# Evaluation of the new Psychology assessment and formulation service pathway for people with Functional Neurological Disorders (FND) at Mid Yorkshire NHS Trust.

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| Table of contents | Page no. |
|---|---|
| *1. Introduction* | 4 |
| 1.1 - Definition and prevalence of Functional Neurological Disorders (FND) | 4 |
| 1.2 - Perceptions of FND | 4 |
| 1.3 - FND in services | 5 |
| 1.4 - Multi-Disciplinary Team working | 6 |
| 1.5 - FND in The Mid-Yorkshire NHS Trust | 7 |
| 1.6 - The Mid-Yorkshire Neuropsychology Service | 7 |
| 1.7 - The FND Psychology Pathway | 7 |
| 1.8 - Rationale for the Service Evaluation Project | 8 |
| 1.9 - Research Aims | 8 |
| *2. Methodology* | 9 |
| 2. 1- Method | 9 |
| 2.2 - Sample | 9 |
| 2.3 - Data collection | 10 |
| 2.4 - Data analysis | 10 |
| 2.5 - Ethical considerations | 12 |
| *3. Results* | 13 |
| *3a. Results part 1* | 14 |
| 3.1a - Theme 1: Professionals' understanding of FND | 14 |
| 3.2a - Theme 2: Professionals' beliefs about FND | 15 |
| 3.3a - Theme 3: Giving explaining the FND diagnosis | 15 |
| *3b. Results part 2* | 22 |
| 3.1b – Theme 1: Professionals' understanding and awareness of pathway | 22 |
| 3.2b – Theme 2: Professionals' responses to pathway | 22 |
| 3.3b – Theme 3: Professionals' thoughts on an FND MDT | 22 |
| 3.4b – Theme 4: Pathway positives | 23 |

| | |
|---|---|
| 3.5b – Theme 5: Pathway suggestions | 23 |
| *4. Discussion and conclusion* | 32 |
| - 4.1 - Main findings | 32 |
| - 4.2 – Links to previous research | 32 |
| - 4.3 – Strengths and limitations | 33 |
| - 4.4 – Recommendations | 35 |
| - 4.5 – Dissemination of results | 36 |
| *5. Reference list* | 37 |
| - 5.1 – References | 37 |
| *6. Appendices* | 43 |
| - 6. 1 - Appendix 1: Participant consent form | 43 |
| - 6.2 - Appendix 2: Participant information sheet | 45 |
| - 6.3 - Appendix 3: Interview topic guide | 49 |
| - 6.4 - Appendix 4: Confirmation of ethical approval | 52 |
| - 6.5 - Appendix 5: Example of coded transcripts | 53 |
| - 6.6 – Appendix 6: Self-evaluation form | 55 |
| - 6.7 – Appendix 7: Thematic maps | 61 |

# 1: Introduction.

## 1.1: Definition and prevalence of Functional Neurological Disorders (FND).

A proportion of people who attend outpatient clinics will have real, distressing and disabling symptoms of neurological disorders that are not caused by a physical neurological illness (Reid, Wessely, Crayford, & Hotopf, 2001; Stone et al., 2002). There is a growing understanding that these difficulties arise due to problems with how the nervous system is functioning, as opposed to problems with its structure (Stone, 2018). This is when there are difficulties with how the brain is sending, receiving or responding to messages to and from the body. This can result in symptoms like weakness, pain or dissociation (Stone, 2018). Whilst psychological events such as distress or trauma were historically considered to cause FND, it is now thought that physical events such as illness, accident or injury combined with psychological stress are often contributing to the development of functional symptoms (Kozlowska, 2017; Kozlowska, English, & Savage, 2013; Kozlowska, English, Savage, & Chudleigh, 2012; Pareés et al., 2014; Stone, 2018).

Some primary care studies suggest that between approximately 50-70% of patients' symptoms are not caused by physical illness or disease (Kroenke & Mangelsdorff, 1989; Nettleton, 2006). In neurological settings, it is estimated that around 30% of outpatients and 9% of inpatients have symptoms that are not caused by a physical neurological illness (Carson, Ringbauer, Mackenzie, Warlow, & Sharpe, 2000; Carson et al., 2000; Lempert, Dieterich, Huppert, & Brandt, 2009; Monzoni, Duncan, Grünewald, & Reuber, 2011; Nettleton, 2006).

## 1.2: Perceptions of FND.

Patients with FND can be perceived by professionals as emotionally unstable, not having a true illness or faking their symptoms (Stone et al., 2002; Wessely, 2000). Patients can feel shamed and guilty (May, Rose, & Johnstone, 2000; Nettleton, 2006; Werner, Widding Isaksen, & Malterud, 2004). They worry about being seen as fraudulent, timewasters or hypochondriacs. They can begin to doubt themselves and question their own symptoms. (May et al., 2000; Nettleton, 2006; Stone et al., 2002; Werner et al., 2004). Stone

et al.,(2002) found that, as well as finding terminology such as 'hysteria' and 'symptoms all in the mind' to be very negative, patients also found the 'medically unexplained' label to be offensive. Labelling symptoms as a functional disorder was found to be most acceptable to patients (Stone et al., 2002). Despite this, 'medically unexplained symptoms' (MUS) is still a widely used and popular term (Nettleton, 2006; Reid et al., 2001; Stone et al., 2002).

## 1.3: FND in services.

Research has highlighted the importance of a thorough and comprehensive medical examination for each patient. It is important that, even if medical teams suspect symptoms are functional, that examinations are not discontinued prematurely. Organic changes could be missed and patients and families will feel that their concerns and fears have not been heard, understood or adequately addressed (Kasia Kozlowska et al., 2013).

When examinations reveal no organic changes, a positive diagnosis of FND can be made. This diagnosis will be made at different times depending on the nature of the investigations and the medical Doctor involved. Once a positive diagnosis of FND is made, it is important that this is explained carefully and clearly to patients and their families (Kasia Kozlowska et al., 2013; Monzoni et al., 2011). These diagnostic conversations can be very helpful for patients if managed well. Patients' symptoms can even resolve in some cases (Hall-Patch et al., 2010; McKenzie, Oto, Russell, Pelosi, & Duncan, 2010). However, some Doctors can find these diagnostic conversations difficult. Research suggests that patients with FND can be seen as both problematic and frustrating by healthcare teams and the patient/team relationship can feel difficult and strained (Nettleton, 2006; Page & Wessely, 2003). Doctors' preconceptions can lead them to be defensive, and being overly delicate can increase patient confusion (Monzoni et al., 2011).

Patients need to feel that they are being taken seriously by their healthcare team and that their healthcare team believe and understand their symptoms (Stone et al., 2002). Patients with FND often feel their healthcare team lacks both empathy and understanding (Katon et al., 1991; Russo, Katon, Sullivan, Clark, & Buchwald, 1994; Walker, Unutzer, & Katon, 1998). Patients can feel both confused and angry at being given an FND diagnosis and told other services like psychology could be helpful for them (Carton, Thompson, & Duncan,

2003; Nettleton, Watt, O'malley, & Duffey, 2005; Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). If a patient can understand and accept their diagnosis at this stage, it can lead to more meaningful engagement with services like psychology in the future (Howlett, Grünewald, Khan, & Reuber, 2007; Monzoni et al., 2011).

## 1.4: Multi-Disciplinary Team (MDT) working.

Deciding which profession should take ownership for patients with FND is a contentious issue (Howlett et al., 2007). Patients often report being unsure where they belong in healthcare services (Aronowitz, 2001; Nettleton, 2006). Psychological therapy is usually considered the most important treatment option for people with FND (Howlett et al., 2007; Reuber, Howlett, & Kemp, 2005), though only few studies have been undertaken to support this (Carson et al., 2012).

However, if FND were treated within a purely psychological framework, not only would patients feel that their symptoms were not being taken seriously (Carson et al., 2012; Katon et al., 1991; Nettleton, 2006; Reid et al., 2001; Russo et al., 1994; Stone et al., 2002; Walker et al., 1998), but physical symptoms such as difficulties with walking, movement, eating and self-care would not be treated appropriately (Kozlowska et al., 2012). Such symptoms can lead to further complications such as muscle wastage if left untreated (Kozlowska et al., 2012; Kozlowska, Scher, & Williams, 2011; Kozlowska & Williams, 2009).

