

REDESIGNING THE CARE JOURNEY

For People Living With Functional Disorder

Final presentation by:

Fiona Summers, Sneha Raman and Gemma Teal
9th March 2023



BACKGROUND

The need for innovation in care for functional disorders in Grampian

No one specialist area responsible for functional disorders

Wide ranging needs of this population, across a large number of settings

Lack of knowledge and treatment options

Clinicians struggling to support patients

Patient needs not met, and inappropriate treatments and assessments cause deterioration

Poor patient experience due to lack of support and understanding: frustrated, angry, feeling dismissed

Inappropriate use of resources resulting in a high financial cost

BACKGROUND

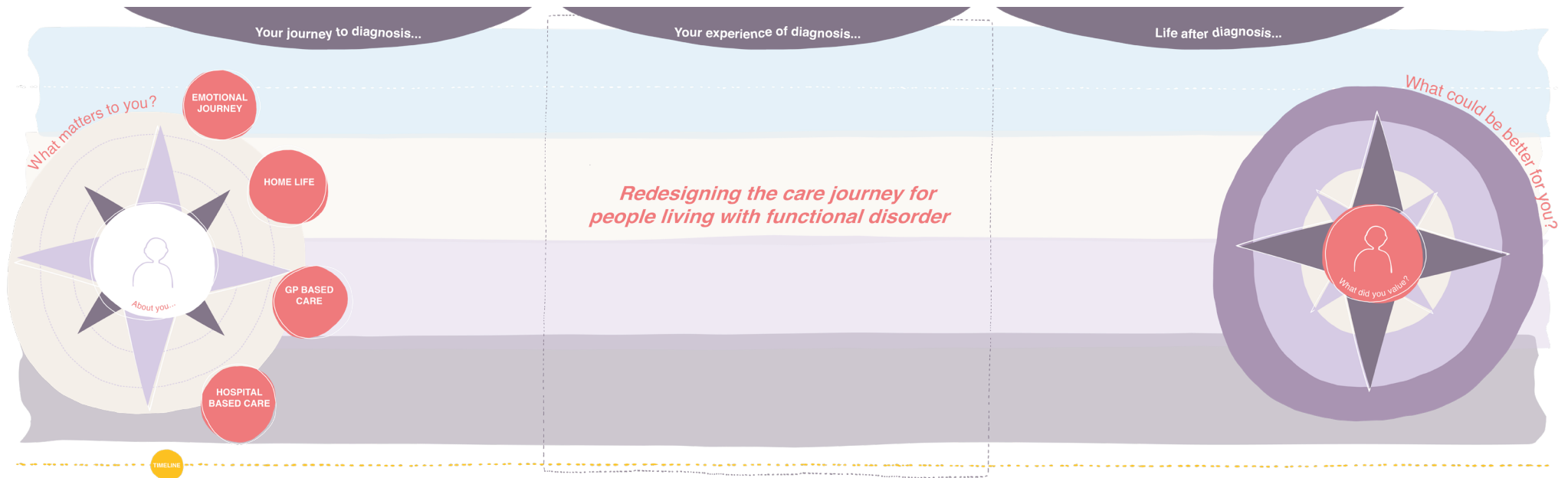
Need a pathway with underlying principle of a patient-centred holistic approach in line with Realistic Medicine to address these challenges

FND		Fibromyalgia		Abdominal pain syndrome	
Average patient	Female, aged 48. She will have 5.6 chronic comorbid conditions.	Average patient	Female, aged 57.8 and in the medium to higher social economic group. She will have 8.7 chronic comorbid conditions.	Average patient	Female, aged 50. She will have 7.2 comorbid conditions.
Appointments	She will have seen 7.2 specialties, had 3.8 admissions for 15.3 nights. She will have had 3.2 emergency admissions, 2.7 MRI scans, 7.4 X-Rays, 3.7 Ultrasounds and 2.6 CT scans.	Appointments	She will have seen 11.2 specialties, had 7.4 ER visits however not likely to have been admitted. She will have had 5.4 MRI scans, 16.9 X-Rays, 4.1 Ultrasounds, 4.4 CT scans and 2.5 other scans.	Appointments	She will have seen 8 specialties, had 2.6 emergency admissions, 2.2 CT scans, 2.5 Ultrasounds, and 3.3 X-Rays.
Cost	Total estimated cost for radiological investigations and ER consultations for 30 patients: £86,476.	Cost	Total estimated cost for radiological investigations and ER consultations for 30 patients: £108,679.85.	Cost	Total estimated cost for radiological investigations and ER consultations for 30 patients: £41,888.

