# “Like living in a house where somebody's constantly rearranging the furniture”

# Narratives of receiving a Functional Neurological Disorder diagnosis.

**Constance Forrest**

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School of Health & Social Care

University of Essex

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# Abstract

**Background**: Functional Neurological Disorder (FND) is a debilitating and poorly understood condition encompassing a range of neurological and physiological symptoms. The past century has seen large shifts in FND's conceptualisation, away from its origins of *hysteria* and *conversion disorder,* however these understandings remain prevalent within healthcare. Despite being one of the most common neurological conditions in the UK, it remains mischaracterised in clinical settings and public awareness is minimal. Against this backdrop, the patient's experience of FND is unclear.

**Aims:** This study aims to explore how receiving a diagnosis of FND shapes patients' meaning-making of their experiences. The study seeks to illuminate the complexities of identity, explanations, and communication in FND, with the goal of informing more effective clinical practice.

**Methods:** Fifteen persons who have been diagnosed with FND participated in semi-structured interviews in which they shared their stories with the researcher. These stories were then transcribed and analysed using both thematic and performative narrative analysis.

**Results:** Four narrative types are identified in the data, Stories of Biographical Disruption, Stories of Inadequate Explanation, Stories of Stigma and Validation and Stories of Embodied Reinterpretation.

**Discussion:** These narratives reveal the impact of diagnostic ambiguity and the resultant challenges to identity. Findings underscore the for greater legitimacy for FND in clinical and social contexts. Implications for clinical practice include the importance of meaningful explanations and the ethical responsibilities of healthcare professionals in supporting FND patients.

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# 1 Introduction

## 1.1 Chapter Overview

To introduce the study, this chapter begins by outlining the historical and contemporary conceptualisations of Functional Neurological Disorder (FND). A systematic review of the literature is carried out to consider the existing literature on the patient experience of FND diagnosis. The review is concluded by presenting a new line of argument from the findings, which is then discussed in the context of the wider literature and theory. Different theoretical concepts are then presented and explored. The chapter concludes by outlining the objectives of the present study.

## 1.2 Background

### *1.2.1 Functional Neurological Disorder*

Functional Neurological Disorder (FND) is a condition characterised by a range of neurological symptoms that cannot be explained by traditional structural or disease-based neurological models. These symptoms, which may include seizures, movement disorders, speech disturbances, and sensory changes, are genuine and disabling, yet they are understood to arise from dysfunctions in the way the nervous system operates rather than from detectable brain damage or pathologies. FND is among the most common reasons for referral to neurology services worldwide (Ahmad & Ahmad, 2016). In the UK, it is estimated that between 50,000 and 100,000 people are currently living with the condition, and approximately 8,000 new cases are diagnosed each year (Hallett et al., 2016). Despite its prevalence, FND is frequently under-recognised and often misdiagnosed. According to Perez et al. (2021), the average time from symptom onset to a confirmed diagnosis is four years, with some patients waiting up to ten years. Before arriving at diagnosis, individuals often undergo multiple tests and consult several specialists, leading not only to frustration and uncertainty. The economic implications of FND are considerable. The condition incurs high costs for healthcare systems due to repeated investigations, hospital admissions as well as inappropriate treatments (Seneviratne et al., 2019). It also places a substantial burden on families and caregivers, who often have to manage complex and poorly understood symptoms without adequate support (Karakis et al., 2014). FND is understood to be profoundly debilitating for those who live with it. Individuals often report lower health-related quality of life than patients with other neurological conditions such as multiple sclerosis or epilepsy (Robson et al., 2018).

### *1.2.2 Historical Conceptualisations*

FND has historically been understood through a variety of cultural and spiritual frameworks. In ancient Greece, it was believed that symptoms arose from a "wandering womb," a theory suggesting that the uterus moved throughout the body, disrupting function and causing physical and emotional distress in women. During the Middle Ages, unexplained symptoms were attributed to demonic possession or spiritual afflictions, requiring treatments such as exorcisms or religious penitence. With the Renaissance, FND-like symptoms began to be reconsidered within a medical context. By the 19th century, *hysteria* became a focus in early neurology and psychiatry. The term derives from the Greek word ὑστέρα (hystera), meaning "womb". Influential figures like Jean-Martin Charcot and Sigmund Freud studied the phenomena extensively, shifting the focus from the uterus to the psyche, though it remained a highly gendered term. In the late 19th century with Jean-Martin Charcot (1980), who stated that "*hysteria is a disorder of the nervous system*", placing it within the realm of neurological disease and influencing the trajectory of psychosomatic medicine.

### *1.2.3 The Shadow of Conversion Disorder*

Freud's theory of conversion disorder (Breuer & Freud, 1995) laid the early psychological foundations for what is now known as FND. Freud & Breur conceptualised conversion disorder as a manifestation of unconscious psychological conflict. Their belief was that repression of repressed emotions or traumatic experiences, particularly those related to early life, were converted into somatic symptoms. Freud posited that this served a dual function for the patient: alleviating psychological distress through expelling of energy in the body (*primary gain*) and more controversially, attracting support or avoiding responsibilities (*secondary gain*). Modern understandings of FND have advanced significantly beyond this framework, but Freud's theories about converted symptoms are taught in psychology and psychiatric trainings (Paris, 2017). These ideas about the origins and intentionality of functional neurological symptoms have cast a long shadow over patients living with FND.

### *1.2.4 Contemporary Conceptualisations*

The conceptualisation of FND has evolved significantly over the past century, reflecting shifts in medical and neuroscientific understanding. Early theories emphasised psychodynamic conversion of emotional distress into physical symptoms. These ideas were complemented by theories like Janet's (1907) dissociation of consciousness and Myers' (1915) conceptualisation of shell shock, which anticipated later models of PTSD. From the 1960s onward, theoretical frameworks began integrating cognitive and affective processes into models (Taylor et al., 1997; Whitlock, 1967).

The late twentieth century has seen a revival of interest in FND research, with contemporary frameworks increasingly drawing on neuroscience. Models have sought to understand FND through brain-based, computational, and integrative biopsychosocial lenses, such as predictive processing models (Edwards et al., 2013), the seizure scaffold model

(Brown & Reuber, 2016), and the RDoC approach (Spagnolo et al., 2025). This illustrates a historical progression from predominantly psychodynamic and neurological views to multidimensional models.

The shift is reflected in changes to terminology and clinical definitions. Diagnostic and Statistical Manual of Mental Disorders (DSM) is designed to provide evidence-based frameworks for understanding, diagnosing, and treating mental disorders across healthcare and research systems (Kupfer et al., 2013). Its categorisations affect how mental illness is understood in both clinical settings and wider public consciousness. In the *DSM-IV* (American Psychiatric Association, 1994), FND was still labelled as "Conversion Disorder". However, the *DSM-5* (American Psychiatric Association, 2013), the American Psychiatric Association acknowledged growing dissatisfaction with the psychodynamic implications of the term. This a term was appended to read Conversion Disorder (Functional Neurological Symptom Disorder). This shift was further solidified in the *DSM-5-TR* (American Psychiatric Association, 2022), which formally reversed the terminology listing *Functional Neurological Symptom Disorder* as the primary name, with *Conversion Disorder* placed in parentheses. The rationale for this change was that Conversion Disorder is not *"an etiologically neutral term"* (APA, 2022).

This move towards *etiological neutrality* has ramifications for clinical practice, patients with functional symptoms are now more likely to diagnosed by a neurologist than a psychiatrist (Scamvougeras & Howard, 2020). The shift is beginning to be studied, Brenninkmeijer (2020) found that those diagnosed by a psychiatrist were likely to be told that their problems are of a psychological nature, whereas those who met with neurologists received an explanation to do with dysfunctions of the nervous system. Different explanations impact how patients experienced their disorder, and the level of agency and control they feel they have to overcome it.

Neurology has been responsible for a renaissance of research into FND, but direction of studies has shifted to disprove the psychodynamic hypotheses in favour of evidencing structural and connective abnormalities in the brains of FND patients (Perjoc et al., 2023) or highlighting the *normal* scores on psychometric measures of anxiety and quality of life for FND patients (van der Hoven et al., 2015). However, this break with tradition is not without concern, Scamvougeras and Howard (2020) argue that fully divorcing FND from its psychological characteristics risks neglecting the complex biopsychosocial processes within the disorder. They argue that if the psychosocial impact of receiving a diagnosis is overlooked or invalidated, it may contribute to suboptimal treatment and has potential for iatrogenic harm.

Despite shifts in understanding, historical perceptions of *malingering* or *feigning* continue to influence clinical attitudes. Nielsen et al., (2020) has found that clinicians working with functional motor disorder (FMD) patients often viewed them as challenging. Clinicians frequently report fear about how to communicate the diagnosis effectively and expressed uncertainty when working with FND patients (Barnett et al., 2022). This uncertainty around FND is also reflected in policy. National Institute for Health and Care Excellence [NICE] (2019) have extensive guidelines on investigating suspected neurological symptoms, but very little once symptoms are deemed to be functional, only a suggestion that patients *“are supported to manage symptoms that are a part of the disorder in non-specialist care.”* (NICE, 2022).

What it means for the patient to experience these diagnostic schisms of FND remains poorly understood. Despite growing recognition of FND as a legitimate condition, the perspectives of those living with the diagnosis are often marginalised within both clinical practice and health policy. The transition from the contested category of "medically unexplained symptoms" (MUS) to a formal diagnosis of FND has not necessarily resolved the epistemic uncertainty surrounding the condition. Crucially, questions remain about how patients experience their symptoms and interpret the FND label. Does it offer clarity and validation, or does it continue to evoke ambiguity and stigma?

## 1.3 Systematic Literature Review

### *1.3.1 Background and Rationale*

A systematic review of the qualitative literature was conducted in order to identify what is already known about the impact of FND diagnosis. Existing qualitative reviews of FND consistently highlight the complex and distressing landscape in which people navigate their condition. Szasz et al. (2025) demonstrate that individuals often grapple with profound feelings of being *lost*, marked by uncertainty, stigma, relational disruption, all shaped by a broader context of mistrust. Their synthesis shows that lived experience is influenced by personal environments, past stressors, and the capacity for supportive co-regulation. Foley et al.'s review (2022) position stigma as a central component of the FND experience, illustrating how delegitimization and social exclusion fundamentally shape patient's understanding and engagement with healthcare. Looking specifically at the experiences of people with motor and sensory FND, recent work by Bailey et al. (2024) emphasises *uncertainty* as the overarching thread. Their review shows how unclear causation, inconsistent communication and interactions with healthcare professionals can erode agency and reinforce stigma. They argue that early, clear diagnosis and validation are essential for recovery and that co-produced care pathways and improved clinician education are needed to reduce stigma and address unmet needs.

While these reviews offer valuable insights into the lived and sociocultural dimensions of FND, they reveal notable gaps that justify further investigation. Across the three syntheses, the patient voice is often filtered through broad thematic structures that can obscure important nuances in how individuals make sense of their symptoms. The existing reviews tend to focus either on specific aspects such as stigma (Foley et al., 2022) or motor/sensory symptoms (Bailey et al., 2024) or on relatively small pools of older qualitative studies (Szasz et al., 2025), meaning that the heterogeneity of patient experiences across the FND spectrum remains underexplored. None fully integrate more recent shifts in clinical practice or diagnostic framing. This leaves a gap for a review that brings together and re-examines patient accounts with greater attention to relational and contextual factors, and which foregrounds patient meaning-making in a more holistic and contemporary way. A new review is therefore warranted to build a more comprehensive understanding of patient experience that can inform practice, service design, and future research priorities. This review aimed to synthesise the existing literature across the patient experience of FND. The search terms defined by Table 1 yielded 1814 published papers.

### *1.3.2 Method*

It is increasingly acknowledged that qualitative research can inform practice and policy development (Grant & Booth, 2009). Qualitative data can provide a rich, nuanced understanding of the subject matter and therefore offers an insight into the human experience. Qualitative syntheses are recognised as important to integrate data from multiple studies to better understand participant experience and perspective (Lachal et al., 2017). Meta-synthesis is a particularly useful tool for identifying gaps in research to stimulate further studies to address them. It is important to select the most appropriate method of synthesis of qualitative data (Barnett-Page & Thomas, 2009; Dixon-Woods et al., 2005). The present study employed a meta-ethnography to create a comprehensive analysis of research findings to date. A meta-ethnography enables researchers to conduct detailed analysis by synthesising data to develop higher-order themes (Noblit & Hare, 1988; Sattar et al., 2021), thereby creating a nuanced understanding of phenomena and identifying gaps in literature to suggest directions for future research (Sattar et al., 2021). Integration of data within a meta-ethnography follows three distinct phases (Noblit & Hare, 1988). The first process, *reciprocal translational analysis,* involves translating concepts from different studies into one another to develop overarching themes. The second*, refutational synthesis,* focuses on examining differences between studies. Lastly, a *line-of-argument synthesis* integrates findings to create a cohesive whole that exceeds the sum of its parts.

Alternative methods for meta-synthesis, such as textual narrative synthesis and thematic synthesis, were considered. Textual Narrative Synthesis (TNS) also seeks to systematically summarise and organise findings from multiple studies. It involves extracting data and developing a new narrative to explain patterns across the studies. The goal of TNS is to provide a clear and coherent summary of existing evidence. TNS is particularly effective for highlighting heterogeneity among studies yet can be less effective in capturing the nuanced, conceptual relationships necessary for deep interpretative work (Lucas et al., 2007). Thematic Synthesis, by contrast, is particularly useful for generating theory. Building on Braun and Clarke’s (2013) thematic analysis, it systemically organises data into shared themes (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). Thematic Synthesis offers a structured process for extracting and synthesising data which enhances the replicability of the analysis (Barnett-Page & Thomas, 2009). However, this method leans towards summarising findings rather than generating deeper insights or theories (Dixon-Woods et al., 2005). Breaking data into codes and themes can strip remove context, potentially losing nuanced meanings important for understanding complex phenomena (Braun & Clarke, 2013).

Thematic Synthesis relies heavily on the depth of the included studies, meaning shallow studies can affect the richness of the synthesis (Barnett-Page & Thomas, 2009). Such studies may offer only surface-level insights, rely on weak or poorly described data, and fail to connect findings to wider conceptual frameworks which could constrain the richness and rigour of the thematic synthesis process.

Ultimately, meta-ethnography was selected because it allows researchers to build a rich, conceptual understanding of complex social phenomena (Dixon-Woods et al., 2005), such as how participants might experience and make sense of a diagnosis. Meta-ethnography provides the best framework for integrating diverse perspectives of author interpretation while maintaining the integrity of the original study findings. This study followed the seven steps of meta-ethnography as outlined by Noblit and Hare (1988).

**Search Strategy.** For the current review, an initial search was conducted on 3rd May 2024 and a final search to check for any updates was carried out on 14th November 2025. This second search added the terms for FND subtypes and their acronyms: Functional Motor Disorder, FMD, Non-Epileptic Attack Disorder, NEAD, Psychogenic Non-Epileptic Seizures, PNES to seek papers may have been missed by the umbrella term FND. All published, peer reviewed studies that explored experiences of FND since 1994 were considered. SPIDER terms (Cooke et al., 2012; see Table 1) were employed to define the research question and translate into searchable terms.

