

# **An evaluation of the Functional Neurological Disorder workbook for use in teletherapy**

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# 1 Introduction

## 1.1 Service Evaluation Project (SEP) Context

The presenting SEP was commissioned by Dr Trishna Gandhi, Clinical Psychologist at the Mid-Yorkshire Hospital Trust. Within the Mid-Yorkshire Neuropsychology Service, a specialist Functional Neurological Disorder (FND) pathway was developed to offer support to patients with a diagnosis of FND. Due to the COVID-19 pandemic, offering in-person appointments to patients was not possible, therefore teletherapy formats needed to be implemented. To support adapting to this way of working, the neuropsychology team created a four session FND workbook for clinicians and patients to work through within sessions. This SEP focuses on evaluating this workbook for use in teletherapy.

## 2 Literature Review / Background

### 2.1 FND: Definition, Cause, and Prevalence

FND is a condition which refers to the presence of neurological symptoms, not caused by an organic neurological disease (Ludwig et al., 2018). FND symptoms are real and can result in patients experiencing motor symptoms such as limb weakness, tremor or seizures, as well as sensory symptoms such as visual disturbance (Stone et al., 2020). Other persistent physical symptoms like pain, cognitive difficulties and tiredness are also commonly reported (Gilmour et al., 2020). FND can have a detrimental impact on quality of life, with symptoms resulting in high levels of emotional distress and disability, which can be similar or greater to those experienced by patients with a diagnosed organic neurological condition (Carson et al., 2011).

FND symptoms are understood not to have any structural correlate, instead occurring from problems arising with the functioning of the nervous system (Stone, 2021). Therefore, the essential wiring of the nervous system is undamaged, however the brain is experiencing difficulties with sending and, or receiving information correctly to other areas of the body (FND Action, 2021). Psychological events including trauma have previously been thought to cause FND (Fobian & Elliott, 2019). However, research now acknowledges that although such events can increase the risk of developing FND, not all FND patients report these experiences (Ludwig et al., 2018). Furthermore, there is a growing awareness that physical events (e.g. injury or illness)

can also potentially contribute to the onset of FND symptoms (Pareés et al., 2014; Stone et al., 2009).

Symptoms of FND are the second most common reason for a referral to outpatient neurology services (Stone et al., 2010). From reports of FND incidences being estimated at as high as 12 per 100,000 per annum (Carson & Lehn, 2016), it is likely that between 50,000 – 100,000 individuals are living with FND in the UK, with an estimated 8,000 new FND diagnoses being made each year (Bennett et al., 2021).

## **2.2 FND Diagnosis Within Healthcare Services**

A diagnosis of FND requires a comprehensive assessment in which positive clinical features are identified, as opposed to mere exclusion of other conditions (Stone et al., 2020). For example, with functional limb weakness, common positive features may include Hoover's sign, where there is weakness of voluntary hip extension, with normal involuntary hip extension when the opposite hip is being flexed against resistance (Bennett et al., 2021). Prompt diagnosis and intervention at the early stages of symptom presentation is important (O'Keeffe et al., 2021). However, for many this journey can be lengthy, typically involving various investigations and referrals (Cock & Edwards, 2018).

When an FND diagnosis is made, how this is delivered can play a significant therapeutic role (Stone, Carson, & Hallett, 2016). It is therefore vital this is shared in a clear, compassionate, and non-judgmental way (Stone et al., 2005), ensuring the patient is fully informed and a rationale for diagnosis is offered (Stone, 2016). Through communicating a diagnosis successfully, this is likely to enhance patient confidence in the diagnosis (Carson, Lehn, Ludwig, et al. 2016), support patient engagement with treatment options such as psychology input (Howlett et al., 2007), and in some cases can result in symptoms resolving (McKenzie et al., 2010; Meierkord et al., 1991).

Unfortunately, it is not uncommon for patients to have more negative diagnosis experiences (Cock & Edwards, 2003), where likely inadequate information offered has left them lacking insight into their diagnosis (Carton et al., 2003). It is recognised that physicians can at times, unhelpfully frame a diagnosis in a way which infer symptoms not being real (Cock & Edwards, 2018). When the legitimacy of a patients FND symptoms are questioned, this can lead to patients having reduced trust in others and increasing their feelings of self-doubt and shame (Dosanjh et al., 2021). Both

inadequately delivered and delayed FND diagnoses can result in poor prognosis and symptoms persisting or even worsening (Espay et al., 2018).

### **2.3 Psychoeducation and Support Available for Patients With FND**

Although there has been a growth in interest surrounding FND, specialist support services for patients with this disorder remain limited (Cock & Edwards, 2018). This is something which needs to change rapidly. The most beneficial way of supporting patients with FND is for services to take a multidisciplinary approach to their care (Rommelfanger et al., 2017). FND patients may experience difficulties with understanding and accepting their diagnosis (Anderson et al., 2019). Therefore, follow-up appointments are needed (e.g. to offer further psychoeducation and symptom management support) (Gilmour et al., 2020).

Patients can be offered psychological therapy, with interventions typically taking a person-centred approach, supporting the patient to explore and understand factors which have contributed to the development or maintenance of their FND symptoms (Gutkin, McLean, Brown, et al., 2021). Although currently limited, there has been a growth in interest and research looking into the effectiveness of different psychological interventions for patients with FND (Gutkin, McLean, Brown, et al., 2021). New research has captured the positive effect short-term psychological interventions with a focus on psychoeducation and shared development of formulation can have on FND patients' wellbeing, quality of life and functioning (Gutkin, Brown, McLean, et al., 2021).

Literature has also acknowledged valuable ways to support patients' continued self-management of FND symptoms, such as being provided with an FND workbook, which patients can keep and reflect on when needed (Gilmour et al., 2020; Nielsen et al., 2015; Sharpe et al., 2011).

### **2.4 Teletherapy**

Due to the COVID-19 pandemic, many healthcare services including those delivering psychotherapy have had to halt in-person appointments and move to offering teletherapy (Markowitz et al., 2021). Teletherapy refers to an intervention delivered by a therapist via video call or telephone (Lin & Espay, 2021). Opinions surrounding teletherapy have been mixed, and there are various ethical arguments raised for and against its use (Stoll et al., 2020). However, it cannot be ignored that teletherapy has

enabled accessing many services, including neuropsychology services, to remain possible during a time when face-to-face has not.

Literature looking into the effectiveness of psychotherapy delivered in teletherapy formats have demonstrated positive findings (Coughtrey & Pistrang, 2018; Thomas et al., 2021). Research exploring psychotherapy delivered to FND patients via teletherapy is scarce, however one study evidenced promising outcomes including patient symptom reduction and improved functioning (LaFrance et al., 2020). Although a vastly different way of working, there are many potential benefits to offering teletherapy for FND patients, including making interventions more accessible by removing barriers such as limited local access to specialised clinicians, time constraints and transportation issues (Lin & Espay, 2021). These findings are invaluable, however further research is needed within this area.