Table 1: Findings from the audit of three most prevalent functional disorders in Grampian

AIM

To identify opportunities and develop new ideas to shape how people living with functional disorder are supported in NHS Grampian



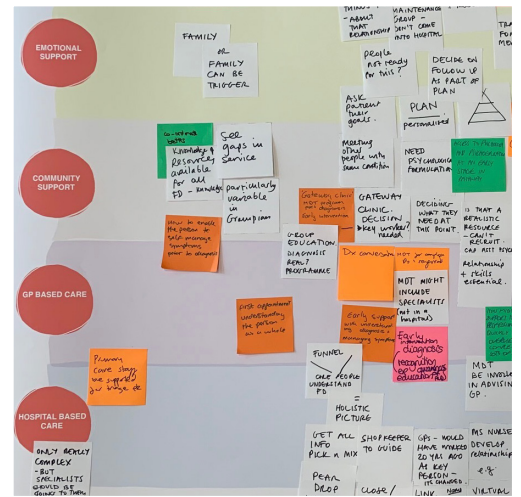
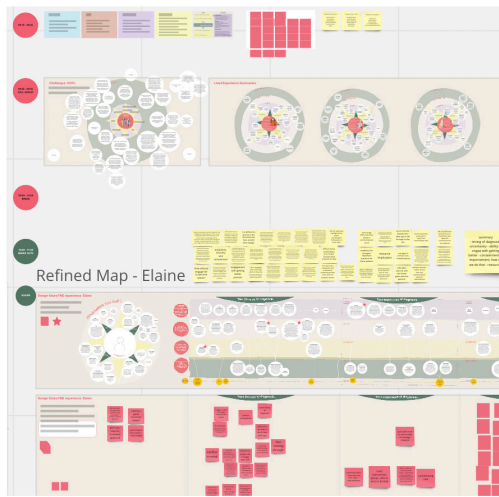
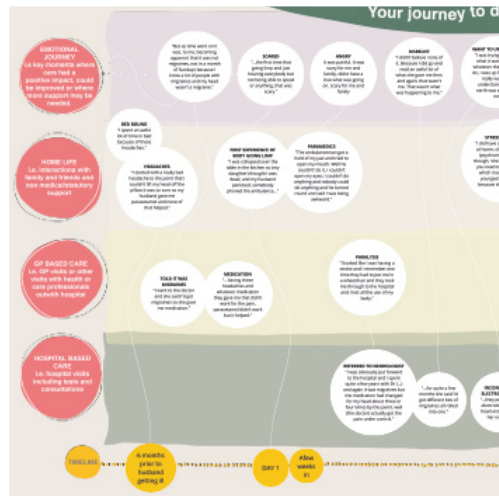
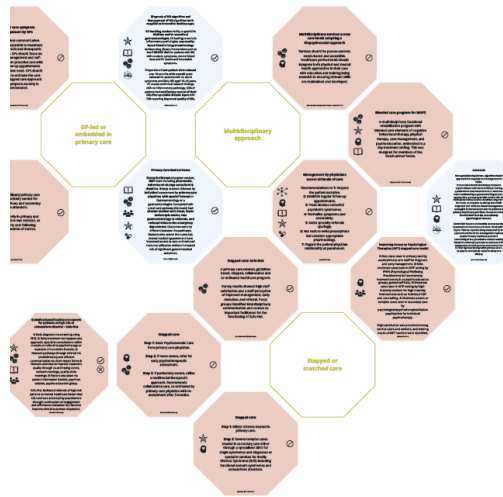
METHODOLOGY

Scoping Review

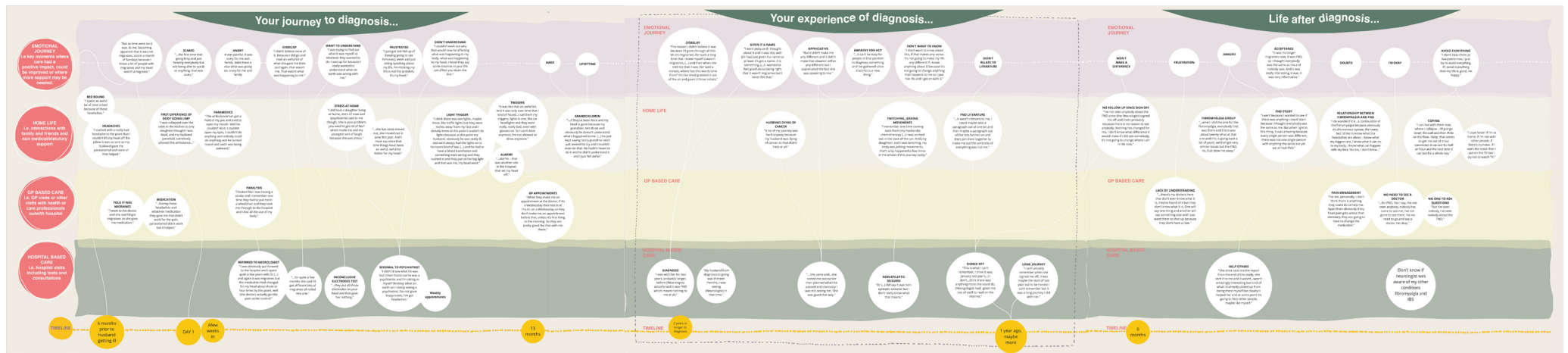
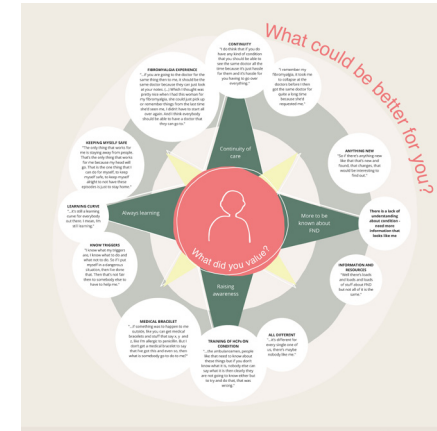
x8
lived experience interviews