**Table 1**

*SPIDER terms defining the parameters of the study*

| Sample | Phenomenon of Interest | Design of Study | Evaluation | Research Type |
|---|---|---|---|---|
| Adults living with Functional Neurological Disorder | Experience of FND diagnosis | Interview, survey and focus group methods, gathering expressed opinions and perspectives | Iterative generation of results relating to patients' experiences, perspectives and opinions. | Qualitative |

Relevant qualitative research exploring the patient's experience of FND was located by using the following search terms:

1. "patient*" OR "adult*"
2. "Functional neurological disorder" OR "FND" OR "Functional Motor Disorder" OR "FMD" OR "conversion disorder" OR "CD" OR "psychogenic" OR "psychosomatic" "Non-Epileptic Attack Disorder" OR "NEAD" OR "Psychogenic Non-Epileptic Seizures" OR "PNES"
3. "experience*" OR "phenom*"
4. "qualitative" OR "interview*"
5. #1 AND #2 AND #3 AND #4

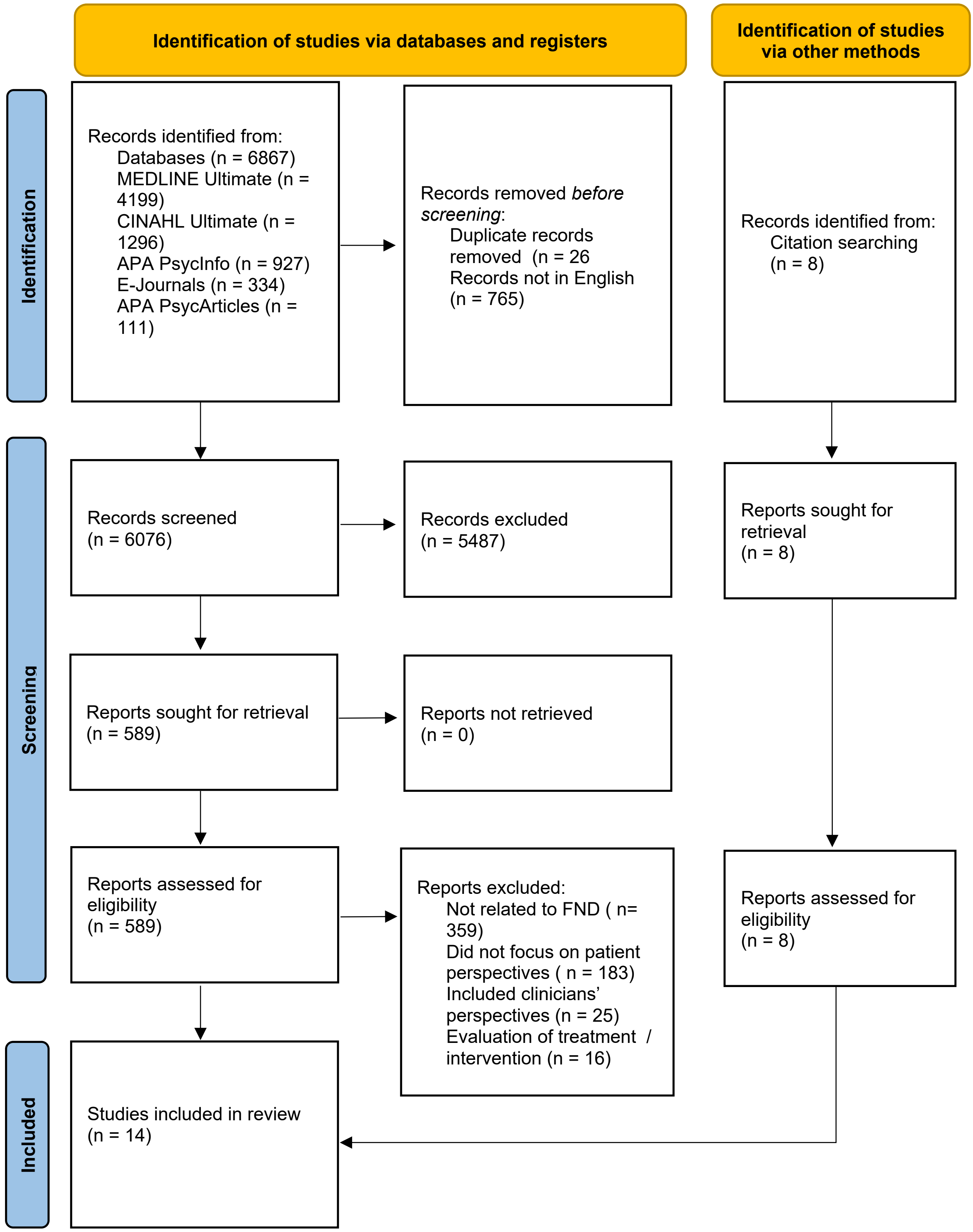
This review used EBSCO host to simultaneously search multiple databases; MEDLINE Ultimate, CINAHL, E-Journals, APA PsycInfo and APA PsycArticles. The review used the limiter 'peer-reviewed' with a publication date limit set from 1994-2025.

**Inclusion / Exclusion Criteria.** The search was limited to UK studies as global variances in terminology, conceptual understanding of FND and access to healthcare were deemed too disparate to synthesise. Studies were sought which focused on adults aged 18 years and over, as treatment paths for children differ (Al-Beltagi et al., 2025). A time limiter of 1994 was employed to reflect terminology since DSM IV "Conversion Disorder". All FND subtypes were considered for inclusion, in the majority of studies participants were required to confirm but not evidence their diagnosis. Studies were excluded that did not focus on the patient experience of FND, such as clinician experiences and perspectives. Studies which solely evaluated specific treatment outcomes were deemed too narrow in scope as to offer a reciprocal translation of the FND experience.

The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) checklist was used (Page et al., 2021), as shown in Fig. 1. An initial search found 6,867 papers; a preliminary screening of titles and abstracts held 589 of these to be relevant. Close reading of the remaining articles was completed and 14 studies were found to be eligible and appropriate for inclusion in the systematic analysis.

**Figure 1**

*PRISMA Flowchart of study selection*



**Critical Appraisal.** Critically appraising studies seeks to ensure that the studies included are methodologically robust as to provide valid and reliable insights into the meta-ethnography. This process helps to identify biases and limitations in study designs, ensuring that the synthesis is based on high-quality evidence (Noyes et al., 2018). The CASP (Critical Appraisal Skills Programme) (Public Health Resource Unit, 2006) critical appraisal tool was employed for this task because it offers a systematic framework for evaluating the quality of qualitative studies. It prompts evaluators to consider the clarity of the research question, the appropriateness of the study design, the rigour of data collection and analysis, and the transparency of the findings. Using the CASP tool ensures that the studies selected for meta-ethnography meet these criteria, enhancing the overall trustworthiness of meta-ethnography findings (Moher et al., 2015). An Excel spreadsheet was created by the researcher to evaluate the quality of each study using the CASP tool, a priori decision was to include all studies due to the relative paucity of qualitative literature on FND, but attention was paid to the scores in relation to the weight each study was given in the final synthesis. Table 1a: Summary of Articles included for Systematic Review including CASP scores for each paper can be found in Appendix A.

All fourteen papers provided clear aims of the research and justification for their use of qualitative methodologies. The authors’ epistemological position (e.g., realist, constructionist) was rarely clearly stated; making it harder to judge how the authors conceptualised meaning and experience in the data. Research designs were broadly well explained. Recruitment strategies were variously described and justified throughout the papers. Those who recruited solely from clinical populations, for example O’Connell et al. (2020) did not always account for this as a limitation and risked overstating the transferability of their findings. This was especially limiting for those with smaller samples such as Peacock et al. (2023) (n=5), and Chan et al., (2025) (n=6), who recruited from single site clinics.

Clinical samples were often recruited with the aid of clinicians such as Neurologists, which risked clinician gatekeeping and selection bias, as discussed by Dosanjh et al. (2021). Staton et al. (2024) was an exception who addressed their use of social media recruitment as potentially skewing to a younger, more tech-literate sample. This was held to improve transparency and validity of their study.

The data collection methods across the included studies were generally well described, with most employing semi-structured interviews and providing adequate detail on how data were gathered and transcribed. However, several inconsistencies reduced transparency and raise concerns, for example, Loewenberger et al. (2021) reported the use of audio-recording but did not clearly articulate how recordings were processed or analysed, which limits the replicability of their analytic approach. Revell et al. (2021) relied on participant diaries, a method that can elicit rich accounts but may inherently privilege individuals who feel confident expressing themselves in writing and risk excluding participants whose narratives are more easily articulated verbally, thereby challenging the representativeness of the sample. Similarly, Rawlings et al. (2018) utilised a therapeutic written exercise as the primary data source, a technique that restricts the researcher’s ability to probe, clarify, or explore emerging meanings. As a result, some participant accounts appear fragmented or ambiguous, potentially constraining interpretive depth.

Across the studies, the approaches to data analysis varied in transparency and robustness, with several recurring limitations that challenge the trustworthiness of findings. Dosanjh et al. (2021) described collaborative coding and validation by multiple team members, yet provided insufficient detail on how individual codes were integrated or what criteria guided thematic consolidation. McLoughlin et al. (2024) offered a stronger account, outlining triangulation by a multidisciplinary team of clinicians and researchers, which enhances interpretive breadth and mitigates single-researcher bias. In contrast, O’Connell et al. (2020) referenced the involvement of multiple coders but did not specify how discrepancies were managed, an omission that obscures analytic rigour. Rawlings et al. (2018) sought to construct typologies; however, themes from earlier publications by the same authors (2017–2018) were used to build typologies, raising questions about circularity. Rawlings et al. (2018) also had explicit awareness of participant diagnoses which creates a risk of confirmation bias, particularly given that diagnostic differences underpin their central conclusions. Revell et al. (2021) provided a comparatively thorough account of analytic procedures, yet their claim of theoretical saturation is difficult to substantiate with a sample of only seven participants and limited diary entries. The presentation of findings across the studies was generally clear and well structured. Several papers (Walsh et al. 2024; Staton et al. 2024, and O'Connell et al, 2020) providing original thematic narratives supported by illustrative participant quotations, enhancing transparency by grounding interpretations in the data. Thompson et al. (2013) however, presented themes that appeared to align closely with established IPA categories (meaning-making and identity) which raises the possibility of analytic confirmation bias, as pre-existing frameworks may have shaped the interpretation of participants' accounts.

Although all studies reported obtaining ethical approval from appropriate NHS or university committees and documented the use of informed consent, most offered only limited reflection on wider ethical considerations relevant to sensitive qualitative research. Notably, Bazydlo and Eccles (2022) demonstrated good practice by involving an expert-by-experience in study design, helping to ensure that procedures were shaped by participant perspectives. Peacock et al. (2023) provided a robust account of ethical safeguards, explicitly recognising the risk of trauma and detailing steps to mitigate potential harm. In contrast, many studies offered insufficient attention to participant wellbeing. Thompson et al. (2013), for example, did not outline procedures for managing acute distress during interviews or descriptions of how emotional risk was addressed in practice. Similarly, Rawlings et al. (2018) provided no description of follow-up, support, or monitoring of participant wellbeing, which is a significant omission given the potentially distressing nature of the research topic.

Across the studies, researcher reflexivity was often recognised but inconsistently enacted, with only a minority of studies providing transparent, critical accounts of researcher positionality. Several authors referred to subjectivity as an inherent aspect of qualitative research (Dosanjh et al., 2021) or as embedded within their chosen analytic approach such as RTA (Loewenberger et al., 2021) yet provided little detail about their own positional assumptions or potential biases. Peacock et al. (2023) noted reflexivity but did not explore power dynamics or the researcher–participant relationship in depth. Rawlings et al. (2018) offered minimal consideration of how the interviewer's clinical background could have influenced interpretive lenses. In contrast, a few studies showed stronger reflexive practice. Bazyldo and Eccles (2022) provided a well-developed account of positionality, outlining how implicit and explicit judgements were bracketed during analysis. Nielsen et al. (2020) demonstrated critical self-awareness by examining how their role as a physiotherapist influenced the research process, while O'Connell et al. (2020) explicitly reflected on their psychological research background and its potential interpretive impact.

Overall, the fourteen studies provide valuable insights into an under-researched area, foregrounding patient narratives and highlighting challenges of living with FND. However, methodological limitations temper the strength of some contributions. Claims of transferability were generally overstated, particularly given the small, self-selecting samples across most studies. The value of Rawlings et al. (2018) is significantly constrained by methodological weaknesses that limit confidence in their conclusions. Apart from O'Connell et al. (2020), few studies provided meaningful ethnicity data, with broad labels such as "predominantly White" (Dosanjh et al., 2021) or "White British" (Wyatt et al., 2024) offering insufficient insight into the diversity, or lack thereof, within samples. While this raises concerns about representativeness, Staton et al. (2024) justified the omission of detailed demographic information on the grounds of protecting participant anonymity within a small UK FND population. Despite these limitations, the studies collectively advance understanding of patient perspectives on FND. In the final synthesis, the relative weight given to each study was calibrated in line with its CASP appraisal, ensuring that studies demonstrating stronger methodological rigour contributed proportionately more to the overall interpretations.

**Data Analysis.** The fourteen eligible studies have been coded by author, aims, methodology and main findings, in Table A1 (in Appendix A). This study followed the seven steps of meta-ethnography as outlined by Noblit and Hare (1988). Each study was read thoroughly, and emergent themes, metaphors and concepts were extracted and collated on an Excel spreadsheet. Efforts were made to capture both first order constructs (participants' views and beliefs) and second order constructs (author's interpretations; Shutz, cited in Britten, 2002). Following Atkins et al. (2008), all themes from the studies were listed and sorted into initial broad categories. It was therefore determined that studies had enough commonality of concepts to be considered related. This review followed Pound's (as cited in Atkins et al. 2008) process of reciprocal translation. Within initial categories, all themes listed were revised and merged, for example multiple themes describing searching for a label and long road to diagnosis could be defined under one key concept – diagnostic odyssey. Checks were made by returning to each paper to ensure concepts encapsulated themes in the data. For each study, a table was created (see Table 2.), listing key concepts, and their corresponding study terminology.

**Table 2**

*Sample of tabulated key concepts and interpretations*

| Thompson et al., (2013) | Study terminology |
|---|---|
| **Key Concepts** | **Study intepretations** |
| Relief and validation | Label as a beginning; Feeling like a human being again |
| Distress and anger | Isolation; Loss; Helplessness: Emotional impact |
| Confusion | Being left in limbo land |
| | |
| Struggle for Understanding | Doubts and certainty |
| Illness Beliefs | Altered consciousness |
| Integration into Personal Narrative | Living with trauma |
| Search for Meaning | Meaning of NES |
| | |
| Stigma | |
| Disclosure | |
| Social Support | |
| | |
| Diagnostic Odyssey | Search for a label |
| Communication of Diagnosis | Label as a beginning; Feeling like a human being again |
| Treatment and prognosis | Healing the scar |
| | |
| **Second Order Intepretation** | Authors emphasise the need for a more patient-centred approach to the diagnosis and management of NES. The study highlights the importance of clear communication, validation, understanding of personal narratives, addressing emotional impacts, and reducing the "limbo" period between diagnosis and treatment. |

Atkins et al. (2008) notes how the order in which studies are translated may influence synthesis; therefore, this review approached synthesis by ordering studies by those interpreted as having highest validity according to CASP score (Barbour & Barbour, 2003). Tables of each paper were laid alongside one another, concepts and themes from the first study were compared the second, then a synthesis of these concepts compared with the third study, and so on.

### *1.3.3 Results*

This meta-ethnography of the fourteen eligible studies identified thirteen overarching key concepts (Table 3). Key concepts were synthesised into four broader categories: Responding Emotionally, Processing Cognitively, Disclosing Socially, Navigating Medically (Fig. 2).

**Figure 2**

*Key concepts and synthesised categories*

| Key concepts found in studies | Synthesised categories |
|---|---|
| Relief and validation<br>Distress and anger<br>Confusion | Responding Emotionally |
| Struggle for Understanding<br>Illness Beliefs<br>Integration into Personal Narrative<br>Search for Meaning | Processing Cognitively |
| Stigma<br>Disclosure<br>Social Support | Disclosing Socially |
| Diagnostic Odyssey<br>Communication of Diagnosis<br>Treatment and prognosis | Navigating Medically |

An overarching model was then created incorporating concepts, categories and second order interpretations to form a line of argument synthesis (Fig. 3). This model identifies the four tasks of adjustment observed in receiving an FND diagnosis.

**Table 3.**

*Contribution of Concepts from Individual Studies*

| **Line of Argument:** | **The four tasks of adjustment to FND Diagnosis** | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Third Order Categories:** | **Emotional Agency: Responding to Diagnosis** | | | **Cognitive Agency: Making Sense of the Diagnosis** | | | | **Social Agency: Negotiating Disclosure and Belonging** | | | **The Structural Domain: Navigating Clinical Systems** | | |
| **Key Concepts:** | **Relief & Validation** | **Distress & Anger** | **Confusion** | **Struggle for understanding** | **Illness beliefs** | **Integration into personal narrative** | **Search for meaning** | **Stigma** | **Disclosure** | **Social Support** | **Diagnostic Odyssey** | **Communication of diagnosis** | **Treatment & Prognosis** |
| Bazydlo and Eccles (2024) | | * | * | * | * | * | | * | * | | * | * | * |
| Chan et al. (2025) | * | * | | * | | * | * | * | * | * | * | * | |
| Dosanjh et al. (2021) | * | * | * | * | * | * | * | * | * | * | * | * | * |
| Loewenberger et al. (2021) | * | * | * | * | | | * | * | * | | * | * | * |
| McLoughlin et al. (2024) | | * | * | | * | * | * | * | * | * | * | * | * |
| Nielsen et al. (2020) | | * | | | | * | | * | | | * | * | * |
| O'Connell et al. (2020) | | * | * | * | | * | * | * | | | * | | * |
| Peacock et al. (2023) | * | * | | | * | * | * | | * | | * | * | |
| Rawlings et al. (2018) | * | * | * | * | * | * | | * | * | * | | | * |
| Revell et al. (2021) | | * | * | * | | * | * | * | | | | * | |
| Staton et al. (2024) | * | | * | | * | * | | * | * | | | | * |
| Thompson et al. (2013) | * | * | * | * | * | * | * | | | | * | * | * |
| Walsh et al. (2024) | * | | * | * | * | | * | * | * | * | | * | * |
| Wyatt et al. (2014) | * | * | | | * | * | * | * | * | * | * | * | * |

### *Emotional Agency: Responding to Diagnosis*

Studies highlight how emotionally responding to a diagnosis of FND is an immense and highly individualised process. The sources reveal complex emotional reactions to receiving a diagnosis. Reactions vary widely and for many involved experiences conflicting emotions simultaneously.

**Relief and validation.** Several studies note relief as a common reaction, primarily associated with the elimination of more aggressive neurological conditions. This relief stems from the knowledge that their condition does not have a sinister or life-threatening cause, for example epilepsy (Loewenberger et al., 2021), Parkinson's or MS (Dosanjh et al., 2021). Studies noted how validation is crucial for patients' ability to accept the diagnosis. Validation can come from various sources with the most sited as the clinical encounter (Staton et al, 2024). McLoughlin et al. (2024) highlights the importance of feeling taken seriously by healthcare professionals, which Dosanjh et al. (2021) describes as enabling a *"warm therapeutic alliance".* Some studies found the experience of a diagnosis validating as it confirmed the existence of something real after so much uncertainty, particularly when it was framed as a rule-in, rather than rule-out diagnosis (Walsh et al., 2024). Thompson et al. (2013) hypothesise this allows the diagnosis to be *"embraced with enthusiasm and a notion that they finally had an answer with which they could identify and which made sense in the context of their lives".* An FND diagnosis was also understood by Wyatt et al. (2014) as an opportunity for empowerment due the shift in perceived agency for recovery accompanying the change in diagnosis, from epilepsy to FND.

