-age beds, because even if they are in their early 40s, that environment for them would be a lot better suited than the general acute psychiatry war because they’re so vulnerable. So, when we get to those wards, and so the issues with Huntington’s disease face looking into the placements, capacity assessments, old-age wards are much better equipped to deal with it than the general adult psychiatry wards. But having said, that ideally probably you would want them to be a neuropsychiatry ward where you’ve got specialist neurophysio, specialist neuro-OT and, you know, they don’t have just old-age people but they’re a mix of patients, so it just probably would be a better environment. It’s not just about one consultant, we’re talking about the wider MDT because multidisciplinary is absolutely critical and extremely important in Huntington’s disease because it affects so many domains in your cognition, your movement and your bowel movements, your swallowing, so it is incredibly, incredibly important to have that multidisciplinary team.

But when they end up, our patients have gone to old age, what happens is that those teams liaise with us, so we do our best to liaise with inpatient units if they get admitted. So, our dietitian does liaison work with local dietitians, SALT does, we as consultants liaise as well if they want some sort of more specific HD advice. So, we do advise. So, we don’t leave those teams completely, so we just do a little bit of hand-holding, if you like. But at the same time there are times where inpatient teams, they had Huntington’s disease patients before, they feel that they know what to do and where to go from there and they don’t always need a lot of hand-holding, but if needs be, we’re there to support. And a lot of our work does mean doing lots of working with different services and a lot of coordination actually.

Interviewer: So, [name 1], so if a patient, for example, goes through A&E, does it signal on their health record that they have Huntington’s and that they should contact your team or how does it work?

Respondent: We don’t have that in place, but what usually happens is the patients usually tell A&E, “I’ve got Huntington’s disease, [location 1], [name 2],” I’m a new consultant so my name is coming up more often as well, so, you know, “Looking after me, so if you need any support, get in touch with them”. And sometimes when patients get admitted, they feel worried and various things have to be addressed, they get in touch with our team secretary. And we have a nurse who actually dose liaison work with nursing homes and general hospitals and she does go and see the patients, sees the patients there, gathers all the information that’s necessary, supports them whenever necessary and then brings back to the team so if they need any further input from the consultant, for example, myself or [name 2] or anybody else in the team, or a dietitian, lets us know. And also we, as a team, we often have meetings twice a week, we will get together on Teams, very quick, just half an hour, just to pick up on any burning issues and something that we’re dealing with. So, sometimes we’ve got a case and it’s just sometimes helpful to talk through with a few people, if that makes sense.

[0:27:08]

Interviewer: Yeah. So, [name 1], what’s your caseload, more or less, in your team? How many patients do you have on your books?

Respondent: I would have to get back to you on that. I need to check.

Interviewer: Oh, I’m not… it’s just… well, I don’t know if you know how many active cases you have or…?

Respondent: Let me check if I can see that on RIO.

Interviewer: I mean once they have Huntington’s, they never stop having Huntington’s until they die, so I’m not sure… you probably never discharge patients, you just add them.

Respondent: I’ll see if I can find that. Or I can send an email about that.

Interviewer: Yeah, I was asking mainly because you, well, you mentioned the specialist nurse and the specialist nurse liaising…

Respondent: Yeah, absolutely. I won’t be able to answer that question because on my caseload I’ve got some patients who have sleep disorders and not Huntington’s, and the same, [name 2] has some general neuropsychiatry patients, so I’ll have to get that information from our secretary.

Interviewer: Okay, I was asking…

Respondent: I can send an email about that.

Interviewer: Thank you. I was asking because you mentioned one specialist nurse, is it just one?

Respondent: Yes, it is.

Interviewer: It is one. And that person is what we would consider the single point of contact, as in if a patient has an issue, would that be the first person they would contact?

Respondent: So, they can ring our secretary. The secretary sends an email to all of us. And also, if it’s an emergency, we advise them to go direct to the GP or A&E.

Interviewer: Okay, but do you allocate, you know, in preschool, for example, children have a keyworker.

Respondent: No, no, we don’t. Yeah, no, we don’t do keyworkers, we don’t do CPAs because we don’t do CPAs because if that’s necessary they have to be under local mental health services, local CMHTs. So, we don’t do CPAs, we don’t do local keyworker because, just to give you an idea, so it’s just myself, [name 2], one nurse who also does Huntington’s disease but also works with chronic fatigue patients, so she’s not full-time HD. Then we’ve got an occupational therapist who’s part time. And then we’ve got SALT, who’s part time. We’ve got a part time in addition who does… (coughs) sorry.