x3
condition specific workshops with professionals

x1
overall FD workshop with professionals

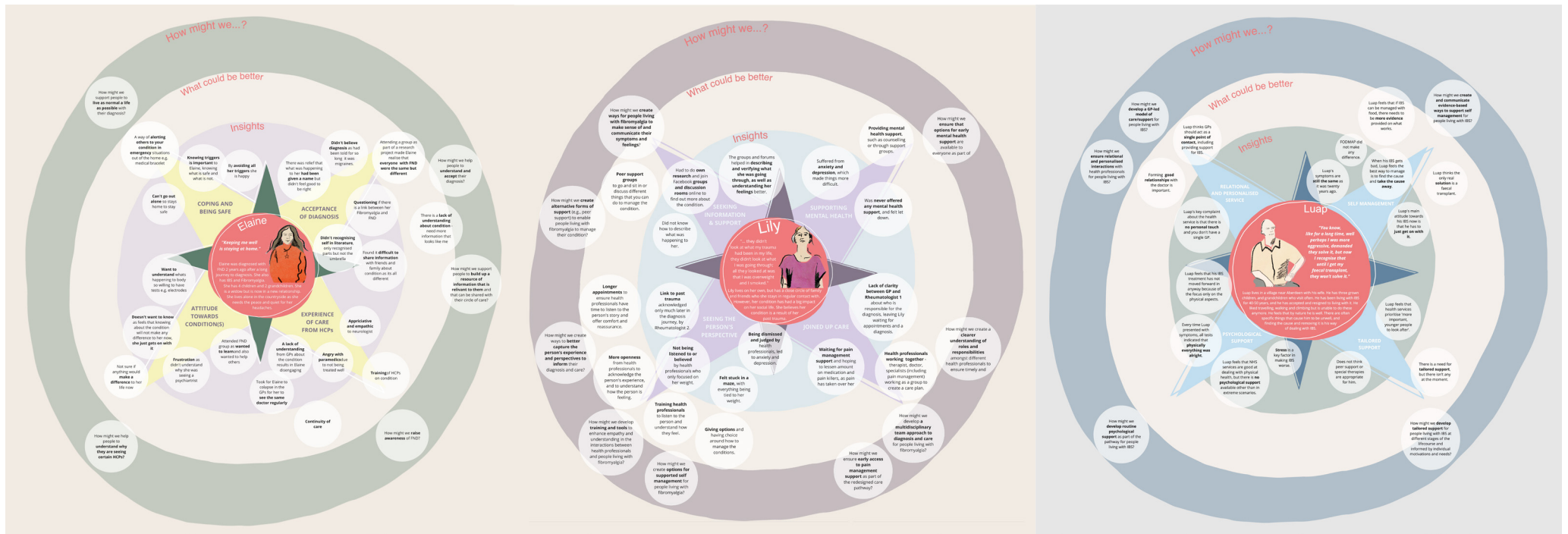


MAPPING LIVED EXPERIENCE



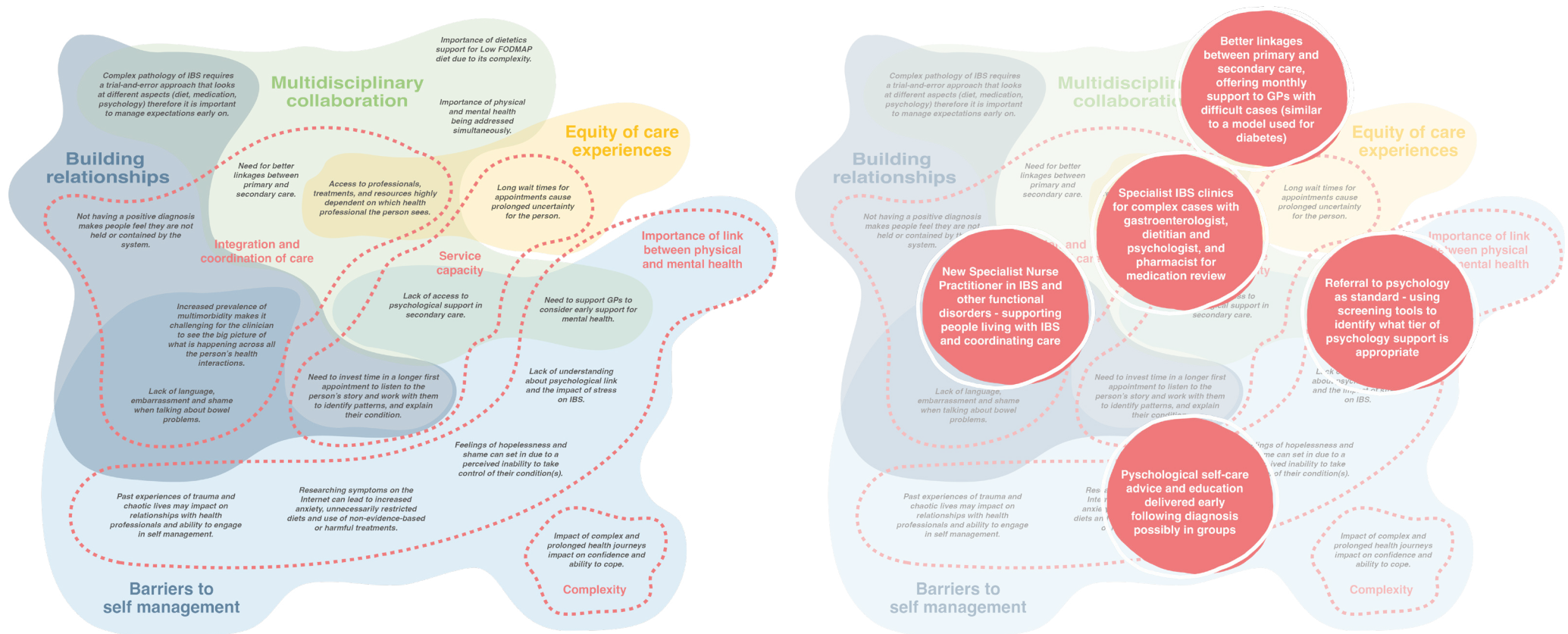
CONDITION-SPECIFIC FINDINGS

Key themes, insights and opportunities from lived experience interviews