In recent years there has been growing acknowledgement and support for a multi-disciplinary approach for FND. Leading FND practitioners and researchers have described that having an multi-disciplinary approach provides the benefit of being able to work holistically with patients and their families (e.g. Carson et al., 2012; Kozlowska, 2017; Kozlowska et al., 2013, 2012). Kozlowska et al. (2012, 2013) describe working with an MDT program where patients receive support for their physical, psychological and social well-being by providing physical therapy, pharmacotherapy, individual and family therapy and psychoeducation. Other benefits of this MDT working are that the team will all be working consistently with the patients and that professionals can easily share knowledge and perspectives (Carson et al., 2012; Kozlowska, 2017; Kozlowska et al., 2013, 2012). However,

this structured MDT approach is not consistently available to FND patients in the U.K and is not supported by national guidelines. The NICE guidelines write

> "… A functional neurological disorder might not require a referral to neurology services; instead, the committee advised assuring people with such fluctuating symptoms that the symptoms were part of a functional neurological disorder and offering psychological support if appropriate" (NICE guidelines, 2017, p. 58).

## 1.5: FND in the Mid-Yorkshire NHS Service.

FND patients within the Mid Yorkshire Trust will typically be diagnosed by a neurologist. Patients will often by referred directly to neurology by their GP, although people can also be referred by inpatient emergency admissions. Depending on the person's symptoms they might be referred to physiotherapy, occupational therapy, or psychology. These services typically offer patients appointments within outpatient clinics, although there is a community team of neurology physiotherapists and occupational therapists.

## 1.6: The Mid Yorkshire Neuropsychology Service.

There is a Neuropsychology team within Mid-Yorkshire Trust who work with patients with FND. They will also work with other healthcare professionals who have FND patients on their caseload. This typically involves liaising with both the physiotherapy and occupational health teams based at Mid-Yorkshire Hospital sites (Pinderfields and Dewsbury) and in the community. This currently happens approximately once a month. Neuropsychology also attempts to provide support on an ad-hoc basis if requested, either by email or in person if time allows. There is not always a representative from each profession (neurologist, physiotherapist and occupational therapist) in each meeting. Having a representative from different professions in meetings is especially difficult in the community team.

## 1.7: The FND Psychology Pathway.

Due to the large number of referrals of patients with FND to the Mid Yorkshire Clinical Neuropsychology service, a new pathway has been implemented. The patients who

are referred are now offered an assessment and formulation, which will be offered across up to 4 sessions. An assessment will include a detailed history from the person, including a description of any events that occurred prior to the symptoms developing. Johnstone and Dallos, (2014) describe formulation;

> "A formulation draws on psychological theory in order to create a working hypothesis or 'best guess' about the reasons for a client's difficulties, in the light of their relationships and social contexts and the sense they have made of the events in their lives" (p. 1).

The aim is that this will enable people to better understand the diagnosis, what might have led them to develop FND and what is now maintaining their symptoms. Patients are then either signposted to long-term psychological therapy in adult mental health services or relevant community services, invited to an in-service FND group or discharged.

## 1.8: Rationale for the service evaluation project.

This project was commissioned by Dr Charlotte Baker and Dr Trishna Gandhi, Neuropsychologists at The Mid-Yorkshire Hospital Trust. The aim of the evaluation is to find out more about other healthcare professionals' view of the new FND psychology pathway, including what works well and what could be changed. The hope is to find out whether other professionals are aware of the pathway's existence and its structure and aims. The project also hopes to find out more about other professionals' views and perceptions about FND and whether they share the emerging view in the literature that a more structured MDT approach would be best for FND patients.

## 1.9: Research aims.

This service evaluation project will interview professionals about FND and the psychology FND pathway. The project aims to better understand:

- Mid Yorkshire Trust healthcare professionals' understanding of FND
- Their perceptions of FND
- Their understanding of the new Psychology pathway

- Their opinions on the pathway.

# 2. Methodology.

## 2.1: Design.

This project used a qualitative method design. One-to-one, face-to-face semi-structured interviews were undertaken at one of the two Mid-Yorkshire Trust Hospital sites (Pinderfields or Dewsbury Hospital). Interviews lasted for approximately 30-60 minutes. Qualitative methods are indicated when a project requires rich and in-depth information about a person's views and experiences which could not be captured by quantitative methods such as questionnaires (Mays & Pope, 2000; Pope, Ziebland, & Mays, 2000; Ritchie & Lewis, 2003). An online survey was considered as an alternative method. However, it was decided that this approach would not capture the depth of information required.

## 2.2: Sample.

The project commissioners wished to capture the views of Mid-Yorkshire Trust healthcare professionals who work with patients with FND and have either referred to the FND psychology pathway in the past or are likely to do so in future. Relevant staff from different professional backgrounds were emailed by the project commissioners and asked if they would be happy to be contacted regarding the project. Thirteen members of staff were happy to be contacted about the project. Five of these staff members did not reply to the researcher's initial or follow-up emails. Eight members of staff took part in the project (see table 1).

**Table 1**: Participant information.

| Participant number | Profession | Team (community or hospital) |
|---|---|---|
| 1 | Physiotherapist | Both |
| 2 | Epilepsy specialist nurse | Hospital |
| 3 | Occupational therapist | Community |
| 4 | Consultant physiotherapist | Hospital |

| | | |
|---|---|---|
| 5 | Neurology Consultant | Hospital |
| 6 | Clinical Specialist physiotherapist | Hospital |
| 7 | Physiotherapist | Both |
| 8 | Rehab Neurology Consultant | Hospital |

## 2.3: Data collection.

Interviews took place between May and August 2019. The information sheet and consent form were sent as attachments to the researcher's original email (see appendix 1 and 2). Copies were also brought to the interviews for participants to re-read if required and give their consent. The interviews were audio-recorded using a Dictaphone and transcribed immediately by the researcher after the interviews concluded. The interviews were semi-structured. The researcher had a topic guide to ensure the project aims were discussed during interviews (see appendix 3).

## 2.4: Data analysis.

Interviews were analysed using thematic analysis, following the detailed processed outlined by Braun and Clarke (2006; see table 2). Thematic analysis is a process of "identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79), which enables a rich description of the data. Thematic analysis was also chosen due to its flexible epistemology. Analysis can be done in an inductive, 'bottom-up' way, where the data does not need to be analysed within a specific theoretical framework (Boyatzis, 1998; Hayes, 1997). Themes are instead driven by the data.

Elliott, Fischer, & Rennie (1999) propose guidelines to ensure good practice within qualitative research. They suggest that analysis must face credibility checks. Both project commissioners evaluated the face validity of the initial coding and themes / subthemes and agreed with the proposed themes / subthemes. One commissioner suggested one subtheme being divided into two subthemes. The researcher amended the subtheme as suggested. Elliott et al. (1999) also highlight the importance of a researcher owning their own perspective and

context as this will emerge in the analysis process. This will be explored in the 'discussion' section.

**Table 2**: Phases of Thematic Analysis (Braun & Clarke, 2006, p. 87).

| Phase | Description of the process |
|---|---|
| 1. Familiarising yourself with your data | Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas |
| 2. Generating initial codes | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code |
| 3. Searching for themes | Collating codes into potential themes, gathering all data relevant to each potential theme |
| 4. Reviewing themes | Checking if themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic 'map' of the analysis |
| 5. Defining and naming themes | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme |
| 6. Producing the report | The final opportunity for analysis. Selection of vivid and compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a report of the analysis |

## 2.5: Ethical considerations.

Following discussions with the project's commissioners and using the Healthcare Research Authority's decision tool (http://www.hra-decisiontools.org.uk/ethics/) it was concluded that NHS ethical approval would not be required. Ethical approval was sought and granted by the University of Leeds School of Medicine Research Ethics Committee (reference DClinREC18-016) on the 11th of April 2019.

Potential participants were sent the information sheet and consent form to review at first contact from the researcher. Time was allocated at the beginning of interviews for any questions regarding the project before gaining written consent from all participants. Participants could withdraw from the project up to 1 week after their interview.

Due to the transcription occurring immediately after the interviews' conclusion and the recordings immediately being deleted, the interview recordings never left the interview room. Participants were assigned participant numbers and no identifiable information has been included in the report. It was not expected that participants would find the interview distressing but were told that the interview could be stopped at any time.

# 3: Results.

The project's research aims fell into 2 categories, and therefore data was analysed in 2 parts. Part 1 looked at professionals' understanding and perceptions of FND. Part 2 looked at professionals' understanding and response to the psychology FND pathway. A map of the main themes and subthemes for both parts are detailed in table 3. Tables 4 and 5 outline a selection of the quotations that led to the formation of each subtheme and theme for both parts of the data, and how many participants discussed this subtheme / theme in their interviews.