## **2.5 Mid-Yorkshire Neuropsychology Service: FND Pathway**

The Mid-Yorkshire Neuropsychology Service provide a range of support to patients who are experiencing various neurological conditions including FND. FND Patients are typically referred into the service by their neurologist. A positive FND diagnosis is required upon referral. The FND pathway would ordinarily consist of patients being offered four face-to-face sessions with a Clinical Psychologist. Following which, an Acceptance and Commitment Therapy (ACT) based group can also be offered to patients needing further support. However due to COVID-19, the service needed to move to offering input via teletherapy. The ACT group was suspended during this time.

## **2.6 The FND Workbook**

To support adapting sessions moving to a teletherapy format, the neuropsychology team created an FND workbook. To create this, they drew on the evidence base for FND interventions which suggests the use of Cognitive Behavioural Therapy (e.g. Lin & Espay, 2021). The psychoeducation content included is consistent with existing service leaflets, including one developed by Sheffield NHS Foundation Trust (2019).

A hardcopy of the workbook is provided to patients prior to their first appointment and is a visual guide which the clinician and patient work through together. The workbook is split into four sections, with each section being delivered over one

session. The workbook encompasses psychoeducation around FND, assessment and shared formulation. It contains visual images to aid understanding and discussion, sections to write notes, and information on external FND support (e.g. websites).

### **3 Aims**

The current evaluation aimed to explore and evaluate participants' experiences of completing the FND workbook within a teletherapy format, and to capture if and how this experience could be improved.

## **4 Method**

### **4.1 Design**

A qualitative method design was used for this SEP. A qualitative method was selected as the project required rich and in-depth information to be gathered about participants' thoughts and experiences, something which cannot be gained through using a quantitative method (Yilmaz, 2013). One-to-one semi-structured interviews were conducted with participants who had completed the workbook. Due to the pandemic restrictions, all interviews were completed by telephone, lasting approximately 25-40 minutes.

### **4.2 Participants**

All participants recruited were individuals with a diagnosis of FND, who had accessed the Mid-Yorkshire Neuropsychology Service and completed the workbook via teletherapy. During their final workbook session, patients were asked if they would be interested in hearing more about the project. Ten patients consented to being contacted and further information regarding the project being sent to them. Following this, seven participants consented to taking part. For the three participants who did not take part; one declined to participate due to having had a more negative experience, one did not receive the information sent, and one was unable to recall having completed the workbook.

### **4.3 Data Collection**

Patients who consented to being contacted about the project were sent a participant information sheet (see Appendix A) and consent form (see Appendix B) by post. Participants were then contacted around ten days later to provide an opportunity to answer any questions and to complete verbal recorded consent if they were happy to take part. All interviews were audio-recorded by Dictaphone, stored securely on a university approved secure drive, and transcribed by the researcher. Interviews took place between March and July 2021. The researcher used an interview schedule (See Appendix C), which was created by the commissioner and researcher, to guide interview discussions. Interview questions primarily focused on participants' experience of completing the workbook. However, some questions regarding participants' experience of FND and diagnosis were also asked to aid exploring their understanding of FND prior to neuropsychology input and to support considering any additional benefits from the workbook.

### **4.4 Data Analysis**

Interviews were analysed using Thematic Analysis, following the detailed six stage process outlined by Braun and Clark (2006) (See Table 1). This process allows for a rich and meaningful description of the data to be formed. Thematic analysis was also selected due to its level of flexibility. An inductive analysis approach was used, meaning that the themes created were driven by the data as opposed to being theory-driven (Boyatzis, 1998). An example theme, subtheme, codes and quotations can be found in Appendix D.

Evolving guidelines to good practice when conducting qualitative research have been outlined by Elliott et al. (1999). Within these guidelines, the importance of credibility checks is highlighted. For the current project, the commissioner reviewed themes and subthemes for face validity. Elliott et al. (1999) also acknowledged the importance of owning one's own perspective, both in advance and as they become evident during the research. This will be explored within the discussion.



**Table 1***Six phases of Thematic Analysis (Braun & Clarke, 2006)*

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 the themes work in relation to the code's 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, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

#### **4.5 Ethical Consideration**

Ethical approval was sought and granted by the University of Leeds Faculty of Health and Medicine Research Ethics Committee (DClinREC 20-002) on 19<sup>th</sup> February 2021. All participants were provided with a hardcopy of the project information sheet

and consent form. Participants were then contacted via telephone to provide an opportunity to ask any questions they might have about the project, after which, informed consent was gained. Participants were provided with another opportunity to ask questions before their interview commenced.

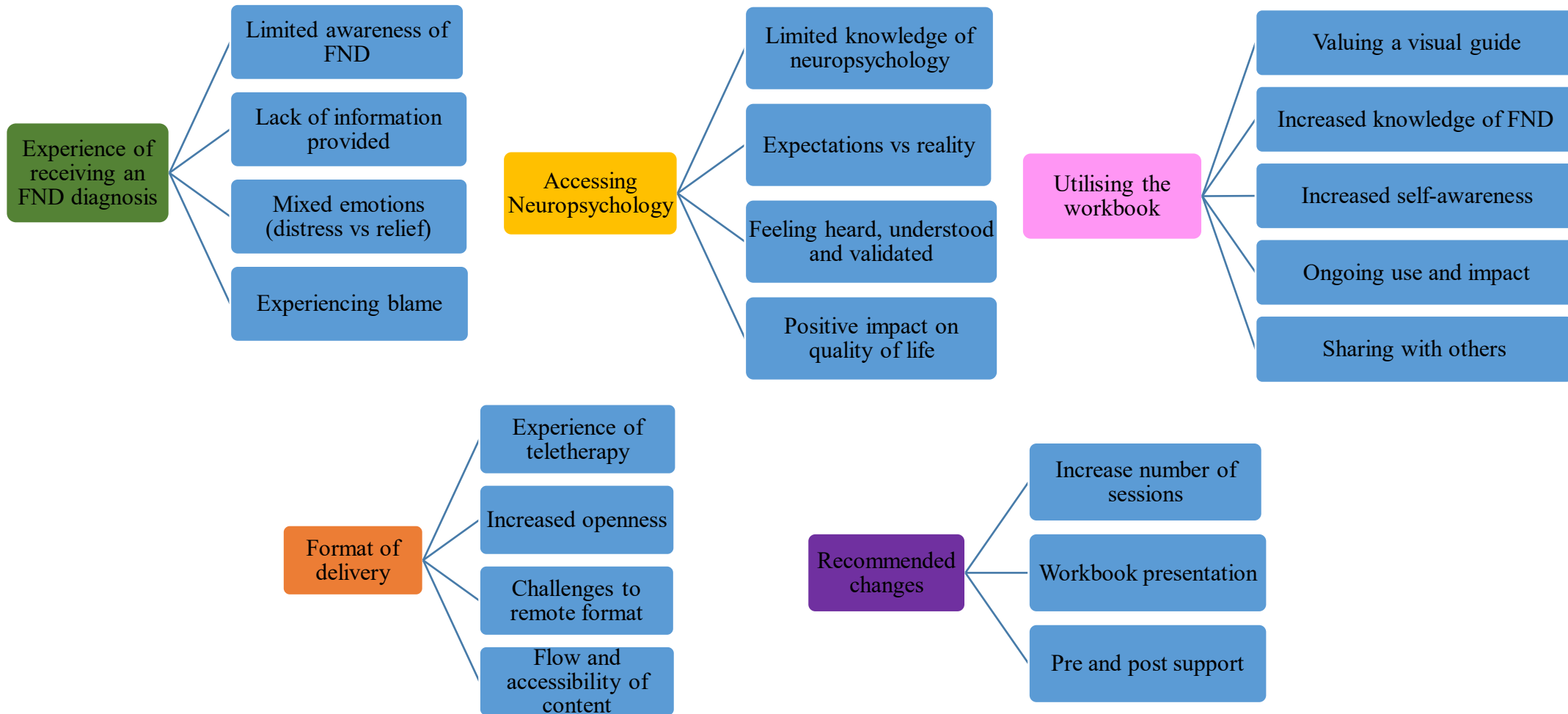
Participants were made aware they could stop the interview at any time and had the right to withdraw their data up until one week after their interview was completed. All participants were assigned a number to maintain anonymity throughout this report. All recordings and transcriptions were stored on a university approved secure drive.