[0:29:57]

Interviewer: That’s alright. Do you need a drink. Yeah, get a drink. I’ve been making you… I’ll have a drink as well.

Respondent: Who does ketogenic diet and Huntington’s disease as well, so quite a bit.

Interviewer: Right, okay. And how do social workers, how are social workers brought to the equation when you have these, for example, multidisciplinary meetings or how do you link with social workers?

Respondent: So, sometimes they contact our team, our secretary, and then we pick that up. Sometimes it’s a complex case and we need to do a bit like a case conference, so we need to have a meeting with that particular specific case, we would do that and invite the social worker depending on the issue. Sometimes, so our occupational therapist supports with CHC assessment and obviously Social Services have to be involved with that, so we contact them directly.

Interviewer: Okay, okay, and you do like a case conference, like that? Alright.

Respondent: We don’t exactly call them case conference, but what we call a meeting about the patient, but in fact it is a case conference because in some meetings, for example, safeguarding meetings, so it is kind of a case conference because you’ve got a clinician, you’ve got Social Services, maybe you’ve got an OT or a nurse or from our team, so yeah, we do that.

Interviewer: Okay. And do you feel… I mean in your experience then with the patient, do you have… are you always linking with the same social workers or do they change?

Respondent: They change.

Interviewer: They change, okay.

Respondent: They change because obviously they cover different patches, and also there is a movement within the jobs as well.

Interviewer: Yeah, yeah, I mean it’s difficult to retain everywhere.

Respondent: Yeah, exactly. It would be great to have more continuity, but it is what it is.

Interviewer: Yeah, no, that’s fine. I mean we know patients, it’s what they report, but I wanted to make sure from your side it’s the same language. Okay. Alright. So, this might be a bit of a personal/professional question, but are you happy with the care you’re providing to the Huntington’s disease patients?

Respondent: I am happy but I think there is room for improvement in terms of, I think… I think we provide a good care in terms of that we’ve got a lot of research going on within the department, we work very closely with voluntary organisations, HDA as well advisors, so they get involved. We’ve got our multidisciplinary meeting. We’ve got very skilled staff, so our nurse is a band 7 nurse, she’s got a master’s in clinical neuropsychiatry. Our occupational therapist, so she’s going to finish her PhD in Huntington’s disease [less than 2 years]. We’ve got lots of talented people. We’ve go ta good follow-up clinical which is multidisciplinary clinic, which is great. But at the same time, I guess I think because Huntington’s disease, it requires so much multidisciplinary work and we spend so much time liaising with different services, and that’s how it should be. So, it kind of would be helpful, thinking ahead, to create a bit more pathways. So, one of them, as I mentioned before, it would be amazing if we could have that more robust inpatient pathway so patients don’t get this toing and froing, if you like, between when they become unwell and perhaps we could admit them a little bit earlier as well if we had that pathway, so that would be really helpful. And then obviously we have some discussions about advanced planning decisions as well, that’s what we think as well to do. We’re also addressing that, so trying to raise awareness as well to the local services about what we can do and what we can’t do, because sometimes our colleagues don’t understand the amount of work that we do and how few of us actually are in the team covering all the regions. So, what we often do is we try to tell that, but what we do, there is a day, an event with HDA with [name 2] and one of the occupational therapists as well, invited all the medics, CMHTs, all the doctors to have a day and they’re going to talk about Huntington’s disease, about the services we provide, to CMHTs just so we could have a better understanding, they could have an understanding of how we work, what we do, what it is to enhance that core working and make it a little bit easier. So, we always look for opportunities for how we could integrate a little bit more because that’s the only way to make it work.

[0:35:51]

Interviewer: So, you mentioned CMHTs, what’s that?

Respondent: Yeah, community mental health teams.

Interviewer: Ah, okay. Yeah, alright.

Respondent: Apologies. (overspeaking).

Interviewer: No, no, that’s okay.

Respondent: Community mental health teams, yeah, yeah.

Interviewer: I just want to make sure I understand what you’re saying. And these educational days or… this is like a conference or where you invite…?

Respondent: Yeah, yeah.

Interviewer: Yeah, alright, to just…

Respondent: So, we’re doing this, I think this is the first time they’re doing it, [name 2] is doing it. So, if it’s successful, we will do more events, but that was one of our ideas to reach out a little bit more.

Interviewer: It sounds very good to me. I hope you have good engagement from people. Good. So, you’ve mentioned that in terms of space for improvement would be to create more established pathways, particularly for inpatient admissions. Do you see other… I mean you’re saying one of the difficulties is to make other teams aware of your boundaries and how stretched you are and what’s feasible to do or not, which of course is really important. I mean I’m really impressed with how much you do already with limited staff members, and many of them part time as well. Can you think of other… I mean from what your patients tell you as well, are there other things you would wish to change on the dynamic of the team? Like if you were given all the money and, you know, what would it ideally look like?

