

Evidence Cards

Future Pathway for Functional Disorders

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Dec 2022



Evidence that supports this from lived experience interviews

"I knew there was something wrong with me and the doctor was like, 'No, it's this, try this', and then I was like, 'No, it's not that, it's something else', and then they give you tablets, tell you to go away and you'd be back a month later with the same problem".

"I know he's interested in me as a whole person and not just which bits of my brain aren't working and which symptoms I get so that means a huge amount, that's massive."

"She [Rheumatologist] dismissed my fat, sort of thing, and went on to what's happened in my life, what trauma it's caused us to have this, like this. So I wasn't...I didn't walk out there thinking 'just another fat person', I walked out of there feeling like a human being."

"Sometimes my health can be really good and then the next time I'm just literally falling to bits, between my chest, my arthritis, obviously my stomach..."

"I've never made the connection. People have never asked me, I suppose, and I've only dealt with what's happening here and now and not so much back then."

Evidence from the scoping review

"Lipsitt et al. (2015) noted the importance of the patient-doctor relationship... and the need to give respect to the patient's narrative of their complaints... In terms of treatment, they recommended that the physician treats comorbid psychiatric conditions..."

Evidence that supports this from the workshop with health professionals

"...now the GPs, they work in a different way, so it seems to be much more kind of specific to whatever problem you are turning up with rather than a more holistic overview."

"...regardless of who that initial longer conversation is with, having the outcomes of that and that discussion somewhere... so that when the next health professional sees them, it's not new and the patient is not having to explain themselves all over again... they've had to tell their story so many times."

"One idea is that the patient holds the story because they are the one that – there's a little bit of continuity rather than they go back and see seven different GPs. So that kind of feeling heard and validated early on."

"...patient-centred, patient-held information... the patient is driving it, the patient knows 'I've been back six times now... this is my story, that's what I've done' rather than... there's a lot of people being pushed from pillar to post and back and forth with no continuity, a joining up of the story."





Evidence that supports this from lived experience interviews

"Throughout my whole diagnosis and treatment... there are other symptoms, physical symptoms, that they kind of forgot about, they just wanted to concentrate down the neurological route."

"...the pain just got worse, I had no answers for the pain and I just kept saying to the doctor 'I'm in pain', and they just kept saying, 'well lose weight', or 'it's your... thyroid.'"

"...when I'm having a major flare up but she [nurse practitioner] seems really nice and she's actually listening to me. And not just fobbing me off, she actually seems to be willing to help rather than, 'Here, have some more tablets'."

"It just took so long... it just seems like such a long process."

Evidence from the scoping review

"Morton et al. (2016) described a model with primary care physicians at the centre. Here, GPs delivered a symptom clinic intervention involving an explanation of the patient's symptoms and suggestions for symptom management.... Results demonstrated that the model was acceptable to the majority of patients, and some reported an improvement in somatic symptoms. GPs could deliver the intervention with acceptable fidelity, although it was identified that the explanation and action components of the model required additional development."