**Distress and anger.** Several studies highlight patient expressions of distress upon receiving an FND diagnosis. This was understood to be caused by the uncertainty surrounding the diagnosis, the social stigma associated with functional symptoms and the lack of treatment pathways. Nielsen et al. (2020) found that distress was heightened when diagnosis was made through exclusion of other disease, which patients could interpret as meaning that the real cause for their illness remains unknown. Psychological aetiological explanations of FND were frequently understood to cause distress to patients. Loewenberger et al. (2021) explored responses to ‘offensive’ terminology such as *pseudoseizures* as causing distress to patients who did not identify with a trauma in their history. Moreover, Thompson et al. (2013) highlights how, for those who did identify with a psycho-aetiological explanations for their FND, the diagnosis may cause renewed distress about their abuse and several patients felt retraumatised by their experience. A number of studies found anger to be a prominent emotion, directed towards healthcare professionals who were perceived as dismissive or incompetent during the diagnostic process, as well as towards the perceived injustice of the condition itself (Chan et al., 2025). Patients’ anger was conceptualised throughout the studies as a response to feeling *othered* or *dismissed* (McLoughlin et al., 2024), *left in limbo land* (Thompson et al., 2013), *marginalised* (Nielsen et al., 2020) or *rejected* (Chan et al., 2025) by medicine.

**Confusion.** Confusion is a prominent theme in most studies. The nature of the diagnosis and its implications for treatment and management was often left unclear for patients. This confusion is heightened by the lack of clear diagnosis experiences and the emphasis on psychological factors in explaining symptoms. Bazydlo and Eccles (2024) found that confusion preceded the diagnosis through the strange nature of FND symptoms which patients experienced as perplexing, which some experienced as something alien or uncontrollable within their own bodies. O’Connell et al., (2020) understood confusion to be mirrored by healthcare professionals which could exacerbate it through ambiguous bedside consultations and a lack of diagnostic clarity. Likewise psychological professionals are experienced as impairing understanding through inconsistent and reductionist formulations

(Staton et al., 2024). In many studies, this confusion meant that the diagnosis could not be readily accepted as the new label failed to provide an explanation for their experience; these patients was characterised by Thompson et al. (2013) as ‘‘unaffected”, whilst Rawlings et al. (2018) defined this narrative typology of ‘feeling lost it’s a lost world I seem to have been put into’.

### ***Cognitive Agency: Making Sense of the Diagnosis***

Receiving a functional diagnosis triggers a significant cognitive process as individuals attempt to understand and make sense of their condition. This was described as a multifaceted process that can evolve as individuals gain a better understanding of their condition and begin to develop coping strategies.

**Struggle for Understanding.** Studies highlight how individuals grapple with making sense of the diagnosis, particularly when faced with a lack of clear biological markers or positive diagnostic signs. Studies frequently identified a central theme of ‘not knowing’, which Loewenberger et al. (2021) understood to cause significant emotional burden to patients. The difficulty for patients is that they are required to make sense of their diagnosis in the context of minimal (Walsh et al., 2024), or disparate aetiological explanations received (O’Connell et al., 2020). For many, understanding could be further impaired by a sense of alienation from, and perceived loss of control over, the ‘self’. Bazydlo and Eccles (2024) conceptualised this as an “‘Intrapersonal battle’ with symptoms” whilst Dosanjh et al. (2021) identified a mind/body splitting for patients with the subtheme ‘My body has a mind of its own’.

**Illness Beliefs.** Patients’ pre-existing beliefs about illness, health, and psychosocial influences play a role in how individuals interpret their diagnosis. Studies discuss how many patients are open to psychological elements of their condition, yet FND was frequently described as a mental illness which felt invalidating to patients experiencing significant physiological symptoms. The term *functional* could be interpreted as *voluntary* which McLoughlin et al. (2024) found patients interpret as attributing blame for their condition. Walsh et al. (2024) emphasise how patients and HCPs often *"worked from an understanding that mind and body are separate"* whereas Peacock et al. (2023) highlights how medicine's simplistic distinction between the *organic* and the *psychological*, reinforces an implicit hierarchy that prioritises the former as more legitimate, can hinder patients' acceptance of *non-organic* diagnoses.

**Integration into Personal Narrative.** The studies emphasise the importance of integrating the diagnosis into one's personal narrative – as Staton et al. (2024) terms *"woven into the tapestry of their lives"* – to facilitate FND acceptance and adaptation (Thompson et al., 2013; Wyatt et al., 2014). This involves making sense of how the diagnosis fits within their life experiences and reconciling it with their sense of self. Distinctive patient responses were proposed by Rawlings et al. (2018) with typologies 'Tackling Adversity' and 'Overcoming Challenges', reflecting the degree to which they have integrated the condition into their self-concept.

**Search for Meaning.** Individuals diagnosed with FND often try to understand why they developed the condition and what it might mean for their future. Walsh et al. (2024) stresses how NEAD symptoms force patients to reflect on how they live their lives. Yet this was often challenging due to the perceived randomness of their symptoms (Chan et al., 2025). Studies conceptualised this meaning-making task using various frameworks; Revell et al. (2021) suggests patients may understand their diagnosis using a behavioural model concept of 'predisposing factors' such as stressors or traumatic life events. For some patients externalising the cause as 'the brain' (Thompson et al., 2013) or the 'nervous system'

(O’Connell et al., 2020) malfunctioning allowed them to make sense of the condition, whilst patients who endorsed a psychological understanding described ‘going deeper’ (Wyatt et al., 2014) through explorations in therapy.

### ***Social Agency: Negotiating Disclosure and Belonging***

FND diagnosis often has a profound impact on individuals' social realities. It could negatively influence their relationships and threaten their sense of belonging.

**Stigma.** A majority of studies found stigma to be an issue for individuals diagnosed with FND. Patients often encounter scepticism and negative judgments from others due to the lack of invisibility of their pathology. A lack of awareness surrounding FND can also lead to self-stigma, where patients internalise negative attitudes about themselves for their perceived inabilities (McLoughlin et al., 2024). Bazydlo and Eccles (2024) highlight the dangers of prejudice from healthcare professionals which left some participants feeling unsafe in healthcare settings, or reluctant to attend A&E (Chan et al., 2025). Many patients felt any physical complaints were overly attributed to FND meaning the diagnosis acts as a barrier to care for other medical conditions or seeking psychological help (Staton et al., 2024).

**Disclosure.** Individuals made decisions about disclosing their diagnosis to people around them. Patients report weighing the potential benefits of receiving support against the risk of experiencing negative reactions. The studies highlighted patients' responsibility to explain functional symptoms to others, including healthcare professionals (Staton et al., 2024). Loewenberger et al. (2021) identified a distinction between individuals who felt exhausted or frustrated by the need to explain themselves and those who saw it as their responsibility to educate others. Several studies noted how patients preferred to misrepresent their FND as epilepsy (Peacock et al., 2023), a brain injury (Bazydlo & Eccles, 2024), or a neurological condition (McLoughlin et al., 2024) to avoid social stigma associated with mental illness. Bazydlo and Eccles (2024) went further, in identifying patients who preferred to state depression as reason for work absence, which led authors to suggest that the label of FND itself might carry an additional, distinct layer of stigma.

**Social Support.** Social support is noted as important for individuals with FND. It is reported as challenging to obtain due to a lack of awareness of the condition. Unpredictability of symptoms was highlighted as a barrier to accessing support from friends and family, as many felt their fluctuating (dis)abilities could undermine their credibility (McLoughlin et al., 2024). Studies frequently highlight how supportive relationships with others can provide validation and a sense of belonging. However, many studies report a withdrawing from social activities and the loss of friendships (Nielsen et al., 2020). Studies discuss how avoiding situations of potential embarrassment (Revell et al., 2021) could intensify feelings of social isolation (Chan et al., 2025). This was understood by Wyatt et al. (2014) as creating a shrinking of social networks with the theme “my world has shrunk”.

### ***The Structural Domain: Navigating Clinical Systems***

All studies consistently highlight the challenges and frustrations individuals face in their interactions with the healthcare system.

**Diagnostic Odyssey.** Individuals often endure a lengthy and arduous diagnostic process, characterised by multiple referrals, misdiagnoses, and inconclusive tests. The overly protracted diagnostic period invokes a lack of confidence in patients, who report receiving negative tests results as frightening rather than reassuring (Nielsen et al., 2020) and leaves patients vulnerable to ‘othering’ (McLoughlin et al., 2024) by healthcare systems who may begin to experience them as bothersome. Chan et al. (2025) found some patients identified healthcare professionals as actively creating barriers to care through unnecessary referrals and dismissive attitudes. McLoughlin et al. (2024) highlights how during medical testing and screenings, FND is almost never mentioned as a differential diagnosis, so subsequently takes patients by surprise. Patients’ pre-diagnostic experiences of feeling undeserving of clinical care may have consequences for post-diagnosis interactions with healthcare systems, which O’Connell et al. (2020) posits may results in delays in diagnosis, increased referrals, and pursuit of alternative treatments.

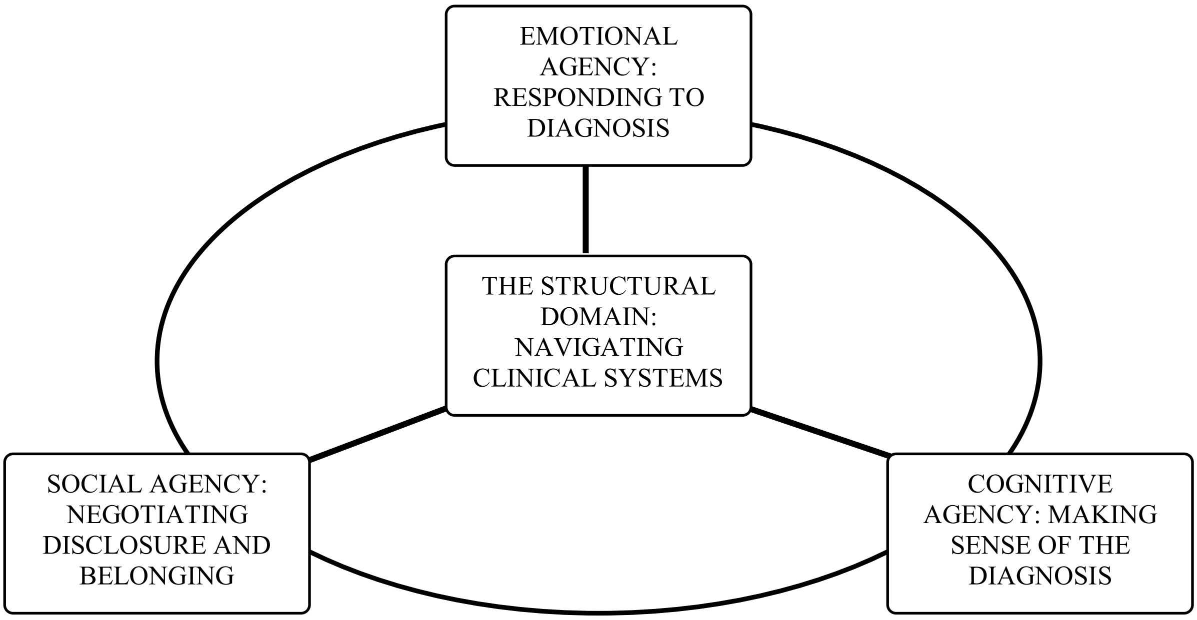
**Communication of Diagnosis.** Studies highlight how the manner in which the diagnosis is communicated can significantly impact patients' responses. FND diagnosis confirmation is noted as distinct from that of organic diseases, with many patients experiencing a lack of satisfactory consultation (Chan et al., 2025). In some cases, being signposted to a website appeared to replace a diagnosis entirely (McLoughlin et al., 2024). Studies suggest that a clear, empathetic, and patient-centred approach is crucial for facilitating a positive experience. Participants found explanations satisfactory when delivered by an expert (especially a neurologist), which Peacock et al. (2023) conceptualise as validating through facilitating epistemic recourse to authority. Diagnosis coupled with clear explanations and informational resources, especially utilizing language that supports a shared understanding, was frequently identified as vital for patient containment and trust (Walsh et al., 2024).

**Treatment & Prognosis.** Themes relating to patient dissatisfaction with the lack of effective treatments and the limited availability of specialised care for FND were present in the majority of studies. This was found to complicate the process of accepting their diagnosis as it did not offer patients any tangible path to recovery (Dosanjh et al., 2021). This lack of agency could be compounded by a history of iatrogenic harm through improper pre-diagnosis treatments (Nielsen et al., 2020) exacerbating patients’ feelings of powerlessness. Studies highlight the need for a more treatment pathways and recommend biopsychosocial approaches to treatment of the physical and psychological aspects of the condition. Wyatt et al. (2014) describes how a referral to psychology could still signal an intention to help, even if there was ambivalence about its potential effectiveness. However, access to psychological support was often hampered by long waiting lists and a lack of specialist services (Staton et al., 2024), forcing patients into general mental health services (Walsh et al., 2024).

### *Line of argument synthesis*

**Figure 3**

*Line of argument synthesis: the four domains of FND diagnosis adjustment*



The line of argument synthesis presented here is a holistic view of the processes involved in receiving a diagnosis of FND. It conceptualises the patient experience of FND diagnosis as a dynamic, cyclical interplay between structural and agentic domains. At its core lies the *structural domain* – the clinical encounter – which functions as the anchor point wherein patients interact with the medical system. This domain is experienced as a site of constraint, through diagnostic ambiguity or invalidation, but it also has potential to be a site of empowerment, particularly when clinicians offer diagnostic clarity. Surrounding this anchor are three *agentic domains*, reflecting the ways individuals *feel*, *think*, and *act* in response to their condition and its framing. All domains are interlinked and may occur simultaneously. Domains can also interact cyclically with patient trajectories shaped by iterative loops. For example, a dismissive clinical encounter may induce distress, confusion, or social withdrawal, which might result in disengagement from care. Conversely, a validating encounter can generate feelings of validation, understanding, and renewed confidence in clinicians, which can in turn encourage further help-seeking behaviour.

### ***1.3.4 Discussion***

This synthesis builds upon Engel's (1977) biopsychosocial model by attending to how structural, cognitive, emotional, and social domains unfold in response to receiving an FND diagnosis. These findings demonstrate that diagnosis initiates a complex sequence of adjustments and negotiations of meaning. Mol's (2002) "body multiple" resonates with how patients' experiences were shaped by which lens – neurology, psychiatry, or psychology – dominated their care journey. The act of naming FND, as Charon's (2006) narrative medicine suggests, becomes an act with lasting implications. This synthesis suggests that patients' diagnostic encounter(s) can script their future FND experiences.

Findings revealed widespread structural obstacles for FND patients: prolonged diagnostic journeys, multiple referrals, and inadequate communication at the point of diagnosis. Where participants are often denied credibility within clinical consultations, reflecting Fricker's (2007) notion of epistemic injustice. Many studies highlighted how patients felt dismissed by clinicians, particularly when their diagnosis was presented as psychological. For example, Loewenberger et al. (2021) noted distress when labels such as 'pseudoseizures' were used as it reinforced the sense of being discredited. These encounters align with Aronowitz's (2001) framing of FND as an ambiguous diagnostic category which leaves patients are at risk of becoming 'spoiled identities' (Goffman, 1963). Mol's (2002) body multiple work is again relevant, patients found themselves differently 'known' and 'treated' depending on whether they were clinical settings, exacerbating their sense of inconsistency in care.

Emotional responses to diagnosis varied widely, from relief and validation to anger and confusion. Antonovsky's (1979) Sense of Coherence (SOC) theory is useful lens to explain why those who reported compassionate and clear explanations reported increased comprehensibility and meaning, which ultimately facilitated acceptance. In contrast, patients who experienced diagnosis as dismissive and uncaring describe feeling alienated or angry (McLoughlin et al., 2024; Nielsen et al., 2020, Chan et al., 2025). Diagnoses administered without care are not neutral acts and may easily exacerbate emotional distress. Frank's (1995) narrative types, particularly the chaos narrative, help frame patient descriptions of being "lost in limbo" or retraumatised by their diagnosis (Thompson et al., 2013). In contrast, validation often initiated a shift toward a quest or restitution narrative.

A key theme across studies was the struggle to cognitively process the FND diagnosis. Patients appear to rethink their identity and sense of self in light of their diagnosis. Findings showed that patients who integrated the diagnosis into their life story were better able to adapt. This could be done creatively, by conceptualising FND through metaphor like "a glitch in the nervous system" (O'Connell et al., 2020). SOC theory (Antonovsky, 1979) further explains how patients without a meaningful or manageable explanation, could not move cognitively beyond their uncertainty (Bazydlo & Eccles, 2024; Loewenberger et al., 2021). For others, therapy or peer support allowed movement towards reinterpretation and growth, what Rawlings et al. (2018) refers to as “Tackling Adversity” or “Overcoming Challenges.”

