



**Redesigning the care journey
for people living with functional disorder**

Project Report →

PROJECT TEAM

The Glasgow School of Art

Sneha Raman, Research Fellow

Gemma Teal, Research Fellow

Angela Bruce, Research Associate

Silvia Cantalupi, Research Associate

NHS Grampian

Fiona Summers, Consultant Clinical Neuropsychologist

Report authored by:

Sneha Raman and Gemma Teal

Background and Call to action contributed by:

Dr Fiona Summers

Copyright

First released: March 2023.

This report has been published and distributed under the terms of Creative Commons Attribution License version 4.0 (CC-BY): <https://creativecommons.org/licenses/by/4.0/>

Disclaimer

This document has been prepared in good faith using the information available at the date of publication without any independent verification. Readers are responsible for assessing the relevance and accuracy of the content of this publication. The Glasgow School of Art and NHS Grampian will not be liable for any loss, damage, cost or expense incurred or arising by reason of any person using or relying on information in this publication.

Purpose of this report

This report describes a collaborative project between The Glasgow School of Art (GSA), NHS Grampian and Robert Gordon University (RGU). The project sought to use the latest evidence and the experiences of people living with functional disorders and health and care professionals to rethink the care journey for functional disorders in NHS Grampian.

This report aims to outline the proposed future pathway for functional disorders. It begins by summarising the need for innovation in care for functional disorders in NHS Grampian, followed by an overview of the participatory approach taken to engage with people with lived experience of functional disorders and health and care professionals to redesign the care journey. The report presents the proposed future pathway alongside the evidence generated throughout the project, concluding with a roadmap of the next steps and a call for action to work towards implementing the new pathway.

A web version of this report, with lived experience interview maps and findings from the condition-specific workshops, is available here:

www.futurehealthandwellbeing.org/functionaldisorder

Contents

Background	4
Introduction	6
Methodology	7
Findings	11
Roadmapping next steps	30
Call to action	32
Appendices	
Visual summary of lived experience maps	34
Condition-specific workshop findings	42

BACKGROUND

The need for innovation in care for functional disorders in Grampian

Dr Fiona Summers

The elective care redesign team in Grampian held a number of workshops with clinicians to establish the needs of elective services and to help identify difficulties in the delivery of care. Those with functional disorders were identified as a clinical population which spanned numerous services and settings including community, primary care, specialities and third sector where there was a lack of an established pathway. Research also informs us that approximately 52% of new attenders at outpatient clinics in secondary care have a functional presentation. This involves a large number of different specialties including Neurology (30-40%), Gynaecology (66%), Gastroenterology (58%), Cardiology (53%), Rheumatology (45%), Dental (37%) and many others such as Anaesthetics, Neurosurgery, General Medicine, and General surgery.

An elective care redesign work stream was established with the purpose of improving patient outcomes, preventing harm, supporting clinician decisions and making the best use of resources.

To establish the needs of this population a number of initiatives were taken:

- a questionnaire, via global NHS email, to establish from clinicians the prevalence of patients with a functional disorder within workloads and which functional disorders were most prevalent;
- three audits on the most prevalent functional disorders (FND, Fibromyalgia and admissions for chronic abdominal pain) to gain a better understanding of the need and difficulties;
- engaging RGU to conduct a scoping review of the literature on pathways and treatments in functional disorder;
- and engaging GSA to interview patients and run workshops with clinicians to establish the themes which need to be considered in a functional pathway.

At the outset it was clear that developing a pathway would be challenging:

- there is no one specialist area who takes responsibility for those with a functional disorder, and the same patient is often seen by many specialties;

FND

Average patient	Female, aged 48. She will have 5.6 chronic 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.
Cost	Total estimated cost for radiological investigations and ER consultations for 30 patients: £86,476

Fibromyalgia

Average patient	Female, aged 57.8 and in the medium to higher social economic group. She will have 8.7 chronic comorbid conditions.
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.
Cost	Total estimated cost for radiological investigations and ER consultations for 30 patients: £108,679.85

Abdominal pain syndrome

Average patient	Female, aged 50. She will have 7.2 comorbid conditions.
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: £41,888

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

- the needs of this population are wide ranging in a large number of settings;
- the lack of an appropriate pathway means that patient needs are not being met and their clinical presentation often deteriorates with inappropriate treatments and assessments;
- there is a lack of knowledge and treatment options for those with functional disorders;
- clinicians struggle to support the needs of these patients;
- patients report a poor experience: frustrated with lack of support and understanding, often angry, and feeling dismissed by clinicians;
- and there is an inappropriate use of resources resulting in a very high financial cost; e.g., inpatients stays, inappropriate medication/ investigations, negative tests.

In establishing a pathway, the underlying principle of a patient-centred holistic approach in keeping with Realistic Medicine is paramount.

INTRODUCTION

This project is a collaboration between GSA, NHS Grampian and RGU. It sought to use the latest evidence and the experiences of people living with functional disorders and health and care professionals to rethink the care journey for functional disorders in NHS Grampian. It was initiated and funded by NHS Grampian, commencing in May 2020 and completing in December 2022.

While the ambition was to consider if an overarching approach to care for functional disorders could be devised, the decision was taken to focus the project on three functional disorders: Functional Neurological Disorder (FND), Irritable Bowel Syndrome (IBS) and Fibromyalgia. This narrowing of scope enabled an in-depth focus on the evidence base, the experiences of people living with the three conditions, and the health and care professionals working in different specialisms. It also provided an opportunity to look across the three conditions to identify common challenges and overlaps in evidence.

The methodology used was guided by the principles of Participatory Design. Participatory Design approaches are based on a process of mutual learning between researchers and participants with lived experience of the challenge being explored. Designers seek to understand the lived experience of participants

and their desired future ways of living and working. Participants with lived experience are supported to share their challenges and ideas while learning how to apply these insights to develop new care pathways that meet their aspirations.

Design Researchers at GSA develop bespoke visual tools to collaborate with participants to document their lived experiences in person and remotely using technology. This approach enables participants who cannot travel to or participate in workshops due to a health condition to be actively involved in shaping future forms of care.

Co-design workshops with health professionals are designed to build on and respond to challenges and aspirations for care highlighted by participants in their care journey. Seeing care pathways from the patients' perspectives enables health professionals to reflect on ways of working and develop person-centred care pathways.

METHODOLOGY



Figure 1: Overview of the four stages of the methodology

Scoping review

The project started with a scoping review on the 'Management of Functional Disorders'¹ undertaken by researchers from RGU, led by Professor Kay Cooper. This mapped the existing evidence base for the management of FND, IBS and fibromyalgia and also considered evidence for medically unexplained symptoms (MUS). The review aimed to provide an overview of the available literature on i) reported pathways for patient management and ii) reported treatments/interventions.

Interviews

Meanwhile, design researchers at the Innovation School at GSA undertook scoping interviews with a GP and a Consultant Clinical Psychologist. These sessions aimed to understand the context to inform the design of interviews with people living with functional disorder. We used the insights from these interviews to design a bespoke experience mapping tool to structure the interviews and record interviewees' experiences (see Figures 2-4). The interview method and mapping tool were designed to enable remote engagement due to Covid-19 restrictions, using video conferencing software (Zoom) and a virtual whiteboard application (Miro).

¹Cooper, K et al. (2021). Management of Functional Disorders: A Scoping Review. Robert Gordon University, Aberdeen.

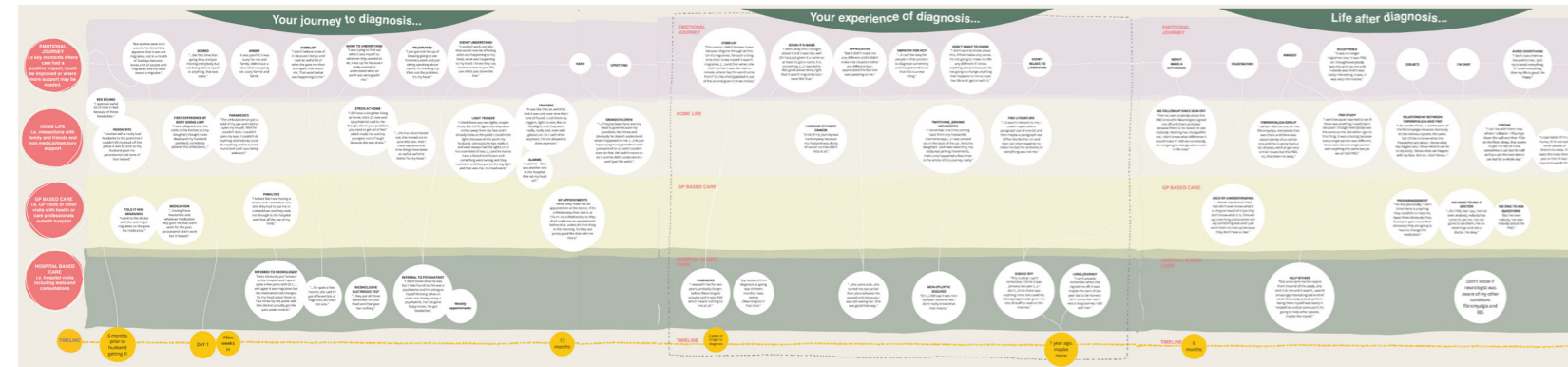


Figure 2: Example of visual tool mapping each person's journey (including emotional journey) across various settings (i.e. home/community, GP, hospital) and stages of pre- during and post-diagnosis



Figure 3: Visual showing what matters to the person

Figure 4: Visual showing discussion of what could be better in their care journey



The lived experience interviews aimed to generate rich accounts of the service/pathway from the perspectives of people living with functional disorder in Grampian to understand what works and what needs to be improved. The aim of the experience maps was for the health professionals to see and understand how patients make sense of their experience and what impact aspects of care have on their attitude and behaviours (e.g. their willingness and ability to engage in self management). In addition, the care pathway for functional disorder is often fragmented and can involve patients ‘going around the houses’ and seeing several different specialists on their journey to a diagnosis. Health professionals currently only see discrete parts of the journey (from their perspective/ part of the system of care), and the experience maps show the individuals’ journeys in their entirety, helping them to understand the pathway from the perspective of those receiving care.