## **5 Results**

Five themes, along with their connected subthemes were generated from the data (see figure 1) and will be further detailed and discussed below. Table 2 presents the themes, subthemes and example quotations.

**Figure 1**

*Thematic map of the five themes and related subthemes*



## **5.1 Theme One: Experience of Receiving an FND Diagnosis**

The first theme focused on participants' experiences of receiving an FND diagnosis, prior to being seen by neuropsychology. This was split into four subthemes; **limited awareness of FND, lack of information provided, mixed emotions (distress vs relief) and experiencing blame.**

### **Limited awareness of FND**

Five participants shared having had no prior knowledge or awareness of FND when they first received their diagnosis. Participants shared how this had not been mentioned to them as a possibility during prior appointments. Participants reflected on how this limited insight into FND resulted in feelings of confusion. For example, one participant shared not previously being aware that neurological symptoms could be linked to a functional cause.

### **Lack of information provided**

Five participants reported that the FND information offered to them at diagnosis was very basic and limited. As a result of an inadequately explained diagnosis, some participants shared leaving their appointment still not understanding what FND was. One participant shared only being provided with the name of their diagnosis, but little further detail. Poorly explained diagnoses left participants seeking out information via other means such as the internet, however for some the information was not always accessible and led to further feelings of confusion.

### **Mixed emotions (distress vs relief)**

Seven participants shared experiencing various emotions when receiving their FND diagnosis. For some, emotions fluctuated between feelings of distress and relief. This feeling of relief for one participant was linked to finally having a diagnosis confirmed, whereas for another it was knowing that their diagnosis was not linked to an organic neurological cause. Experiencing confusion was also commonly reported, which again was linked to lacking understanding around the diagnosis.

### **Experiencing blame**

Two participants shared how their journey to diagnosis had included more negative experiences. These participants reported moments where they were made to feel that their neurological symptoms were feigned or that they were to blame for them. One participant reflected on feeling that the adverse way in which the diagnosis was shared with them was linked to the professional lacking a good understanding of FND.

## **5.2 Theme Two: Accessing Neuropsychology**

The second theme focused on participants experience of accessing neuropsychology support. This was split into four subthemes; **Limited knowledge of neuropsychology, expectations vs reality, feeling heard, understood, and validated, and positive impact on quality of life.**

### **Limited knowledge of neuropsychology**

Seven participants shared having very limited or no knowledge of what the role of neuropsychology was prior to being seen. Some participants reported previous experiences of accessing support from psychology or counselling services in different contexts, but not neuropsychology. Although having this limited knowledge, participants reflected on having an openness and eagerness to be seen by neuropsychology, expressing hopes that this would increase their understanding of FND and support them to learn ways to manage their symptoms.

### **Expectation vs reality**

Five participants reflected on the difference between their anticipated expectations of neuropsychology support compared to what their actual experience was when sessions began. Participants shared how before being seen, they did not foresee any positive changes or outcomes occurring. However, once the support began these views quickly changed, and participants reflected on how beneficial these sessions were in improving their quality of life and wellbeing.

### **Feeling heard, understood, and validated**

Seven participants shared positive reflections on their overall experience of engaging with neuropsychology, with sessions providing a space where they felt well supported. Participants found having their feelings and experiences validated and normalised by the Psychologist to be an extremely important and empowering moment for them. Participants valued not feeling rushed in sessions and when the Psychologist

clarified information which they had shared, this supported them to feel heard and understood. Some participants reflected on how accessing neuropsychology had increased their confidence and reduced feelings of self-blame.

### **Positive impact on quality of life**

Six participants reflected on how accessing neuropsychology had contributed to positive changes and improvements in their quality of life. Participants found gaining a deeper understanding of FND and having their feelings normalised, both beneficial and validating. Some participants reported feeling happier and more connected with themselves, as a result of this support. Through exploring and understanding the triggers for their FND symptoms, some participants expressed feeling more aware and better able to manage them.

### **5.3 Theme Three: Utilising the Workbook**

The third theme focused on participants experience of utilising the FND workbook within and outside of sessions. This was split into five subthemes: **valuing a visual guide, increased knowledge of FND, increased self-awareness, ongoing use and impact, and sharing with others.**

#### **Valuing a visual guide**

Seven participants offered positive reflections around having the FND workbook as a visual guide to work through. Some participants commented on feeling connected to the content of the workbook and valuing having this to read through and to feel better prepared for sessions. Some participants reflected on being more visual learners and valuing the diagrams within the workbook to aid discussion and understanding. Participants also found it helpful having the workbook available to refer to outside of sessions to aid recalling content discussed.

#### **Increased knowledge of FND**

Seven participants reported that completing the workbook supported them gaining a better understand of FND and what may have contributed to their symptoms developing. One participant reflected on how gaining a greater insight into their FND was the needed first step to enable them to really work on making changes in their life. Many participants commented on how they found the use of diagrams and analogies

within the workbook further aided their understanding of FND, and references to external resources were also valued.