**Table 3:** Map of main themes and associated subthemes for part 1 and 2 of the data

| Part 1. Professionals' understanding and perceptions of FND | | Part 2. Professionals' understanding and response to the psychology FND pathway | |
|---|---|---|---|
| *Themes* | *Subthemes* | *Themes* | *Subthemes* |
| **1. Professionals' understanding of FND** | Neurological symptoms without an organic cause<br>Professionals' confusion<br>Training and learning<br>'Change over time' | **1. Professionals' understanding and awareness of pathway** | Awareness and understanding vs lack of awareness and misunderstanding<br>Referral confusion – who, when, how? |
| **2. Professionals' beliefs about FND** | 'The sort of people': beliefs about FND patients<br>Hopeful vs challenging<br>Beliefs regarding best ways of working | **2. Professionals' response to the pathway** | Response to pathway outcomes<br>Response to group element<br>Response to amount of sessions offered |
| **3. Giving / explaining the FND diagnosis** | Confidence vs discomfort<br>Validation and empathy | **3. Professionals' thoughts on an MDT for FND pathway** | Importance of consistent MDT<br>Barriers to consistent MDT |

| | | | |
|---|---|---|---|
| | Patients' reaction | | Departments needed |
| | Positive and timely diagnosis | | 'Most appropriate use of people's time' |
| | | **4. Pathway positives** | 'MDT nature' |
| | | | 'Filling the gap' |
| | | | Structure (individual and group) |
| | | **5. Pathway suggestions** | Increasing awareness of pathway |
| | | | Increased joint working |
| | | | Increased psychological input |
| | | | Clarity regarding referrals |

## 3a: Results part 1: Professionals' understanding and perceptions of FND (3 themes).

### *3.1a: Theme 1: Professionals' understanding of FND (subthemes highlighted in bold).*

Most professionals had some understanding that FND results in real **neurological symptoms without an organic cause**, instead developing due to psychological factors. However, two participants also spoke about how physical events such as an illness can also precipitate FND. However, some participants spoke about either their own, or other **professionals' confusion** regarding elements of FND. Some professionals were unclear about the origin and meaning of the term 'FND' and were unsure why FND was seen in physical as opposed to mental health services. Other participants spoke about how FND is not very well known or understood by other healthcare professionals. Participants identified that

there is a lack of **training and learning** for FND. Professionals must learn on the job or attend voluntary classes to develop their knowledge. Two participants believed there is a need to develop some formal learning, especially for new staff. Despite this, two professionals described how they had noticed a **change over time** in how FND is treated and perceived by health professionals. They described a more consistent and sympathetic healthcare system who will make a positive diagnosis of FND.

### *3.2a: Theme 2: Professionals' beliefs about FND.*

Some participants had beliefs about **'the sort of people'** who might have an FND diagnosis. Two participants believed that it was people who 'bottled up' their emotions who developed FND. Two participants had some negative beliefs about FND patients, saying that they can 'catastrophise', tell 'fairy stories', have chaotic lives and could choose to improve if they wanted. One participant implied they might not view it as a 'true' illness. Participants differed in whether they saw treating FND as **hopeful or challenging**. Four participants felt hopeful as, unlike many other neurological conditions, clients can improve and have good outcomes. Two participants felt that working with FND clients could be very challenging. Participants also had different ideas about the **best ways of working** within FND, even within the same health discipline.

### *3.3a: Theme 3: Giving / explaining the FND diagnosis.*

Participants spoke about their own, and other professionals' levels of **confidence vs discomfort** when explaining the diagnosis of FND to patients. Most participants felt confident, though some felt that it was a more difficult diagnosis to explain compared to other conditions and that the diagnostic conversation can sometimes be glazed over. Many professionals spoke about **patients' reaction to an FND diagnosis**. Whilst some patients can accept the diagnosis and move forward, professionals spoke about how a diagnosis of FND is often not accepted or understood by patients due to a general lack of public awareness regarding FND. Onw participant believed that a patients' acceptance of their diagnosis correlates with their recovery progress. All participants felt that a **positive and timely diagnosis** was important, as well as **validating and empathising** with the patients'

experiences. However, one participant's suggestion regarding how to best validate and empathise with patients could be experienced as invalidating (see table 4).

**Table 4.** Participants' quotations and their associated themes and subthemes for part 1: Professionals' understanding and perceptions of FND

| Theme | Subthemes | Number of participants | Participant quotations |
|---|---|---|---|
| **1. Professionals understanding of FND** | Neurological symptoms without an organic cause | 5 | *It's a condition which has neurological symptoms but does not have an organic cause – instead, it's related to an emotional cause and has a psychological root.*<br><br>*It's neurological symptoms that are real symptoms and present for the person but that are not due to neurological pathology but instead due to underlying psychological factors.*<br><br>*It's possible that there was an event, but it doesn't necessarily have to be a psychological event, it could be a physical event or illness.* |
| | Professionals' confusion | 5 | *I think it (the term FND) means that a lot of them are still functioning. Whether the term is saying 'oh actually it's a disorder you can function very well in' so a literal meaning, that actually everything is still functioning literally speaking.*<br><br>*FND, well it's something which you guys (neuropsychology team) can unpick. But it's a fine line between mental health! Like I had a functional patient recently and she told me her husband died – is that not mental health? Should she go there? A severe bereavement reaction?* |

| | | | |
|---|---|---|---|
| | | | *FND isn't always well understood by health professionals, which makes it hard.* |
| | Training and learning | 5 | *There's no training day or competency module or anything we have to complete.*<br><br>*There aren't any official modules in MSc or BSc.*<br><br>*I've worked with people with the condition and also with other physiotherapists who are very experienced in the condition…, I've developed an understanding of it on the job.*<br><br>*It might be a training need that needs to be addressed in a more formal way, especially for newer staff.* |
| | 'Change over time' | 2 | *I think things have changed over time. I think over time, approaches have become more consistent. For example, when I first started work generally people were not as sympathetic.*<br><br>*I would say more recently they've got that diagnosis more consistently and it's a definite positive diagnosis. I'd say that the consultants have definitely gotten better over time.* |
| **2. Professionals' beliefs about FND** | The 'sort of people': beliefs about FND patients | 4 | *It's the sort of people who bottle things up and that 'just get on with it' and don't have the time or are not able to deal with difficult thoughts and feelings and memories that might be more likely to develop FND.* |

| | | | |
|---|---|---|---|
| | | | *Functional patients tend to catastrophise – they speak about their seizures in a catastrophic way, whereas someone with epilepsy tends to be more pragmatic.*<br><br>*She (FND patient) used to tell me all sorts of fairy stories… a lot of them have really chaotic lives.*<br><br>*I believe it (FND) can improve if they (FND patients) want it to improve…. It's not quite like a stroke, or MS or any other true, I mean….* |
| | Hopeful vs challenging | 6 | *I feel like it is a condition where we can actually do something to help with it.*<br><br>*There are very few things that we can help with in neurology – very few conditions can improve, most conditions are incurable and degenerative and progressive… FND is actually something where you can improve people's life and if it's managed well you can have a really good outcome.*<br><br>*They (FND patients) can be really challenging to work with.* |
| | Beliefs about best ways of working | 3 | *I find that if you break it (a task) down they overall perform badly as a whole group.* |

| | | | |
|---|---|---|---|
| | | | *Goal setting is quite a big thing. Setting small, realistic, timely goals.*<br><br>*You go really heavy and even the littlest task you would really praise. It's an unusual tact because usually physios are more demanding and might say 'oh I want 10 more' kinda thing. It's completely the flip with FND, you're really happy with anything they can do.* |
| 3. Giving / explaining the FND diagnosis | Confidence vs discomfort | 7 | *I feel pretty confident in explaining FND.*<br><br>*It's a difficult concept to get across. If you use one metaphor and they don't get it, and then you need to find another way to explain, it's often not easy… It's less well explained compared to other conditions like Stroke or Parkinson's disease or MS.*<br><br>*There are certain consultants that I know about that do avoid the subject and they do skip past it and tend to just – I don't know what they say to them – but the patients definitely don't know they've got that diagnosis.* |
| | Patients' reaction | 5 | *People can vary in how much they are willing to accept the diagnosis.*<br><br>*Acceptance is a big part of all neurological conditions and isn't isolated just to FND but FND is not commonly well known and understood.* |

| | | |
|---|---|---|
| | | *..how accepting someone is of the FND has a huge impact on the effectiveness of therapy – a huge correlation between acceptance and therapy outcome. If someone is not ok with this diagnosis, it is much harder to work successfully.* |
| Positive and timely diagnosis | 8 | *If people receive an earlier the diagnosis and a clear diagnosis then they are in a much better position to be supported in rehab to reach their goals.*<br><br>*I think the earlier (the diagnosis) the better.*<br><br>*Part of the treatment for it (FND) is just a good explanation. A clear and positive diagnosis is so important*<br>. |
| Validation and empathy | 6 | *It's nothing that they've done wrong and it's not their fault. Because people automatically think that they've done something wrong or that you think they're putting it on.*<br><br>*People are concerned about being judged, about not being believed by health professionals and getting the 'it's all in your head, it's not real' stuff – I feel comfortable in saying that the symptoms are real and helping a person feel believed.*<br><br>*There are a couple of ways of delivering it – like 'this is good news, there's nothing structurally wrong, it's not an epileptic seizure'.* |

## 3b: Results part 2: Professionals' understanding and response to the psychology FND pathway (5 themes).

### *3.1b: Theme 1: Professionals' understanding and awareness of pathway (subthemes highlighted in bold).*

There was great variety in the participants' **awareness and understanding vs lack of awareness and misunderstanding** regarding the FND pathway. Two participants were aware, and had a good understanding, of the psychology pathway. Four participants said that they had no awareness or understanding. Two participants had some awareness but had misunderstood the pathway's structure and / or aims. Most participants had some **confusion regarding referrals** regarding **who** should refer and be referred, **when** patients should be referred, and **how** the referrals are made.