We aimed to conduct nine interviews – three each with people living with Fibromyalgia, IBS and FND. Recruitment for IBS and FND fulfilled the required numbers; however, only two participants volunteered for Fibromyalgia. Thus, eight interviews were completed in total.

Condition-specific co-design workshops with health professionals

Following the lived experience interviews for each condition, three condition-specific workshops were organised with health professionals currently supporting people living with each condition (i.e. FND, fibromyalgia and IBS). The aim was to co-design the ideal pathway for a person living with that condition by responding to the in-depth journeys of people with lived experience and the evidence of effective treatments and pathways gathered by the scoping review.

The workshop activities and tools were designed to enable remote engagement due to Covid-19 restrictions, using video conferencing software (MS Teams) and a virtual whiteboard application (Miro). Activities in each workshop focused on: understanding the different professionals involved and their roles in providing care for people with FND, fibromyalgia or IBS; capturing key challenges for health professionals when working with people with the condition; and reviewing the experience maps of people living with the condition alongside evidence relevant to that condition from the scoping review (summarised visually); to inspire and inform the development of a new pathway for that condition.

Overall co-design workshop for functional disorder with health professionals

A final in-person workshop brought together health professionals working across the three conditions. It aimed to review emerging outputs from the three condition-specific sessions; identify commonalities and differences across the pathways and model(s) of care for people with different functional disorders; and redesign the future experiences of diagnosis and care for people living with functional disorders in NHS Grampian.

Key activities in the final workshop focused on:

- reviewing a mixed set of experience maps of people living with FND, fibromyalgia and IBS and capturing commonalities and differences in their needs and experiences by working in two multidisciplinary groups;
- working individually to identify ‘key ingredients’ for a new functional disorders pathway by reviewing ideas and ‘how might we?’ questions on opportunities emerging from the condition-specific workshops, alongside ideas for good practice identified in the scoping review;
- and working in two multidisciplinary groups to collaboratively develop a new combined pathway for functional disorders.

At the end of the workshop, participants worked together to discuss the short to long-term actions required to implement these new pathways, including other departments or people who may need to be involved.

FINDINGS

Key insights from each lived experience interview were synthesised into a visual summary, including ‘how might we...’ questions as prompts for redesigning the care pathway in response (see Appendix 1 for visual summaries of the eight lived experience interviews).

At the end of each condition-specific workshop, key findings were thematically analysed and synthesised to identify: the challenges of providing care for people living with FND/ fibromyalgia/ IBS from the perspective of health professionals working in each area; opportunities and ideas for improving care; and emerging ideas for future care pathways for each condition (see Appendix 2 for visual summaries of themes and opportunities from condition-specific workshops).

Each condition-specific report (see web report) was reviewed by health professionals who attended the workshop and informed the development of the overall care pathway in the final co-design workshop.

The following section focuses on the proposed future pathway for functional disorders. We present an overview of the key principles of the future pathway, followed by an explanation of the overarching structure. The detailed stages of the pathway are described alongside supporting evidence drawn from

the scoping review, lived experience interviews and co-design workshops. Note that all participant quotes are attributed to their chosen pseudonyms.

FUTURE PATHWAY FOR FUNCTIONAL DISORDERS

The future pathway for functional disorder is non-linear and should be tailored to respond to each individual's unique experiences and needs.

Moving beyond a clinical view of service pathways which focus on steps for treatment and management of a condition pre-, during and post diagnosis from a delivery perspective, the future pathway is modelled from the perspective of people living with functional disorders focusing on the overarching structure of their care journey and experience: feeling heard, feeling held and feeling empowered.

Participants in the final co-design workshop also identified two key principles that cut across and guide new ways of working for health professionals to support the person's journey along the future pathway: building a relationship with the person and ensuring psychologically-informed care for all.

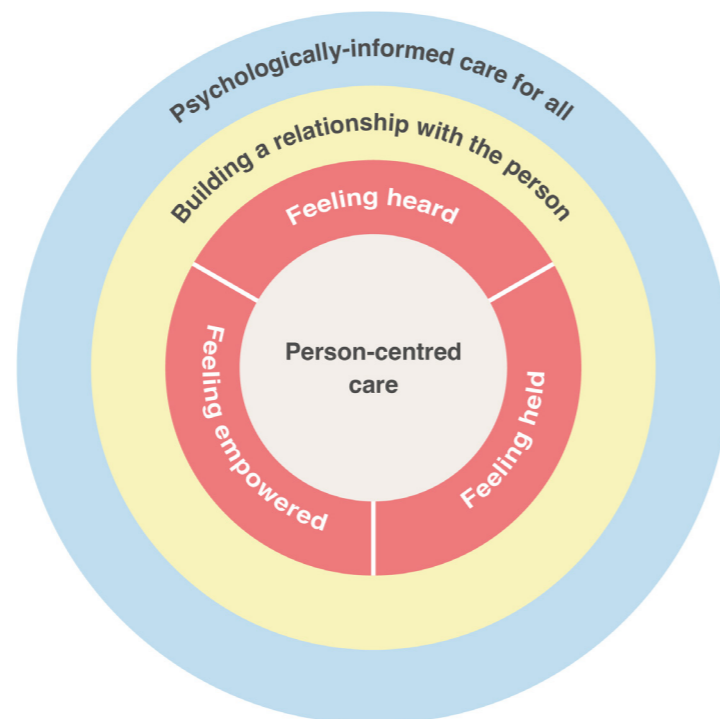


Figure 5: Future pathway modelled around what matters to the person

KEY PRINCIPLES OF THE FUTURE PATHWAY

Building a relationship with the person

Building a relationship with the person underpins the overarching pathway structure of feeling heard, feeling held, and feeling empowered, reflecting both the aim of the future pathway and how the future pathway could be realised in practice. Building trust and relationships was one of the shared themes that emerged from the experience maps across all three conditions.

For example, Luap reflected on a lack of personal touch in his interactions with the NHS. Linda noted that having a connection and building trust with all the people involved in her care is important to her.

"...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..."

"A connection is really important to me, it really is. I've kind of chosen this GP at the practice as the one I want to see and he's happy with that."

"...it's not about what hat you wear, whether you are a really experienced consultant neurologist, you might be a voluntary worker at a project, it might just be somebody who you relate to and they understand you and you don't even have to explain it..."

Psychologically-informed care for all

Adopting psychologically-informed care for all will ensure a more integrated biopsychosocial approach to care throughout the future pathway and help to address the stigma associated with functional disorders. To meet this goal, all health and care professionals caring for people living with a functional disorder would require training and support to build skills in psychologically-informed care practices. This would address current challenges around accessing specialist support and improve the quality of care for everyone. Stigma and a lack of focus beyond physical health were overlapping themes from the experience maps across all three conditions.

For example, Luap reflected that in his experience, the focus was never on the psychological aspects of his condition and that psychological support was only available to people in extreme scenarios. William felt that the focus on stress as the leading cause of his condition was stigmatising and lacked evidence.

"Again, it is purely an analysis of my physical health, it's not at any stage an attempt to move forward."

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

"...obviously it does exist in extreme cases, but I mean, people who can just get on with life, get on with it and make the most of it."

"...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 OF THE FUTURE PATHWAY

The future pathway is structured around what people living with the condition desire in terms of care and support. It focuses on an individual's emotional journey when dealing with the 'unknown', as in the case of functional disorders. Through this, it broadens the focus and scope of the pathway to holistically address people's biopsychosocial needs. It builds on learning from the approach taken during the lived experience interviews to elicit insights on people's emotional journey, alongside mapping interactions and experiences of support pre-, during and post-diagnosis across different care settings, i.e., home and community, primary care and secondary care.

This structure will enable a person-centred care pathway that builds on each individual's story to ensure tailored support that focuses on the need for 'feeling heard', 'feeling held' and 'feeling empowered' to live well with a long-term condition.

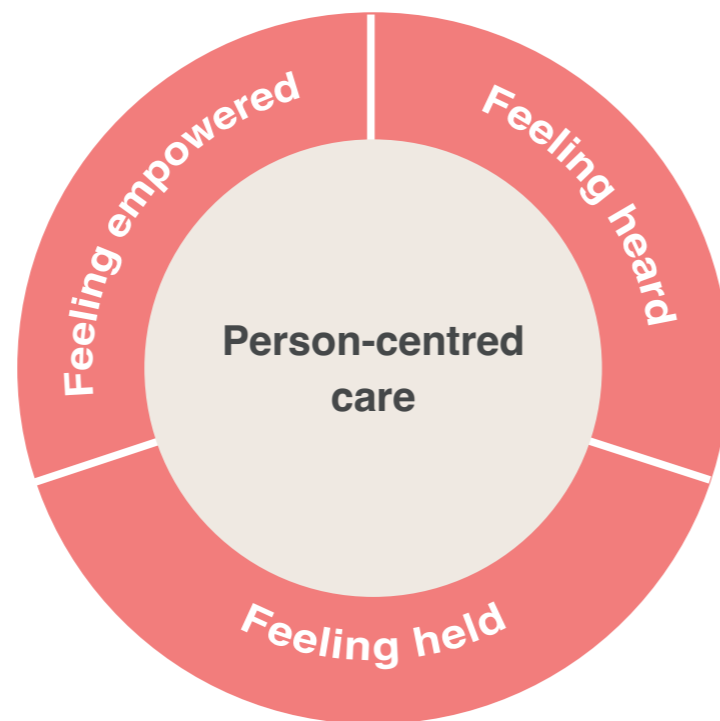


Figure 6: Overarching structure of the future pathway

Feeling heard

Ensuring the person feels heard and validated and knows that their unique experience is understood and acknowledged by all health and care professionals 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'."

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 in making 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.”

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 enable them to take control while ensuring they can easily access health professionals 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.