Findings show patients frequently grappled with whether, how, and to whom they disclosed their diagnosis. Theories of stigma (Goffman, 1963) are highly relevant, participants repeatedly expressed fear of being disbelieved, particularly in healthcare contexts. Bourdieu’s (1991) concept of symbolic power helps explain why some opt for strategic disclosure, describing their condition as epilepsy or a brain injury (Bazydlo & Eccles, 2024; Peacock et al., 2023). By aligning with neurologically legible terms, patients might be seeking to accrue symbolic capital in a clinical culture that privileges organic illness. Where disclosure did lead to invalidation, patients described social withdrawal (Staton et al., 2024) and a “shrinking world” (Wyatt et al., 2014). Conversely, when it was met with understanding, it could become a catalyst for connection.

This synthesis finds that patients experience FND diagnosis as a relational process, continuously unfolding through interactions with clinicians, family and peers. However, many patients currently described the diagnosis moment as a rupture that required repair. Therapeutic alliance theory (Horvath & Greenberg, 1989) supports the finding that relationships with empathic clinicians can facilitate engagement in care. SOC theory (Antonovsky, 1979) suggests that diagnosis could only be metabolised by when it restored a sense of coherence. In this synthesis, positive feedback loops were initiated by relational recognition: a clinician who named FND with clarity, warmth, and conviction enabled emotional and cognitive coherence, which in turn supported social disclosure and engagement.

### ***Clinical Implications***

These findings strongly support a shift away from a reductionist or exclusion-based approach to FND diagnosis. They highlight instead the importance of *positive* diagnosis and the relational dimensions of clinical encounters. This would align with recent literature which demonstrates that diagnosing FND on the basis of identifiable clinical signs rather than by exclusion improves diagnostic accuracy and legitimises patients' experiences (Stone et al., 2010; Edwards & Bhatia, 2012; Perez et al., 2021). Recent reviews have mapped more than sixty reliable "rule-in" signs across FND subtypes, supporting a move towards confident, early diagnosis (McWhirter et al., 2022). This positive diagnostic model stands in direct contrast to older paradigms which are now recognised as contributing to delays, diagnostic overshadowing, and potential iatrogenic harm (Crimlisk et al., 1998; Kanaan et al., 2023).

Research has increasingly shown that how the diagnosis is communicated is as consequential as the diagnostic process itself. Stone and colleagues (2005; 2011) were among the first to articulate the therapeutic potential of a clear and empathetic diagnostic explanation; one that names the disorder, outlines the specific clinical signs supporting the diagnosis, and underscores the legitimacy of the symptoms. More recent work continues to show that patients respond positively when the diagnosis is delivered using neutral language (e.g., "functional neurological disorder") that acknowledges the reality of symptoms and avoids implying that they are feigned or merely psychological (Hall-Patch et al., 2010; Nielsen et al., 2013).

Previous research aligns with the findings of this review that patients frequently describe diagnostic experiences as invalidating or stigmatising, reporting that ambiguous, dismissive communication amplifies uncertainty and shame (Lidstone et al., 2022). However, a diagnostic conversation that contributes to the development of a shared understanding can itself be therapeutic (Stone et al., 2021). This framing aligns with broader findings that negative clinical encounters and diagnostic ambiguity are themselves risk factors for worsening symptoms and disengagement from care (Kanaan et al., 2023).

### *Limitations*

Challenges were encountered in translating nuanced experiential questions into rigid search terms for the database searches. The diagnosis of FND is inherently complex and lacks a universally defined terminology, which meant that inclusion criteria required a degree of interpretive flexibility. As such, relevant studies may have been omitted inadvertently if they used divergent terminology or less explicitly qualitative terms. This review was limited to studies published since 1994 and therefore reflect evolving conceptualisations of FND in a shifting diagnostic and policy landscape, rather than a comprehensive historical view. Finally, as with all qualitative synthesis, the interpretive process bears the imprint of the researcher. An interest in identity-forming processes may have shaped the synthesis towards meaning-making frameworks and underemphasised other aspects of the studies. These limitations also illuminate directions for future research that can privilege depth and complexity.

### *1.3.5 Conclusion*

The findings of this synthesis suggest that future research on FND would benefit from a shift in approach towards narrative-centred inquiry. Patients' experiences of diagnosis emerged in reaction to medical information and were experienced as a disruption of life story and ability to make meaning. Yet many existing studies limit their exploration to thematic categories, leaving the narrative shape and structure of these experiences underexamined. There is therefore a need for methodologies that can better capture the relational and moral dimensions of FND narratives, how people live with their diagnosis stories.

Narrative approaches may offer a more ethical and clinically relevant account of diagnostic adjustment by attending to voice, metaphor, and plot, especially in a population whose credibility is often undermined. Future work might explore the conditions under which diagnostic stories become intelligible or survivable, and how these stories are co-authored within clinical relationships. This forms the foundation for the next phase of this project, which will employ a narrative methodological framework to explore how individuals make sense of and potentially re-author their experience of receiving an FND diagnosis.

## 1.4 Theoretical Frameworks

*Frame Analysis* (Goffman, 1974) offers a powerful lens through which to understand how individuals interpret and give meaning to their experiences. Frame analysis suggests that people rely on "frames" as interpretive schemas, to make sense of what is going on in any given situation. These frames help organise experience by providing a context that defines roles, actions, and expectations of a given situation. Goffman distinguishes between *natural frameworks*, which account for events without human intent (such as illness or natural disasters), and *social frameworks*, which involve deliberate human action and interpretation. However, these frames can be disrupted through unexpected events, leading to individuals experience what Goffman terms a *frame break*. Goffman describes frame breaks as becoming *"disoriented; for a moment or more we are not sure just what is going on, what role we are playing, or what game we are in"* (Goffman, 1974, p. 302). In such moments, individuals must work to re-establish shared understanding, which is understood as a process of *frame negotiation*. Through further processes such as *keying*, where the same behaviour is understood differently depending on the context (e.g., real fight vs. play fight). The term describes the way social actors reinterpret situations through established conventions, much like a melody changes tone when played in a different musical key (Goffman, 1974).

Goffman's *frame analysis* has previously been applied in medical sociology to explore how individuals make sense of illness and manage the disruption to their sense of identities. Charmaz (2014) have drawn on Goffman to examine how people with chronic illness reconstruct a coherent self through impression management and narrative adaptations. Similarly, Kaufman (1988) applied Goffman's lens to ageing, showing how older adults work to reframe bodily decline in socially acceptable terms. Frank (1995) also draws on frame analysis to conceptualise storytelling and the construction of illness narratives as a means of reframing bodily chaos into meaningful experience. These studies provide a strong precedent for employing Goffman's (1974) frame analysis in this study of FND to explore how patients, clinicians, and family members may apply differing frames to the same symptoms viewing them alternately as medical, psychological, behavioural, or even illegitimate.

## 1.5 Aims and Objectives

The proposed research aims to address gaps in understanding by exploring patients' first-hand narrative accounts of how they experience and conceptualise their FND diagnosis. The objectives of this study are:

- To explore how illness narratives are constructed and performed by persons with FND
- To examine the impact of receiving the FND diagnosis on sense making of their experience

It is hoped that these objectives may provide insight into the clinical implications for service provision and support for patients and clinicians alike.

# 2 Method

## 2.1 Chapter Overview

This chapter outlines the methodological foundation and procedures used in this study. It begins by establishing the research paradigm, a section on researcher reflexivity, then details the author's positionality and its influence on the study design. The chapter details the justification for selecting narrative inquiry as the primary methodological approach. Subsequent sections describe the theoretical frameworks informing the study, including illness narrative typologies (Frank, 1995) and frame analysis (Goffman, 1974). The chapter also presents the participant selection criteria, recruitment strategies, and ethical considerations that shaped data collection. The process of conducting narrative interviews is described in depth, including how accessibility and participant agency were prioritised. The latter part of the chapter discusses data analysis, detailing a dual-layered approach that combines thematic and performative narrative analysis. Finally, the chapter addresses issues of methodological rigour, reflexivity, and researcher wellbeing, ensuring transparency and ethical integrity throughout.

## 2.2 Research Paradigm

### *2.2.1 Researcher Reflexivity*

Research questions and designs are influenced by the social context of the researchers' identities. If this influence, along with other biases, is not critically examined, the notion of validity itself should be called into question (Jamieson et al., 2023). Reflexivity enables researchers to examine how their assumptions may influence data collection and interpretation. This process is crucial to mitigate undue researcher influence and ensure that findings accurately reflect participants' perspectives. In order to clearly state my positionality, the following section is written in the first person.

I am a 33-year-old trainee clinical psychologist with an interest in mind-body connection, illness and disability. My perspective has been profoundly influenced by personal experience: a sudden and unexpected period of serious illness at the age of 28. Having previously considered myself to be able-bodied, it was immediately clear to me that I had no prior frameworks for understanding what was happening, no map to navigate the experience. I became sharply aware of how I was being perceived from the outside, how my body had, in some ways, been handed over to medicine and was no longer entirely my own. I found myself seeking out stories of others, looking for narratives that could help me make sense of my experience. This personal history fuels my academic and clinical curiosity about how people construct meaning from illness, how they negotiate their identities in the face of medical narratives, and how storytelling plays a role in reclaiming agency.

In qualitative research, axiology concedes that research is value-laden, meaning that researchers bring their own perspectives, biases, and ethical commitments into the study (Creswell & Poth, 2018). I acknowledge the ways in which my experiences might influence my research focus. First, I recognise that my experience has orientated me toward the subjective experience of illness, towards tensions between medicalised understandings and individuals' lived experiences. I may be more attuned to how individuals navigate disruption to their identities and how they reconstruct meaning in the aftermath of changes. This interest reflects my academic curiosity and a personal desire to explore the processes that helped me make sense of my experiences. Second, my interpretations will be seen through the lens of someone who has lived through a health crisis. I may be more likely to notice certain themes, that could be less salient to a researcher without similar experiences. While this perspective may introduce a certain subjectivity, reflexivity allows me to use that insight as a strength rather than a limitation. It can heighten my sensitivities to participants' stories, allowing for a deeper analysis. Finally, my experience will shape the questions I ask, I may be more inclined to explore how participants feel about language, how they perceive interactions with healthcare professionals.

This study is guided by a desire to understand how people interpret their experiences in ways that are meaningful to them, and to reflect on what this might reveal about FND within broader society.

### *2.2.2 Rationale for Qualitative Methodology*

Qualitative methodology has been chosen as the most epistemologically congruent approach for this study to facilitate an in-depth exploration of the lived experiences of individuals diagnosed with FND. Unlike quantitative research, which emphasises numerical data and statistical correlations, qualitative research prioritises meaning-making, personal narratives, and the complexity of human experience (Creswell & Poth, 2018). FND is multifaceted in nature, with distinctive psychological, neurological, and social implications (Stone et al., 2020). Qualitative research can allow for a rich understanding of how individuals interpret their diagnosis within these domains. The present study seeks to explore lived experience, to generate insight into the ways in which people construct meaning from an FND diagnosis (Clandinin & Connelly, 2000).

Qualitative research encompasses a range of ontological and epistemological perspectives which has led to the development of diverse methodological approaches (Willig, 2013). These following sections will examine various paradigms to identify the most appropriate methodology to align with the study's research aims and the researcher's philosophical stance.

### *2.2.3 Ontology*

Ontology is a branch of philosophy concerned with assumptions about the nature of reality and what can be known about it. Ontological perspectives shape how researchers approach the study of human experiences, behaviours, and social phenomena. In qualitative research, ontologies range from realism (which assumes an objective reality independent of human perception) to relativism (which suggests that reality which suggests that reality is more malleable, subjective, or context-dependent) (Guba & Lincoln, 1994). It is important therefore, for the researcher to consider their ontological position, as it will influence methodological choices and guide how they interpret meaning and construct knowledge (Crotty, 1998).

This research takes the position of constructivist-relativist ontology. These ontological positions are closely related and can overlap in qualitative research. Constructivism suggests that reality is socially and individually constructed, meaning people create knowledge based on their interactions and cultural contexts (Crotty, 1998). Proponents such as Piaget (1970) and Vygotsky (1978) argued that reality is only accessible as a product of human cognition shaped by cognitive processes and social exchanges. It emphasises subjectivity and the idea that different individuals or groups may construct different meanings of the same phenomenon. Relativism takes this idea further by arguing that there is no single, objective reality. It maintains that culture, history, and language shape multiple, co-existing realities (Guba & Lincoln, 1994). This implies therefore, that knowledge and truth are context-dependent and what is considered true in one society or cultural context might not be seen as true in another.

This study intends to apply a synthesis of these two perspectives to reflect an understanding of reality that incorporates individual meaning-making and the fluidity of ‘truth’ dependent on contexts. While this dual approach offers valuable insights, it creates one fundamental challenge that merits consideration: the tension between individual agency implicit in constructivism and the social/cultural influence that relativism emphasises. When these ontologies are synthesised, the researcher must address how to reconcile the individual's autonomy in *constructing knowledge* with the social and cultural context that relativism places at the centre of *knowledge construction*. A focus on individual agency could ignore the powerful influence of social systems (such as class, race, or gender) on shaping that agency; whilst an overwhelming emphasis on social context might obscure individual autonomy in the process of constructing reality.

The structure-agency debate has been central to social theory, with thinkers such as Durkheim (1982) emphasising determinism of social structures, whilst Weber (1978) and later Giddens (1984) highlighted the role of an individual’s agency in shaping social realities. Social theorists have wrestled with this ontological dilemma and proposed innovative frameworks to bridge the divide. For example, Mills’ (1959) concept of the *sociological imagination*, which calls for an awareness of how individual experiences are always embedded within broader social and historical contexts. Sociological epistemologies can help to expose the tensions between structure and agency and equip us with nuanced ways of analysing how they co-exist to construct our realities.

### ***2.2.4 Epistemology***

Epistemology refers to the question of *how we know what we know.* It is interested in discussions of the nature, sources, and limits of knowledge. Careful consideration of epistemological foundations is essential to inform the research design, interpretation of data, and ensure that the chosen methods are coherent with the underlying ontological assumptions. Epistemological pluralism suggests that various types of knowledge, and methods of acquiring knowledge, can be mutually supportive in the process of 'meaning-making'. This following section examines two epistemological positions, interpretivism and social constructionism. These are both aligned with a constructivist-relativist ontological position as they prioritise the subjective meanings individuals assign to their experiences. Both also recognise that knowledge is co-created through social interaction and embedded within specific contexts. However, each position can have limitations when applied in isolation; interpretivism tends to understate the influence of structural conditions on meaning-making, while social constructionism can overlook the individual aspects.

Rooted in the constructivist and hermeneutic traditions, interpretivism states that reality is understood as multiple and fluid (Gadamer, 1975). It is shaped by individual and collective interpretations rather than existing as a fixed truth (Lincoln & Guba, 1985). As such, research within an interpretivist paradigm seeks to explore the ways in which people construct meaning in their lives (Schwandt, 1994). This is particularly relevant when investigating experiences of illness such as FND, using personal narratives to explore how individuals make sense of their condition.

Social constructionism states that knowledge is actively constructed through social processes and interactions. Thinkers such as Berger and Luckmann (1966), and later Gergen (1985), argued that most concepts we may take for granted as reality are only the product of shared cultural practices. Institutions, such as education, the media, healthcare systems, and the family will play a central role in shaping constructions, which are in turn embedded in individual's everyday lives. Social constructionism acknowledges that people also possess the capacity to challenge discourses. This position is particularly attuned to the role of power in influencing which constructions become dominant. By applying ideas from social constructionism to FND research, this study can employ a critical lens to examine how participants' understanding of the disorder is sustained within broader sociocultural systems. This lens seeks to uncover external meanings assigned to an FND diagnosis and how these meanings influence individual understandings of the condition.

Symbolic interactionism offers a micro-level, interpretivist approach that complements these two approaches by revealing the mechanisms through which social constructionism is enforced. Emerging from the work of Mead (1934) and later developed by Blumer (1969), it examines the interactional processes through which people interpret meaning and perform identities. It shares interpretivism's focus on agency, while recognising that experiences unfold within culturally shared frameworks shaped by norms and discourse – core concerns of social constructionism. Frame analysis (Goffman, 1974) offers an application of this perspective, enabling researchers to examine how individuals use "frames" to make sense of their experiences and positions themselves within broader social narratives. For this study, frame analysis serves as an interpretive tool to explore how participants with FND draw on or resist dominant frames when telling their stories. In this way, symbolic interactionism supports aims of the project by illuminating how meaning is co-produced as a dynamic interplay between individuals and social constructions, as interconnected elements in a relational process.

## 2.3 Qualitative Framework

### *2.3.1 Choice of Method*

Through examination of this research's ontological and epistemological positions, two methodological approaches became the most salient options within the stated paradigm: phenomenology and narrative inquiry. Whilst phenomenology would tend to be more interpretivist, both approaches reflect epistemological pluralism, accommodating multiple ways of knowing and understanding reality. These approaches could offer valuable approaches to exploring lived experiences.