### *3.2b: Theme 2: Professionals' responses to the pathway.*

Participants had an overall positive **response to pathway outcomes**, including helping patients understand why they developed FND. Two participants also felt that the pathway offered a streamlined service for patients with FND. One participant was unsure about what the pathway's outcomes were. Most participants also had a positive **response to the group element** of the pathway, specifically the peer support it could offer, although one participant felt groups are not a good fit for everyone. Participants' **responses to the number of individual sessions offered** was less positive. Only two participants felt that it was likely to be enough. Other participants felt that the number of sessions offered should depend on patient need, although one participant did acknowledge the psychology service constraints which might make this difficult.

### *3.3b: Theme 3: Professionals' thoughts on an FND MDT.*

There was an agreement that the core **departments needed** for an FND MDT are psychology, OT, physiotherapy, consultant neurologists and neurology rehabilitation consultants. Some participants mentioned the need to involve other departments on occasion e.g. speech and language therapists, housing and social workers, dietitians, pain management

clinics. Most participants agreed on the **importance of a consistent MDT** when working with clients with FND. They felt that this enables a consistent treatment approach where everyone is 'on the same page', which could help assuage patients' anxieties and uncertainties around their diagnosis. They also felt it provided an opportunity for inter-disciplinary learning. Most participants identified that the main **barrier to a consistent MDT** is logistics – getting everyone together at the same time. One participant felt that other barriers included the lack of NICE guidance for FND, the general lack of awareness around FND and the heterogeneity of FND patients. Whilst acknowledging the importance of an MDT approach, two participants wondered whether having a regular FND MDT was the **most appropriate use of people's time**, due to the suspected small number of patients seen with FND. However, one of these participants then wondered whether the FND MDT could be utilised in the same way as the motor-neuron disease MDT– an illness where patients are small in number but often high in complexity.

### *3.4b: Theme 4: Pathway positives.*

Most participants had positive feedback regarding the pathway. Two participants felt that psychology had identified a patient need and that the pathway is **filling a gap** for FND patients who might have previously fallen through the net. Other participants felt that the **MDT nature** – the monthly meetings, the ad-hoc conversations between psychology and other professionals – is a strength, although it should be noted that this is not technically part of the new pathway. Two other participants felt that the pathway's **structure (the individual and group** elements) was a positive.

### *3.5b: Theme 5: Pathway suggestions.*

All participants had suggestions regarding the pathway's future. Four participants suggested that psychology should **increase professionals' awareness of the pathway** by, for example, creating a leaflet, advertising on the intranet or via a screensaver. Three participants suggested that **clarity regarding referrals** would be useful using, for example, a referral template or flowchart. Five participants felt that an **increase in joint working** across teams and departments would be useful, with psychology taking a lead. One participant mentioned

the potential benefits of forging links with departments such as A+E and acute wards. This participant also spoke about standardising links between departments, as opposed to relying on professionals with an interest in FND to make and maintain links. Two participants spoke about the need to increase the joint working in the community team. Participants also suggested an **increase in psychological input** across different areas. These areas were delivering training and education to different wards / departments, offering peer support for colleagues when working with complex or challenging FND clients, working more into the community team and offering an increased number of individual sessions to FND clients if needed.

Table 5. Participants' quotations and their associated themes and subthemes for part 2: Professionals' understanding and responses to the psychology FND pathway.

| Theme | Subthemes | Number of participants | Participant quotations |
|---|---|---|---|
| **1. Professionals understanding and awareness of pathway** | Awareness and understanding vs lack of awareness and misunderstanding | 8 | *If someone has particular emotional trauma then they will be referred on to mental health services for support in working through that. I think our psychology team are offering 4-6 individual sessions.*<br><br>*No, I'm not aware of it!*<br><br>*My impression was that they (psychology sessions) don't talk about what could have caused it so they steer away from the causes of FND.* |
| | Referral confusion – who, when, how? | 5 | *I do think it would be useful if it was something that the GPs could also refer in to?*<br><br>*So should everybody with FND do this (the psychology pathway)? Should I be referring everyone? Any FND?*<br><br>*Is it (referral) through system one, or by email or through the intranet?* |

| | | | |
|---|---|---|---|
| **2. Professionals' responses to the pathway** | Response to pathway outcomes | 3 | *It is very important that someone understand their diagnosis, so it is a good outcome for me.*<br><br>*I believe it's psychology trying to the volume of patients in the most efficient and effective way you can with your resources.*<br><br>*I'm not too sure (about the pathway outcomes… I imagine it's trying to look at the individual sessions being the individualised part.* |
| | Response to group element | 5 | *I think that meeting other people with the same condition is really valuable, really helpful, you see that with other conditions.*<br><br>*People with FND are very isolated... People often say things like 'my family don't understand' or 'people just don't get it, how I can be well one day and ill the next' – I think being in a group to make sense of it is very helpful.*<br><br>*I think the group will work for some people… A group isn't for everyone is it?* |
| | Response to number of sessions offered | 7 | *I think it (the number of sessions) sounds plenty!*<br><br>*It's a good initial taster for people but I would imagine it's likely that people would require longer term input in general. I think it would depend on the person and their needs.* |

| | | | |
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| | | | *I would imagine for the majority it's probably ok but some people will need more sessions… But at the end of the day you need to be realistic because of the huge number of patients you have you do have to manage your caseload.* |
| **3. Professionals' thoughts on an FND MDT** | Departments needed | 5 | *Physio, psychology, OT, GPs, Consultant neurologists, Neuro rehabilitation colleagues.*<br><br>*…you can be looking at a much bigger team e.g. SALT, dieticians, orthotics department, wheelchair services, housing and social services, pain management clinics…. But I think there's a core team there of physio, OT, clin psych, and the neurologists.* |
| | Importance of consistent MDT | 7 | *So we're all on the same page and we're all approaching something the exact same way – we all know what each other are doing. It saves confusion and it's clear for the patient.*<br><br>*If the MDT are a little bit inconsistent or perhaps there's a little bit of doubt in how they're communicating to the patient I think that could be counter-productive... I think a consistent MDT approach is helpful, definitely.*<br><br>*It (MDT working) also gives you that opportunity to learn from each other's knowledge as well, and you learn what everyone's roles are and what everyone can offer.* |

| | | | |
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| | Barriers to consistent MDT | 5 | *Getting everyone together at the same time.*<br><br>*But logistically how we would do that – that is the challenge.*<br><br>*It's still relatively uncommon compared to other more well-established conditions… the patient population is much more varied as well – because it's a bit more heterogenous it may be more challenging to pull together all the right skills. Also I'm not aware of any NICE guidelines for FND?* |
| | 'Most appropriate use of people's time' | 2 | *We would need to make sure it's the most appropriate use of people's time…*<br><br>*I don't know what the numbers are like for FND compared to other conditions in our service and if we were putting time aside how that would be managed… But the MND (motor-neuron disease) caseload is not huge in number but they require high levels of input from staff…* |
| **4. Pathway positives** | 'Filling the gap' | 2 | *They've identified a need and they're trying to fill the gap… they're trying to get to people as early as they can.*<br><br>*It's great that it exists, you get the feeling that patients with FND fall through the net sometimes.* |
| | 'MDT nature' | 4 | *I think the MDT nature of it is really of value.* |