STAGES OF FUTURE PATHWAY FOR FUNCTIONAL DISORDER

This visual details the stages of care (circles) and opportunities for tools (triangles) to support each stage. Although presented as a linear flow in the order in which health professionals placed them on the pathway, they stressed that individuals would be ready for these aspects at different times. Therefore the order of the stages should be tailored to the person’s story,

needs and readiness. Evidence for each stage drawn from the scoping review, lived experience interviews and co-design workshops is presented on the following pages.

The tools represent opportunities identified to implement existing tools or develop new tools (e.g. new digital tools for information sharing or clinical tools for screening and triage) and ways of working to support health professionals.

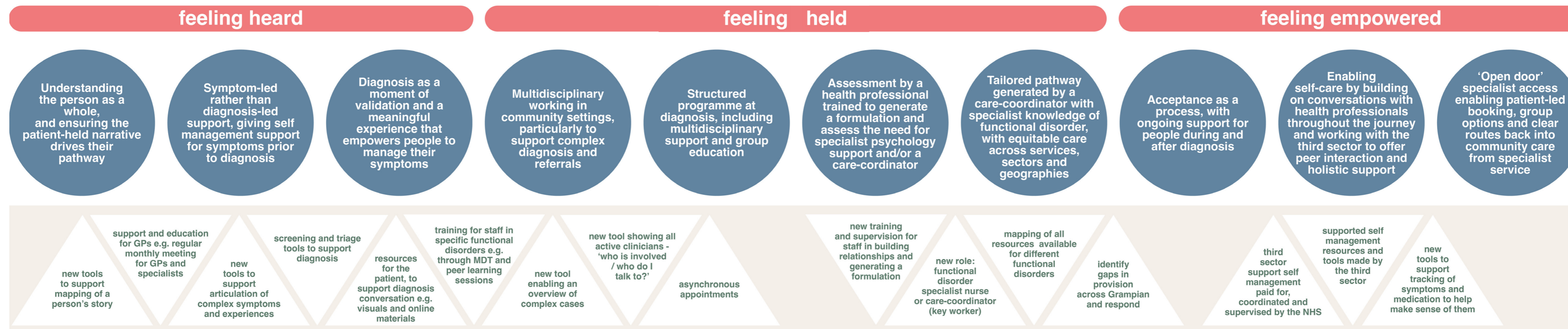
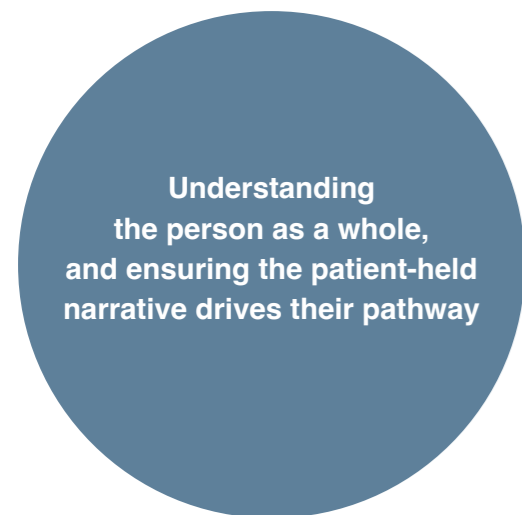


Figure 7: Stages of future pathway and tools identified as enablers



Evidence that supports this 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 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.”

“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”.

“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 as well ...”

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. (..) 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 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 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.”

“...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”.

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?”

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

‘Waiting Well’

“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 that supports this 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 described in the scoping review:

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

Describing 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."

"...physio has been a good experience... the physio I have isn't a neuro-physio but I've had her since I've had orthopaedic 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."

"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!'".

Evidence that supports this from the workshop with health professionals

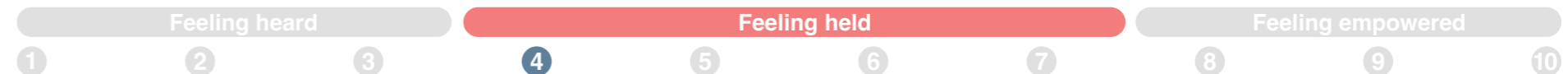
"I suppose that's the benefit for a health professional, of being part of a team that I would kind of know what you might say, and I can reinforce that and vice versa, that when you work quite closely with people for a while, I can't do your job but I can back you up. Because, do you know, that's really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

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

"...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."

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."

"...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."





Evidence that supports this 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 throughout the scoping review.

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.”

“...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.”

“...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...”

“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.”

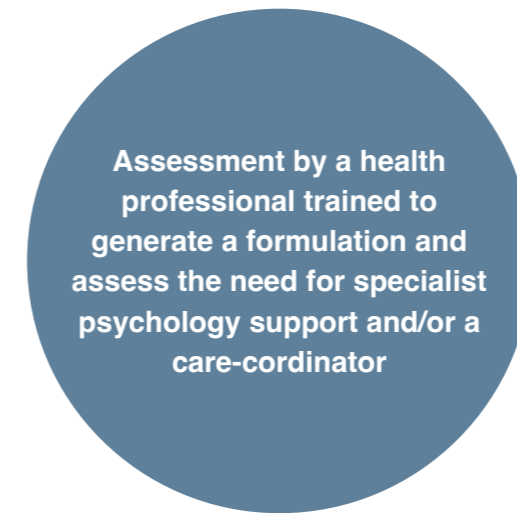
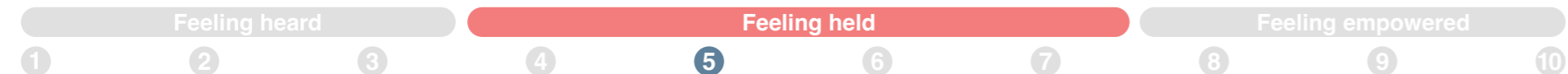
Evidence that supports this from the workshop with health professionals

“...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.”

“...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.”

“...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.”

“...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.”



Evidence that supports this 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 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.”

“...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.”

“...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.”

“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.”

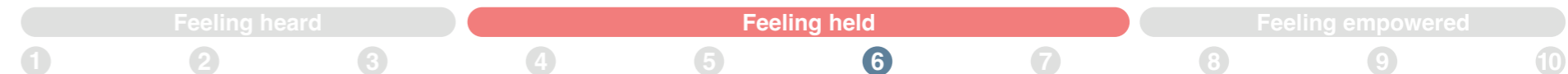
Evidence that supports this from the workshop with health professionals

“...‘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...’”

“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.”

“...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’...”

“...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.”





Evidence that supports this 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.”

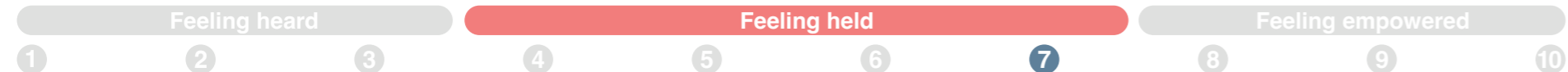
“...we aren’t going to be ready for all the same things at the same time, so they might need to come to things in their own time, or they might need a focus on mental health aspect early on or that might come much later and they might be ready to engage with an AHP or they might not.”

“...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 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 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.”

“...you absorb that information you kind of then started to question 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.”

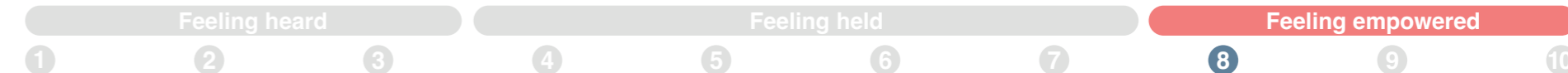
“So from first seeing the GP and really believing the diagnosis, it [acceptance] was probably a year.”

“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.”

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...”





Evidence that supports this 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."



Evidence that supports this 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 levelled 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..."



ROADMAPPING NEXT STEPS

During the final workshop, participants discussed short- and long-term actions required for implementing a new pathway and potential challenges that need to be addressed.

Participants noted that some emerging ideas, such as creating web resources for FND, could be started in the short term. However, there are not enough staff to implement others, such as 'open door' patient-led appointments, which will require longer-term planning.

This section discusses three key focus areas for implementing the new pathway.

"To be responsive if everyone... decides – what if everyone one week decides they want an appointment."

"...one of the difficulties I have sometimes with that, is that actually it's used as an excuse for you to rush off and get more reports and more evidence when we've got (this) here, we've got experts in the area here around the table... to show that change needs to happen"

"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."

"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."

"We've deliberately not made it a nurse; we've said it can be pretty much any profession. It's about their understanding of FND that's most important. And we've said for two years, fund that and we will do - an assistant psychologist to actually collect the data, analyse the data and produce a report on its effectiveness at the end."

Building leadership

A key focus of this discussion was the need to secure clinical and managerial leadership and capital investment to guide implementation. Participants agreed that presenting the findings and future pathway emerging from this work to the leadership team in NHS Grampian and identifying the top three priorities should be the first step towards this. Participants agreed that these need to be supported with evidence from research and evaluation. However, participants cautioned that there is a need to build on what we already have before gathering further evidence.

Implementing care coordinators

It was noted that currently, there is a funding bid for a FND practitioner. There is an opportunity to build on learning from this and explore how similar new roles might be created to work across multiple functional disorders.

Participants noted that these roles would be similar to the current MND specialist roles. However, capacity was identified as a potential challenge for functional disorders.

An increasing number of people are being diagnosed with functional disorders, which could result in large caseloads for care coordinators. Participants recommended that this could be addressed by focusing on providing care coordinators for the most complex cases, while wider community-based services (all trained in psychologically-informed care in the future) could be involved in supporting others.

"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."

"...sometimes my heart sinks because you see that model, don't you, could it be tried in one area but then it doesn't get past [the test of change stage]..."

"It's only going to be these ones that really... the complex ones. The same with FND. I know we're going 'oh...' but actually you can probably count on two hands, maybe three or four, the complex ones, but there's oodles that have got it and have had one-off sessions or a little bit of work and then they've gone on and managed."