Phenomenology seeks to recognise the essence of an experience by identifying themes across participants' accounts of a specific phenomenon (Smith et al., 2009). By exploring how people *perceive* and *interpret* their lived experiences, phenomenology recognises that meaning is constructed through consciousness and cannot be separated from the individual's perspective (Smith et al., 2009). This approach is appropriate for capturing subjective experience, yet some have argued that it can overlook the contexts that shape those experiences (Finlay, 2011). In contrast, narrative research focuses on the way experiences are storied, including recognising that meaning is constructed through the act of telling (Clandinin & Connelly, 2000). A narrative approach considers how individuals position themselves within their own stories.

Given this study's aim to understand how individuals with FND make sense of their condition, narrative inquiry was deemed to offer a richer framework. By focusing on *what the story reveals about the person and the world from which it came*, a narrative approach will seek to story the complexities of participants' lived experience, highlighting both individual meaning-making and the wider sociocultural landscape in which their narratives unfold.

### *2.3.2 Narrative Inquiry*

An increasing number of scholars recognise that storytelling is deeply embedded in both our personal and social lives (White, 1980). Fisher (1984) coined the term *Homo Narrans,* to describe the centrality of our natural human impulse to narrate. Consequently, research has increasingly sought to explore how *"we 'story' the world, construct the worlds of experience, through the act of telling."* (Mishler, 1995: p. 117). Narrative inquiry refers to a number of analytic methods for interpreting such stories. The approach requires two layers of narrative interpretation - first the participants interpret their own lives through narrative, second the researcher interprets the construction of that narrative (Riessman, 1993).

Narrative research practice *"remains a relatively open intellectual space characterized by diversity but also fragmentation"* (Stanley & Temple, 2008, p. 27). Within this diverse and evolving landscape, the present study adopts narrative inquiry as a way of exploring how individuals with FND construct meaning through storytelling. Stories are treated as relational and performative acts, co-constructed between participant and researcher, and influenced by wider societal and medical discourses. This study is particularly interested in how participants use narrative to navigate the ambiguity of FND: how they make sense of a condition that is frequently misunderstood, how they position themselves in relation to medical authority, and how they manage questions of legitimacy, identity, and agency. This interpretive stance underpins the analytical strategy, which combines thematic narrative analysis, performative analysis, and frame analysis to explore both the content and the function of participants' stories.

### ***2.3.3 Illness Narratives***

Historically, the dominant conceptualisation of illness has been shaped by the biomedical model established in the early twentieth century, which achieved the status of both scientific orthodoxy and cultural common sense (Engel, 1977). This is characterised by a dualistic view of the mind and body. It treats the body as a malfunctioning machine separate from the mind.  A modernist paradigm reduces illness to biological processes that can be treated through scientific intervention. Within this paradigm, Parsons' (1951) concept of the *sick role* outlined societal expectations for how ill persons should behave. They can be exempt from usual responsibilities and should not be blamed for their condition, *as long as* they seek treatment and express a desire to recover from their illness. The idea of the sick role remains influential yet has several important critiques. Most notably, it assumes medical neutrality and does not acknowledge power dynamics inherent within healthcare systems. It is also ill-equipped to address chronic illnesses or disability, where full recovery may not be possible. It therefore reinforces hierarchies in which certain narratives are marginalised.

In contrast, post-modern conceptualisations of illness challenge the biomedical model without entirely rejecting its contributions. They recognise that illnesses are but deeply entangled with psychological and cultural forces, from stress and lifestyle factors to systemic inequalities and environmental conditions. Illness, in this view, is increasingly understood as an experience *constructed* at the intersection of biology and culture. This important reconceptualization was informed by Foucauldian theory. Foucault's (1973) work invites a critical lens on how dominant medical discourses regulate which stories are prioritised. A postmodern perspective shifts narrative authority away from medical professionals and toward the individual living with illness, who is now seen as capable of reclaiming their story and reconstructing meaning in the aftermath of what Frank (1995) calls "narrative wreckage." These post-modern perspectives open space for narrative inquiry into illness, to reveal how the specific narrative is consciously or unconsciously shaped by dominant cultural master narratives.

Traditional biomedical frameworks struggle to accommodate the complexity of FND, a condition that resists clear diagnostic categorisation and often leaves individuals caught between neurology and psychiatry. Within this paradigm, people with FND may find their symptoms questioned, their experiences delegitimised, and their identities fragmented. Using a narrative approach can enable this study to foreground how participants make sense of their condition and navigate the dominant master narratives that shape their understandings. This study will use narrative to explore how individuals give meaning to FND, opening space for a complexity of voices.

### *2.3.4 Typologies and Frameworks*

Frank's (1995) typologies of illness narratives offers a useful framework for exploring how individuals make sense of disruptive health experiences. He identifies three core narrative types. The restitution narrative, which reflects the linear story of diagnosis, treatment and recovery to *restore* individuals back to where they began. The chaos narrative, which conveys the disorientation and lacks coherence when illness overwhelms the individual's ability to create meaning; and the quest narrative, in which illness becomes a journey that transforms identity and teaches the sufferer something worthwhile. These narrative forms are understood as fluid modes of storytelling that individuals can move between. This model could be particularly relevant to FND because many individuals find themselves excluded from clear restitution narratives due to the condition's lack of clear treatment pathways. Their experiences often reflect elements of chaos narratives but may also include moments of transformation central to quest narratives. Applying the lens of Frank's typologies allows this study to attend to the ways participants move between stories as they seek to make sense of their condition. By noticing the narrative forms that participants draw upon, the study can examine how storytelling acts as a means to reclaim a sense of agency and identity in the face of an FND diagnosis.

This study will also draw upon Goffman's (1974) frame analysis as a supplementary lens to examine how individuals with FND interpret and present their experiences within socially recognisable structures of meaning. Frame analysis is concerned with how people organise experience by applying "frames", culturally shared schemata that help define *what kind of event is happening* and *how it should be understood*. Rather than analysing content alone, frame analysis attends to how individuals navigate interpretive frameworks during communication. This makes it particularly suited to exploring conditions like FND, where individuals may constantly negotiate competing frames (medical, psychological, and moral) and understandings of their symptoms. Frame analysis offers insight into the subtle ways participants seek to make their experiences socially intelligible. In this study, frame analysis provides a way to examine how participants align their stories with dominant discourses, how they rekey events, and how their framing choices shape their accounts.

## 2.4 Participants

A purposive-opportunity sampling technique was employed alongside broad inclusion criteria to maximise participant recruitment. Regarding sample size, the question of how many qualitative interviews is enough has long been debated amongst researchers. Charmaz (2014) has argued that this cannot be answered definitively and the question itself is problematic as it assumes the existence of such a number. Instead, she argues that what is important is to examine one's epistemological positioning within the research paradigm to prioritise what matters most in the study, balancing the depth with breadth of data in line with the research objective. Becker (2012) agrees that there is no magical number of interviews and data collection should instead be guided towards *theoretical saturation*, the point at which no new insights are gained. Since qualitative research is inherently iterative, it would not be possible to prescribe such a number in advance.

### *2.4.1 Inclusion Criteria*

Participants for this study were selected for the following inclusion criteria.

- Participants must be 18 years old or over
- Participants must be living in the UK

- Participants must have received a clinical diagnosis of Functional Neurological Disorder from a registered healthcare professional

An inclusion criterion of 18 years or older was employed to ensure that participants could legally provide informed consent without requiring parental or guardian approval (Patton, 2015). Ethical guidelines emphasise that research participants must fully understand the purpose, risks, and voluntary nature of their participation in research (Wiles et al., 2007). Such considerations felt crucial when recruiting persons with FND as research has shown they may have higher rates of medical trauma, misdiagnosis, or psychological distress (Stone et al., 2020), making fully informed and voluntary participation a priority.

A requirement for participants to be *living in the UK* was specified in an attempt to ensure relative parity of access to healthcare, e.g., free access to the National Health Service (NHS). Carson and Lehn (2016) argue that healthcare systems significantly shape FND patients' diagnostic journeys. For example, individuals in countries with private or insurance-based models such as the USA, likely experience different pathways to care. Additionally, including only UK residents sought to maintain some consistency in how FND is conceptualised and named. Kirmayer and Sartorius' (2007) cross-cultural research of medically unexplained symptoms (MUS) including FND, demonstrates that interpretations vary between countries, from emphasising psychosocial explanations to a focus on organic pathologies. Healthcare professionals in the UK largely adhere to biopsychosocial models of FND (Edwards et al., 2013). Limiting the sample to UK residents therefore meant that participants share a common socio-medical context, facilitating comparability of their experiences and therefore enhancing internal validity of this study.

Participants were required to state that they had received a clinical diagnosis of FND from a registered healthcare professional (as opposed to self-diagnosing with the disorder). A priori decision was made that participants would not be required to provide formal evidence of their FND diagnosis. Research has shown that many individuals receive their FND diagnosis informally, depending on the clinician's framing and communication style (Stone et al., 2020). Requiring proof could exclude individuals whose diagnosis was not clearly recorded, despite their genuine interactions with healthcare services (Edwards & Bhatia, 2012). The requesting of formal evidence was not only a potential barrier to participation but raised some ethical and practical considerations. The sharing of medical records posed significant privacy concerns and had the potential to influence power dynamics and reinforce a medicalisation of participants' narratives. From a narrative ethics perspective, Frank (2000) argues that the value of a story does not lie in its objective accuracy through medical verification, but in what it reveals about the person's sense-making, suffering, and identity. This aligns within the present study's constructivist and interpretivist paradigms, which holds that the subjective meaning participants attribute to their experience is more relevant than objective facts found in medical records (Willig, 2013).

An initial conceptualisation of this research project considered recruiting participants through NHS services. However, upon consideration of the literature, it was decided that this would have excluded individuals who lack access to specialist care and limit the representativeness of the sample. Stone et al.'s (2020) research was particularly useful in highlighting significant geographical disparities in specialist FND clinics with many regions entirely lacking dedicated services. As a result, many individuals with FND receive their diagnosis and care through neurology, primary care, or mental health services, and in many cases, they are no longer engaged with formal healthcare due to lack of treatment options post-diagnosis (Stone et al., 2020). Through discussions with research supervisors, it was agreed that in widening recruitment, this study might ensure a more representative sample, rather than privileging those who have had formal access to specialist FND services.

### *2.4.2 Exclusion Criteria*

The only exclusion criterion applied during recruitment was that participants should not be experiencing severe mental health difficulties at the time of the research. This criterion was not defined operationally through specific diagnostic labels or assessments but approached flexibly and ethically through contact with potential participants. This contact would take place via email, and if necessary, a telephone conversation to ensure participants felt able to engage in an in-depth interview. In practice, no exclusions were required as all individuals who expressed interest were assessed to be well-positioned to participate meaningfully in the research.

### *2.4.3 Recruitment*

After gaining approval from the University of Essex Faculty Ethics Committee (see Appendix J), a recruitment poster was circulated on social media platforms Facebook and X (formerly Twitter). This poster (Appendix B) invited participants to contact the primary researcher via email to express interest, ask questions about the research and find out whether they were eligible to take part.

The researcher approached specific organisations and charities that support people with FND, such as FND Hope and FND Action to request circulation of the recruitment poster with varying success. FND Hope invited the researcher to complete their internal ethical approval process, which was granted by the end of August 2024, however at this point the research project was deemed fully recruited and therefore circulation of the poster was no longer required. The research poster was shared by the primary researcher across several FND peer support Facebook groups associated with FND Hope UK, FND Action UK and FND Matters (Northern Ireland).

Recruitment took place in July and August 2024. Eligible participants were provided with a Participant Information Sheet (see Appendix C) and given the opportunity to ask any questions before proceeding. Following consultation with an FND expert by experience, a simplified flowchart of the research procedure was created to ensure that individuals with certain sub types of FND could more easily understand the study requirements. FND is known to impact information processing and concentration, (Stone et al., 2020), meaning that a five-page text-based Participant Information Sheet could be deemed overwhelming. A step-by-step flowchart (Appendix D) was co-created with the FND expert by experience and shared alongside the participant information sheet to reduce cognitive load by making the key information visually digestible. This sought to increase participants' ability to make an informed decision about participation in the study, in alignment with universal design principles in research (Braun & Clarke, 2013). Six participants asked clarifying questions via email and two participants requested an initial call with the researcher, a further seven were happy to proceed to the interview without additional information. Participants were required to give written, informed consent before taking part (see Appendix E), which was returned to the primary researcher via email.

A total of 51 individuals initially expressed interest, but some did not follow up after receiving further details about the study. Ultimately, 15 participants were successfully recruited and included in the final analysis. This sample size was chosen on both methodological and practical grounds. From a narrative methodology perspective, a sample of this size is sufficient to generate rich, detailed accounts while still allowing for in-depth analysis of individual narratives (Reissman, 2008). In addition, the researcher considered it important to reimburse participants for their time and contribution, in line with good ethical practice and to reduce potential barriers to participation. However, the available university research funding placed limits on the total reimbursement budget, meaning that recruitment beyond 15 participants was not financially feasible. Consequently, the sample size represents a balance between ensuring high-quality qualitative data and working within constraints of the project.

## 2.5 Data Collection

Interview scheduling was coordinated between participants and the primary researcher via email. Following conversations with the FND expert by experience, the researcher agreed that flexibility in approach must be prioritised to allow participants to choose a time that best suited their needs. Each interview was arranged as a 90-minute video call, following the FND expert by experience's suggestion, participants were given the option to request breaks as needed. This approach ensured that participants could comfortably engage throughout the interview (Braun & Clarke, 2013). The duration of interviews varied in practice, with actual interview lengths ranging from approximately 45 to 95 minutes.

At the beginning of each interview, as outlined in the interview schedule (Appendix F), participants were asked to provide demographic information, including age, gender, ethnicity, and disability status. The collected demographic details are summarised in Table 4.

### *2.5.1 Demographics*

**Table 4**

*Research Sample Demographics*

| Demographic | | Frequency |
|---|---|---|
| Age | *18-20* | 0 |
| | *21-30* | 1 |
| | *31-40* | 6 |
| | *41-50* | 3 |
| | *51-60* | 4 |
| | *61-70* | 1 |

| Demographic | | Frequency |
|---|---|---|
| Gender | Female | 9 |
| | Male | 6 |
| Ethnicity | White British | 6 |
| | White Irish | 2 |
| | British Pakistani | 1 |
| | Indian | 1 |
| | Black British Caribbean | 1 |
| Religion | None | 8 |
| | Christian | 2 |
| | Jehovah’s Witness | 1 |
| | Spiritual | 1 |
| | Buddhist | 1 |
| | Muslim | 1 |
| | Sikh | 1 |
| UK Region | Southern England | 4 |
| | Midlands/East Anglia | 3 |
| | Northern England | 3 |
| | Northern Ireland | 3 |
| | Scotland | 2 |
| Sexuality | Heterosexual | 13 |
| | Gay | 1 |
| | Bisexual | 1 |

### *2.5.2 Narrative interviews*

Interviews were conducted as video calls via Microsoft Teams to allow participants to engage from their own homes, thereby reducing potential barriers related to travel or fatigue. A high number of participants would have had difficulty attending an in-person interview due to the fluctuating nature of their symptoms. Remote participation ensured that participants could take part from an environment that was familiar and supportive. This reduced the potential for stress and symptom exacerbation. On a practical level, it also accounted for the geographic distribution of participants located in various regions of the UK.

The interview process was grounded in principles of accessibility and emotional safety. Participants were offered the option to receive the interview schedule in advance to help them prepare, six out of fifteen participants opted to do so. At the beginning of the interview, the researcher ensured that participants were in a setting where they felt able to speak freely. In one case, a participant requested that his wife be present during the interview to support his memory and reduce anxiety. This request was accommodated in line with the participant-led ethos of the study. The interviews followed a semi-structured schedule, which had been co-developed with an expert by experience (an individual with lived experience of FND), to ensure that the language used was sensitive to participants' experiences and aligned with appropriate non-pathologizing framings of the disorder. The schedule consisted of six open-ended questions (see Appendix F). Participants were made aware that they could chose not to answer any questions and were encouraged to share as much or as little as they felt comfortable with.

The researcher positioned herself as the discreet facilitator whose role was to create the conditions for participants to speak freely about their experiences. Following Chase's (1995) guidance, the researcher refrained from directing the narrative. She provided a supportive presence that encouraged participants to shape their own storytelling. The six core open-ended questions (Appendix F) were consistently used across all participants to ensure some comparability. Again, the FND Expert by Experience suggested to order these questions in a way that might feel most natural to participants, starting with less emotionally demanding questions and building towards more reflective or sensitive areas. However, the order of these questions remained flexible, allowing stories to unfold naturally according to each individual participant's narrative choices. Participants were not interrupted or redirected unnecessarily. At times, the researcher employed some follow-up questions and prompts as needed to gently encourage elaboration or reflection. These follow-ups were used sensitively to support the dialogical nature of the interview while allowing each narrative to unfold in a way that felt natural to the participant.