| | | | |
|---|---|---|---|
| | | | *I think having the monthly meetings with Trisha is the most useful thing…*<br><br>*Having regular contact with other department, especially psychology.* |
| | Structure (individual and group) | 2 | *I think the individual and group focus is very good…* |
| **5. Pathway suggestions** | Increased awareness of pathway | 4 | *I think what could be useful is if we could give patients an information leaflet on the clinical psychology pathway in clinic… I don't know exactly what you are providing for them, so yeah a leaflet might be helpful.*<br><br>*I don't think there's anything on the intranet either so yeah… they should sell themselves! I'm not sure if there's a department for them (neuropsychology) on the intranet if you were to look….*<br><br>*The communications team are also really good, like they can give you a screensaver for a week or something like that.* |
| | Clarity regarding referrals | 3 | *Better communication I think – it would be great to know how to refer, whether it's on system 1. A template to refer would be good.* |

| | | | |
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| | | | *Sharing who should be referred? Our pathways are a diagram pathway and within that pathway you can have a flowchart of who's appropriate…* |
| | Increased joint working | 5 | *Having MDT meetings run by psychologists would be good – you're trained, and I think you're certainly the best placed to lead it. Just a regular, once a month get-together to discuss the clients would be good.*<br><br>*We don't have contact with the acute wards… That could possibly be a better link?... I think some of the links are there but not everyone is linked together and it's not a formalised link. It's mainly based on therapists, psychologists' interests rather than as a standardised approach.*<br><br>*I wonder how we could put that (regular MDT meetings) across the whole community team…* |
| | Increased psychological input | 5 | *I wonder whether there would be scope for psychology maybe offering some training and education around it (FND).*<br><br>*From a staff well-being point of view as well, it's good to meet with psychology and have those chats because some of these patients can be quite exhausting and mentally challenging for the therapists, so just having some peer support can be very useful really.* |

| | |
|---|---|
| | *We're very community-based and psychology are very clinic based… I wonder whether psychologists could input into the community? For example, I see some people who would struggle to make it to clinic.*<br><br>*Maybe the sessions going on for a longer time – people are often symptomatic for years with this so I think 4 sessions is unlikely to be all that they need."* |

# 4: Discussion

## 4.1: Main findings

This project aimed to explore the views of healthcare professionals at The Mid Yorkshire Trust regarding FND and the new psychology pathway for FND. There was a degree of inconsistency between participants across both parts of the data. Professionals understood that FND has a psychological basis, and the importance of empathy and validating their patients' symptoms and experiences. However, there was some confusion about the terminology and an acknowledgment that overall FND is poorly understood, possibly due to a lack of training and education across health disciplines. Participants felt this impacted on some professionals' confidence in giving or explaining the diagnosis. Whilst some participants felt hopeful when working with FND, others found it challenging and had some negative narratives about FND patients. There was also some inconsistency regarding beliefs about the best ways of working with FND. There was agreement that a positive and timely diagnosis was important and helpful for patients accepting their diagnosis.

There was also inconsistency regarding professionals' awareness and knowledge of the psychology FND pathway, with some having good knowledge and some having none. There was also some confusion about the referral process for the pathway. Overall, participants were positive about the pathway's outcomes and the group it offers, although most felt that the number of psychological sessions offered to patients should be needs-led. There was an agreement that an MDT approach is important and useful and an acknowledgment that it faces logistical challenges. Whilst participants were positive about the MDT nature and structure of the pathway, they suggested that increasing awareness of the pathway will be important in the future, as well as clarifying the referral process. Participants also felt that increased joint working and increased psychological input for FND (both direct and indirect working) would be beneficial.

## 4.2: Links to previous research

Most participants agreed with the historical thinking that psychological events such as distress or trauma cause FND. Only few participants spoke about more recent research which

suggests that physical events, such as illness or injury, combined with psychological stress often contribute to the development of symptoms (Kozlowska, 2017; Kozlowska, English, & Savage, 2013; Kozlowska, English, Savage, & Chudleigh, 2012; Pareés et al., 2014; Stone, 2018).

There was some understanding amongst participants that patients with FND can feel shamed and guilty (May, Rose, & Johnstone, 2000; Nettleton, 2006; Werner, Widding Isaksen, & Malterud, 2004), but this was not universal. Research suggests that some healthcare teams can find patients with FND problematic and challenging (Nettleton, 2006; Page & Wessely, 2003), and this view was shared by some particiants in this project. Previous research has identified similar negative narratives to the small few seen in this project, where FND patients are seen as emotionally unstable or not having a true illness (Stone et al., 2002; Wessely, 2000).

There was an awareness of the importance and power of diagnostic conversations, but that some professionals can struggle with this conversation (Hall-Patch et al., 2010; McKenzie et al., 2010). There was also an awareness that early understanding and acceptance of the FND diagnosis can lead to better engagement and prognosis for FND patients (Howlett et al., 2007; Monzoni et al., 2011).This project illustrated the growing acknowledgement and support for an MDT approach to FND seen in the research (e.g. Carson et al., 2012; Kozlowska, 2017; Kozlowska et al., 2013, 2012), though there are logistical barriers to overcome if a consistent MDT is to be implemented. The project is also in agreement with the research that a lack of support for an MDT approach from formal guidelines, for example, NICE guidelines might be impacting its formal implementation.

## 4.3: Strengths and limitations

This project had a variety of strengths and limitations. A limitation of this project is that there was no service user voice. There was a delay in starting this project, as the researcher had originally committed to a different project which fell through, making timeliness and ease of recruitment more prominent issues. The project focused on staff views instead of patients', believing recruitment would be simpler. Research suggests that service users value collaborative care planning with services, but are often not given enough

opportunities to do so (Bee, Price, Baker, & Lovell, 2019; Grundy et al., 2016; Hall & Callaghan, 2008).

Another limitation is that participants were selected by, and have a good working relationship with, the project's commissioners. Participants were aware that results would be fed back to the commissioners, and they might not have wished to criticise a pathway developed by colleagues with whom they have a good working relationship. The sample also had experience and awareness of FND (if not the pathway). Participants spoke of how newly qualified staff do not always have the same experience of working with clients with FND or have the same working links with psychology and other departments.

There was an over-representation of both one profession (physiotherapy) and one clinical setting (outpatient) within the sample which might have impacted on the results. Findings cannot be generalised to all health professionals at Mid Yorkshire Trust. Despite this, the study ensured that members from all core professions that support patients with FND were interviewed. Community workers were also represented (if not equally). Therefore, whilst the findings from this qualitative research cannot be generalised to all staff, a strength of this study is that attempts were made to capture the views of the main professions that work with FND.

Another strength of the evaluation is that the semi-structured interviews provided the freedom to elaborate on certain topics and areas, whilst ensuring that the research aims were met. The study also adds to the current knowledge and evidence base around FND – that health professionals value both psychological work as well as an MDT approach for this client group. It provides the commissioners, the service and the trust some guidance regarding future developments, not only for the psychology pathway, but for FND care more widely.

It is important for researchers to examine the potential biases and assumptions they might have when analysing qualitative data as this can impact the identified themes and subthemes (Holloway & Todres, 2003). As a trainee psychologist, I could be positively biased about psychology's effectiveness and assume a psychological pathway designed by commissioners whom I also know as respected lecturers will be beneficial. Honest

conversations with both commissioners about the usefulness of hearing other professionals' suggestions and criticisms helped guard against an overly positive picture of the pathway, as well as having a balance of questions in the interview schedule (see appendix 3). Credibility checks also helped ensure face validity (Elliott et al., 1999), although checking themes with participants would have provided an additional check if time had allowed (Elliott et al., 1999).

## 4.4: Recommendations

To summarise, professionals were supportive of the FND pathway's outcomes, of increasing psychological involvement in FND and of implementing a consistent MDT. Participants also made suggestions to address the lack of knowledge and awareness regarding FND in general and the psychology pathway for FND. The proposed recommendations are based on both these professional suggestions and on the limitations of this project.

Table 6. Key recommendations.

- If possible, a future evaluation where FND patients are interviewed about their first-hand experiences of the pathway and their suggestions regarding pathway development.
- If possible, a future evaluation where newly qualified staff with less experience of FND are interviewed, as well as professionals from other departments who might have different views and experiences e.g. acute wards or A+E.
- Publicise the psychology FND pathway e.g. through emails, through email signatures, through the intranet (on the neuropsychology department page), through arranging a screensaver advert via the communications department.
- Create a referral form (accessible via intranet or by request via email) with clear guidelines about who can refer, when patients could be referred, and which patients might benefit from accessing the FND psychology pathway.
- Create a leaflet for professionals and service users regarding the pathway and what it entails i.e. information about the 4 sessions of assessment and formulation, the group and potential referrals to other services. The professionals leaflet could also

contain some information regarding who and how to refer and signposting to the referral form.