"...if we have a pathway and GPs are all doing different things, then that's not going to work."

CALL TO ACTION

Dr Fiona Summers

The findings of this report, in particular the in-depth conversations with patients, are sobering. **The message is clear – the current system is not working** and doing nothing is costly to patients in terms of physical and mental health, clinicians in terms of workforce stress by disempowering them to ‘make a difference’ and financially to the NHS with inappropriate use of resources.

The challenge is **how do we hear, hold and empower** individuals with functional disorders? Patients have clearly stated that they want support in managing their own symptoms – they do not want repeated tests, admitted unnecessarily to hospital, uninformed clinicians, more inappropriate medication. What they do want is a holistic biopsychosocial approach that is centred on their needs in a psychologically informed way. What is helpful and encouraging however is that clinicians and patients agree. **There is, however, an urgent need to develop a sustainable pathway for the future.**

These are some of the initiatives that could be implemented or developed:

- it is recommended that the organisation creates a programme for functional disorders with a

clinical and managerial lead to take forward some of the recommendations of this report, oversee implementation and add to the evidence base;

- map out the services currently being used by patients with functional disorders within the community with a view to better coordination and helping to identify gaps – particularly within AHP and Psychology services;
- the employment of functional specialist professionals to support (hear, hold, empower) patients by providing guided self management, being a point of contact, coordinating services and linking with third sector agencies. This can initially be done through a two year pilot (such as that already suggested by the FND services);
- developing tools that coordinate care through an online ‘portal’ that can be accessed by all those involved in someone’s care including patients;
- developing online resources for guided self management as part of a robust pathway;
- developing training packages on functional disorders including interviews and learning from patients (experts by experience). This needs to include that functional disorders are not ‘in your head’ and ‘made up’;

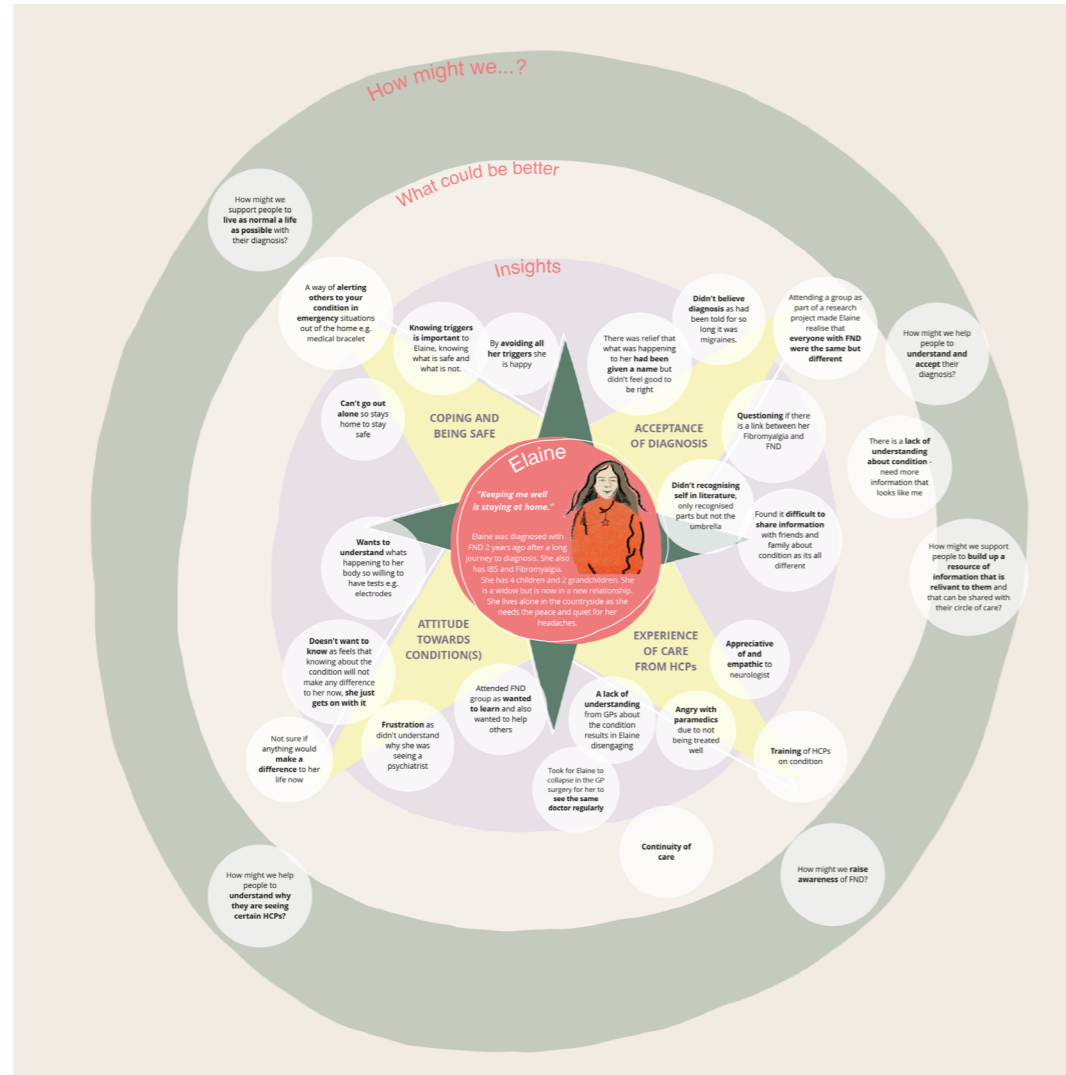
- ensure initiatives that have been implemented with success (such as the FND brief intervention group which is due to end in April 2023) continue to be resourced and explore how these can be evolved to include other functional disorders.

Ignoring the needs of this group of patients will not make it go away. It is incumbent upon us to not let these findings sit and gather dust on a shelf. The Managing Patient Pathways Programme, through the Centre for Sustainable Delivery, has also highlighted the lack of holistic pathways for this group of patients and, aware of this work, is keen to know the findings and potential solutions that can be shared throughout Scotland.

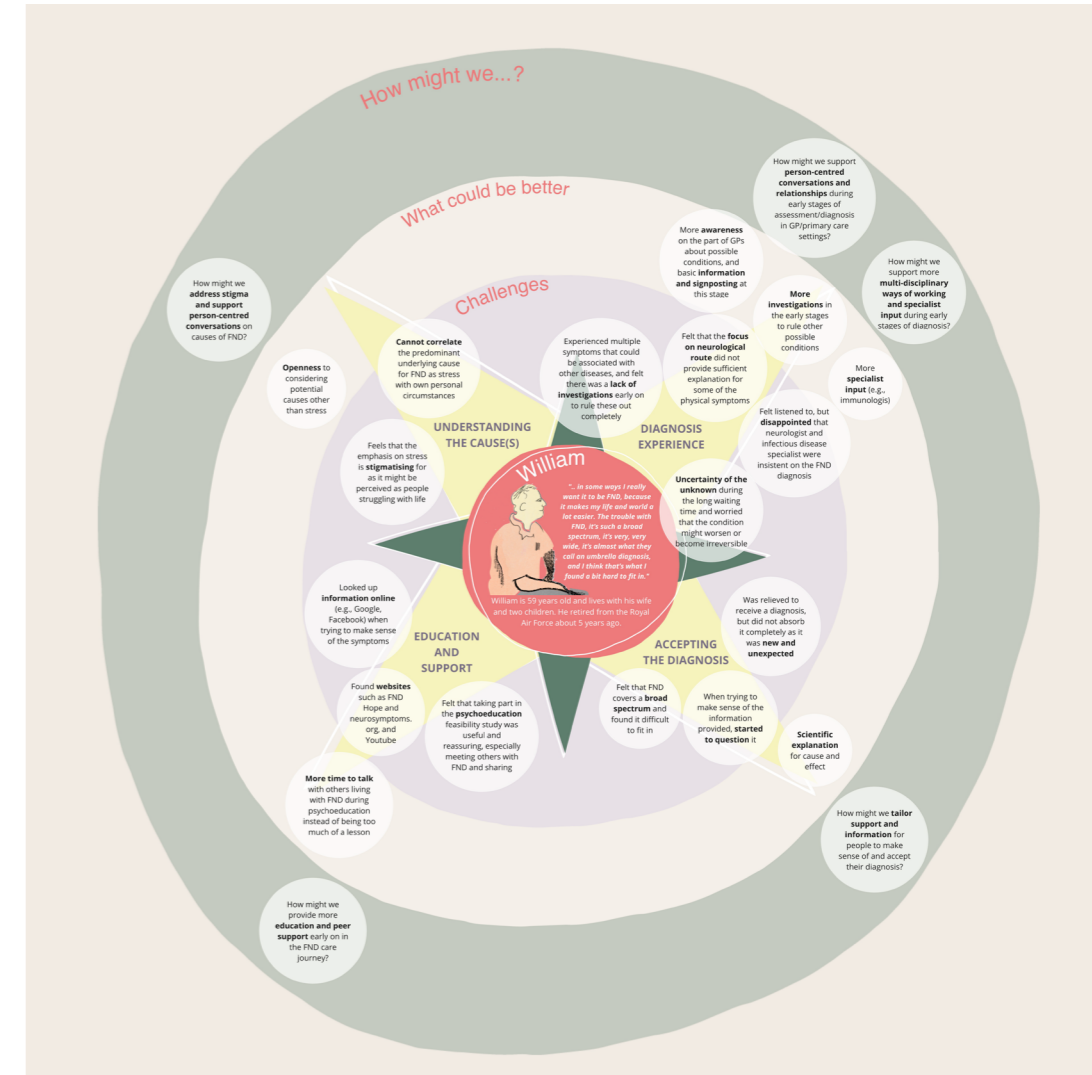
I would like to thank RGU and GSA for their hard work and enthusiasm for this project. Above all, I would like to thank the individuals (both patients and clinicians) for their incredible engagement and contribution during very challenging times. Their time and effort reflect a genuine passion and desire to make a real meaningful change and make a difference.