## 2.6 Data Analysis

### *2.6.1 Transcribing Storied Experiences*

The transcription of narrative interviews was conducted solely by the primary researcher. It followed a methodology that sought to capture the full dimension of the participants' narratives. Frank states that the *"voices of the ill are easy to ignore, because these voices are often faltering in tone and mixed in message, particularly in their spoken form before some editor has rendered them fit for reading by the healthy."* (Frank, 1995, p. 25). Therefore, the researcher transcribed the interviews verbatim, prioritising the words spoken but including some non-verbal cues such as pauses, or other emotional expressions (laughter, crying). These elements were carefully included to maintain the narrative as it was told. This decision to include additional speech elements was grounded in the dual goals of thematic and performative analysis. Riessman (2008) claims that inclusion of non-verbal elements can highlight relational and emotional dimensions of a narrative. For example, pauses might signify moments of reflection, laughter or crying might signal emotional release. These non-verbal cues serve as important markers of how the participant is emotionally engaged with their story and help the researcher to interpret its significance. While some transcriptions go further, to include elements like vocal tone, body language and facial expressions, these were not included in this study to avoid overwhelming the analysis and risk introducing too much complexity. This approach maintains a manageable scope while capturing the emotional and relational dimensions of the storytelling (Riessman, 2008). An example of a transcript can be found in Appendix G. In order to protect confidentiality, participants were pseudonymised and anonymised during the transcription process.

### *2.6.2 Analysing Storied Experiences*

Mishler (1999) recommends that researchers reflect on the potential benefits of various analytical approaches before settling on a specific method for narrative analysis. The researcher explored various models of narrative analysis in psychology, extensively consulting Riessman’s (1993) handbook as well as the numerous studies she references (Ginsburg, 1989a, 1989b; Bell, 1988; Labov, 1972; Gee, 1991; Radley & Taylor, 2003). Additionally, she attended a one-day Narrative Analysis workshop hosted by the Social Research Association.

Thematic narrative analysis (TNA), as described by Reissman (2008), primarily focuses on the "what" of the stories, emphasising the content and themes expressed in the narratives. Through a comparative approach, the researcher identifies and codes the patterns and themes that emerge from the stories. Focusing on the content of stories, TNA seeks to identify the issues that are central to participants' narratives, identifying commonalities across stories. However, Riessman (2008) also highlights how TNA can lean towards objectivism. The contexts surrounding participants’ phrase might not be fully explored and as a result, when multiple narratives are grouped into the same thematic category, readers are left to assume that everyone in the group interprets their statements in the same way. There is an assumption of transparency of meaning and hegemony of experience, for example that all participants mean the same thing when they speak about *health*. Through a singular focus on the text of the narrative, this approach can inadvertently become reductionist and disregard the individual.

While TNA focuses on the *what* of the story, performative narrative analysis (PNA) adds an additional layer by exploring the *why* - why the storyteller chooses to present their experience in a particular way and what that performance seeks to achieves. Where TNA might identify themes, such as *health*, *pain,* or *loss* in a story, PNA goes further to examine how these themes are performed and what that might reveal about the speaker's sense of agency and identity. PNA seeks to understand how what is being communicated reflects the speaker's intentions. To mitigate the more objectivist stance of TNA, PNA considers the researcher's role in shaping the performance of the narrative. It recognises that the act of storytelling is always influenced by the context in which it is shared, therefore attention is also paid to the relationship between the researcher and the participant.

This study will using an integrative approach for a richer and dynamic analysis capturing both *what* participants say about their experiences of receiving an FND diagnosis and exploring *why* they communicate their identities and perspectives through the stories they tell. Given the variety in approach to narrative inquiry, there are no fixed rules for conducting the analysis. As such, the process enjoys flexibility and adaptability of scope. However, in order to ensure transparency and validity of findings, it is important to outline the process.

### ***Thematic Analysis - Building Narrative Types***

In this study, the researcher followed the five stages outlined by Fraser (2004); *Transcription and Familiarisation, Identifying the Core Themes, Line-by-Line Analysis, Contextualisation, and Comparative Analysis*. This helped guide the analysis with a systematic approach that allowed for flexibility in interpretation.

The researcher applied this framework during the transcription process, first reading through each transcript to understand it as a complete narrative. Next, individual transcripts were analysed line by line, with key elements highlighted with a focus on content and context (Riessman, 2008). Themes from all 15 participant narratives were then transferred to an Excel spreadsheet to facilitate a comparative analysis between accounts. An example of a thematic narrative coding its presentation in the Excel spreadsheet is included in Appendix H.

The process of grouping narrative types in this study draws on Frank's (2000) view that such frameworks can help disentangle and shed light on the basic life concerns being addressed and the way each story articulates a particular relationship between the body and the world. Frank (2000) argues that frameworks should seek to focus attention on the truths existing within the stories. This aligns with the approach of this study, where the narrative types were developed as means to organise and focus on specific narrative elements that reflect the participants' lived experiences with FND. Therefore, narrative types are not presented as fixed classifications but seek to categorise the data in a way that makes it meaningful to the reader.

Methodologists identify at least two ways of coding the data. A deductive approach follows the Weberian (1978) tradition of sociology, where abstract and ideal types are deduced from theory as pre-established types. An inductive approach, however, relies on a trial-and-error method. Researchers identify key units as they emerge from the data that are then compared to broader patterns or categories across multiple narratives (Grémy & Le Moan, 1976). The choice for an inductive approach in this study is justified by the commitment to remain closely aligned with the realities of the participants, which could be compromised by imposing preconceived theoretical frameworks onto the data. Researcher reflexivity will be acknowledged: throughout the researcher will document their decisions regarding the development of the narrative types. This transparency will seek to ensure a more accurate and ethical representation of the participants' voices that remains firmly grounded within the data.

### ***Performative Analysis – Triangulation of Experience***

The narrative themes presented in this study were initially identified using thematic narrative analysis, organising participants' accounts into patterns of meaning with some coherency across interviews. Triangulation through use of performative narrative analysis then explored how participants *tell* their stories, paying attention to structure and interactional context. This dual-layered approach enables an examination of the identified common themes as *phenomenologically distinct experiences*, shaped by how individuals construct and perform their identities within their stories.

For each narrative type, multiple stories were analysed further using PNA and one exemplary story is presented and discussed in detail in the results section. To counter the argument that all narrative interpretations are equally plausible, this study adopted elements of structural narrative analysis, which anchors interpretation in the formal features of the text and the way narratives are organised. This approach attends to how participants structure their stories, providing a grounded basis for analysis. This allows for a more accountable interpretive process, demonstrating that while multiple readings are possible, they are supported by identifiable features within the narratives themselves.

This study followed performative narrative analysis followed the process as outlined by Riessman (2008) in her example study on Masculinity and Multiple Sclerosis (Riessman, 2003). For example, narrative form can be analysed by looking at constructed *scenes*, dramatization can be interpreted through linguistic features such as use of direct speech, repetition and expressive sounds. Reissman also suggests paying attention to dialogic features of storytelling, for example *asides* where participants may step out of the action to engage directly with the audience. An example of a performative narrative coding can be seen in Appendix I.

The analysis maintains transparency by drawing attention to the broader research context in exploring *why* participants might they feel a need to perform certain aspects of their identity when storying their experiences of FND diagnosis. Attention was paid to the relational dynamics of the interview setting, including how participants may have shaped their narratives in response to their perceptions of the researcher, or in anticipation of other imagined audiences. These interactional layers were explored through a reflexive journal, which helped surface assumptions and responses during the interview process. For selected performative extracts, micro-context was also considered, such as when this particular narrative emerged within the flow of the interview, and how they connected to earlier or later moments in the conversation. Alongside this, macro-contextual factors such as participants' family, cultural background, and personal history were taken into account, especially where these gave meaning to the stories being told.

### *2.6.3 Methodological Rigour*

In positivist or post-positivist paradigms, rigour is assessed through objectivity, reliability, validity, and generalisability which aims to ensure that research findings are measurable and reproducible (Clandinin & Connelly, 2000). Since constructionist and interpretivist paradigms acknowledge the co-construction of knowledge between researcher and participant, rigour cannot be assessed 'objectively' as any assessment would rest on the premise that there is such a thing as purely objective knowledge. If we understand that meaning is negotiated rather than discovered, rigour must be assessed through criteria that reflect transparency, reflexivity, and contextual integrity, rather than objectivity. In this view, rigour is not about reaching a single "truth" but about demonstrating the credibility and trustworthiness of the interpretive process. Debates have arisen between qualitative researchers as to how to assess methodological rigour, with various standards and priorities foregrounded, for example Clandinin and Connelly (2000) have focused on verisimilitude and transferability of findings. However, the purpose of the present study is not to assume transferability but instead to hear the stories of a small group of individuals who have undergone a specific experience (receiving a diagnosis of FND). The aim of this type of research is to illuminate a particular aspect of social reality, offering a deeper understanding and new perspectives on said reality, rather than seeking a definitive explanation of the phenomenon.

### *Methodological Integrity*

Levitt et al. (2017) discusses instead the idea of methodological *integrity*. Through recognising that different paradigms have different goals, Levitt's framework supports epistemological diversity in qualitative research and allows methodological flexibility.

She suggests methodological integrity can be assessed by considering two main criteria. The first is *Fidelity to the Subject Matter* meaning that the research must authentically represent the experiences, meanings, and perspectives of participants. The second criteria suggested is *Utility in Achieving Research Goals*, that the study effectively answers the research questions in a way that is coherent and meaningful. Her approach suggests that operationally, methodological rigour is contextually appropriate rather than imposing universal criteria.

As such there is no template for assessing integrity in narrative research, but the present study implemented the following strategies to meet the first criteria and authentically represent participant experience. Firstly, by employing semi-structured interviews the research design prioritised participant-led narratives that allowed individuals to tell their own stories rather than imposing predefined categories or theoretical assumptions (Frank, 2005; Riessman, 2008). Sensitive interviewing techniques combined with a non-directive stance sought to create a non-judgmental space for participants to share their experiences (Levitt et al., 2017). Thick description (Geertz, 1973) was employed to preserve the nuances of participants' accounts. Direct quotations are included in the findings, using pseudonyms and to uphold participant confidentiality. An iterative reflexive analysis process was followed, revisiting transcripts multiple times to ensure that interpretations remained faithful to participants’ accounts. Finally, member reflections were sought by inviting participants to provide feedback on the study’s preliminary interpretations. While this was not a formal member-checking process, it sought additional assurance that participants’ stories were represented accurately and respectfully.

To meet Levitt et al. (2017) second criteria for integrity, that the study answers its question in a coherent and meaningful way, this research employed upon dual processes of distanciation and appropriation (Ricoeur, 1976) as essential for maintaining meaningful interpretations of texts. Distanciation encourages the researcher to first examine the text through a neutral lens. This critical detachment ensures that the researcher engages with the narrative data on a deeper level than accepting at face value. Distanciation therefore, is crucial for avoiding oversimplification a narrative’s meaning. Appropriation involves weaving insights derived from the narrative into the researcher’s own understandings and situating them within broader theoretical frameworks. In narrative research, this step allows insights to be reinterpreted in broader contexts (Ricoeur, 1981). Appropriation ensures that the research findings can be connected to societal concerns, making the research more impactful (Ricoeur, 1976). Maintaining transparency about the researcher’s role is crucial to appropriation. The researcher’s stance is not external to the process, they are understood to actively influence the *appropriation* of narratives. This influence is not considered a hindrance but a fundamental feature of narrative research. A statement on researcher’s background is included in the following section in order to critically reflect on the researcher’s role and enhance the depth and authenticity of the findings. Riessman (1993) argues that researchers can also enhance transparency of their work by clearly outlining their interpretive processes and providing access to primary data for other researchers, as such, a sample transcript has been included in Appendix G.

### *Researcher background*

As a White British woman, a trainee clinical psychologist, and someone with lived experience of illness, I occupy multiple positionalities that inevitably shaped the research process and my interactions with participants. I did not disclose my personal illness experience during interviews. This decision was aligned with my stance on self-disclosure and the importance of maintaining appropriate boundaries. It was important to me that the focus remained on participants' narratives. I anticipated (correctly) that some participants might ask about my interest in FND. When this occurred, I explained my stance that FND has multiple definitions and conceptualisations depending on who you ask, and that my aim was to hear directly from individuals living with the condition, an answer that appeared to satisfy and resonate with participants. Though my interest in FND is academic, my curiosity will undeniably be shaped by my own experience of illness. Throughout the research process, I engaged in reflexivity, keeping a reflective journal to critically examine how my perspectives may be influencing the interviews and interpretive process. By making my positionality transparent, I aim to contribute to the trustworthiness and ethical integrity of the study. I recognise that my own lived experience will be present in this work inevitably shape the findings and I see this as a strength rather than a limitation. I believe in the power of stories not as data, but as a means of making sense of our lives. Through this research, I seek to honour the stories of others whilst acknowledging the ongoing impact of my own.

## 2.7 Ethical Considerations

Prior to commencing this study, a risk assessment was completed, and ethical approval was gained from the University of Essex ethics committee (see Appendix J).

### *2.7.1 Participant Wellbeing*

This research prioritised participant wellbeing throughout due to emotionally sensitive the nature of FND as a disabling and debilitating condition. The researcher carefully considered risk of harm in interviewing this population, and to prevent any misunderstandings, participants were clearly informed that the interviews were not intended to serve as therapy or counselling.

Participant wellbeing was actively prioritised at every stage of the research process in alignment with ethical principles of respect and care (British Psychological Society, 2021). The researcher consulted with an individual with lived experience of FND to ensure that all study materials (such as recruitment poster, participant information sheet) were sensitive and accessible. This consultation helped amend clinical language, making the materials more welcoming to potential participants. The participant information sheet was adapted to a more visual format to reduce the risk of cognitive overload associated with certain FND subtypes.

At the beginning of each interview, the researcher and participant negotiated comfort and accessibility for the research encounter. Participants were offered the option to take breaks as needed or to pause and complete the interview at a later date if this felt more manageable. The researcher also initiated conversations about communication preferences, explicitly asking: *"Is there anything you would like me to know about how your FND might impact this interview?"* This opened space for participants to disclose, for example, if they experienced speech difficulties (such as a stammer) and allowed for individuals to share whether they would prefer the researcher to allow more time or offer possible word suggestions. Similarly, participants who disclosed the possibility of seizures were invited to express how they would like the researcher to respond should one occur during the interview. All participants were informed that they were not obligated to answer any questions, were invited to share as much or as little as they felt comfortable with and retained the right to withdraw from the study at any time without consequence.

At the end of each interview, a deliberate period of debriefing was built into the process. Participants were given time to reflect on the experience and were offered reassurance, support, and signposting to relevant organisations should they wish to seek further information or assistance. Additionally, a follow-up email was sent one week later, which included an offer for a debrief call if desired; no participants took up this offer, though many responded positively to the email, expressing appreciation for the opportunity to share their stories. Several participants reported that they had experienced the interview process as meaningful and validating.

### *2.7.2 Potential Disclosures*

FND, in some conceptualisations, was historically understood to have links with ‘repressed’ or unexpressed traumatic events (Breuer & Freud, 1995). Therefore, it was important to consider the possibility of potential disclosures during the research. The primary researcher would follow a clear escalation protocol in line with ethical guidelines and safeguarding procedures (British Psychological Society, 2021). Participants were informed of the ‘exceptions to anonymity’ in advance in the Participant Information Sheet and gave their informed consent to take part with the understanding that confidentiality would be maintained unless they disclosed information indicating risk of harm to themselves or others. For non-recent traumatic events, this would be discussed on a case-by-case basis. Several participants chose to share experiences of childhood sexual and physical abuse during their interviews. These disclosures emerged organically as they reflected on their life histories and made connections between events and their FND symptoms. The researcher responded with empathetic listening and emotional containment, while remaining within the boundaries of the research role. While the nature of these disclosures was deeply personal and at times distressing, none indicated a current risk of harm, and therefore no safeguarding action was required by the researcher. Where appropriate, participants were signposted to relevant organisations such as the Male Survivors Partnership and other specialist support networks.

### *2.7.3 Confidentiality, Anonymity, and Data Storage*

Participant consent forms were stored in password-protected files on either an NHS computer (EPUT) or a university computer (University of Essex). Appropriate access controls were implemented to restrict access to confidential information to only the primary researcher and her supervisors. Appropriate safeguards were put in place to protect personal data present on the consent form, and participants' email addresses were stored in a password-protected file. No paper copies were kept, only electronic copies were stored for the duration of the research on either an NHS laptop or a University of Essex computer with appropriate access controls.

Once an interview was completed, the audio recording was stored on either an NHS laptop or a University of Essex computer with restricted access. Audio recordings were transcribed, and all participant-identifiable information was removed, with pseudonyms applied from this stage onwards. After transcription, all audio recordings were deleted. The researcher also redacted or modified any specific contextual or personal details that could potentially identify participants (e.g., specific dates, place names, hospital details). Due to the qualitative nature of the research design, direct quotations are included in this report. This approach helped to elaborate on and illustrate key points, themes, and codes that emerged within the data and results, ensuring that participant narratives remained information-rich and authentic. Quotations from participant interviews are only used to reinforce findings relevant to the study. No identifiable participant information was accessible to anyone except the primary researcher and her supervisors. At no point during the research process was personal data disclosed, and participants are not identifiable in any reports that arise from this study.

### *2.7.4 Researcher Wellbeing*

Frank (1995) emphasises the moral responsibility of the researcher as a witness to stories of illness, stating that listening is an ethical engagement requiring openness, presence, and responsiveness. Frank recognises that this engagement with narratives of pain and suffering can be emotionally draining as *"These voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to."* Frank (1995, p. 25). To safeguard my well-being as a researcher, I drew upon my clinical psychology training and therapeutic skills to maintain appropriate boundaries. It felt important to remind myself as much as the participant, that these interviews were not designed as a therapeutic space. However, psychodynamic concepts of *identification* and *countertransference* were found useful to negotiate emotions arising in myself from participants' narratives. A reflective journal entry was completed after each interview and throughout the transcription and analysis phases, allowing me to engage with my personal responses in a more critical and structured manner. Additionally, I brought relevant personal reflections into supervision when appropriate to explore their possible influence on the research process. To process any more personal challenges that arose, I also continued attending weekly private psychodynamic therapy sessions. By integrating these strategies, I sought to ensure that I could remain emotionally regulated and attuned in my role as a researcher whilst seeking to uphold Frank's (1995) vision of ethical witnessing.