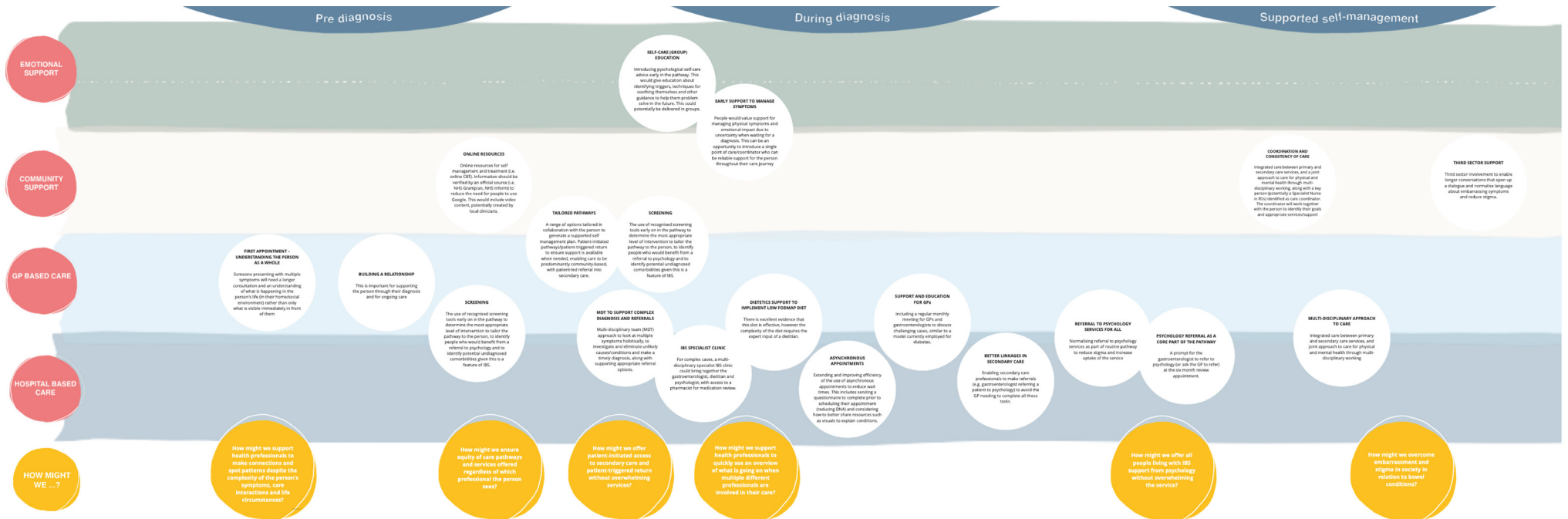
CONDITION-SPECIFIC FINDINGS

Challenges and opportunities from health professionals' perspectives

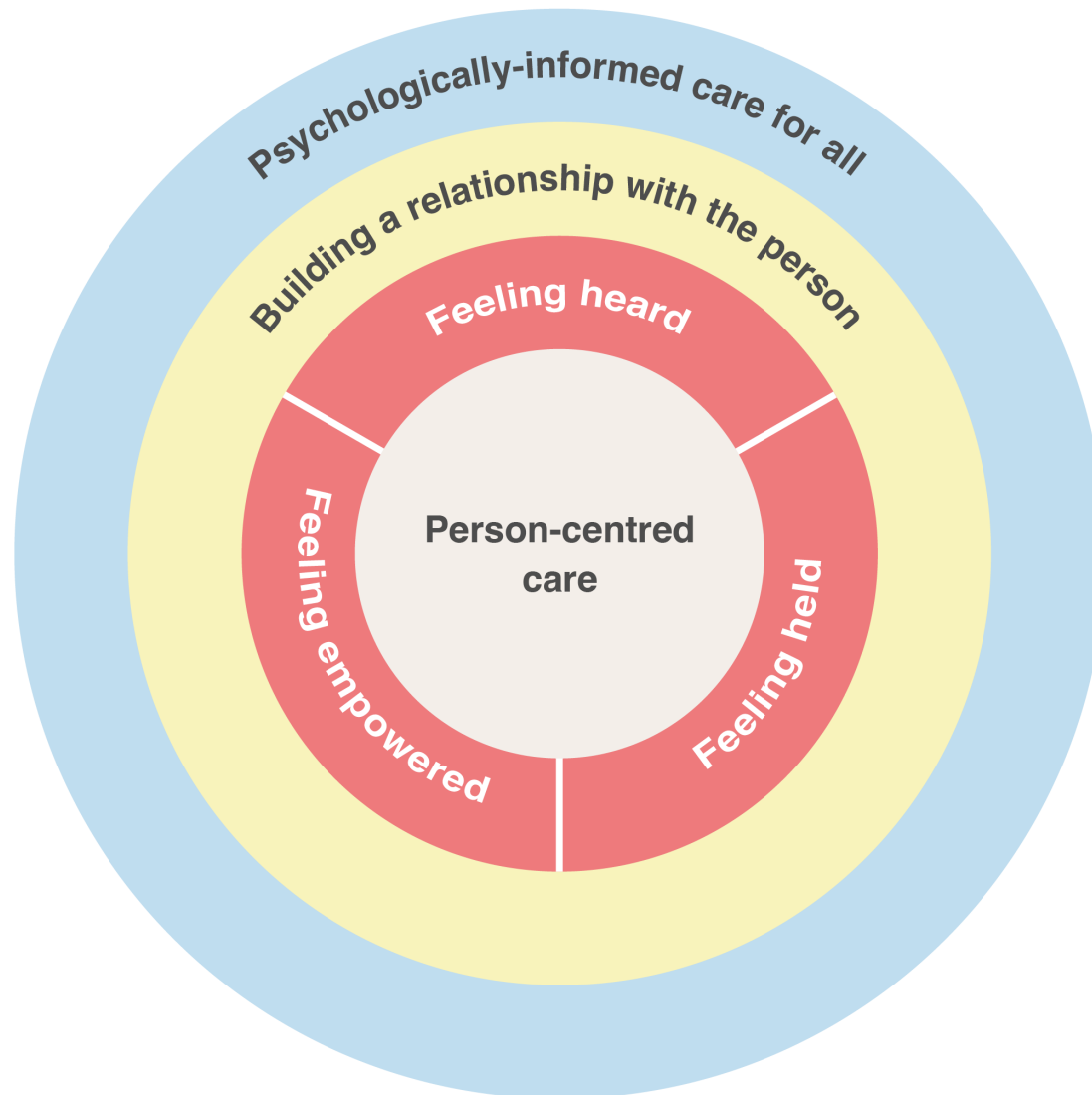


CONDITION-SPECIFIC FINDINGS

Ideas and ‘how might we..?’ provocations for future pathway



FUTURE PATHWAY FOR FUNCTIONAL DISORDERS



KEY PRINCIPLES

Building a relationship with the person

Building a relationship with the person underpins all three stages of feeling heard, feeling held, and feeling empowered, reflecting both the aim of the future pathway as well as how the future pathway could be realised in practice.