APPENDIX 1

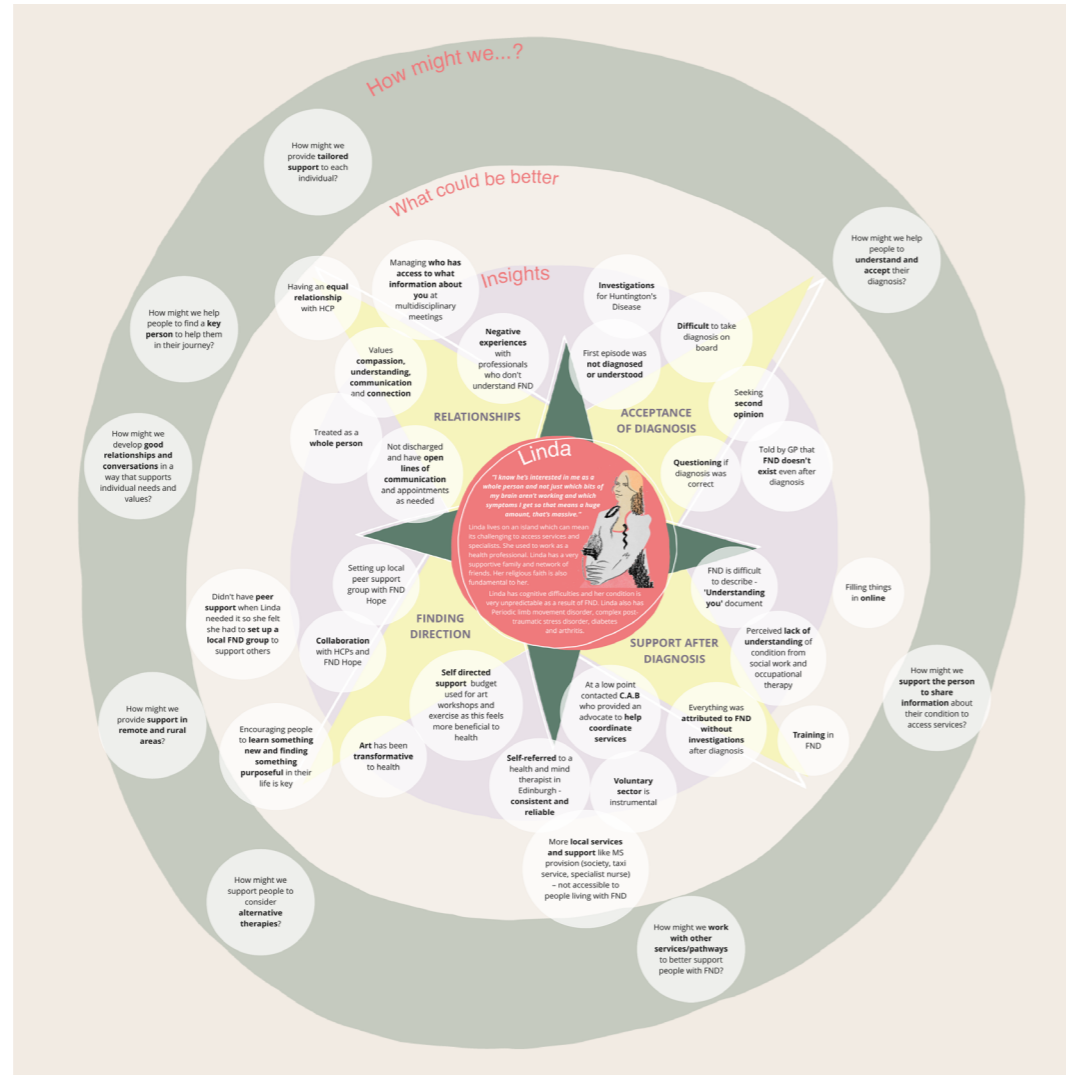
VISUAL SUMMARIES OF LIVED EXPERIENCE INTERVIEWS