### **Increased self-awareness**

Six participants reported increased self-awareness from completing the workbook. For example, participants reflected on how this support had enabled them to learn new things about themselves. Participants valued the opportunity to explore their past, as this enabled them to consider and identify experiences which had continued to have an impact on them. Some participants also reflected on how completing the workbook sessions had supported them to think about what could be beneficial for them going forward, for example accessing further support.

### **Ongoing use and impact**

Six participants reported continuing use of the FND workbook since their neuropsychology sessions ended. Participants shared how the workbook had continued to support their journey with FND and normalisation of feelings surrounding their diagnosis. Some shared appreciating having the workbook to look back on when feelings of self-blame relating to their diagnosis were triggered. Participants also reflected on finding the references to extra resources helpful to refer to.

### **Sharing with others**

Seven participants reported that they had shared the content of the workbook in some way (e.g. directly showing the workbook or through verbal discussion) with friends, family or other professionals supporting in their care. Participants found sharing this information helpful in supporting others to better understand FND.

## **5.4 Theme Four: Format of Delivery**

The fourth theme focused on the format of delivery. This was split into four subthemes; **Experience of teletherapy, increased openness, challenges to remote format, and flow and accessibility of content.**

### **Experience of teletherapy**

Seven participants reflected positively of their overall experience of completing the workbook via teletherapy. For most, engaging in this virtual format did trigger some initial feelings of apprehension, however these quickly dispersed once sessions began.

In contrast to attending an appointment in person, some participants reportedly valued being in the comfort of their own home, finding that this was less time pressured and had less of an impact on their daily life. Participants appreciated the option of being seen via video or telephone call. One participant shared that they would prefer face-to-face appointment going forward.

### **Increased openness**

Three participants reported that engaging in the workbook via teletherapy resulted in them feeling more able to open up during appointments. Participants reflected on factors such as not having the pressure of talking to someone face-to-face or being at an appointment and feeling time pressured, contributed to these increased feelings of openness. Some participants reflected feeling that it was unlikely they would have opened up as much if the appointments had of been in person, or if they had, it would have taken more time to do so.

### **Challenges to remote format**

Seven participants reported some challenges arising because of the remote format of sessions. These challenges were typically related to technical difficulties, such as issues with the internet connection which would result in the screen freezing or audio issues. The rates of these occurrences were reported as minimal, and participants generally did not express this having any significant impact on their overall experience of engaging in the sessions. One participant reflected on finding engaging in remote sessions more challenging, as it was difficult to find a quiet space at home where they would not experience interruptions from family or pets.

### **Flow and accessibility of content**

Seven participants reflected positively on the overall flow and accessibility of the workbook content. Although participants shared not feeling rushed, some felt they would have benefited from further sessions. In contrast, others felt that four sessions was the right amount. Several participants valued having a recap of the previous session at the beginning of each new week. One participant reflected on feeling that some of the workbook content was not relevant to their personal experience. Another shared finding one of the diagrams somewhat confusing, therefore valued having the Psychologist in session to talk through this with them.



## **5.5 Theme Five: Recommended Changes**

The fifth theme focused on recommendations for changes offered by the participants. This was split into three subthemes; **increase number of sessions, workbook presentation, and pre and post support.**

### **Increase number of sessions**

Five participants expressed feeling they would have benefited from more sessions. Three participants specifically indicated that an extra two sessions would have been preferred. Participants reflected feeling this extra time would have allowed them to explore some of the discussions had in more depth. Although participants did not report feeling rushed, some did feel that the sessions were quite intensive and that they ended just at a point when they were fully getting into them.

### **Workbook presentation**

Three participants offered individual recommendations for changes to the overall presentation of the workbook. One participant shared not feeling they connected with some of the content, therefore recommended including a section where participants can add comments if they did not feel something fitted with their experience and possibly why. One participant valued being provided with mindfulness strategies and grounding exercises and felt information on these could have been included in the workbook. Another participant reflected on feeling the workbook could have been more colourful to promote engagement.

### **More pre and post support**

Three participants shared thoughts around pre or post support they would have valued. In terms of pre-support, one participant shared experiencing some anxiety whilst awaiting an appointment and felt a leaflet normalising these feelings may have been beneficial. With post-support, some participants expressed feeling unsure where to access further support after sessions ended. One participant shared not feeling their GP would fully understand their diagnosis. Some felt they would have valued connecting with others experiencing FND and doing the ACT support group, however acknowledged that this group had not been running during the COVID-19 lockdown.

**Table 2***Themes, subthemes, example quotations*

<b>Theme</b>	<b>Subthemes</b>	<b>Example participant quotations</b>
<b>Experience of receiving a diagnosis</b>	Limited awareness of FND	<i>“I’d never heard of it so when the consultant in the hospital said, I remember, not crying, but you know when tears just escape that you can’t really control. I just felt really confused”</i> [participant 2]  <i>“I’d never heard of it, it had never been mentioned previously when I’d seen the neurologist or anyone, erm so I had no prior knowledge”</i> [participant 7]
	Lack of information provided	<i>“Although the hospital consultant gave me a very like basic explanation, I didn’t understand and I did go home and I googled it and I found there was so many variations, that I didn’t bother reading anything else because I didn’t know where I came in, in any of that”</i> [participant 2]  <i>“No, they pretty much said you’ve got, well it was functional fixed focal dystonia they basically said, and that was it basically”</i> [participant 5]
	Mixed emotions (distress vs relief)	<i>“(felt) quite upset and relieved that something had been diagnosed”</i> [participant 6]  <i>“I was relieved that actually yeah it wasn’t MS which is what my GP thought it was, and it had a name, I felt like it had a label then”</i> [participant 7]
	Experiencing blame	<i>“If you break your arm, you have a broken bone. If you have a cut then you’ve got that, you can see it physically happening. If you’ve got epilepsy, you can see the patterns in the brain</i>