- If possible, arrange a regular MDT session (one meeting a month) with professionals supporting patients with FND. Encourage attendance from professionals in both outpatient and community settings or consider 2 MDT meetings / virtual attendance e.g. via Skype.
- Depending on capacity, psychology to offer training and education sessions to other departments regarding FND on a rotational basis e.g. once every few months so that newly qualified staff and less connected departments have an awareness of FND, the FND MDT and the psychology FND pathway.
- Depending on capacity, psychology to offer peer support sessions for staff working with FND. This could become a generalised peer support session where staff could discuss the impact of working with other physical conditions.
- Make links with other departments such as acute wards or A+E and invite them to attend MDT / training and education sessions / peer support sessions.
- Depending on capacity, psychology to work more in the community to support people who would struggle to access hospital every week.
- Depending on capacity, psychology to be able to offer additional individual sessions if required.

## 4.5: Dissemination of findings

The findings from the project were shared in person with the project's commissioners and the wider neuropsychology department during a meeting on the 5th of November 2019. They were also shared via a brief presentation and poster at a service evaluation poster conference, as part of the Leeds University Clinical Psychology Doctorate training programme on the 25th October 2019.

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# 6: Appendices

## 6.1: Appendix 1: Participant consent form

UNIVERSITY OF LEEDS

| **Consent to take part in <u>Evaluation of the new assessment and formulation service pathway for people with functional neurological disorders (FND) at Mid Yorkshire NHS Trust</u>** | Add your initials next to the statement if you agree |
|---|---|
| I confirm that I have read and understand the information sheet dated 06/02/2019 explaining the above service evaluation project and I have had the opportunity to ask questions about the project. | |
| I understand that my participation is voluntary and that I am free to withdraw at any time up until 1 week after my interview without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. I understand that if I withdraw from the evaluation for up to 1 week after my interview, all my data will be destroyed. | |
| I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in any report or reports that could result from the research. | |
| I agree for the data I provide to be archived for 3 years at Leeds University in case any questions are raised following the evaluation, or in the event of a report or paper being written. I understand that all my data will then be destroyed. | |
| I understand that other genuine researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form. | |
| I understand that other researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form. | |
| I agree to take part in the above service evaluation project | |

| | |
|---|---|
| Name of participant | |

| | |
|---|---|
| Participant's signature | |
| Date | |
| Name of lead researcher | Angharad Jones |
| Signature | |
| Date | |

| *Project title* | *Document type* | *Version #* | *Date* |
|---|---|---|---|
| Evaluation of the new assessment and formulation service pathway for people with functional neurological disorders (FND) at Mid Yorkshire NHS Trust | Consent form | 1 | 06/02/ 2019 |

## 6.2: Appendix 2 – Participant information sheet

UNIVERSITY OF LEEDS

**Information sheet:**

Title of service evaluation project: Evaluation of the new assessment and formulation service pathway for people with Functional Neurological Disorders (FND) at Mid Yorkshire NHS Trust

Name of Researcher: Angharad Jones, Psychologist in Clinical Training.

**You are being invited to take part in a service evaluation project.**

Before you decide it is important for you to understand why the evaluation project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

**What is the purpose of the project?**

Due to the large number of referrals of patients with Functional Neurological Disorders (FND) to the Mid Yorkshire Clinical Neuropsychology service, a new pathway has been implemented. This project hopes to evaluate professionals' views regarding FND and this new pathway.

FND is the name given for symptoms in the body which appear to be caused by problems in the nervous system, but which are not caused by a physical neurological disease or disorder (sometimes called 'medically unexplained'). For example, dissociative epileptic attacks or functional motor disorders.

Clients referred are now offered an assessment and formulation (up to 4 sessions) with the aim that this will enable them to better understand the diagnosis. Clients are then either signposted to more long-term therapy, invited to a group or discharged.

This evaluation wishes to know what health professionals' views are regarding the new pathway. The evaluation project is particularly interested in professionals who are currently referring on to the new pathway or who might do so in future. You have been chosen because you are such a professional. This evaluation is aiming to recruit between 8-10 professionals.

**What do I have to do?**

Participation in this evaluation will involve a one-off interview that will last for about 30-60 minutes. The interview will contain a mixture of both open and closed questions. It is hoped that this evaluation will help inform any future FND pathway development.

**What are the possible disadvantages and risks of taking part?**

There are no obvious disadvantages or risks to taking part. You do not have to discuss anything that feels too difficult or distressing and you are free to stop the interview at any time. Additional support is available by self-referral to Occupational Health. To find out more information on what services they can provide, please visit the Health and Wellbeing Portal, www.healthassuredeap.com or contact 0800 030 5182.

**What are the possible benefits of taking part?**

The evaluation could result in changes being made to the FND pathway and / or how people with FND are supported within Mid Yorkshire Trust. These changes could be beneficial to both the referrer and the client themselves.

**Do I have to take part?**

No – it is completely up you. You are also free to withdraw at any time up until 1 week after your interview has taken place. After this, analysis of the interviews might have begun and removing data will affect the results. You do not have to give a reason if you wish to withdraw.

**Will my taking part in this study be kept confidential?**

The interviews will be audio-tape recorded and then transcribed for analysis. All interviews will be anonymous and identified by a unique study number alone. No personal details will appear in the transcripts. Any information you provide during the interviews will remain totally confidential.

**What will happen to the results of the study?**

All audio-tape recordings will be transcribed and analysed. The results will be based on the analysis of all transcripts together. The results may be presented at conferences and published in academic and medical journals. The anonymised transcripts and signed consent forms will be kept securely by The University of Leeds for 3 years and then destroyed.

**Who has reviewed the study?**

This study has been given ethical approval by the School of Medicine Research Ethics Committee (SoMREC project number ref: DClinREC18-016).

**Consent**

You will be asked to sign a consent form before you take part in the study.

**What if there is a problem?**

If you have a concern about any part of this study, or if you would like more information, you can contact the people linked to this service evaluation. Contact details for the researcher and commissioners working on this evaluation are detailed below:

**Contact details for further information**

Angharad Jones (Psychologist in Clinical Training), Clinical Psychology Training Programme, University of Leeds, Level 10, Worsley Building, Clarendon Way, Leeds, LS2 9NL; email: umaj@leeds.ac.uk;

or Dr Charlotte Baker (Consultant Clinical Neuropsychologist / Teaching fellow in Clinical Neuropsychology), Leeds Institute of Health Science, Faculty of Medicine and Health, Clinical Psychology, Level 10, Worsley Building, University of Leeds, Clarendon Way, LS2 9NL; email: C.F.Baker@leeds.ac.uk; telephone: (01924 541510/541512);

or Dr Trishna Gandhi (Clinical Psychologist), Clinical Neuropsychology, Pinderfields Hospital, Aberford Rd, Wakefield WF1 4DG; email**:** Trishna.Gandhi@midyorks.nhs.uk); telephone: (…).

| *Project title* | *Document type* | *Version #* | *Date* |
|---|---|---|---|
| Evaluation of the new assessment and formulation service pathway for people with functional neurological disorders (FND) at Mid Yorkshire NHS Trust | Information sheet | 2 | 21/03/2019 |

## 6.3: Appendix 3 – interview schedule / topic guide

**Topic Guide – Professionals' views of Functional Neurological Disorder (FND) and the new FND pathway at Mid Yorkshire Trust.**

**Aims of the interview**:

To explore

- What are professionals' understanding of FND?
- What are professionals' understanding of the new pathway (what Psychology can offer / is offering)?
- What are professionals' opinions on the pathway – what works well, what could be different (this isn't limited to psychology e.g. would MDT working be useful for the pathway).

**Introduction**

Thank you for agreeing to take part in this service evaluation. We are asking professionals who are currently working with clients with FND, referring client to the new FND pathway or who might refer clients in the future, to help us think about FND and the new pathway. We want to ensure that people with a FND diagnosis receive the best support from our team and will be using this information to guide future service development for people with FND.

This interview is in three parts:

- The first part will ask you about how your understanding of FND.
- The second part will ask you about your understanding of the new FND pathway.
- The third part will ask for your views and experiences of the new FND pathway.

*Participant questions*

*Part One*

1. What is your understanding of FND? (prompt: Medical vs Psychological? Changing terminology?)
2. Are there any particular professional or personal experiences of FND that have helped shape your understanding?
3. How long have you worked with clients with FND? (prompt: in same service, or different service? If different services, was there a difference in FND care / support?)
4. Do you feel it is your role to explain (give) this diagnosis to client and families?
5. How comfortable do you feel explaining (giving) this diagnosis?
6. How important do you think timing / profession is in relation to giving an FND diagnosis? (prompt: better to give diagnosis at a certain time / better that diagnosis comes from certain profession(s)?)