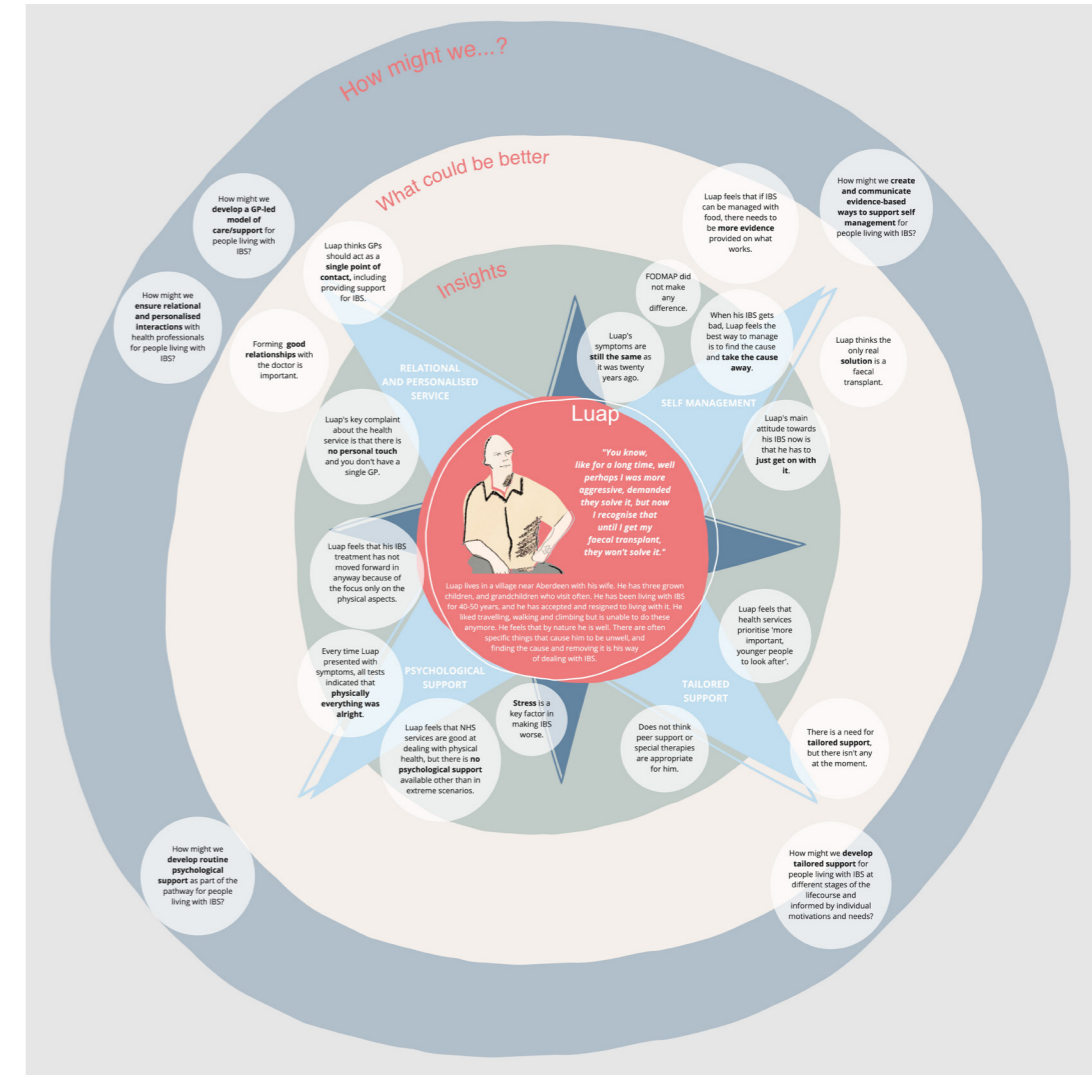
Elaine
Person living with FND



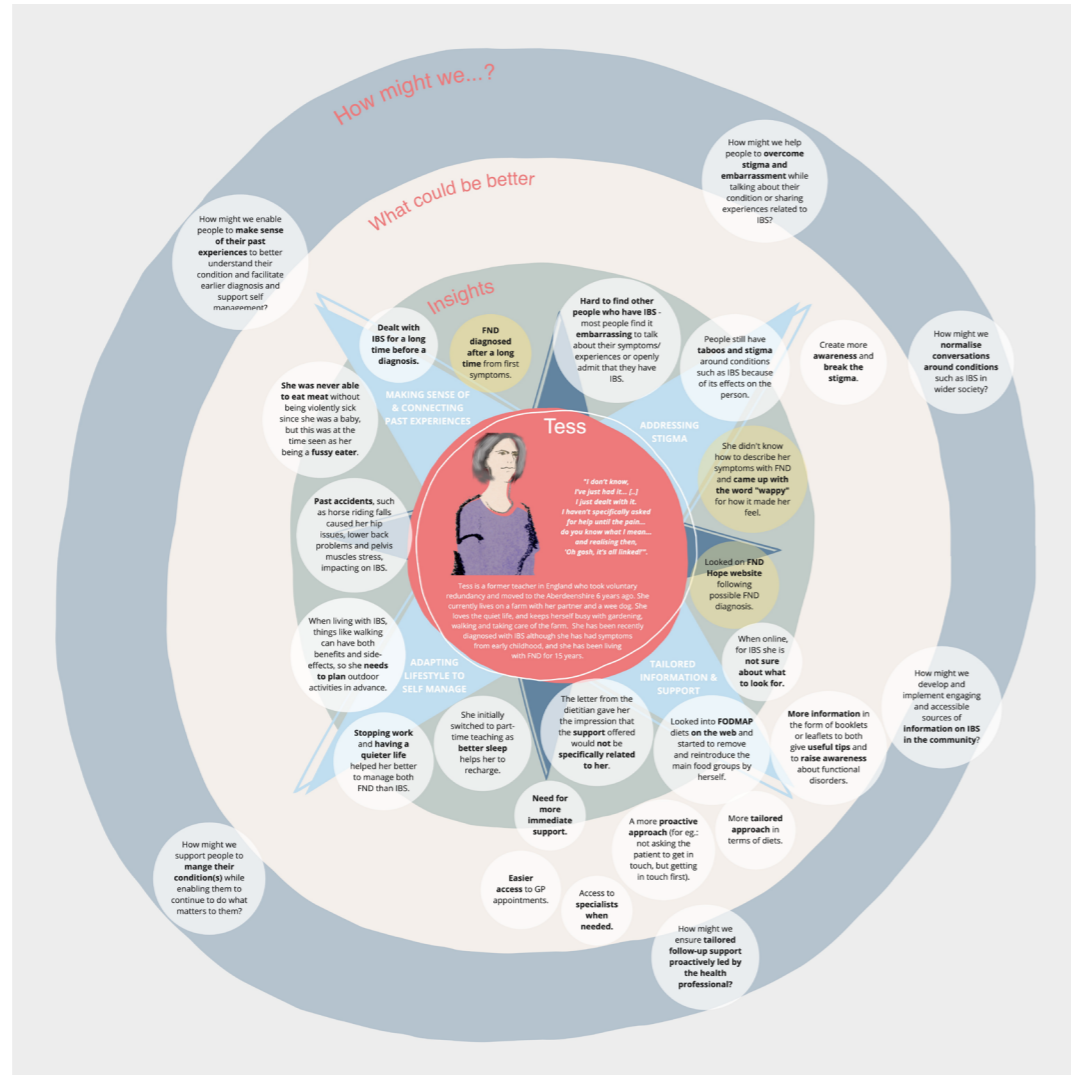
William
Person living with FND



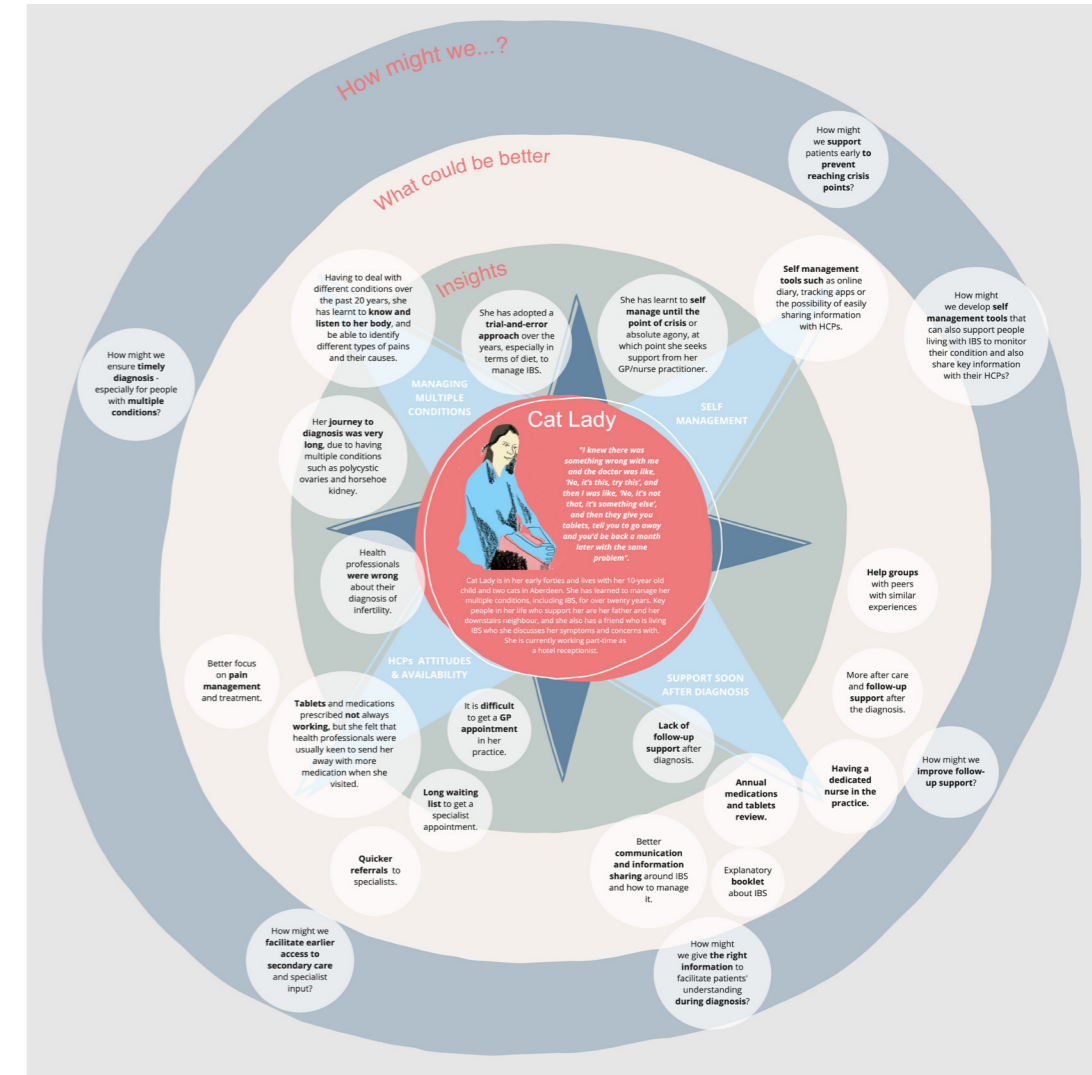
Linda
Person living with FND



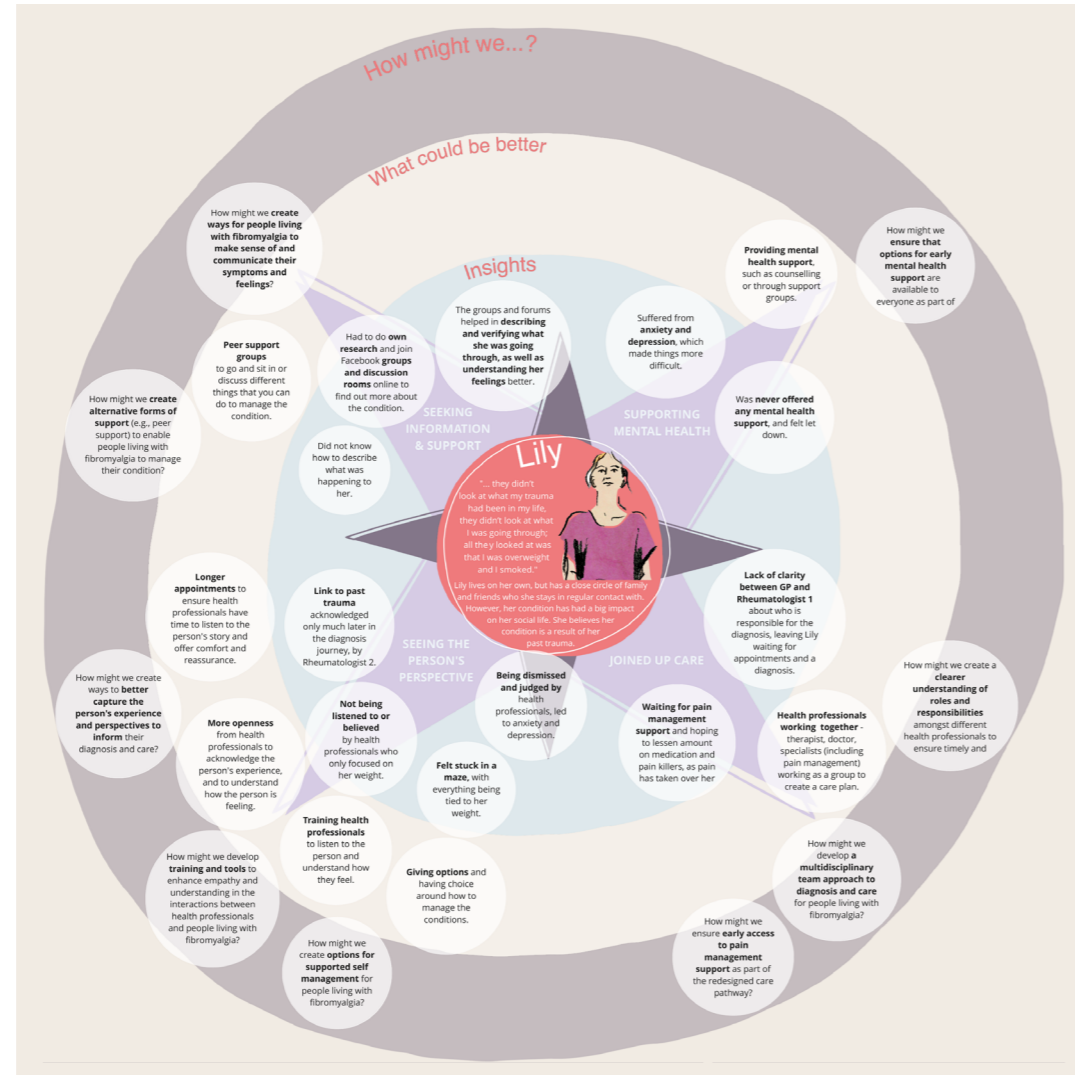
Luap
Person living with IBS



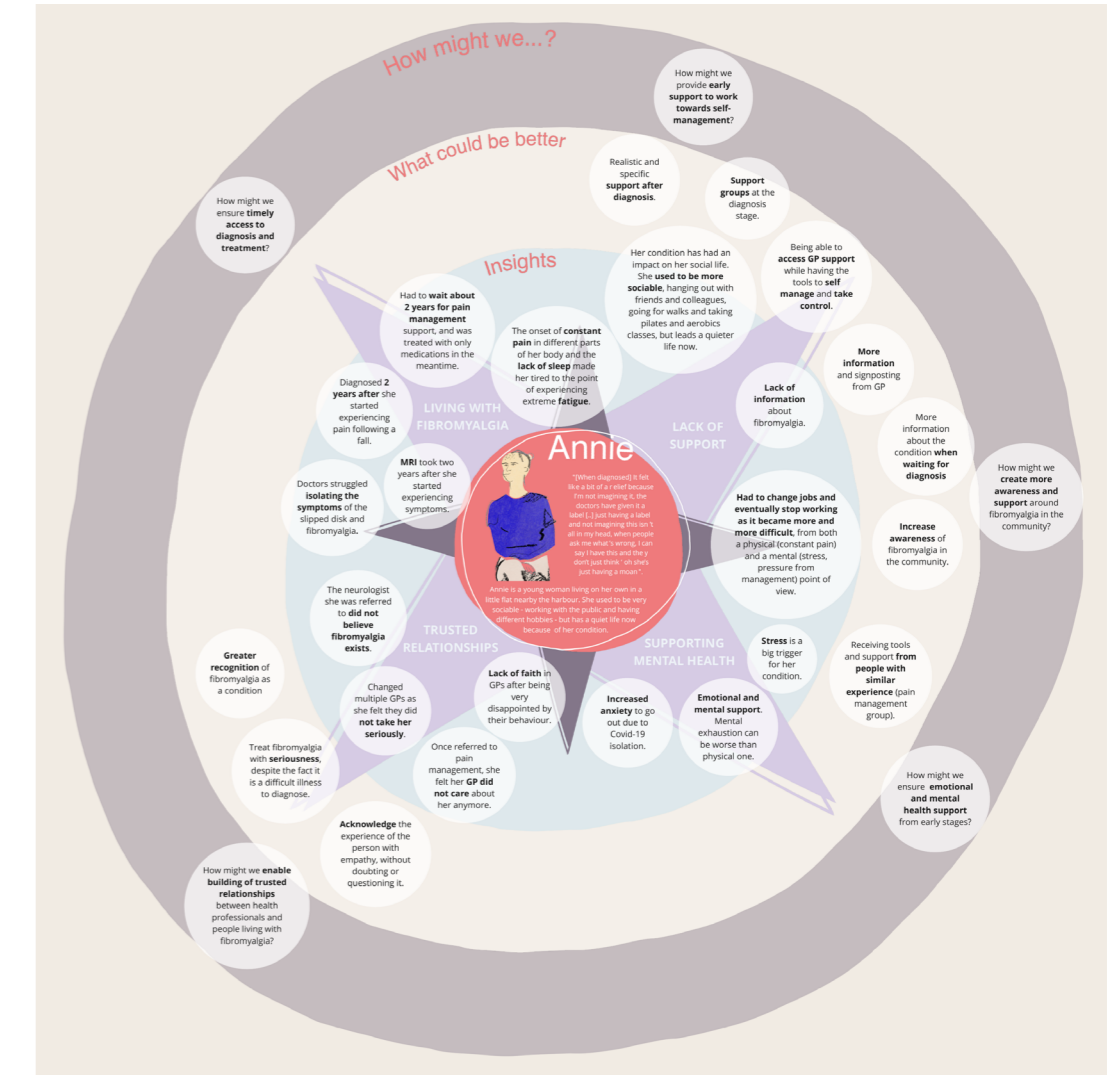
Tess
Person living with IBS



Cat Lady
Person living with IBS



Lily
Person living with Fibromyalgia

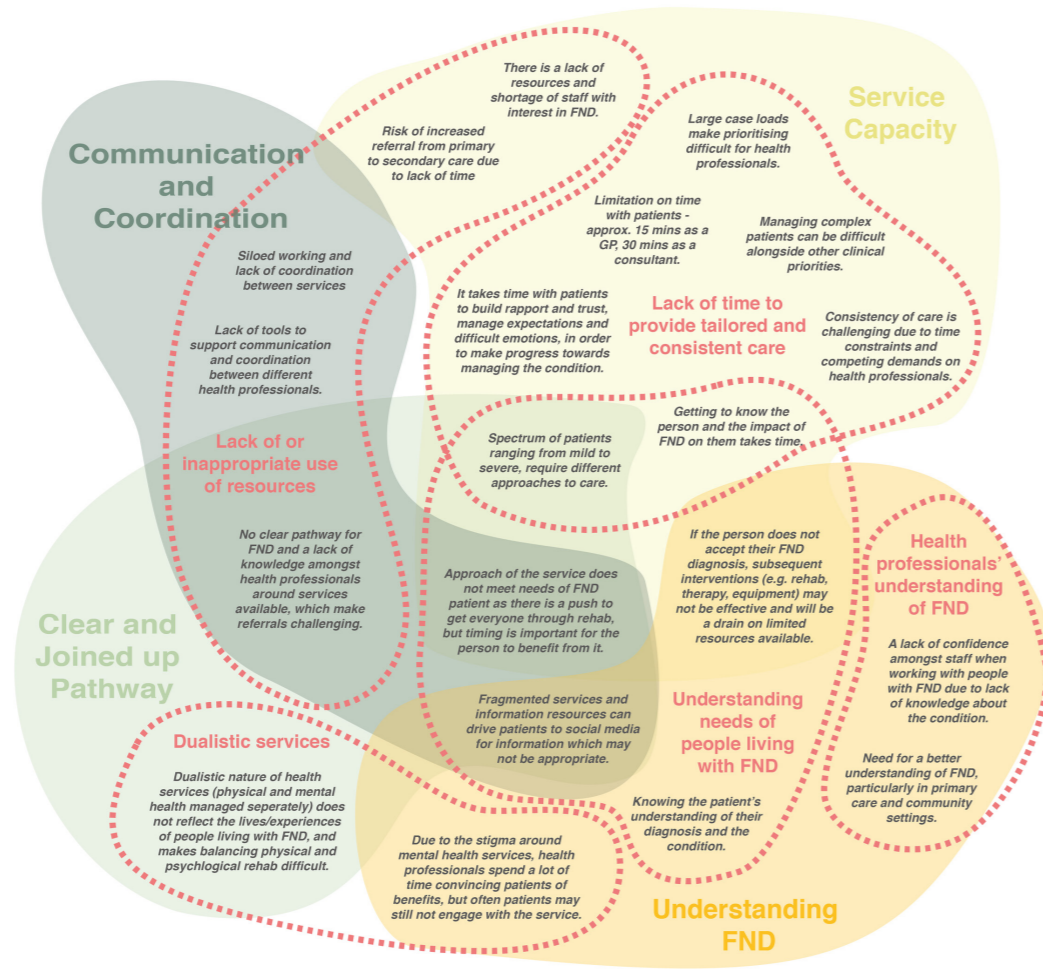


Annie