		<p><i>as it's happening. But with this, it's kind of, sometimes, before this, I don't know, I was kind of made to feel I was making it up. You know, it's sort of, it's like, now look this is an actual condition, its real" [participant 3]</i></p> <p><i>"How they were talking to me, they were basically saying that it was all my fault and I'd caused it and I'd done it because I was basically messed up in the head, is how I got told basically. And that, I saw a lot of unprofessional doctors shall we say, but to me they didn't know enough about it, so they just put it down to me and that's how they worded it to me" [participant 5]</i></p>
<p><b>Accessing Neuropsychology</b></p>	<p>Limited knowledge of neuropsychology</p>	<p><i>"I had bad anxiety when I were younger, I have spoken with a psychologist at the crisis team. Erm, but that's the only type of psychology I had heard off before. I'd never heard of a neuropsychologist" [participant 1]</i></p> <p><i>"I tried counselling and seeing a psychologist in the past, but I'm not one to open up so at first I was a bit like dubious like I didn't want to do it, but then I though like because of neuro, I thought they might be more understanding, so I'll give it a go and I'm glad I did" [participant 5]</i></p>
	<p>Expectations vs reality</p>	<p><i>"So, I won't lie, at first I thought I couldn't understand how talking would change things. Erm, I was a bit sort of naive to that, but erm, yeah I did think it wouldn't work and what would be the point, but I quickly realised on the second session that this was going to be really beneficial, and it was going to change my life" [participant 2]</i></p> <p><i>"If I'm 100% honest, no. I didn't (expect change). like I say I've done quite a lot of counselling and like I say I'm a (profession named). So, I've always classed myself as quite self-aware on certain things anyways, so in a lot of ways I wasn't expecting anything from it. But</i></p>

		<i>when we talked through the different sessions, yeah it did, it really did open my eyes and change the ways I looked at things and I wasn't expecting it at all" [participant 3]</i>
	Feeling heard, understood, and validated	<i>"It was only when I had the psychologist appointments and she normalized it for me, that it made me feel better in myself because I was so confused as to why it was happening" [participant 1]</i>
		<i>"I felt (psychologist) was very good at, like every so often she reiterated it and erm, explained what she understood from me, which made me know that what I'd said was what I'd expressed" [participant 2]</i>
		<i>"I just felt understood for the first time, I felt like I could think about it and I know it's not my fault, I'm not doing this, I can't possibly do this to myself" [participant 5]</i>
	Positive impact on quality of life (QOL)	<i>"(QOL is) a lot better because I know now, it's been normalized for me now that this isn't, it's not just something taking over my body forever. It's something that I can have good days now, and is something I can learn to live with" [participant 1]</i>
		<i>"It has been a lot better (QOL) in that, I mean I said to a friend a few weeks ago, this moment now I feel more myself and a lot happier than I realise in a long time. I feel I probably wouldn't have been there without those sessions" [participant 2]</i>
<b>Utilising the workbook</b>	Valuing a visual guide	<i>"Having the workbook as well, it meant that I had something to focus on and I knew the kind of, erm like the flow and set up of the meeting, and I'd been able to read it beforehand and made me think about things" [participant 2]</i>
		<i>"I am quite a visual person, so that visual prompt was really quite useful" [participant 3]</i>

*“I actually found it really really helpful. As someone who was coming into something really confused and not quite sure what it was they were trying to talk to me about, I found out, I found reading the book it actually made a lot more sense, explained what FND was, so I was really grateful to kind of be able to work through that” [participant 4]*

Increased knowledge of FND

*“It (workbook) helped normalise like how I felt. Just getting diagnosed and then leaving from the neurologist, it was all on my own then, and I didn’t know what FND was apart from people describing on Facebook about their bad days. Whereas the workbook explained what symptoms are and why they are doing it to you” [participant 1]*

*“It’s definitely given me a greater understanding of it... I felt that workbook made a lot of sense. It’s like everything I’d already known, it was in there, but it had all been put together in a way that I understood, and it were, I found it really helpful” [participant 5]*

*“There’s a piece about, brain tabs, you know like your brain is like a computer with all the tabs open, and that’s my brain all the time and I’m trying not to do that. But that, that was a brilliant part of it. To me it was a awakening. It was like yep that is exactly how I feel” [participant 7]*

Increased self-awareness

*“I found it really enlightening really. A lot of things that I had never realised about myself, you know spanning quite a few years back, erm I could see that it had been a problem for longer than I’d realised. Working through the workbook, if I hadn’t worked through the book, I probably wouldn’t know half of what I know now” [participant 2]*

*“She (psychologist) made me realise because we went through my, basically my background, so she’s made me realise a lot of things that I might not have dealt with, a lot of things at the time and about this opening all the tabs. I’ve shut a couple down since doing it, I’ve gone back*

		<i>over them and dealt with them. Whereas I hadn't before, I'd just left them like open"</i> [participant 5]
	Ongoing use and impact	<i>"I do read it every now and again. I read the last couple of sessions because I think like moving forward, they are the ones I found most valuable. Now I know what the issues are but I keep reading it for sort of reference, especially when I'm feeling a bit overwhelmed with life. Just to remind myself that I can get through this"</i> [participant 2]
		<i>"My mental quality of life has improved. My impression of myself is improving, that will always, I'll always need to work on that I think, there's no fix to that. Erm, but I'm using the things I've learnt from it to change how I let people treat me and the fact that my leg feels like pins and needles all the time, I'm going to need other help with fixing that. But I will always use this workbook to keep working on myself"</i> [participant 7]
	Sharing with others	<i>"(shared workbook) with the physio people that come here, we look through it together"</i> [participant 1]
		<i>"With my wife, I sort of went through stuff after some of the sessions and at the end of it as well. Like I say, its helped"</i> [participant 3]
<b>Format of delivery</b>	Experience of teletherapy	<i>"At first, I would have much preferred having gone into the hospital and sat there, definitely. But having had done it, I can see the value in it. You know because I was at home, I felt comfortable, and relaxed that I was in my own environment"</i> [participant 2]
		<i>"I suppose I was worried that I wouldn't be quite as invested in it, that I wouldn't be quite as you know, that it wouldn't really make as much of an impact because it was over the phone... but to be honest when we were actually doing it, I didn't find that to be a problem. I found it quite useful"</i> [participant 3]

		<i>“It was just handy (being online), I could take my son to school and sit straight back here in the garden” [participant 7]</i>
	Increased openness	<i>“That whole thing of not having to look face to face in some ways enabled me to open up” [participant 3]</i>
		<i>“I probably wouldn’t have opened up as much as I did do over the phone. I mean, I probably would have done in time, which is where the extra sessions would have come in useful. It would have probably taken me longer to open up” [participant 5]</i>
	Challenges to remote formats	<i>“There were a couple of times where (psychologist) broke halfway through a sentence. Erm and there were, the last meeting, I could hear her when she logged on, but she couldn’t hear me. So, it was just a case off logging out and logging back in. But nothing major and I’ve had far worse things on teams” [participant 2]</i>
		<i>“The only issues I suppose did come across was obviously with it being at home, there’s the whole, like now, the dog barking, there were times when the kids were at home and having to sort of getting them to leave the room” [participant 3]</i>
	Flow and accessibility of content	<i>“Yeah, the buildup was really good. Yeah, each day led onto a different subject and then it built on really well. Like each day were different in the appts, but also we’d have a recap of the week before” [participant 1]</i>
		<i>“It wasn’t rushed, and it was really good but I think it would have benefited from being a little more spread out” [participant 3]</i>
<b>Recommended changes</b>	Increase number of sessions	<i>“Just an extra two maybe, just to, because the first day was quite intensive because I still didn’t know what was happening, and I think there could have been another day where it just</i>