"...in my eighty-six years, the only people who have never learnt to call me by my name, is the health service. And that, in part, says it all. After forty-three years in the practice, I'm still [full name]. There's no personal touch."

"...he's got experience and therefore there's a trust, I think trust and respect and good listening skills. And he's very reassuring..."

KEY PRINCIPLES

Psychologically-informed care for all

Adopting psychologically-informed care for all will ensure a more integrated biopsychosocial approach to care across all stages of the future pathway and help to address stigma associated with functional disorders.

"...medically I have nothing but praise for the National Health Service for physical treatment. But psychological, it doesn't exist!"

"...there was too much emphasis as the supposed cause as being stress-related and I don't think in my case...and I got that from the other people in the feasibility study, that they weren't saying – they were normal, average Joes, people with no real issues in life. And the stigma that if you've got FND it's been caused because basically you are struggling with life. But not really, no!"

OVERARCHING STRUCTURE

Feeling heard

Ensuring that the person feels heard and validated and knows that their unique experience is understood and acknowledged by all health and care professionals right from the beginning and throughout their care journey.

People living with functional disorders often find it hard to articulate their symptoms or make connections between their condition and psychological factors such as trauma. A psychologically-informed approach and building a relationship based on listening, trust and respect will support the formulation of their experiences and story to inform a meaningful diagnosis and a tailored approach to care.

Feeling held

Enabling coordinated care, whether through multidisciplinary working or a dedicated care coordinator, this part of the pathway aims to ensure that ongoing care is patient-centred and community-based, providing a sense of the person feeling held.

People living with functional disorders often feel let down or confused by not knowing who to turn to for informed and holistic support. This part of the pathway focuses on building trusted circles of care and education to support people to make sense of their condition and its impact on their everyday life.

Feeling empowered

Acknowledging that the process of acceptance can be different for each individual and supporting people to explore options and choose ways to self manage that work for them. This part of the pathway aims to make them feel able to take control, while ensuring they can easily access health professionals at times when they need support.

People living with functional disorders often find it hard to accept their diagnosis due to a lack of clear distinction between different conditions with similar symptoms and go through cycles of questioning or accepting it. Empowering a person to make their own journey towards acceptance and self management requires a psychologically-informed approach to enable the person to make their own choices and develop supportive relationships with health and care professionals, third sector organisations, peers, family and friends.

OVERARCHING STRUCTURE

Feeling heard

Ensuring that the person feels heard and validated and knows that their unique experience is understood and acknowledged by all health and care professionals right from the beginning and throughout their care journey.

People living with functional disorders often find it hard to articulate their symptoms or make connections between their condition and psychological factors such as trauma. A psychologically-informed approach and building a relationship based on listening, trust and respect will support the formulation of their experiences and story to inform a meaningful diagnosis and a tailored approach to care.

Evidence that supports this from the workshop with health professionals

"It's nothing, which is what they hear, even if you say it in the best terms."

"there's something about waiting well... a lot of people's functional symptoms will get worse... if you are feeling really stressed about 'what's wrong with me? People haven't heard me and they are saying it's in my head and is it in my head?'"

"...balance between an individualised approach that really allows the person to feel heard and validated and their unique experience to be understood. When equally, to see this in the context of something that has a name and other people have... who could do a psychological formulation, as there's a bit of debate because the reality... there's not millions of psychologists out there... And that's why it's a psychologically informed workforce – OTs, physios and things but being trained in that kind of approach."

"...for certain people it's more difficult to articulate what's going on for them. I suppose that's sort of health inequalities and also just the key bit of this... is trauma. So I suppose there's a significant proportion of people who perhaps have had difficult experiences in their lives, therefore find it more difficult to engage, to trust, not turn up for appointments, so there's something about an awareness there. So that little bit of that...I suppose psychologically informed but, yeah, just thinking about choice and empowerment."

Evidence that supports this from lived experience Interviews

".. sometimes it felt that there was no point in going to the GP with the symptoms I was having and on at least one occasion one GP said to me 'it's all in your head', and statements like that."

"I felt like they thought I was making it up all the way along, especially the neurologist in the end and I think he wanted me to see a psychiatrist and the way he said it made me think, 'I'm not making this up, I'm not going loopy, I'm not nuts, this is happening'."