## 2.8 Chapter Summary

This chapter discusses the methodological foundations of this study, rooted in a constructivist-relativist ontological paradigm and guided by epistemological pluralism. Reflexivity is embedded throughout, with the researcher's positionality acknowledged to maintain transparency and to deepen the interpretive processes. The rationale for adopting narrative inquiry is stated and linked to the study's aim of exploring how individuals with FND story their experiences. Processes of recruitment are outlined and emphasis on a participant-led approach to data collection is foregrounded. An integrative approach to data analysis is explained, thematic narrative analysis seeks to capture salient content across narratives, while performative narrative analysis can examine the ways participants construct their stories. Finally, methodological rigour was established through the application of Levitt et al. (2017) framework for methodological integrity, prioritising fidelity to the subject matter. The chapter concludes with a reaffirmation of the study's commitment to centring participants' voices to fostering a deeper understanding of FND beyond the limits of biomedical definitions.

# 3 Results

## 3.1 Chapter Overview

This chapter presents the results of a narrative analysis of interviews with 15 adults diagnosed with Functional Neurological Disorder (FND). It begins by introducing the narrators, providing relevant symptom and diagnostic context for each pseudonymised account. The core findings are organised into four overarching narrative types: *Stories of Biographical Disruption*, *Stories of Inadequate Explanations*, *Stories of Stigma and Validation*, and *Stories of Embodied Reinterpretation*. These narrative types are first presented in a table to offer a framework to categorise the diversity of stories from the participants. Each narrative type is then explored using a thematic and performative lens, emphasising what was said and how the stories were told.

## 3.2 Introducing the Narrators

Providing contextual information for each narrator is crucial for interpreting the significance of their stories within the broader circumstances of their lives. However, this must be carefully balanced with the ethical obligation to preserve participant's confidentiality. Even with the use of pseudonyms, over-contextualising could unintentionally reveal identities, especially within the relatively small clinical population of FND patients. Therefore, information provided is limited to symptoms and diagnostic timelines and interactions in order to preserve anonymity. Other demographic factors are included in the text when deemed relevant to contextualise the findings.

**Table 5**

*Contextual Diagnostic Information for the Narrators*

| Pseudonym | FND Symptoms (participant's own language) | Symptom onset (years, months) | Diagnosis (years, months) | Diagnosed by |
|---|---|---|---|---|
| Alison | Hoarse voice, spasmodic dysphonia, stammer, language and speech processing difficulties, physical and cognitive fatigue, | 2yrs, 7ms | 1yr | NHS Neurologist |
| Angela | Fatigue, persistent cough, leg weakness, tremors, falls, cognitive difficulties, speech issues, vision problems | 3yrs | 2yrs, 6ms | Private neurologist (after self-diagnosed) |

| Pseudonym | FND Symptoms (participant's own language) | Symptom onset (years, months) | Diagnosis (years, months) | Diagnosed by |
|---|---|---|---|---|
| Andre | Pain, Seizures, Sensory hypersensitivity, Balance and coordination issues, Muscle weakness and fatigue, Lockjaw, jaw pain, teeth grinding, Cognitive and processing difficulties | 2yrs | 1yr | NHS Neurologist |
| Christine | Loss of dexterity, Weakness and fatigue, Cognitive issues, Speech changes, Bladder issues, Auditory processing issues, Functional swallowing issues | 12yrs | 7yrs | NHS Neurologist |
| Craig | Left-side weakness, Foot drop, Speech difficulties (stammer, word-finding issues), Chronic migraines, Bowel issues | 13yrs | 3yrs | NHS Neurologist |
| Damian | Difficulty walking, Tremors, seizures, and light-headedness, Sensory overload and stress-triggered symptoms, Chronic pain, migraines, Functional gastrointestinal symptoms, Fatigue, dissociation | 1yr, 6ms | 7ms | Neurologist |
| Kirsten | Limb weakness, Drop attacks, Severe speech difficulties, stuttering, Memory lapses, confusion, dissociation, Chronic fatigue, dizziness, sensory overload, Cognitive issues, Pain and movement limitations | 8yrs | 2yrs | NHS Neurologist |
| Lorraine | Left-side weakness, Balance issues, Tremors in hands, Episodes of paralysis, Loss of limb function, Cognitive and physical disconnect | 9yrs | 7yrs | NHS Neurologist |
| Martin | Limb weakness, Drop attacks, Paralysis episodes, Seizures, Memory loss, Dissociation, Eye spasms, temporary blindness, Choking, & breathing issues, | 6yrs | 4yrs | Neurologist |

| Pseudonym | FND Symptoms (participant's own language) | Symptom onset (years, months) | Diagnosis (years, months) | Diagnosed by |
|---|---|---|---|---|
|  | Fatigue, brain fog, sensitivity to light and noise, Confusion and cognitive lapses |  |  |  |
| Maya | Numbness, weakness, and reduced sensation on left side, Limb heaviness, Balance issues, Facial weakness, Dystonia, Difficulty with chewing, taste, speech, and tongue movement, Word-finding issues, memory lapses, Chronic fatigue, Pain, Migraines, Functional paralysis | 1yr, 7ms | 3ms | NHS Neurologist |
| Nicola | Limb weakness, heaviness, tingling, and loss of function, Paralysis episodes, Dizziness, light-headedness, balance problems, Speech and jaw issues, Visual disturbances, Emotional overload and dissociation | 1yr, 6ms | 8ms | NHS Neurologist |
| Rebecca | Sudden leg paralysis and drop attacks, Loss of ability to walk, Whole-body tremors, fatigue, and functional movement issues, Difficulty with coordination and balance, Limited mobility | 1yr | 8ms | NHS Neurologist |
| Ross | Speech issues and balance problems, Functional limb weakness, unsteadiness, falls, Fatigue, headaches, Cognitive issues, Tremors | 3yrs, 6ms | 2yrs, 6ms | NHS Neurologist |
| Sharon | Seizure-like episode followed by right-sided paralysis, Speech problems, headaches, flashing lights, pins and needles, Functional limb weakness, Fatigue, tremors, unpredictable energy | 1yr | 1ms | Private Neurologist |

| Pseudonym | FND Symptoms (participant's own language) | Symptom onset (years, months) | Diagnosis (years, months) | Diagnosed by |
|---|---|---|---|---|
| | crashes, Loss of mobility, emotional exhaustion, Memory issues and dissociation | | | |
| Tariq | Sudden paralysis, collapse, non-epileptic seizures, Functional limb weakness and unsteady gait, Involuntary facial twitching, breathing tics, chronic fatigue, Sensory hypersensitivity, Dissociation and shutdowns | 1yr, 6ms | 6ms | NHS Psychiatrist |

Table 5 shows the diversity of FND experience of participants in this study. Symptoms are reported here as described using participant's own language. All participants reported experiencing multiple symptoms and FND subtypes, which could occur simultaneously. The symptoms were characterised by their unpredictability in both presentation and timing. The table also presents an overview of each narrator's FND timeline, with symptom onset ranging from one to 13 years ago, and diagnoses occurring between three months to seven years ago. These timings refer to the point at which the interview took place in either August or October 2024. The majority of narrators underwent investigations within the NHS with several opting to pay privately for neurologist consultations. All but one narrator were diagnosed by within neurology settings, with Tariq being the exception to receive the diagnosis from his psychiatrist.

## 3.3 Narrative Types

### *3.3.1 Summary of Findings*

The thematic narrative analysis resulted in a total of 22 themes, which were then grouped into four narrative types. These narrative types were not intended to serve as fixed or rigid categories, but rather as a way to organize and highlight particular stories that reflect participants' lived experiences.

**Table 6**

*Overview of Key Themes Identified Across Participant Narratives*

| Narrative Type | Sub-themes | Brief Description |
|---|---|---|
| 1. Stories of Biographical Disruption | Suddenness of Onset, Personal Identity Loss, Professional Identity Loss, Protracted Diagnosis (liminal states), Loss of Imagined Futures, Ruptured Understandings of Past | Narratives focus on ruptures experienced as FND disrupts identity and fractures personal, professional, and temporal continuity. |
| 2. Stories of Inadequate Explanations | Unclear Diagnosis Experiences, Personal Search for Understanding, Psychological Explanations, Neurological Explanations, Lacking Follow Up & Treatment Pathways | Narratives convey the struggle to make sense of FND amid ambiguous explanations and fragmented treatment options. |

| Narrative Type | Sub-themes | Brief Description |
|---|---|---|
| 3. Stories of Stigma and Validation | Overt Stigmatising Experiences, Covert Stigma from Healthcare Professionals, Societal Ignorance of FND, Self-stigma & Shame, Feeling Seen & Validated, Seeing Themselves in FND; Identity & Advocacy | Narratives explore encounters with diverse forms of stigma, alongside moments of recognition and individual identification with FND. |
| 4. Stories of Embodied Reinterpretation | Reappraisal Of Physical Injuries & Co-Morbidities, Reappraisal of Mental Health Symptoms, Embracing of Neurodiversity, Problems with Interoception, Adaptation Strategies | Narratives describe reframing of symptoms and bodily experiences and developing adaptations for living with FND. |

Table 6 provides an overview of the narrative types and key themes identified across interviews. The four narrative types are presented in this order as participants, in general, appeared to progress through them in a chronological manner over the course of their experiences with FND. However, it is important to note that not everyone experienced or described their FND in this sequence; for most participants these stories could unfold concurrently. During the interviews, participants jumped back and forth in their timelines or moved between the four different story types. The four narrative types are described as integrated wholes, encompassing their associated sub-themes without exhaustively detailing each one individually. Narrative extracts are used throughout to illustrate and support the analysis. For each narrative type, one indicative account is presented in full and analysed performatively, shedding light on *how* these stories are told, and *why* participants may feel compelled to perform their story in response to receiving an FND diagnosis.

### *3.3.2 Stories of Biographical Disruption*

Narratives frequently depicted the onset of symptoms as sudden, propelling participants into a state of confusion and disorientation. Several cited the precise moment their symptoms began, with four including the date, and one participant (Sharon) specifying the precise time of day. Most appeared to recall the approximate month and year of onset with ease. Participants commonly situated the emergence of symptoms within their everyday activities, such as returning from the shops, out walking, playing football, or studying. Many expressed difficulty pinpointing any direct causality:

> *"I have absolutely no idea why... it was all fine the day before. I genuinely can't... shed any light as to why that Friday morning"* (Sharon).

In some cases, participants linked symptom onset to a physically traumatic event and a period of hospitalisation, such as Nicola being kicked by a horse or Martin seeking treatment for back pain. Others, like Ross, described waking up with new symptoms:

> *"I woke up and I couldn't speak properly, but it was worse than this now. So I, I couldn't, I just. I woke up and I just couldn't speak properly and and and then I was falling over. And the balance was really bad. And when, when, when I, when I gathered myself I just couldn't walk properly and it just, it just spir- like kind of spiralled".*

Descriptions of rapid escalation of symptoms were common and often involving dramatic presentations, such as paralysis, loss of speech or mobility, or seizure-like episodes. This narrative type included descriptions of how FND symptoms lead to profound shifts in sense of self, through the loss of abilities and identities. Participants frequently described a decline in independence and mastery, portraying the loss of ability to engage in activities such as painting or playing musical instruments – several spoke of the need to surrender their driving licenses.

As Angela describes, this loss of independence can be linked to an increased dependence on other people:

> *"I haven't left the house on my own for two years. So if [partner] isn't here to take me somewhere, well, I'm just in the house but, and I think I've, I've found it very, very hard, I was, I was actually a very, very fit person. I used to exercise. I used to go for like two or three mile walk every day. I walked fast everywhere, we played tennis, we, you know, I did all this sport and everything whereas now I struggle to do stuff just because of the fatigue."*

A recurring theme across narratives was this articulation of contrast between past and present selves. Like Angela, many participants offered unsolicited portraits of pre-FND selves that positioned their former identities as healthy and capable. Ross described himself as *"a very, very fit person"* in contrast with his current weight gain. Craig expressed a desire for the interviewer to understand changes to his personality:

> *"...just for you to know that since I started to have the, before I had the problems I was really outgoing. I'd have a good circle of friends. I'd be a, be a confident person, but since having the difficulties, it's knocked my confidence. I don't like to be on my own."*

Stories frequently included expressions of disorientation, with several participants conveying a sense of being unrecognisable to themselves. For Kirsten, the changes to her physical functioning resulted in disruption of her core identity, citing *"the way my health is* *it, it feels like the old me is dead and like I'm a completely new person.".* These stories highlight the emotional labour involved in reconciling a changed sense of self.

Participants told stories of how FND had either paused or brought an end to their professional lives. Of the fifteen participants interviewed, only three were still working full-time in their original job roles, and a further two had transitioned into less physically demanding employment. Some identified themselves as being temporarily signed off sick; others reported taking early retirement on medical grounds, and several self-identified as disabled. There was a notable use of self-deprecating humour in work related stories, such as Ross' assertion that *"I'm 36 going on 66"* or Lorraine declaring *"if I was a horse, they'd have shot me".* Again, comparisons with their past selves were notable: *"there wasn't anything I wouldn't tackle when it came to work. And I just can't. I just... it's not in me now."* (Martin).

Narratives could reflect overextension or unsustainable work pace preceding a burnout and the emergence of FND symptoms. Angela described her work pace as "*horrifically stressful and and I I kind of think that was like the final, the final straw really."* Maya told multiple stories of interpersonal difficulties with colleagues and management as a direct link to her FND onset and subsequent job loss:

> *"when I did start having panic attacks and crying to people, she would tell me off for talking to them, tell me to stop talking. That it was unprofessional to tell anyone."*

Andre diagnosed himself with "*Sick Building Syndrome – the building was making me sick"* through the repetitive strain of inadequate ergonomics. Differences emerged among participants' intentions to return to work with many prioritising a period of rest and recovery. However, a consistent theme across all narratives was the assertion of reluctance to relinquish employment in the first place. Participants frequently shared narratives of perseverance, continuing to work until symptoms made it impossible to do so:

> *"the panic attacks were kind of getting the better of me so I thought, I can't do this, it was too many, too frequent at work. So I thought, you know I can't do this anymore*." (Tariq)

The biographical disruption of symptom onset could be further compounded by a protracted diagnostic journey. All participants gave accounts of repeated referrals and assessments creating a drawn-out period of medical ambiguity. This diagnostic journey disrupted participants' expectations of a 'normal' illness trajectory, many made comparisons with resolved health conditions that had followed more linear courses of symptoms leading to a swift and understandable diagnosis. These stories were marked with expressions of surprise and distress that their FND experience had diverged so significantly from expected patterns. *"I've been referred to five different hospitals seven times"* Craig shared, *"I mean, I've had difficulties for 11, 13 years, but I only got the diagnosis three years ago."* Participants spoke of the ambiguity surrounding their symptoms resulting in feeling "*left in limbo – because we didn't have a diagnosis, we were just left in limbo."* (Nicola). For many, this was an alienating experience, particularly when their own confusion was mirrored by healthcare professionals, as Tariq describes *"seeing, you know, doctors coming to my bed and saying, 'oh, Mr Tariq, you're the mystery man'. You know, because they can't figure out what's wrong with me."* Before receiving their formal diagnosis, participants expressed feeling uncertain as to how to locate themselves within their experiences, contributing to their emotional suffering and feelings of broader dislocation:

> *"To have that lengthy and drawn-out process to get to the diagnosis, you know, it's no wonder that so many people end up with mental health problems, which may not necessarily have been there in the first place."* (Alison)

These liminal states were understood as eroding temporal coherence; participants' ability to integrate past, present, and future into a continuous narrative. Many participants spoke of how FND had damaged or stolen their idea of an anticipated future. For Sharon, this disruption was expressed poignantly:

> *"Why me? When life was just meant to be getting easier for us, we'd sold the farm and we'd actually moved to the town or the outskirts of town. Here, life was meant to be getting easier. We were meant to be able to enjoy life, and then all of a sudden FND appeared out of nowhere."*

For others, FND could also rupture their understanding of their past. Damian reflected on the irony of resilience in the face of early traumas and his current experience with FND:

> *"I feel I've managed to pull myself through some very traumatic experiences and for me it was a bit of an insult to myself – not because they were saying it – but to myself, I'm like, 'Wow, Damian, you managed to go through all of that and your only reward for it is now being disabled, quote unquote?!'"*

Damian's account reflects how FND upends his moral timeline; becoming disabled was not the reward he anticipated for suffering. He expresses discomfort with a retrospective reading of his life and makes efforts to reclaim authorship over his timeline to protect a resilient self-identity under threat.

### *Performative Narrative Analysis – The Unwilling Subject*

The story presented below was told at the beginning of our interview, as Christine describes the biographical disruption caused by the onset of her difficulties that led to her seeking an FND diagnosis. Christine's wider narrative is characterised by uncertainty and shame. She was diagnosed by a neurologist who she experienced as dismissive and demeaning. The lack of clear communication about FND left her doubting the diagnosis and herself. Although she later received more supportive care, Christine remains ambivalent about the FND diagnosis and struggles with the suggestion that her symptoms are self-generated. Yet she is empathetic toward others with the condition, recognising the stigma and systemic neglect many face. Formerly self-employed with a cleaning business, below she recounts the series of events that led to her stopping work.