Evidence that supports this from the workshop with health professionals

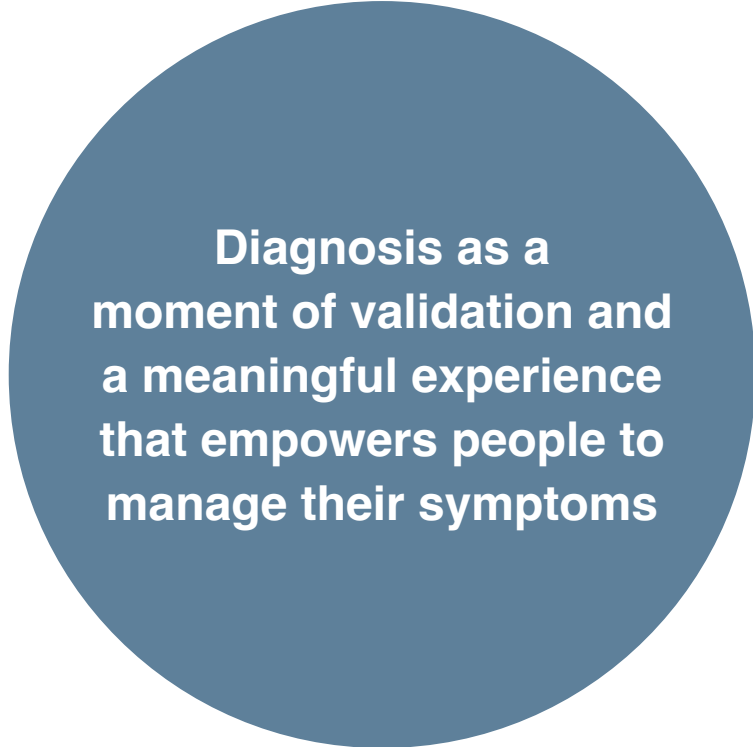
"...even if a GP was happy to support them or say 'well try a functional approach while we're waiting to see..' because that will help towards getting a diagnosis, you know?"

'Waiting Well'

"...the only way that you are going to have a pathway that's flexible, for me, is symptom-led rather than diagnosis-led..."

"I think that's where training comes in, I think that's a problem at the moment, that you have a lot of services saying 'oh we can't do that, can't accept the referral', and then people are waiting, then people aren't getting discharged and then people can't go here... can't move them anywhere and then they have to wait a year to be seen by somebody. Whereas actually, this person is way better seen closer to their own home by their local team, but that team needs to be better skilled, so that's the training."





Evidence that supports this from lived experience interviews

"It felt like a bit of a relief because I'm not imagining it, the doctors have given it a label... just having a label and not imagining this isn't all in my head, when people ask me what's wrong, I can say I have this and they don't just think 'oh she's just having a moan.'"

"...when I met him, it was... one of the best feelings in my life: he knew exactly what I was going through. And before I hadn't had this, so I was explaining it to him and in the end I started crying because he knew exactly what it was and he gave it this name of FND and he explained it which was bang-on right."

"I initially saw a consultant for one appointment and that was a horrendous experience and he was just about to retire, he had junior doctors coming in and out of the room, I found him patronising, I felt very anxious. I remember lying on the examination couch and him telling me to relax, relax, relax and it was the one thing I could not do. And then at the end of the appointment he just said, 'You have FND' and he wrote down one of the websites, neurosymptoms.org, on a bit of paper and gave me it and just said, 'live your life', and that was it."

Evidence from the scoping review

The importance of validating the patient's experience as a key part of diagnosis and communication was highlighted in two studies:

Morton et al. (2016) noted that *"Essential to this model is the GP's validation of the patient's experience, and ongoing learning for both parties about what is helpful."*

Olde Hartman et al. (2017) *"...discussed the importance of clear communication and explanation of the patient's symptoms."*

Evidence that supports this from the workshop with health professionals

"...the diagnosis will give people the explanation and a sort of framework to hang their difficulties on and validates it to get a specific name..."

"Yes, there's the validation that this is a real thing, this is real. Because there's this real question for everybody, being believed, I suppose, is it real and this idea that it's in your head, which doesn't really make sense because everything stems in your head when it comes to pain, when it comes to physical – you know, they are all linked to the brain. But this is a real experience, that validity that it's all real."

"...a meaningful diagnosis that in some way empowers, rather than disempowers... what can you do, how can you manage these symptoms, what can you do that will make your life workable."

"...so there's something about that first contact which also shapes expectations in a helpful way."

"[quoting a patient] 'they told us it's not going to go away... but actually that was the most helpful thing that was empowering because we were no longer looking for a thing to fix it. We were then starting to think, well what can we do to live our lives well, with this.'"