"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 couldn't get through to them that I was twelve stone heavier and I didn't have an inkle of the pain I've got now."

"...she [nurse practitioner] knows that I know myself... 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'."

OVERARCHING STRUCTURE

Evidence that supports this from the workshop with health professionals

"The difficulty at the moment I think is sometimes with something like FND they'll get their diagnosis, and then whoever made the diagnosis will say 'we'll review you in a year', and they are sort of left to go and look at these resources."

"...And if they do refer to physio, to the likes of ourselves, we've got a waiting list, unless they are urgent, they are waiting at least six months to a year."

"...we see that very much in the pain service, which would include patients with fibromyalgia, sort of fosters the belief that there's going to be some fix at the end of that wait..."

"I think what we need to acknowledge as well is often it's the patients that drive their referral to secondary care. So they would see the GP and perhaps have some basic management... And then they would come back and say, 'but I'm no better', and 'I want to see somebody else, I've not found the right doctor just yet', or the right person, just yet. So, it is difficult to say the GPs need to contain all of this, it's very hard for them."

Feeling held

Enabling coordinated care, whether through multidisciplinary working or a dedicated care coordinator, this part of the pathway aims to ensure that ongoing care is patient-centred and community-based, providing a sense of the person feeling held.

People living with functional disorders often feel let down or confused by not knowing who to turn to for informed and holistic support. This part of the pathway focuses on building trusted circles of care and education to support people to make sense of their condition and its impact on their everyday life.

Evidence that supports this from lived experience Interviews

"And you form good relationships but once John retired, recently it was just anybody... I certainly think everybody should have their doctor."

"...there's my doctors here that don't even know what it is, they've heard of it but they don't know what it is. One will say one thing and another will say something else and I just want them to shut up because they don't have a clue."

"I think I had such a long period of time without going to the doctor to complain about it, I literally just got on with it and then I'm like, 'What's the point? Because they don't do anything!'"

"I didn't have faith that if I went to see him that I would get any results and that just was frustrating and upsetting, so rather than have to deal with extra emotions on top, I'd just deal with things, which is not really how you should go."

"...you feel that... you are being passed around the departments and nobody is going to do anything about it."

"...that was a big weight off my shoulder because finally people who knew what I was going through, knew why."

OVERARCHING STRUCTURE

Evidence that supports this from the workshop with health professionals

"...acceptance isn't just an overnight thing, it's probably a back-and-forth thing, isn't it? And you almost just need to go away and think about it, and they need a bit of time and not pressure, 'maybe I can try that'."

"But there is something about empowering people and then investing in this because it's for them, rather than being told I should do it. Feeling that it's your choice, rather than... 'you must do it'..."

"...she'd been to the national pain programme and she [patient] said, 'they told us it's not going to go away. And we were like, '[sighs]' 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

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

"I do have to plan a bit but I can – I'm getting better at regulating what I eat before that it isn't any of the FODMAP type things, so I am getting a bit better at managing it".

"I know myself that I have to lose weight and that will help it as well. But that wasn't the main situation of what she was telling us; she [Rheumatologist] was just helping us out to manage it, we can try different medications, we can try – she was giving us other options."

"If [neurologist] was to discharge me, I think I'd feel lost and scared. I think I'm very dependent on him because I know he gets it. Even the thought of that is causing me anxiety thinking about it! I think if the GP was here full-time, all year and never going to leave the job and all that, then maybe...but [name of neurologist] has been a constant in my FND journey."

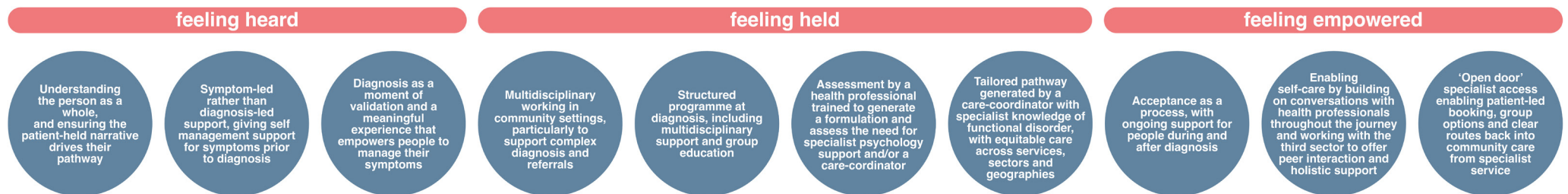
Feeling empowered

Acknowledging that the process of acceptance can be different for each individual and supporting people to explore options and choose ways to self manage that work for them. This part of the pathway aims to make them feel able to take control, while ensuring they can easily access health professionals at times when they need support.