Person living with Fibromyalgia

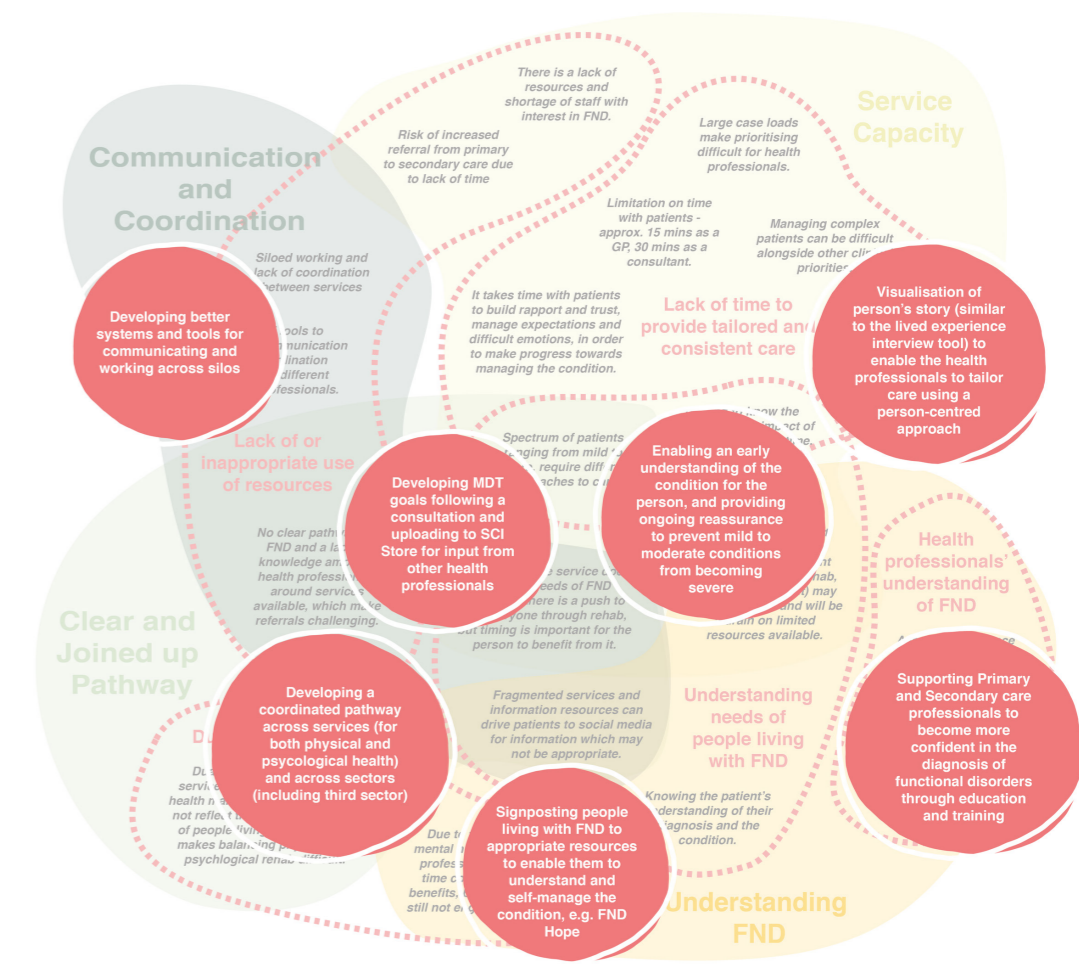
APPENDIX 2

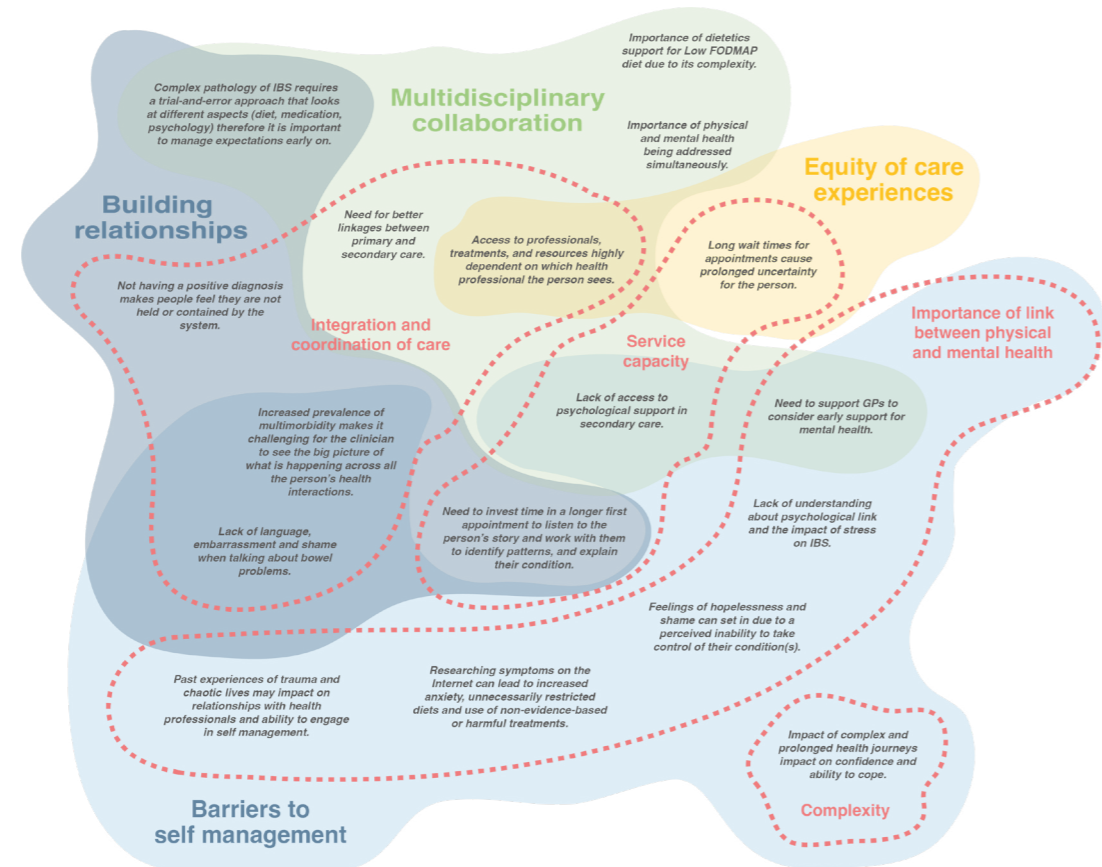
VISUAL SUMMARIES OF THEMES AND IDEAS FROM CONDITION-SPECIFIC WORKSHOPS

Challenges of providing care for people living with FND from the perspective of health professionals.



Opportunities and ideas for improving care for people living with FND from the perspective of health professionals.

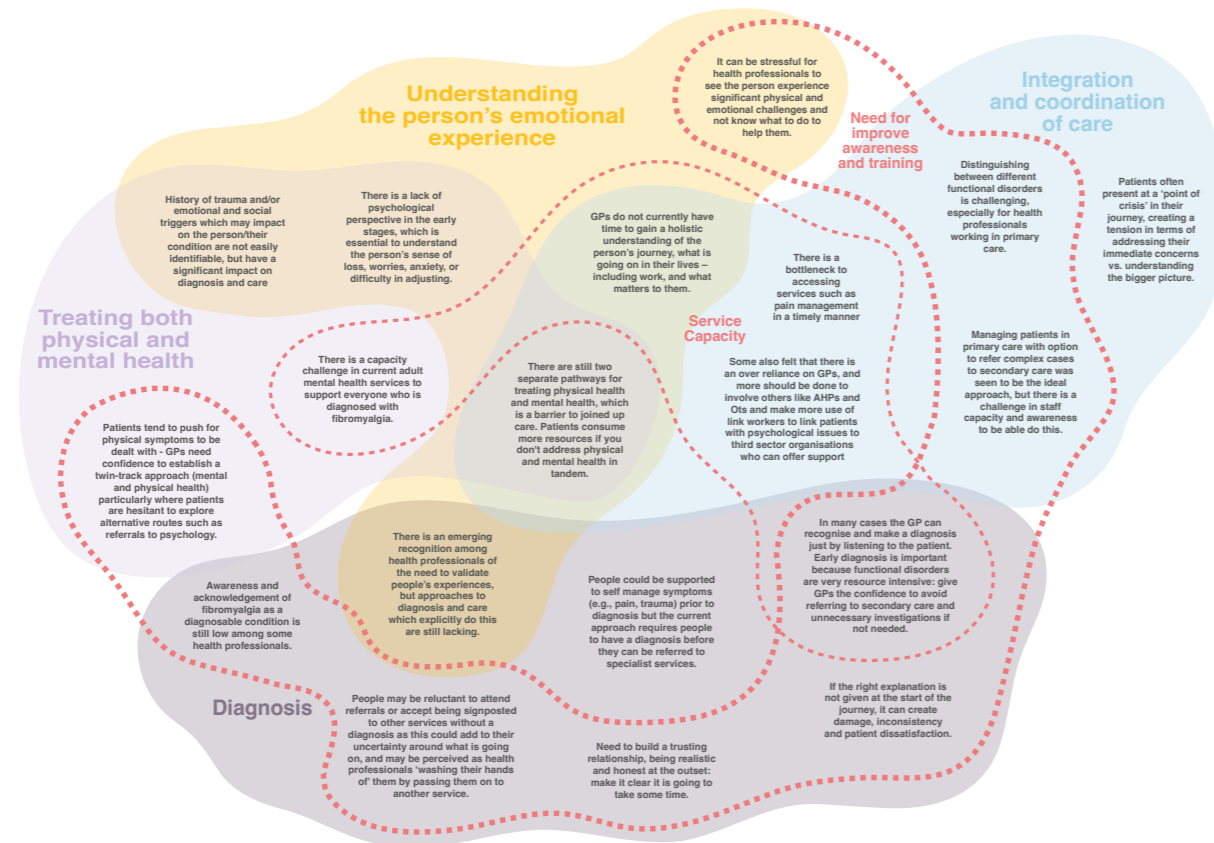




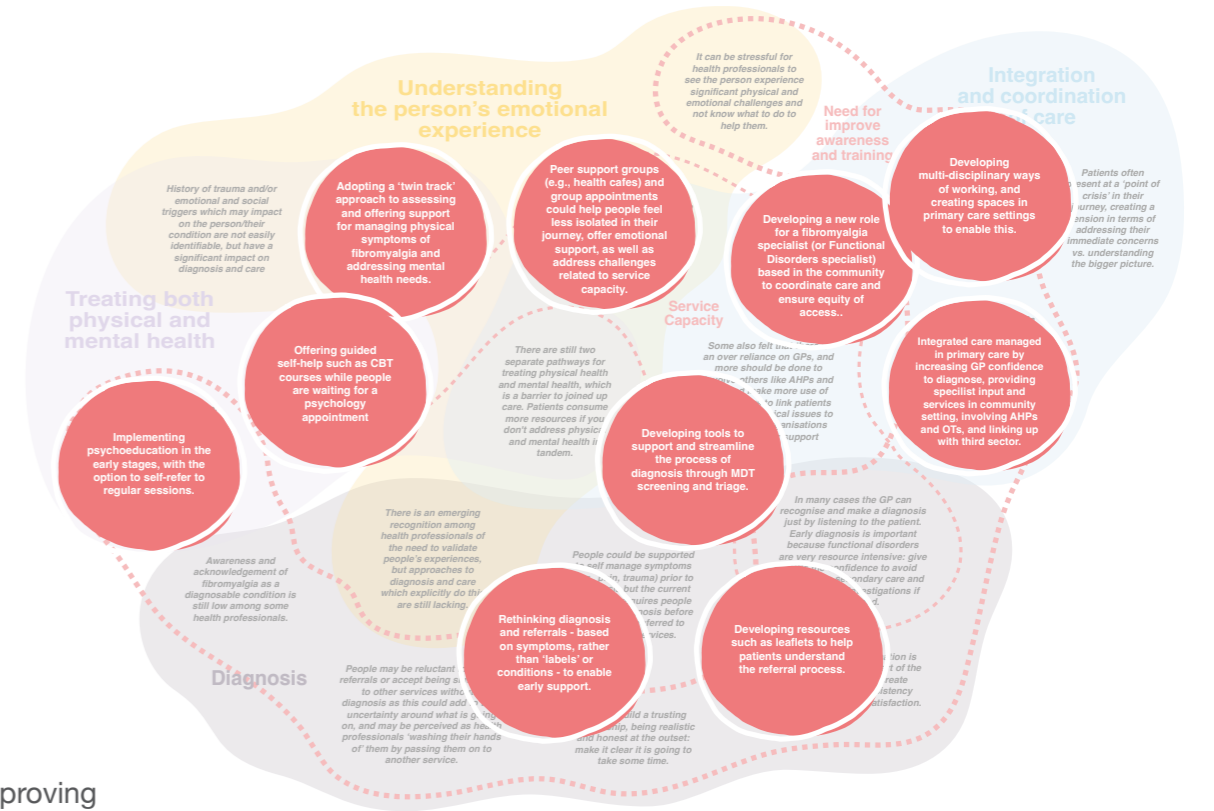
Challenges of providing care for people living with IBS from the perspective of health professionals.



Opportunities and ideas for improving care for people living with IBS from the perspective of health professionals.



Challenges of providing care for people living with Fibromyalgia from the perspective of health professionals.



Opportunities and ideas for improving care for people living with Fibromyalgia from the perspective of health professionals.

**INNOVATION
SCHOOL
THE GLASGOW
SCHOOL OF ART**