*Part Two*

I am interested in your understanding of the new FND pathway so the next questions will relate to that:

1. What do you know about the new FND pathway?
2. (If know about pathway) How often do you refer to the new pathway? (prompt: weekly, monthly, every few months?)

- If haven't heard of the FND pathway, provide information and then ask the following:

3. What is your understanding of the new FND pathway's purpose? (prompt: to 'get rid' of symptoms vs living with symptoms?)
4. What are your thoughts on the number of sessions offered? (not enough / too many? If not enough / too many, why?)
5. What are your thoughts on the pathway's outcomes?

*Part Three*

I am interested in your views, opinions and experiences regarding the new pathway so these next questions will relate to that. So far, we have just spoken about what Psychology can

offer regarding the pathway. For these next questions, could you please think more broadly about how other services might also support FND:

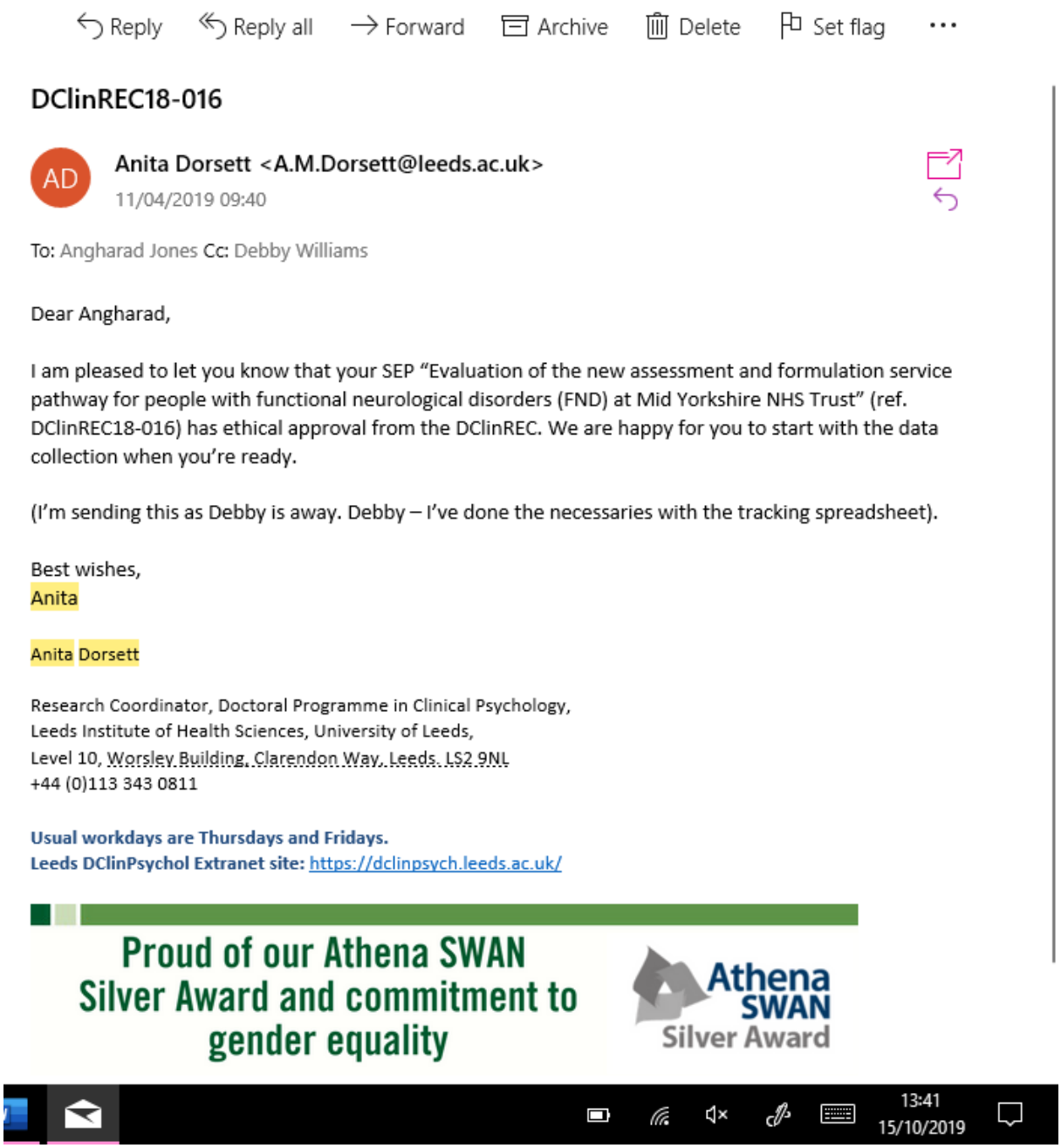
1. In your view, what other departments would be useful in supporting someone with FND?
2. What are your thoughts regarding an MDT approach to FND? (Prompt: why important / not important?)
3. What do you feel would be the barriers to involving other services, if you think this would be helpful?
4. What would be the advantages?
5. What do you think works well regarding the new pathway?
6. What do you think could be different?

I have now asked you all of the questions are there any issues/questions that you would like to talk about that have not been covered?

Thank you, just to say once again that everything you have told me today is confidential and completely anonymous.

| *Project title* | *Document type* | *Version #* | *Date* |
|---|---|---|---|
| Evaluation of the new assessment and formulation service pathway for people with functional neurological disorders (FND) at Mid Yorkshire NHS Trust | Interview topic guide | 2 | 23/03/ 2019 |

## 6.4: Appendix 4 – confirmation of ethical approval (copy of email)



Reply  Reply all  Forward  Archive  Delete  Set flag  ...

**DClinREC18-016**

AD **Anita Dorsett <A.M.Dorsett@leeds.ac.uk>**
11/04/2019 09:40

To: Angharad Jones Cc: Debby Williams

Dear Angharad,

I am pleased to let you know that your SEP "Evaluation of the new assessment and formulation service pathway for people with functional neurological disorders (FND) at Mid Yorkshire NHS Trust" (ref. DClinREC18-016) has ethical approval from the DClinREC. We are happy for you to start with the data collection when you're ready.

(I'm sending this as Debby is away. Debby – I've done the necessaries with the tracking spreadsheet).

Best wishes,
Anita

Anita Dorsett

Research Coordinator, Doctoral Programme in Clinical Psychology,
Leeds Institute of Health Sciences, University of Leeds,
Level 10, Worsley Building, Clarendon Way, Leeds, LS2 9NL
+44 (0)113 343 0811