Evidence that supports this from lived experience interviews

"Say you went in a room and you had a therapist, a doctor, a specialist, a pain management...as a group, so that one person can say one thing and they can work with each other to have a solid solution."

"Being referred to someone sooner would be helpful, like a gastroenterologist or someone like that, just to rule out other stuff, rather than just saying 'It's IBS! we don't know really what it is, but here, have some tablets!'."

"...physio has been a good experience... the physio I have isn't a neuro-physio but I've had her since I've had orthopedic problems with my shoulders and she just kept me on... And she's interested and she's done research in my condition and she speaks to neurology."

Evidence from the scoping review

The scoping review highlighted integrated multidisciplinary team (MDT) working and community-based care as overarching similarities across pathways for all three specific conditions and the MUS studies. The different professionals that made up the MDT varied across the studies and conditions.

Evidence that supports this from the workshop with health professionals

"I suppose that's the benefit for a health professional, of being part of a team that I would kind of know what you might say, and I can reinforce that and vice versa, that when you work quite closely with people for a while, I can't do your job but I can back you up. Because, do you know, that's really helpful I think and gives a consistency..."

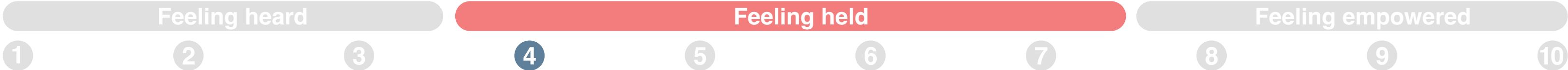
Need for understanding of functional disorders

"So, as a psychologist and I'm seeing somebody with IBS and they go, 'what is IBS and how is it diagnosed?' And I go... [mumbling...] don't really know. I need to know that stuff if I'm seeing patients like that."

"If you want to move forward quickly with a decision, that requires an email or a better way to communicate."

"...so it needs to be in psychology, it needs to be in psychiatry... but it also needs to be in the specialist training as well, functional, not just you are a neurologist, you need to understand about FND, you also need to understand about other functional disorders and how they interact with each other. Two hour module on functional disorders, it's mandatory."

"...community based, for the MDT, so actually the MDT actually links in with the community rather than the patient shuttling to different places by themselves."





Evidence that supports this from lived experience interviews

"Why can't you offer them counselling or even like a support group or – they've never offered me anything like that at all and I just feel like I've been really let down."

"...they were aware that FND was a very real thing, that you weren't making it up, so there was a lot of reassurance in that fact..."

"...by talking to other people we gained a lot more encouragement and satisfaction and trading off each other's symptoms, there was a common cause."

"I didn't have that when I first started going to FND Hope, as a charity, that group wasn't available to me, it wasn't around. And I kept moaning that there wasn't a group in my part of Scotland... I kind of felt I had no choice but to set one up."

Evidence from the scoping review

"For fibromyalgia one small service evaluation was identified (Joire, 2019, n=17) of a multidisciplinary approach to fibromyalgia (Gateway clinic) based on four pillars of health (food, movement, relaxation, sleep) based at Guy's and St Thomas, London. The service involves 12-weeks of acupuncture combined with a range of other traditional and complementary interventions. The evaluation reported high compliance with acupuncture and dietary changes and a 34% reduction in patients' symptoms."

In addition, group psychoeducation was a common feature of pathway design found throughout the scoping review.

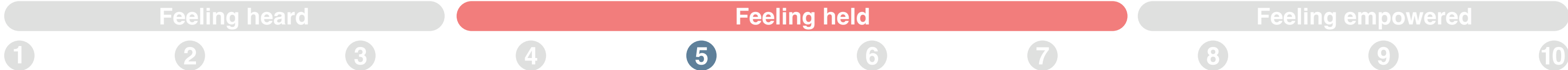
Evidence that supports this from the workshop with health professionals

"...the gateway clinic, so they had an actual almost programme, like twelve weeks and they had access to certain things, which I think involved education and almost with FND, is that something we need to look at, that they get offered some sort of programme like that? And on diagnosis, do they get that support that's given to them and it's giving them education and helping with self-management."