Respondent: I don’t know if I’ve mentioned that [name 2] and I, we are job sharing, so we both work part time. I think if we were given all the money, I think the first thing, probably I would sort out that inpatient pathway, that’s the first thing, and not just with [location 5], but across the regions that all patients that need admission got inpatient unit and they can go there, because at the moment the only limitation is the money. There is a unit, there are people that are skilled to do it, they’ve got beds, so we just need to access that pot of money and make it work. And listening from the patients’ feedback, they do get distressed when admission comes because it’s not nice for the families and for the patients to be… you know, if somebody says, “Oh, no, you can’t get admitted because you haven’t got a mental health problem,” then we get involved, then we have to convince them, and then we are in a situation everybody agrees that they need admission but there’s no beds to admit because one trust would say, “Oh, we don’t access HD patients,” and so on. So, that’s a challenge that we face at the moment. I think it would be really helpful, so that’s something that I would definitely do. I think I would get more rooms, if possible, because rooms is an issue for us.

[0:39:17]

Interviewer: In your clinics, you mean?

Respondent: Yeah, yeah, because we started at 11.30 and then the other team members will have to come at 1.00 because there’s room only available from 1pm. But luckily we almost managed to secure a room for a HDA representative who’s going to be just outside the outpatients and have a separate room during that clinic so that the patients could have a bit of space and could have a chat about it with an HDA advisor if they need more support, because obviously we very closely work with voluntary organisations as well.

Interviewer: Are they always participating in the clinic? That’s the normal?

Respondent: They sometimes come to the clinic. So, one of our HDA advisors has an honorary contract with the trust.

Interviewer: Oh, oh, right.

Respondent: So, that means there’s no issue with information sharing.

Interviewer: Yeah, yeah.

Respondent: Those who don’t, those can only participate in those patients’ care that they’re directly involved, otherwise obviously they can’t because it’s confidentiality, unless the patient gives specific consent, obviously. So, at the moment, we provisionally secured the room so we’re just waiting for confirmation for that room. So, we’re hoping to give additional room for HDA just outside the clinical space, could have a poster and their own things and make it nice so the patients could come and have a little chat.

Interviewer: That sounds nice, yeah. And you mentioned research as well, how do patients get directed to research. You mentioned you were a research-active…

Respondent: Yeah, absolutely. So, what we do is we… so one of the studies is social cognition on quality of life, so obviously we’ll get them, get pieces of paper where the patients talk about the research, and then obviously there’s the dedicated room because our trust is active in research. It’s got a dedicated room, so where the research assistant, if they feel that they would like to learn more about the study and perhaps to sign the consent form, they would go then and talk to the research representative, whichever the project is, in that dedicated room and talk about that and see and fill in the forms and address all the questions. But again, it very much depends on the study as well because each have different protocols, but we’re always very mindful that the patients aren’t coerced in research. So, we talk about it, but then we don’t want to put the pressure to take part in research unless they absolutely want it, so we always have to be mindful about when we talk about it, when they see the research assistants, who actually does consent forms, so it depends on the research project, so we do that as well.

Interviewer: Yeah, you don’t want patients…

Respondent: But having more rooms would definitely be a bonus.

Interviewer: Yeah, yeah, I can imagine. So, [name 1], the people from [location 10] and [location 7] are being cared in [location 5] because there’s no expert centre there, is that it?

Respondent: Yeah, yeah.

Interviewer: Okay. Alright. So, you said you act as tertiary centre.

Respondent: Yeah.

[0:43:18]

Interviewer: Okay, alright, just so that I… I mean it’s a bit far, too far counties for me to really know what’s available there. I did suspect, and that’s why I got in touch with [name 2], because I was like, well, maybe they’re going to [location 2], so there you go. Alright, thank you. So, you were saying about people having to… sometimes being moved far away to get people admitted closer to home, so have that smoother admission. I mean it’s hard enough to be admitted, let alone not being able to be admitted is even worse, so what do you think would quality look like. If I wanted to measure like a difference, a change, if a change is being positive to the patients, what is that positive change we’re trying to make?