**Usual workdays are Thursdays and Fridays.**
**Leeds DClinPsychol Extranet site:** https://dclinpsych.leeds.ac.uk/

Proud of our Athena SWAN Silver Award and commitment to gender equality

Athena SWAN Silver Award

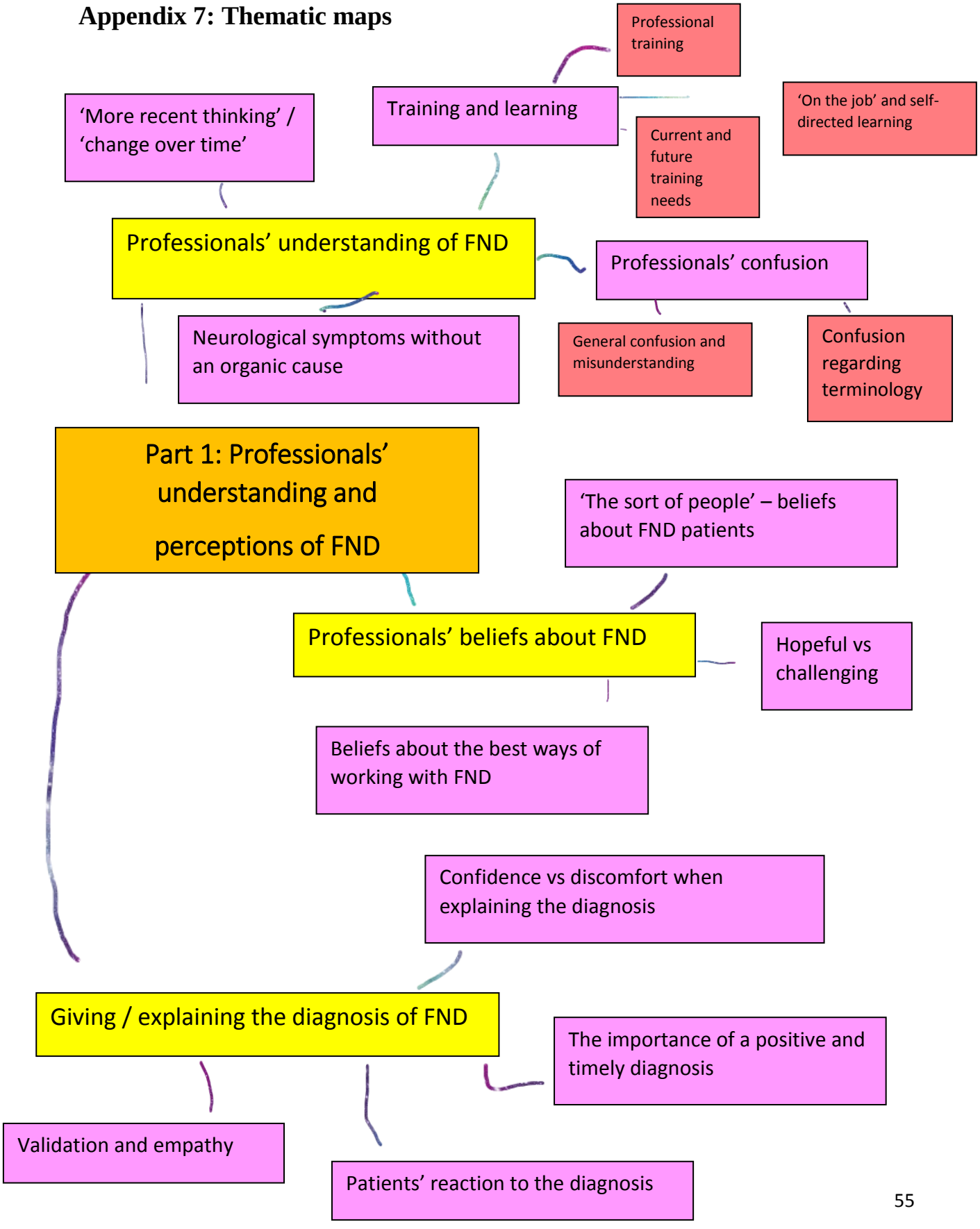
13:41
15/10/2019

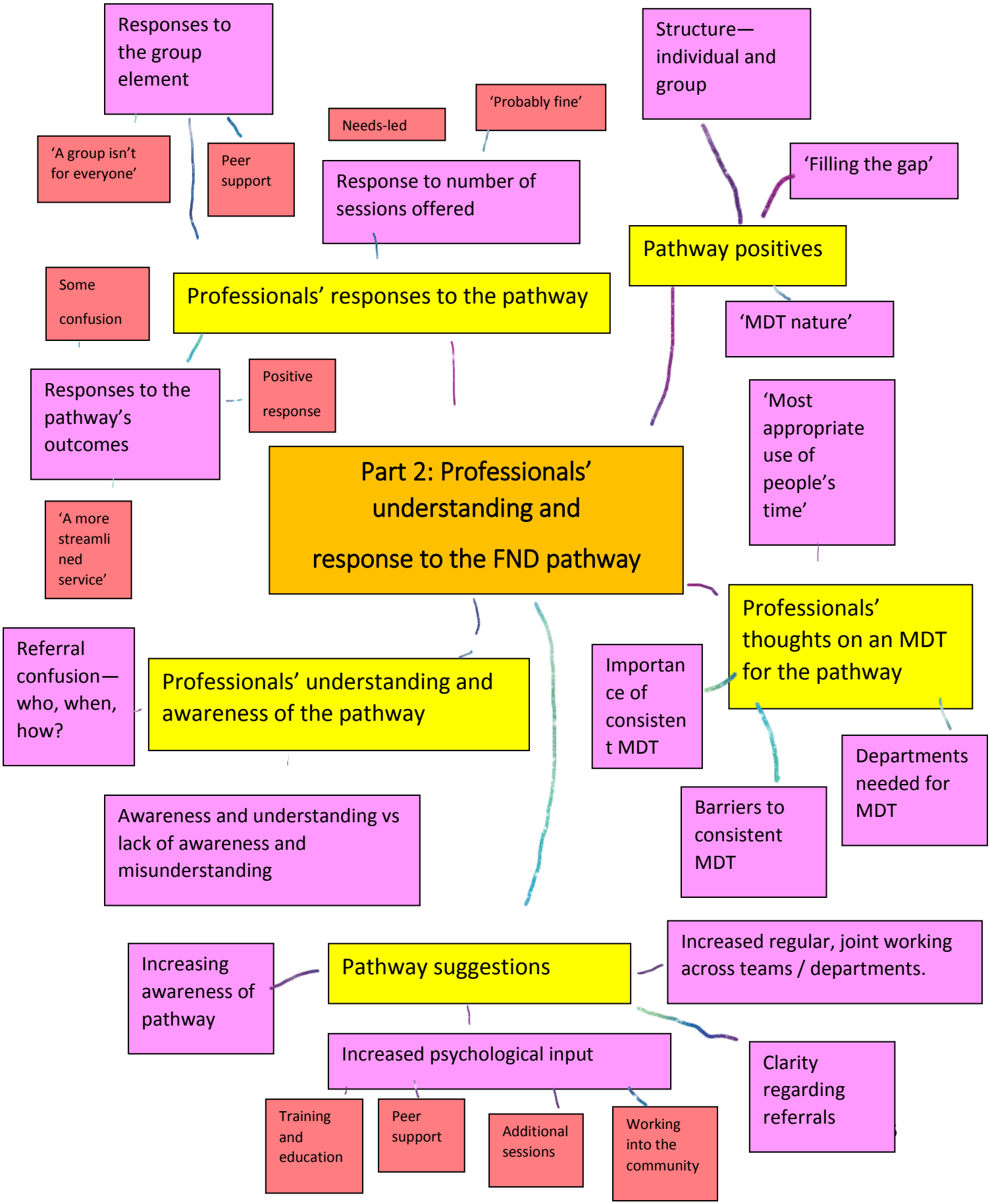
## 6.5: Appendix 5 – example of transcripts and initial codes (extract from interview 7)

| | |
|---|---|
| Researcher: What is your understanding of FND? | |
| Participant: We see more the movement disorder side of things in physio, but I know people can also have memory and cognition difficulties, dissociation or seizures as well. Sometimes we see a combination of symptoms. From the physio side mainly see people with a motor component to their presentation. | Professional differences in symptoms<br><br>Variety / scope of symptoms<br><br>Physiotherapy symptoms |
| It's a condition that when you assess for and test for tests would be normal, all medical investigations would be normal. But there is a deficit there – a deficit in the function of the nervous system as opposed to a structural deficit. This could be picked up or determined through investigations. I know the old school thinking was that it was thought that it was a physical manifestation of psychological difficulties, but I know | No organic cause<br><br>True problem / difficulty<br>Function vs structural difficulty<br>Awareness of terminology<br><br>FND as a positive diagnosis<br><br>A change in thinking / understanding<br><br>FND not just due to psychological causes |

| | |
|---|---|
| more recent thinking has moved away from that. It's possible that there was an event, but it doesn't necessarily have to be a psychological event, it could be a physical event or illness. | Physical event or illness leading to FND |
| I think it's often very difficult if you haven't got a diagnosis – I think some people, some therapists have a misunderstanding of it. Like if they see someone who's got a behavioural component to a presentation they can jump to say that it's a functional disorder. I think there's a difference in people's understanding of whether someone has functional disorder or just some behavioural parts to their presentation. Things could get mis-labelled. If someone has functional difficulties, there would be inconsistencies in your assessment e.g. where someone can | Empathy<br>Professional misunderstanding of FND<br>Professional misunderstanding<br>Behavioural presentation vs functional disorder<br>Professional misunderstanding<br>Behavioural presentation vs functional disorder<br>Mislabelling / misunderstanding<br>Making a positive diagnosis<br>Functional presentation |

## Appendix 7: Thematic maps




Part 2: Professionals' understanding and response to the FND pathway
Professionals' responses to the pathway
Responses to the group element
'A group isn't for everyone'
Peer support
Response to number of sessions offered
Needs-led
'Probably fine'
Some confusion
Responses to the pathway's outcomes
Positive response
'A more streamlined service'
Pathway positives
Structure—individual and group
'Filling the gap'
'MDT nature'
'Most appropriate use of people's time'
Professionals' thoughts on an MDT for the pathway
Importance of consistent MDT
Barriers to consistent MDT
Departments needed for MDT
Professionals' understanding and awareness of the pathway
Referral confusion—who, when, how?
Awareness and understanding vs lack of awareness and misunderstanding
Pathway suggestions
Increasing awareness of pathway
Increased psychological input
Training and education
Peer support
Additional sessions
Working into the community
Increased regular, joint working across teams / departments.
Clarity regarding referrals