People living with functional disorders often find it hard to accept their diagnosis due to a lack of clear distinction between different conditions with similar symptoms and go through cycles of questioning or accepting it. Empowering a person to make their own journey towards acceptance and self management requires a psychologically-informed approach to enable the person to make their own choices and develop supportive relationships with health and care professionals, third sector organisations, peers, family and friends.

FUTURE PATHWAY

A future pathway for functional disorder, which is non-linear and can be tailored to respond to the unique experiences and needs of each individual



FUTURE PATHWAY

feeling heard

Understanding the person as a whole, and ensuring the patient-held narrative drives their pathway

Symptom-led rather than diagnosis-led support, giving self management support for symptoms prior to diagnosis

Diagnosis as a moment of validation and a meaningful experience that empowers people to manage their symptoms

FUTURE PATHWAY

feeling held

Multidisciplinary working in community settings, particularly to support complex diagnosis and referrals

Structured programme at diagnosis, including multidisciplinary support and group education

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

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

FUTURE PATHWAY

feeling empowered

Acceptance as a process, with ongoing support for people during and after 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

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

FUTURE PATHWAY



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 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".

"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."

"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."

"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 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."

"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."

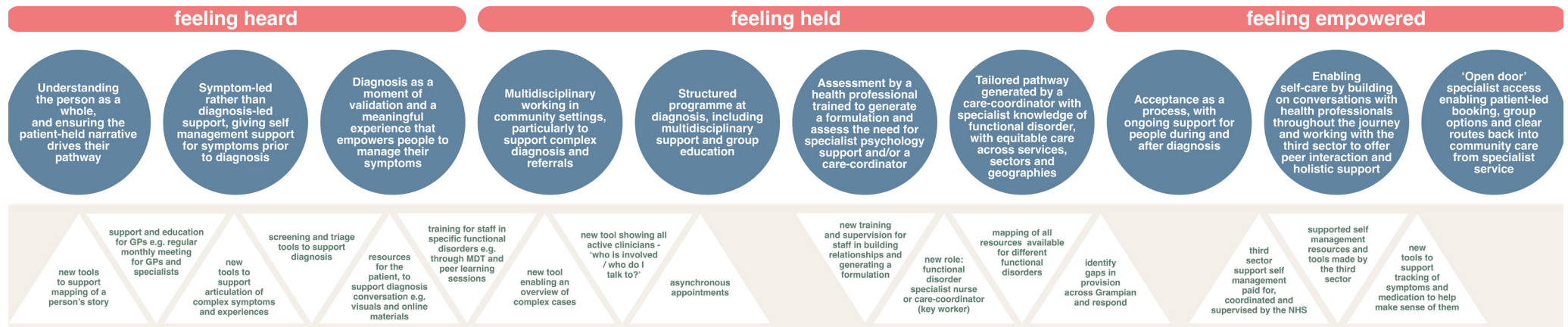
"...regardless of who that initial longer conversation is with, having the outcomes of that and that discussion somewhere... so that when the next health professional sees them, it's not new and the patient is not having to explain themselves all over again... they've had to tell their story so many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

"...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."



FUTURE PATHWAY AND TOOLS

A synthesis of the tools and resources required for supporting the implementation of the new pathway



ROAD MAP / NEXT STEPS

Building leadership

"You need to have a manager who has responsibility for a functional disorder and you need to have a clinician, that's not necessarily their full-time job, but the clinician who has responsibility for this. It's on somebody's portfolio."

Implementing a care coordinator

"I think with the MND ones it works really well because there's one, and we all know who she is, and we all have her contact number. But her caseload is always pretty much consistent... Someone with FND or IBS, you are talking a whole lifetime's (worth) and how many people and then it becomes harder to have a key worker."

Ensuring equity

"Yeah, or when I say 'I think we need to do this', they go, 'no, but that's funded by a different pot so that doesn't...' 'Okay, well I don't know that.' So, for us, as clinicians, that's very hard to influence those types of things."

CALL TO ACTION

How do we hear, hold and empower individuals with functional disorder?

Clinical and managerial lead for functional disorders to oversee implementation

Functional specialist professionals to support (hear, hold, empower) patients

Tools to co-ordinate care through online 'portal' - accessed by all, including patients

Online resources for guided self management

Mapping current services to better coordinate care and identify gaps, mainly AHP and psychology services

Training packages, e.g., online and through TURAs, on functional disorders

Resourcing successful initiatives, e.g., FND group, and exploring how to evolve to include other conditions

Thank you!

Sneha Raman
s.raman@gsa.ac.uk

Gemma Teal
g.teal@gsa.ac.uk

Full report available at:
<https://futurehealthandwellbeing.org/functionaldisorder>

**INNOVATION
SCHOOL
THE GLASGOW
SCHOOL OF ART**