"...so something there about trying to get really helpful understanding and advice, meaningful diagnosis, empowered information that enables people to do things that help. At that earliest possible stage, even if there are other things along the way that another health professional can bring in, that basic self-management."

"...someone gets a diagnosis, they get referred to the gateway clinic and then as part of that there is the FND group, there is AHP assessment or whatever and then they have a sit-in and talk about their diagnosis."

"...one of the most strongest things that they say is it's hugely helpful to hear some other people that have been through the same thing."



Assessment by a health professional trained to generate a formulation and assess the need for specialist psychology support and/ or a care-coordinator

Evidence that supports this from lived experience interviews

"...they didn't look at what my trauma had been in my life, they didn't look at what I was going through; all they looked at was that I was overweight and I smoked."

"...it's [mental health] not something I've thought about, I try not to think about it. But when I have needed it, there is one doctor down the road...she understands me very well and I really don't have to say a lot."

"...another GP... who was very much into herbal remedies, persuaded me to go privately, not on National Health, to a [natural therapist]... Well I went two or three times but I have to be honest and say I wasn't really impressed. Maybe psychologically I'm the wrong person. But that is the only non-physical treatment I've had in forty years."

"I couldn't work out why that would now be affecting what was happening to my body, what was happening to my head. I know they say some traumas in your life can affect you down the line."

Evidence from the scoping review

"Bestall et al. (2017) reported on the development of a new liaison psychiatry service based in three GP practices. GPs referred patients to the service for them to receive formulation (a review of medical notes to evaluate current diagnoses and medication), care with a function-based approach, and psychological interventions. They identified a reduction in patient healthcare utilisation, along with a reduction in cost following the establishment of the service."

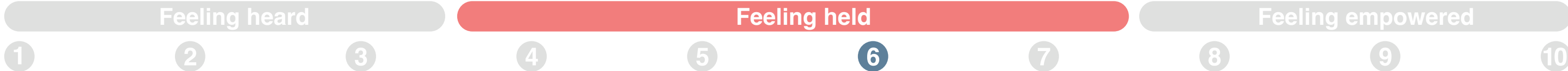
Evidence that supports this from the workshop with health professionals

"... 'what is the background here? When did this start, how did it start, what's the triggers, what's the maintaining factor, what is perpetuating those problems?' That's what we do, that's our bread and butter. Every patient we do, we go tick, tick, tick and then you clip it all together and you go 'then what's the plan?' including what they want. And then you might do that and then go 'actually, what they need is...'"

"...the important bit is the individual's interpersonal skills to get that relationship, to get the information they need because what happens if you don't do that, is they'll go to physio and you'll do your stuff but you'll go 'actually we know this is not the problem'..."

"I think it's a trainable skill. I don't think it needs to be a clinical psychologist, it may well be... an assistant psychologist who could do some of that... supervised by a qualified clinical psychologist."

"...some of that could be done in a group setting, you could do some of the early formulation stuff in a group setting and then break into your – if somebody goes 'actually there is a lot of psychological background stuff here', you can work individually."



Tailored pathway generated by a care-coordinator with specialist knowledge of functional disorder, with equitable care across services, sectors and geographies

Evidence from the scoping review

Matched and stepped care models were common in the pathways identified by the scoping review. In our workshops, health professionals described something similar to a matched model, but took this further in describing the need to work with the patient to tailor their care to their goals, formulation and readiness to engage.

Doebel et al. (2020) found that “NHS services for people with fibromyalgia are highly disparate, with few professionals reporting access to care pathways. The greatest perceived unmet need for people with fibromyalgia is a lack of available services.”