Respondent: So, I think first of all, the patients potentially would get admitted earlier, which is helpful because what happens is they have to… you have to convince them that they need admission, then to find a bed, and then if you’ve got, “Oh, we don’t have a bed,” and there are discussions where actually they should go to, you’re looking at time. And if somebody is neglecting, the longer you leave it, the harder it’s going to be. So, obviously then we could admit patients a little bit earlier in terms of that they’re less unwell, especially if somebody has behavioural issues on the top of that, not necessarily… I’m just giving self-neglect as an example because it can…

Interviewer: Well, it happens a lot, yeah.

Respondent: It happens a lot, that’s why, because there’s lack of motivation, etc., etc., but other things happen. You’ve got comorbid mental illnesses as well that can happen. You can have somebody, you know, not all the time, but you can have a patient who has Huntington’s and bipolar disorder, Huntington’s and schizophrenia, and that can get discussions on what is this? Is it more Huntington’s or is it more mental health? So, if you leave that and treat it, the longer you leave it untreated, the more risk to the patients, so the more likely they will have physical health problems, malnutrition, they’ll lose more weight, mental health going to be affected even more, so obviously if you admit them earlier you can prevent potentially very long admissions. And if you think about Huntington’s disease, time is ticking really. You don’t want to spend the time, prolonged times in hospital when you can actually be somewhere else, because time is precious and the clock is ticking. So, with shorter, potentially the length of admissions would be shorter because they would be caught early, be less restrictive as well because if you offered somebody earlier admission, they’re less likely to need Mental Health Act assessment, so they might go in voluntarily, but obviously it depends if they have capacity to consent admission and all these things. So, it’s very difficult to generalise, but that’s another potential as well.

Also, in terms of anxiety of the patients, they’re always anxious, their families, okay, we’ll need admission, but where are they going to go? So, if there was one unit where they could go, the families would feel a lot more safe, “Oh, well, I’m just going to that place,” so they know what’s happening so there’s a little bit more certainty about that. And also because that particular unit that I’ve got in mind, they have specialist physios, specialist OT. They have got all multidisciplinary team and all they do is neuropsychiatry, so they have a very good understanding of the care homes and the whole MDT approach. And the whole environment, the ward environment is much more suited for Huntington’s disease because, for example, if a patient suffering from Huntington’s disease ends up on general adult psychiatry ward, they’re highly vulnerable, especially on male wards. They can get assaulted, because I saw very unwell people, acutely unwell people. So, that would be better as well if you look at the risk management and the vulnerability management as well. Yeah, so these are just a few things.

And I think that’s got a direct effect, but if you think about indirect things, if health professionals spent less time ringing around, “Who’s going to take my patient?” we could be doing other things to improve the patient care. Maybe perhaps we could do another home visit.

Interviewer: Yeah, no, no, absolutely. I mean you’re speaking about afternoons of correspondence and calls and trying to…

[0:49:02]

Respondent: Yeah, yeah, exactly. And sometimes I spend days, a few members of the team can spend days without getting anywhere, so we could do other things to improve patient care. We could do an extra phone call for the patient or an extra home visit, or maybe have another meeting with… so there’s so many things that could be done with our time because it’s not the time, the consultant’s time or specialist OT time used to ringing around, “Can you please take my patient?” is not kind of the best use of the time if you think about the scale. And obviously, it does affect patients indirectly because obviously we could be doing other things. So, you know, of course we’re going to need to see patients, of course we’re going to need to do clinics, but also I think it’s important to think about efficiency as well.

Interviewer: Yeah. And as you’re saying, it’s not just… it’s the anxiety that is generated from all these situations and the patients that are waiting while we’re ringing around. I mean you don’t need years of training to be doing phone calls, chasing people to take your patients.

Respondent: No.

Interviewer: Yeah, as you’re saying, it’s just not smart, a smart use of time, I mean.

Respondent: No, exactly. And also sometimes I think the families tend to be a bit reluctant to get admissions sometimes because they think, “Oh, yeah, so and so being in hospital and they didn’t want them and I don’t want them to be there,” so there is that as well.

Interviewer: Like they gain a bit of aversion because of a negative experience.

Respondent: Yeah.

Interviewer: Okay, okay. I was going to ask you about what could an intervention look like to improve the coordination, but from what you were saying it sounds like you really are focused on mainly getting a service that would receive the inpatients with Huntington’s without all this, I don’t know what to call it, just, yeah, conflict or with, yeah, all these struggles just to move a patient to inpatient. Would that be it? Or does any other solution in terms of, yeah, I mean this is pretty much where… I’m going to leave it there. I don’t want to be just prompting you more on this, unless there’s anything else.