*explained who they were and what my condition was firstly and then talk about why I was experiencing it afterwards” [participant 1]*

*“It just felt like because we had obviously the initial one, and then it felt and then obviously the last one is like an evaluation of it all, it just felt like we were just getting into it as it finished. So definitely another two I would have said. So, six rather than four definitely” [participant 5]*

Changes to workbook presentation

*“I think maybe just a bit of, or even just a section to kind of just to say, ‘does this not resonate with you, no, put why’, do you know what I mean. Just so that person can have a, if they feel confident enough or they want to share it they can make notes or something” [participant 4]*

*“The content is good and it leads you off into different directions...but I just think to look at its not very stimulating” [participant 7]*

More pre and post support

*“I feel if something goes wrong, it would be the GP, but I honestly don’t think the GP has the understanding. So, I feel just a little bit, when I say it ended, it felt like the safety net ended as well” [participant 2]*

*“The actual sessions in the workbook itself I found that great. It was sort of the follow up from there because there was talk of there being a group thing or service stuff afterwards, but obviously because of covid and everything else, that’s gone by the wayside. I think having that sort of follow up of either being with other people that have got it to sort of, sometimes you can help each other through that type of thing, stuff like that, that could have been beneficial” [participant 3]*



## 6 Discussion

### 6.1 Key Findings

This SEP aimed to evaluate participants overall experience of completing an FND workbook, delivered via teletherapy. From the interviews conducted, it is evident that the workbook has been an invaluable tool, aiding in increasing participants understanding of FND, supported in the process of developing individual formulations, and has been a helpful resource for participants to look back on. Five themes were drawn from this evaluation which acknowledged participants experience of receiving a diagnosis, accessing neuropsychology, utilising the FND workbook, format of the workbook delivery and finally recommendations for improvements.

All participants reflected on their diagnosis journey, prior to being seen by neuropsychology. Poorly delivered FND diagnoses are unfortunately not uncommon (Cock & Edwards, 2018), and many participants in this SEP shared how their more negative diagnosis experiences left them feeling confused and lacking insight around FND. Participants reflected on how their diagnosis triggered an array of emotions including both distress and relief. Similar to findings in wider literature, some participants shared adverse experiences where they felt disbelieved or even blamed for their symptoms by healthcare professionals (Dosanjh et al., 2021; Robson & Lian, 2017).

Participants shared finding their overall experience of accessing neuropsychology to be highly beneficial, providing a space where they felt truly heard, understood, and validated. Participants reflected positively on the incorporation of the FND workbook within sessions, finding that working through this supported them to develop a deeper understanding of FND, increased aspects of self-awareness, and helped them to explore symptom triggers and management strategies. The value of sharing the workbook with others was also acknowledged. These findings support wider literature recommending the use of workbooks with FND patients (Gilmour et al., 2020; Nielsen et al., 2015), and support the positive impact short-term psychology input, focused on psychoeducation and shared development of formulation can have on FND patients' quality of life and wellbeing (Gutkin, Brown, McLean, et al., 2021).

Psychotherapy can be effectively delivered via teletherapy to FND patients (LaFrance et al., 2020) and this evaluation supports the value of incorporating the use of

a workbook in this format of delivery too. Teletherapy did pose some challenges, including technical difficulties arising. However, this did not impact on session engagement and many participants valued accessing this support from the comfort of their own home. Participants commented positively on the flow and accessibility of content, however some reflected feeling they would have valued the material being spread out over more session, allowing time for further discussion. Many participants found the combination of verbal discussion, typed text (including use of analogies) and visual diagrams within the workbook to be beneficial to their learning.

Some participants offered feedback on areas in which they felt the workbook and their experience could have been improved. These included reflections around number of sessions offered, support provided pre and post workbook and on aspects of the workbook presentation. These are all acknowledged in the recommendations (See Table 3).

## **6.2 Strengths and Limitations**

This project had several strengths and limitations. Firstly, a key strength was that the qualitative methodological design selected was both feasible and appropriate in meeting the project aims. By conducted semi-structured interviews, this provided freedom and flexibility to explore certain topics in more depth, enabling more valuable and meaningful data to be gathered. This SEP provided evidence highlighting the value of the FND workbook in neuropsychology services. It also captured how adaptable neuropsychology services have been during the COVID-19 pandemic, and how the use of teletherapy formats can be an effective alternative to face-to-face appointments.

In terms of limitations, seven participants took part in this SEP, which although is an acceptable number for qualitative research (Tracy, 2019), it is acknowledged that a bigger sample size would have been more representative. All participants who did take part reported positive experiences of completing the workbook. One participant who agreed to being contacted but then declined interview, shared not wishing to take part due to having had a more negative experience. This highlights how potentially, some participants may have experienced worry around the impact sharing more negative feedback could have had (e.g. on future care). By only capturing the more positive experiences, this could mean the data was at risk of bias and is not generalisable to all FND patient experiences of completing the workbook.

Furthermore, with this SEP only focusing on participants who had completed the full four session workbook, it neglects to acknowledge participants who may have started the workbook and then discontinued. Gaining feedback from these participants would be highly valuable, as this may have provided more insight into the potential barriers some participants experienced completing the workbook in a teletherapy format.

As discussed earlier, Elliott et al. (1999) highlights the importance of owning one's own perspective within qualitative research. Having previously worked in neuropsychology services, I have seen how valuable the support offered within these services can be. Therefore, I have been mindful of my experiences and possible pre-existing assumptions throughout this SEP, and do not feel it is likely these will have bias the results. Delivering a balance of questions in the interviews and carrying out credibility checks to ensure face validity, will also have supported preventing this.

### **6.3 Dissemination**

The finding from this SEP were presented to the Leeds Clinical Psychology programme at a conference in October 2021. A presentation was also made to the project commissioner and their neuropsychology team in November 2021. This report will also be shared with the commissioner.

## **7 Conclusion and Recommendations**

Overall, this SEP captures helpful insight into the value of the FND workbook for use in teletherapy. It was evident from the findings that participants found the workbook to be a beneficial tool which supported their overall learning and understanding of FND and has been something which they have continued to refer to. Although majority of feedback was positive, some participants offered constructive reflections on aspects of the workbook and their experience which could have been improved. These have been acknowledged within themes/subthemes and within the recommendations below.