Evidence that supports this from lived experience interviews

“...if you are going to the doctor for the same thing then to me, it should be the same doctor... I had this woman for my fibromyalgia, she could just pick up or remember things from the last time she’d seen me, I didn’t have to start all over again. And I think everybody should be able to have a doctor that they can go to.”

“It would be nice if you had a bit more support in that you actually had follow-up or reviews, even like an annual one, you get your annual asthma review, they take you in and ask you if your medication is working and how you are getting on but they don’t do that with any of your other tablets.”

“...the only reason that I have social work in my life is it gives me a budget and I use that budget to go to art workshops. So paying for art is what I need, that’s my choice... I do use it for sport, exercise, swimming as well but I don’t use it for having a carer and the whole-set up is it should be about carers, here in [island], whereas self-directed support across Scotland isn’t about just having carers.”

“I think being on an island is quite relevant to my pathway as well, access to things is different.”

Evidence that supports this from the workshop with health professionals

“It needs to be somebody who then can pull it together and operationalise it. It’s all very well going to speak to somebody and then going, ‘yeah, that sounds horrible and being empathic’ but they ought to then go....it needs to be solution-focused.”

“...we aren’t going to be ready for all the same things at the same time, so they might need to come to things in their own time, or they might need a focus on mental health aspect early on or that might come much later and they might be ready to engage with an AHP or they might not.”

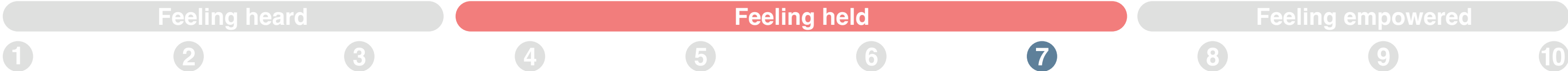
“...they are often having these experiences of trying to kind of straddle two services, it shouldn’t really be for

the patient to work it out.”

“it’s kind of a matched model where you go ‘this person needs an FND group, this person doesn’t, but they need – maybe rehab medicine because actually they are chronic long-term, you know, this one here is early diagnosis, engaged well with the diagnostic...”

“So we can go ‘why are this little community here not doing it and the rest are?’ And then we can say... ‘well you need a service there’. Finding gaps in service and filling them - equitable access...”

“...if you’ve got a GP that understands FND, you’ll get a different service from a GP that doesn’t...”





Evidence that supports this from lived experience interviews

"I didn't believe none of it. Because I did go and read an awful lot of what she gave me then and again, that wasn't me. That wasn't what was happening to me."

"So from first seeing the GP and really believing the diagnosis, it [acceptance] was probably a year."

"...you absorb that information you kind of then started to question it..."

"But even then, I think because I was a psychologist, I really struggled to accept it and I was referred down to Edinburgh to see [a Professor], at the Western... for about four appointments and it was only then I started to believe the diagnosis. He is one of the world experts on the condition and I reckoned if he thought I had it, then I must have it."

"...in some ways I really want it to be FND, because it makes my life and world a lot easier. The trouble with FND, it's such a broad spectrum, it's very, very wide, it's almost what they call an umbrella diagnosis, and I think that's what I found a bit hard to fit in."

Evidence from the scoping review

Cope et al. (2017) piloted a programme of CBT group-based psychoeducation for Functional non-epileptic attacks (FNEA) and as described in the scoping review, found that, *"...patients showed increased acceptance/understanding of FNEA post-treatment."*

Evidence that supports this from the workshop with health professionals

"...one of my patients said this to me the other day, so she's got FND, fibro and chronic fatigue diagnosis, and... she was not what I was expecting, she kind of said to me, 'you know, I think it's all the same thing, but it just depends on what specialist I see and how they view it.'... Yeah, hallelujah! Discharged!"

"...you want to understand what the person's hopes or expectations or their goals are, as a starting point, and to understand where they are in the understanding and acceptance of the diagnosis..."