Respondent: Yeah, I guess the other thing probably would be we’re constantly working on it, but I think to raise an awareness of other professionals, because you can’t create a pathway for every single thing, it’s just literally not possible. But to raise awareness of our colleagues in general hospitals and GPs about Huntington’s disease a little bit, so it’s just sometimes very simple things. So, obviously, Huntington’s might not be able to express their thoughts very well in later stages. But, at the same time, they can understand very well and sometimes they can be mistakenly thought, “Well, he doesn’t talk very much so probably doesn’t understand very much,” when it comes to colleagues from other disciplines. So, it’s just raising awareness about these things and having all these discussions when somebody’s unwell. And families sometimes in general hospitals, they feel that they’re a bit written off, if you like, or feel that people are just giving up on them. Sometimes I have to advocate for those patients and say, “Well, have you thought about this? Have you thought about that?” and of course services are incredibly overstretched and things are tough, but at the same time, I guess, yeah, it’s just raise awareness and obviously some things are done because there’s scarcity of resources, but then at the same time certain things perhaps could be done a little bit better if there was a little bit more of awareness. But, you know, I’m going to say this because I’m a champion in Huntington’s disease, of course I want everybody to know about it, but equally I’m sure there are other conditions that our team wouldn’t be as much aware of as the others. So, we all have our blind spots and it’s our role as a team to raise a little bit of awareness, I guess.

Interviewer: When you do this, well, you’re already a consultant, but when you do this consultancy with these other teams that are directly caring for these patients, do you feel they are receptive to what you’re telling them or do you feel it’s well received on the other side?

[0:54:50]

Respondent: Yeah, yeah, they’re grateful, yeah, they’re grateful.

Interviewer: Okay.

Respondent: We’d probably like to have a bit more resources to do that more often, if we could, but yeah, it’s usually well received, yeah.

Interviewer: Okay. They don’t question, I mean, you know, “Oh, no, he’s just a meanie,” or, you know, if you’re saying to people, “This is the condition, it can cause changes in behaviour, in mood,” whatever, however you explain it, if they accept it or if you say, well, they can’t work or they can’t drive, if they accept it or if they question it, put it in cause, if they…

Respondent: Yeah. I think it depends on the profession that you’re talking to, and it just depends on the person. I think if you spend a bit of time, if you talk about somebody, a person, they’re usually very well received. Sometimes obviously it can be difficult if sometimes somebody mentions something, but usually when we get involved, sometimes we’re finding it difficult to get hold of people, our colleagues, because you can’t know every single staff member in general hospital, especially not in your area. So, sometimes we face challenges in getting hold of people that we have to get hold of to talk to. But once we finally manage to get hold of them and have that conversation, it’s usually well-received.

Interviewer: That’s good.

Respondent: It’s usually well-received. And I think the main challenges, if you like, would be if there is some lack of communication where we can’t get hold of a particular clinician or there’s misunderstanding between clinicians and the families that occur or simply something happened for a very short time over the weekend or during the week and nobody managed to do any liaison work because there just wasn’t enough time to do it, so yeah, so that can happen. But having said that, if we do get the right people and we do have that conversation, it’s usually well received. But, yeah, except for some situations where we had quite difficult when it comes to admitting to mental health units and not finding a bed and that sort of thing, so that’s the toing and froing that comes into it. But when it comes to general hospitals, it’s usually well-received. But yeah, it’s a very difficult question to answer because each situation is so different, each patient is so different, each service is so different that we deal with and there’s so many services involved that it’s very difficult to generalise, if you know what I mean.

Interviewer: Yeah, yeah, and probably not fair to do so, so you’re doing very well. You’re not generalising. [name 1], we’re nearly there. I’m going to ask you a few questions just in terms of characterising my sample, so please don’t take me wrong, I will ask you for your age right now.

[redacted]

Interviewer: Alright. So, is there anything about the topics we’ve been covering that you want to add that we didn’t get to speak about?

Respondent: No. Thank you very much for taking time and I’m very curious to know the results and if there are any interesting events about that study, please let our team know. We’d love to know, even though I know [location 4] is not very close, but we would make our best to attend because it’s really interesting because it’s so important for HD to have this integrated care and to work across the services. It’s so, so important. So, you know, I think it’s great that you’re doing the project. Perhaps I should mention, so I’m a [redacted roles]. So, obviously, if you’ve got some results or you’re in the field that you think that would be helpful for us to raise awareness or pick up some… you’ve got some interesting projects, feel free to get in touch. We’re always curious. We always want to be active and participate in things, and I just can’t wait to see those results. I know it’s going to be a while.

Interviewer: Yeah, yeah.

Respondent: It’s a lot of work, but yeah, just really, really looking forward to that.

[redacted]

[End of Transcript]