**Table 3***Summary of recommendations*

Recommendations
<ul style="list-style-type: none"> <li>• Participants spoke highly of their overall experience completing the FND workbook. This visual guide enabled participants to feel prepared for sessions, have all the needed materials available in one place, and is something which they have been able to look back on and share with others. This positive feedback supports the ongoing use of the FND workbook for use in teletherapy. It would be recommended that this workbook also be considered for continued use when in-person appointments recommence.</li> <li>• Several participants shared how they would have valued the opportunity to have had more sessions with their Clinical psychologist, so they could have explored some of the discussions had in greater depth. From this feedback, it may be beneficial for the service to continue the workbook running over four sessions, however providing the opportunity of two additional sessions for those who would find this further input valuable.</li> <li>• Some participants expressed finding it empowering to be given the option of having telephone or video call sessions. Therefore, it would be encouraged that both these options remain available, but also that patients are made aware they can also switch at any time.</li> <li>• It was captured from participant feedback that the period between receiving a diagnosis and waiting to be seen by neuropsychology may trigger some feelings of anxiety for patients. Therefore, it may be beneficial for patients to receive an interim call from the service, providing an opportunity for the patient to ask any questions they might have whilst awaiting to be seen. Alternatively, a leaflet providing some further information about the FND pathways could be sent out to patients.</li> <li>• Some participants shared feelings of uncertainty around who to access further support from following completing the FND workbook and reflected on not feeling other healthcare professions (e.g. GPs) would have a good understanding of FND. Therefore, it may be beneficial for GPs to receive a summary letter of the</li> </ul>

input provided by the neuropsychology service, to aid other professions supporting in the patients care having a better understanding of FND.

- Some participants shared how they would have valued accessing the ACT support group after finishing their four sessions. Unfortunately, the impact of COVID-19 has meant that this group has stopped running at present. However, the charity 'FND Hope' are currently offering a zoom peer support group. Therefore, information on this could be provided to patients at the end of their final session.
- Two participants offered recommendations linked to the presentation and content of the workbook which the service may wish to take forward. These recommendations included the design of the workbook being more colourful, to promote engagement. Also, it may be helpful to include a section in the workbook which acknowledges that some of the content may not always connect with the patient.
- It would be beneficial to consider completing a further SEP to also explore staffs' experience of using the workbook within teletherapy.

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## 9 Appendices

### 9.1 Appendix A: Participant Information Sheet



## Service Evaluation Project

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### Participant Information Sheet

#### **Project: An evaluation of the Functional Neurological Disorder (FND) workbook for use in tele-therapy.**

You are being invited to take part in a Service Evaluation Project. A Service Evaluation Project is designed to help evaluate how effective a service being offered is and to identify any improvements which could be made to change or better that service. Before you decide to take part, it is important for you to understand why the project is being done and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish. Please also feel free to contact us if there is anything that is not clear, or you would like more information on.

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

The aim of this project is to evaluate the workbook you have completed with your psychologist.

#### **Why have I been chosen?**

You have been asked to take part in this project as you have now finished your four sessions with your psychologist in which you worked through a workbook together. I am very interested to hear about your experience of completing the workbook, how you found completing this remotely, what you found most helpful and anything you felt could have been adapted or improved.

#### **Do I have to take part?**

No. Taking part is entirely voluntary. If you would like to take part, you will be given a consent form to read through and complete. However, if you do not wish to take part, you can do so without needing to give a reason.

**What if I agree to take part but then change my mind?**

If you decide to take part but change your mind after the interview, your information can be withdrawn from the study up to one week after the interview has been completed. This can be done by contacting Dr Trishna Gandhi, Clinical Psychologist, Clinical Psychology Department, Pinderfields Hospital on 01924 541510.

**What happens if I do decide to take part?**

If you agree to participate in the project, I would like to contact you via telephone at an agreed time which is convenient for you. The telephone call will last approximately 30-45 minutes and will involve talking about your experience of completing the workbook. At the end of the interview, details on how you can access further support will be provided if needed.

**Will I be recorded and what will happen with my information?**

The telephone interview will be recorded using an audio recording device. The researcher will also be making some written notes during the telephone conversation. The lead researcher of this project, Clare Charman, is independent from the clinical team you have been seen by and it is important to note that your responses will not affect your future clinical care in any way. Following the interview, the researcher will listen back to your experiences and other peoples to see if there are any similarities or differences. All recordings will be deleted following the full completion of this project.

A report will be written up which will highlight the key findings from the interviews completed. The report may use direct quotes taken from the interviews, however, all participant details will remain anonymised. Findings from this service evaluation may also be written up and submitted to an academic journal for publication, however again all participant data will remain anonymised. Findings from this project will also be presented to the commissioning service.

Please also find attached with this document a copy of the University Research Participant Privacy Notice. Alternatively, please click on the following: [Privacy Notice for Research](#).

**Are there any benefits for taking part?**

There are no direct benefits to you taking part in the project. However, your participation will support us to think about how the service can continue to improve the delivery of the workbook for use in tele-therapy in the future.

**Who has reviewed the project?**

This project has been reviewed and given approval by the Doctorate in Clinical

Psychology Research Ethics Committee (DClinREC project number 20-002)

**Who do I speak to if I have any questions?**

If you have any questions about this project, or would like further information, please contact Clare Charman (Psychologist in Clinical Training) at [umcac@leeds.ac.uk](mailto:umcac@leeds.ac.uk). Alternatively, you can also contact Dr Trishna Gandhi, (Clinical Psychologist), within the Clinical Psychology Department at Pinderfields Hospital on 01924 541510.

**What if I have a complaint?**

We think this is unlikely to happen, but if it does you can contact either Dr Gary Latchford or Dr Trishna Ghandi on the email addresses provided at the end of this participant information sheet to raise any concerns you have in regards to the project.

**Thank you for taking the time to read through this information sheet.**

Clare Charman | Psychologist in Clinical Training | [umcac@leeds.ac.uk](mailto:umcac@leeds.ac.uk)

Dr Gary Latchford | SEP Academic Tutor | [G.Latchford@leeds.ac.uk](mailto:G.Latchford@leeds.ac.uk)

Dr Trishna Gandhi | SEP Commissioning supervisor | [trishna.gandhi@nhs.net](mailto:trishna.gandhi@nhs.net)

Clinical Psychology Training Programme  
Leeds Institute of Health Sciences  
Level 10 Worsley Building | Clarendon Way  
University of Leeds | Leeds | LS2 9NL

## 9.2 Appendix B: Consent Form



### Service Evaluation Project

#### Consent to take part in the project: An evaluation of the Functional Neurological Disorder workbook for use in tele-therapy

*Please read each of the below statements and place a tick in the box on the right if you agree to the statement:*

I confirm that I have read and understand the information sheet (version 2, dated 27/1/2021) provided to me explaining the above research 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 from the study at any time up until the point of the interview being transcribed (one week after) without being required to provide a reason for withdrawing. In addition, should I not wish to answer any particular questions, I am free to decline.