Enabling self care by building on conversations with health professionals throughout the journey and working with the third sector to offer peer interaction and holistic support

Evidence from the scoping review

Many of the pathways identified by the scoping review had a focus on building self management skills and empowering patients. Several of the studies tested resources for self management such as eHealth tools.

Evidence that supports this from lived experience interviews

"...I've also got that support system of people who maybe don't necessarily have the same diagnosis but who have been through the group with me and in that similar situation. So although I've got the support of friends, I've also got support of people who are in pain."

"But just having shared experience, I think everyone said that they found that was the most beneficial."

"...it [facebook group] was just like sort of a support group that helped me more, understand the feelings and what I was going through."

"I did have a daughter living at home, she's 27 now and [psychiatrist] said to me though, 'she is your problem, you need to get rid of her!' which made me and my youngest sort of laugh because she was stress."

"I've got tools now that I feel I can use to help me... once or twice things were posted, sometimes it was an emailed link that I could print out myself but all the slides are there in the talk that we had emailed each week, so I can watch it all back... there was links to talks and things on YouTube and I've got movement exercises."

Evidence that supports this from the workshop with health professionals

"...it could be generic to certain things like sleep, food hygiene, dietary needs, that kind of stuff! But – you know, reducing stress, how you manage stress, all that sort of stuff. But then we need to coordinate the third sector because... it needs to be evidence-based as much as possible and quality assured."

"We actually pay them [third sector organisation] to do a job rather than scrabbling around to get donations to provide a service to our patients."

"...there's no point in peer groups and the third sector groups saying one thing and all of the professionals say something else, because that'll just cause conflict."

"...if you ask them about their life and ask them how they would like things to be different, 'actually, I'd like to be able to go to the park with my kids', so what steps...so I suppose it's that little bit more individualised signposting to achievable steps..."

"...a series of NHS Grampian links, take these three and maybe look at these three topics or something that are relevant to you, and whether that's diet or sleep or actually explaining FND."

"It might be a recorded online talk that's ten minutes, that backs up what you've just said."



'Open door' specialist access enabling patient-led booking, group options and clear routes back into community care from specialist service

Evidence from the scoping review

Olde Hartman (2018) provided guidance on the need for "follow-up appointments based on patient need".

Evidence that supports this from lived experience interviews

"...she [the gastroenterologist] also said, again - like the neurologist – if there was anything I was untowardly worried about or whatever, I could contact her direct if I wanted, or I could go through the GP and I felt quite comfortable, I felt that was fantastic, that if I wanted to, I could sort of contact her directly if I needed to."

"...so if I need to see him more, I see him more. If I need to see him less, I see him less..."

"I phoned and says can I make another appointment [with Rheumatologist], all my medication is leveled out, I'm all fine, can I make an appointment? And she was like, 'no, you've got to go through your GP, your GP has to diagnose the fibromyalgia' ."

Evidence that supports this from the workshop with health professionals

"...you'd like to get to the point that actually these patients don't have ten different specialists involved, that they've had advice and people have discharged them and then there's the key worker and actually you don't just – you have six months follow-up from neuro, six months follow-up from rehab, six months from GI, six months from the pain team all just going, 'hi, how you doing?' blah blah. Actively discharging people... with access, obviously again."

"...having that kind of open door; instead of them being discharged at a certain point, is allowing them to come back whenever, at the point where they are ready to engage. Because a lot of these conditions are peaks and troughs."

"...key worker goes – the pain is getting worse again, let me speak to the pain team, I will speak to the pain team rather than make a referral."

"You get some patients who, because they maybe know that there is a discharge at some point in the future, will want to be seen again and again and again, whereas actually, if they know that it's not a case of that's it, they know that they can come back when they need to."

"...if they do come in, being able to do what needs to be done within the hospital but then having an established pathway to then manage them back out in community, rather than having a long hospital stay..."

Feeling heard

Feeling held

Feeling empowered

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