I agree to take part in the interview and for this to be recorded and used in the write-up of this project. I understand that quotes from the interview may be used within the report from this research, however all identifiable information will be removed, and my anonymity will be preserved.

I agree to my non-identifiable data for this service evaluation project being submitted to an academic journal in the event of being written up for publication, without further consent being sought.

I agree to take part in the above project

**Participant details:****Date:****Name of participant:****Participant signature:****(If viewing this online, please type your name via the OnlineSurvey to consent to this study)**

Clare Charman | Psychologist in Clinical Training | [umcac@leeds.ac.uk](mailto:umcac@leeds.ac.uk)

Dr Gary Latchford | SEP Academic Tutor | [G.Latchford@leeds.ac.uk](mailto:G.Latchford@leeds.ac.uk)

Dr Trishna Gandhi | SEP Commissioning supervisor | [trishna.gandhi@nhs.net](mailto:trishna.gandhi@nhs.net)

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### 9.3 Appendix C: Interview Schedule



## Service Evaluation Project

### An evaluation of the Functional Neurological Disorder workbook for use in tele-therapy

#### Interview schedule

##### Introduction:

Good morning/afternoon, my name is Clare Charman and I am a Trainee Clinical Psychologist at the University of Leeds.

You may recall during the final session of completing your FND workbook, which was delivered by your Psychologist, being asked if you would be interested in taking part in a study evaluating this workbook. Further information about the project was sent out to you and following consented to taking part we are organizing this interview call today.

I would like to ask you some questions about how you found completing the FND workbook remotely (either by telephone or video call), such as what you found most helpful and if there was anything which you felt could have been improved. By gaining your valuable thoughts and reflections on completing this workbook, the hope is that this will help in the ongoing development and delivery of the FND workbook to others in the future.

The interview should take around 30-45 minutes to complete but if you would like to stop or re-arrange this at any point, just let me know. There may be times in which I need to move the conversation along as I will be keeping an eye on the time.

##### Consent:

As a reminder, the interview today will be recorded, however all information will be stored securely and anonymized during the write-up. Recordings will be deleted once the project has been fully completed.

If there are any question you would prefer not to answer, that is absolutely fine, just let me know and we will move onto the next question. If there are any questions which you feel are unclear or you are unsure on the answer, again just let me know and I will try my best to reword this.

Please feel free to ask any questions at this point?

<b>If Yes:</b>	Thank you for agreeing to participate ( <b>proceed to the interview</b> )
<b>If No:</b>	I would like to thank you for your time speaking with me today. To remind you, your decision will have no impact on your treatment and care you receive within the healthcare service.

Do you consent to still take part in the study?

### **Interview schedule:**

**1. Prior to your diagnosis, what symptoms were you experiencing and how did it impact on your quality of life?**

*(prompts: Symptoms most experienced? Impact day to day?)*

**2. What were your initial feelings when first diagnosed with FND and how would you describe your understanding of FND at that time?**

*(prompt: had you thought about FND up until this point? What emotions do you recall experiencing? What info were you provided?)*

**3. When first referred to neuropsychology, what were your initial thoughts and hopes?**

*(prompts: Did you have some ideas about the role of psychology and what they can support with? Did you have any initial apprehensions?)*

**4. How would you describe your overall experience of completing the FND workbook?**

*(prompt: length / number of sessions. Session content – did it feel fully accessible? Flow of the 4 sessions? Having the workbook as a visual and guide?)*

**5. How did you find completing the workbook in a remote format?**

*(prompts: did you have any initial thoughts or worries about this style of delivery? tech difficulties during sessions? Was there anything you particularly liked or didn't like about this format?)*

**6. What difference do you think it would have made if the sessions had been face to face?**

**7. Has the workbook contributed to your learning and knowledge about FND?**

*(prompt: what was your understanding around the purpose of the workbook? Has your understanding of FND increased? What did you find most helpful learning about? Was there anything you would have liked more information on?)*

**8. How has your quality of life been since engaging with your psychologist and the workbook?**

*(Prompt: If yes, what changes have you noticed? (e.g. if having seizures, how frequently are these happening now? do you attribute these changes to having completed the workbook? Were you expecting any changes?)*

**9. What did you find most helpful about completing the FND workbook?**

*(prompts: have you continued to use the workbook? Have you shared the content of these with others such as friends/family?)*

**10. What did you find least helpful about completing the FND workbook?**

**11. Finally, can you think of any ways in which your experience of completing the FND workbook could have been improved?**

That is now the end of the interview. thank you for your time. Did you have any questions following completing this interview?

*\*Provide information on sources of support if needed (e.g. support websites such as 'FND Action' or 'neurosymptoms'. The contact number for the Neuropsychology team seen at Pinderfields can also be provides where a review appointment can be offered).*

*\*Ask participant if they would like to receive a summary of the findings and if they would ask if they would prefer this to be sent via email or post. To those who would like a summary, explain that this will be sent around September / October time when the study has been completed.*

#### 9.4 Appendix D: Example Theme, Subtheme, Codes and Quotations for 'Accessing Neuropsychology'

Theme	subtheme	codes	Quotation
Accessing neuropsychology	Feeling heard, understood and validated	Experience was normalised	"It was only when I had the psychologist appointments and she normalized it for me, that it made me feel better in myself because I was so confused as to why it was happening"
		Feeling heard and valued	"I thought the hour was good and I never felt rushed off neither. I think a few times we may have overrun by about 5 minutes, but I felt like in that moment I felt valued and what I had to say was valued, rather than the time..."
		Feeling heard and understood	"I felt (psychologist) was very good at, like every so often she reiterated it and erm, explained what she understood from me, which made me know that what I'd said was what I'd expressed"
		Increased openness and reduced feelings of self-blame	"She ( <i>psychologist</i> ) helped me come to terms with a lot of things, I've felt like I can open up more after it as well and am more confident with the functional side not being my fault. Yeah, it's helped my mindset as well"
		Feeling understood	"I just felt understood for the first time, I felt like I could think about it, and I know it's not my fault, I'm not doing this, I can't possibly do this to myself"
		Feeling understood	"Just to talk to somebody really, and ( <i>psychologist</i> ) was really good. You know, erm, to talk to somebody that understood..."

		Feelings being validated	“It (workbook) says why have I been referred to a psychologist do you think I’m making it up and it’s like saying your symptoms are real and it’s just validating how you feel”
		Feeling understood and supported	“Yeah definitely ( <i>psychologist</i> ) was really great in kind of just listening to me and if something went off on a slight tangent, it was really great because she’d let me explore that but would then help me understand how it came back into this”
		Feeling believed and understood	“They understood me rather than told me I was just basically putting it on and it was just me... That was the first time I felt understood definitely”