> *I was like, really struggling to work, to have energy, getting odd sensations and then I was at work, working for this lady who I had worked for, for a few years. She went on holiday and then she come back and then she said, 'I've got to speak to you' and she says, 'your face has changed and we think you should see a doctor'. She says, 'your face has dropped since last saw you', which was odd – she says, 'I want you to go and see your doctor and I'll go with you and I'll explain'.*
>
> *But I didn't, I thought I just I was losing weight, so I thought it's me weight that's changed my face. And then I was at the dentist and I mentioned, just a check-up, and I mentioned I was noticing I was lisping and I thought it must be an age thing, or maybe with age your teeth move. And he says, 'I think you should see your doctor'. But I didn't, but the next week he phoned us up and he said, 'have you seen your doctor?'*

> *Which I thought was really odd, your dentist phoning you up. And I says 'no', but I made an appointment so I saw me doctor and I said I was feeling… me body wasn't working properly and basically my hands, it's mostly my hands and my brain but my hands weren't doing what I wanted them to do. It's like you know, the, it's like my hands are you know, your hands are really cold and you can't do a zip or you can't do laces, you lose your… your dexterity? So I've lost me dexterity in my hands, so she made me an appointment to see a neurologist.*
>
> *And then I went to work one day and me body just wouldn't, it just got too, too hard to work. So I just told the lady 'I've got, I can't do anymore'. And I got in the car and I drove home. Luckily it's an automatic and I didn't have the power in my hands and me legs to drive safely but we live very rural area so I got home and I told my husband I cannot work anymore. And I don't drive anymore.*
>
> \- Christine

Christine structures her story around four key scenes: cleaning at her employer's house, visiting the dentist, seeing the doctor, and driving herself home, each illustrating a moment in the gradual recognition of her illness. By doing so, she compacts into a narrative sequence that appears to shorten the timeline of her journey. This enhances the immediacy of her account, drawing the listener into re-experiencing it alongside her. Christine's story foregrounds the observations her employer and her dentist to construct a narrative of involuntary revelation. In foregrounding laypeople she also subtly critiques medical professionals who later appear distant or dismissive, in contrast to non-specialist figures who are attentive and empathetic. Christine elevates relational above institutional authority, to signal where meaningful recognition of her illness first emerged. Her use of direct speech plays a central role in this, allowing her to locate insight and urgency into others. Christine repeats the phrase *"see your doctor"* four times in this story, underscoring the external insistence that ultimately compelled her to seek medical attention – it is twice followed by *'but I didn't'*. Whilst others are portrayed as alarmist, she presents herself as downplaying her symptoms. By doing so, she can affirm her own credibility, depicting herself as reluctant to medicalise herself, brushing off her own concerns as aging or weight loss, and expressing surprise at her dentist's unusual follow-up. The final scene of driving herself home underscores her reluctance to seek help, even at the point of collapse. It also serves to subtly evidence vulnerability and the seriousness of her condition – yet she narrates without sensationalism. Her final line serves as the coda to Christine's narrative, marking a shift from externally prompted recognition to personal agency. In her re-telling, her decision to stop working (and driving) is framed by recognition of risk, not panic or impulsiveness, reinforcing her identity as a responsible person.

### ***3.3.3 Stories of Inadequate Explanations***

Stories of the FND diagnosis moment varied significantly in terms of the clarity and manner of explanations given yet was often expressed as insufficient. Aside from Maya, who worked as a speech therapist, or Damian who knew someone with the condition, for most, the point at which they were diagnosed was their first time hearing the term *Functional Neurological Disorder*. Most participants described being given little explanation, and eight described being sent away to a website (primarily Neurosymptoms.org, with two directed to FND Hope). Andre typifies this, stating: *"Nothing was really explained more than that. 'Here's neurosystems.org. Look at that.' Right… OK."* Most experienced this as a dismissive and unhelpful act, with the exception of Kirsten who experienced it as an invitation to come to terms with the condition. Notably, she was given a follow up appointment to discuss which information on the website she identified with. Conversely, Christine described receiving the link in place of a concrete diagnosis and described how *"that confused us. I came out and I thought – is he saying it's FND? Why is he getting us to read this link?"*

This confusion was echoed in Martin's (lack of) diagnosis story. His literal disorientation reflects his psychological state and serves as a metaphor for post-diagnosis life with FND reflecting his sense of being cast out without direction:

> *"They literally said, "you're being discharged. Here's your paperwork, off you go". And I spent, I think, 15 minutes walking around the hospital trying to find my way out because I didn't have a clue where I was and where I was going. I just wandered up and down, up flights of stairs, and eventually found a door."*

In the absence of a comprehensive diagnostic experience, many participants described their own research process to understand FND, often relying heavily on online sources. Lorraine reflected on the irony that she *"did what every doctor tells you never to do. You start Googling."* Participants frequently described this process as creating more fear, as Sharon asserts *"You know what Google's like, when you start to Google, you need everything but the undertaker."* Alison spoke of her fear when confronted with lists of symptoms she did not yet experience, such as seizures:

> "*I have to say, I was like, Oh my God, it's like, is this going to be my life? Touch wood, there's been nothing like that."*

Andre, who had a background in science, described his own obsessive, research instincts as both a strength and a burden, noting that he *"was able to compartmentalise myself from the problem, actually work out what was going on."* Some participants found online communities and peer-led resources valuable in filling gaps. Craig and Angela, for instance, described attending educational sessions online from FND Hope as helpful and informative. However, not all experiences with online communities were positive, Damian and Nicola spoke of distancing themselves from forums because *"all they do is like to moan about the symptoms… it's just kind of a negative vibe"* (Damian).

All participants told stories that reflected their awareness of a psychological conceptualisation of FND, with most describing how healthcare professionals had at some point, suggested a link between their symptoms and trauma. Some participants shared accounts that conveyed an outright rejection of this model. Others, however, expressed more nuanced or ambivalent positions. Craig shared multiple stories of being told that his FND must have a trauma aetiology, yet expressed confusion when he could not identify such an experience:

> *"They've always said have I had a family trauma or something? Something significant in my life that could have brought the FND on? But I can't think of anything that would have brought it on."*

Similarly, Alison described engaging in psychotherapy in the hopes of unearthing a trauma but was unsuccessful, casting doubt on the usefulness of this explanation. Other participants reflected on earlier life events or periods of intense stress, such as Rebecca's references to domestic violence:

> *"There could be a trauma there that's triggered when I'm stressed or something. You know, I'm quite willing to accept that because it was, it was a traumatic time, and there are certain things that I respond to in quite an internal way".*

Maya, Kirsten, and Sharon told stories that suggested the diagnosis had prompted them to re-examine their life histories more closely, and they had begun to identify patterns of hardship or emotional strain. However, these reflections often appeared tentative and exploratory, as if they were working through their thoughts in real time during the interview to search for a trauma narrative that might justify their diagnosis. These tentative identifications were often undermined with statements like *“other people that have been through a hell of a lot worse than me and they don't have FND”* (Sharon).

In contrast, two participants who disclosed experiences of childhood sexual abuse endorsed a trauma-based explanation as a viable and meaningful lens through which to interpret their condition. Tariq described how it created a link between his life experiences and subsequent symptom development, while Lorraine felt that it brought meaning to her broader health challenges.

Most participants recounted being introduced to a neurological explanation of FND, through professionals or online materials, which invariably included a version of the metaphor that their *hardware* is intact, but their *software* is malfunctioning. Many found this analogy an intuitive way to understand their symptoms as neurologically material but structurally intangible. Several participants adapted or expanded on this metaphor in ways that reflected their own experiences. Kirsten expressed her sense of cognitive overload as *“like a computer, when it is working absolutely fine, but then you get lots and lots and lots of tabs up and everything seems to slow down, and like sometimes you just need to close all the tabs for it to work again.”* Tariq, drawing on his engineering background, interpreted his symptoms in terms of safety shutdown mechanisms, *“you put safety procedures in place, you write this code, so it's software, to make sure it works without breaking down. So I tried to compare that to the mind as well.”* Similarly, Andre, a scientist, described his FND as his *“hard drive is used up, your RAM's used up, and it is just grinding to a halt"*.

A recurring theme in participants’ narratives was the absence of a coherent treatment plan following diagnosis, which rendered the diagnostic label hollow. Even if a formal diagnosis of FND offered initial relief or validation, participants frequently described how this quickly gave way to frustration when no meaningful treatment pathway followed. Many highlighted stark regional disparities in access to care, which was either explicitly expressed to them in the case of Angela whose neurologist *"said there's no treatment in this area for it though, CBT, he said, might help with your anxiety and good luck with it, that was it. Good luck with it.",* or Martin, who noted geographical inequality by comparison that *"You sort of read some of what other people have, and they've got neurologist appointments and this appointment. And I'm like, they must live in a different part of the country with a better system than we've got down here."*

Two participants based in the Greater London area, Tariq and Maya, had been referred to a leading specialist FND clinic, with Tariq describing *"proper like FND physiotherapists, FND doctors, and people really interested in this stuff who know this thing".* However, such access was the exception. For most, treatment appeared to depend not on clinical need but luck – i.e. whether their local GP or physiotherapist happened to have heard of or taken an interest in FND. Those who did find support expressed their awareness of their good fortune. Rebecca explicitly described feeling *"I've been really lucky with the physios. One of the physios was from Australia and she knew exactly what to do with FND. Taught me different strategies."* Alison similarly acknowledged her luck in having a good physiotherapist from a past shoulder injury, as well as a personal trainer familiar with FND. For Sharon, too, it was a single physiotherapist who stood out as "*the only person that seemed to know anything much about FND, and he was very good at the physio, and he certainly helped me*". Participants' accounts illustrated how access to FND care is governed less by systematic provision than by chance, compounding the inadequacy of the explanations they received at diagnosis and leaving many with a label that lacked meaning or pathway to recovery.

### *Performative Narrative Analysis – The Faulty Script*

Rebecca describes her FND onset as following a period of acute stress: bereavement, viral illness, and physical overload. Her diagnostic process was ambiguous and dismissive; a neurologist vaguely likened her condition to PTSD and offered minimal follow-up. Rebecca's narrative is emotionally rich, blending moments of humour, insight and frustration. Rebecca seeks recovery through self-funded neuro-physiotherapy and use of creative rehab strategies. She challenges dominant trauma narratives, instead situating her FND in the context of chronic overextension and under-supported health conditions. For Rebecca, the FND diagnosis has been more confusing than helpful and she remains sceptical of the healthcare systems meant to care for her. This story was told later in the interview context and demonstrates the *Inadequate Explanations* narrative type through her critique of the repeated use of metaphor.

> *Rebecca: The explanation that I found, that's quite generic but did help me the first time I heard it. They say, 'your brain is like a computer, sometimes the software is faulty', which is really useful. However, when you hear it from everyone, from all of your appointments, it becomes a bit like, is that just something textbook that everybody says now? Obviously, I was studying as a student then, so I did a lot about anatomy and I've always worked in care, so I've always been interested in the human body, if you like. So that made a lot of sense, and I could, I would be OK with that. But like I said, the first time I heard, I thought that's a great analogy, but it's kind of like just a spiel now that I get quite regularly from most.*
>
> *Researcher: Mm hmm. Yeah, but I suppose, as you say, when you hear it for the 10th time or if that's all you're hearing, sounds like it's not quite enough of an explanation?*

> *Rebecca: Yes, yes. It's kind of like, oh, is that what you're, is that what you've been taught to say to people? Sure, it's a great analogy, I just don't need to hear it. Sometimes you just need to be listened to without someone telling you that 'your brain's like a computer and sometimes the software glitches'. Or it's, it's very – because that's exactly how it is you know, if you say, I don't know, 'I get these tremors in my legs' for instance, it's 'oh your brain is like a computer and just glitches sometimes', and it's sort of, [shrugs] you know… it's like that quite often. So you're not really helping me, you're just telling me what I already know.*
>
> - Rebecca

Rebecca rejects externally imposed explanations by recounting how this metaphor has become an overly scripted response. She appears to question whether the analogy reflects genuine care or rehearsed speech. Rebecca asserts her authority to interrogate the metaphor by referencing her knowledge of anatomy through her background in care work. With this, she resists the passive role often assigned to FND patients. The researcher enters briefly, signalling alignment as a kind of performative cue, which allows Rebecca to continue with greater intensity. She grounds her frustration in an embodied experience, using the example *"I get these tremors in my legs"* to highlight how the scripted responses feels irrelevant rather than helpful. Her mimicry of clinical language and gestures like shrugging, express her cynicism. In stating, *"Sometimes you just need to be listened to"* her narrative suggests relational attentiveness as holding more therapeutic value than rehearsed explanations. Her final phrase "*you're just telling me what I already know."* summarises the critique into a single line which underscores to the hollowness of overused metaphor.

### *3.3.4 Stories of Stigma and Validation*

Many participants shared accounts of stigmatising and dismissive experiences prior to their FND diagnosis. They told multiple stories of feeling that they were wasting healthcare professionals time, that their symptoms were feigned, and that nothing was wrong, such as Christine's encounter:

> *"So I had an appointment with this neurologist and I walked in and his whole attitude… was… I just didn't really understand what was going on. he was so dismissive, and so he was like, back in his chair, and it was just so… I felt I'd done something wrong. I felt he was annoyed at me for coming"*

Several felt their concerns were overlooked based on appearance or background. Damian, for instance, recalled being asked if he used ketamine when reporting back and kidney pain, an assumption he believed stemmed from stereotyping:

> *"I was like, why are you going on about ketamine all the time? I'm coming to you saying that in my kidney area. I may look like I may do drugs, but you can't just say that. That puts me on the back foot straight away."*

For most participants, experiences of stigma and dismissal continued after receiving their FND diagnosis, like for Alison:

> *"Label or no label, it's, there is no… There's a big lack of understanding and then if you chuck the label on top of that you're completely dismissed."*

Sharon and Craig, despite being in different regions, were both told that FND was simply a term used when the cause of symptoms is unknown. Sharon shared *"I've had my local GP go 'oh, so they don't know what's wrong with you, and they've just given you a fancy name for something'"*. Christine recounts being told explicitly by her neurologist that he preferred treating other conditions, such as MS. Participants frequently expressed concern that the FND label now works against them in healthcare encounters. This created a common fear among participants that new or unrelated health issues would be attributed automatically to the diagnosis and therefore not be properly investigated. Nicola described her anxiety that FND had become a catch-all category:

> *"So my fear now is that, like, I'm already pretty crap at telling people I'm sick. So whenever I get sick, it's just going to be put in that basket and then maybe something more sinister could happen because I'm not vocal enough, if that makes sense."*

Many participants resisted using the term stigma to describe their experiences, instead framing the challenges they faced as a lack of understanding. Several shared stories of feeling more informed about FND than the professionals treating them:

> "*Every time you have to go to hospital to get treatment, the first thing you have to do is explain to a doctor, 'I've got FND' and then actually teach them about your condition so that they can try and do something about something they know nothing about. You know, it's like this vicious circle, you know, you sort of think doctors spend so many years training, but I have to go to the hospital and teach them about this.*" (Sharon)

Tariq recounted experiencing a dissociative seizure during routine cardiology testing, which led to emergency alarms being triggered under the assumption he was having a heart attack or stroke:

> *"The people doing the test, they panicked, called the doctor, she don't know. The consultant came, he doesn't know. Even the cardiologist, he doesn't know anything*

> *about FND, so then when they see it on a medical record, I think it triggers them to go and learn about it."*

Many others described feeling compared to patients with more widely recognised conditions, reinforcing a sense of being overlooked rather than actively stigmatised. Ross expresses his frustration about the use of comparison, expressing a desire for his FND to be understood and recognised in its own right:

> *"The physio I had, he used to say quite regularly, "you need to just stay positive. I've seen people far worse off than you, so just keep thinking of that." Well, cheers, you know. That-that, you know, I know there are people worse off. But, you know, what-what am I supposed to do with that?"* (Ross)

Participants shared numerous accounts of encountering a lack of understanding in broader society. Maya, for instance, described sensing that her workplace questioned the legitimacy of her diagnosis. Several reflected that they too might have responded with scepticism prior to their own diagnosis. Angela explained this as due to the fluctuating nature of symptoms:

> "*I think people can find it hard to believe. Well, well, you're all right a minute ago so why aren't? Why aren't you like that now? They think that if you've got something wrong with you, it's got to be all the time. Umm, so I think I think that's possibly one of the reasons and just the fact that nobody, nobody's heard of it, so nobody talks about it."*

As a result, many participants described carefully managing how and when they disclosed their diagnosis; many spoke of opting to describe their condition more generally, like Martin saying he doesn't *"even bother saying FND, we just now say oh, I've got* *neurological issues which make me poorly and that's because that's the easiest way to describe it really, isn't it, to people."*

A lack of understanding could be especially painful when it came from within the family. Maya, for example, shared that her mother believed that she simply needed to *will* herself to get better:

> "*She's made comments like, 'You just need to get on with things. You just need to be better. It's all in your head.' She says it's all psychological and that I just need to want to get better. Those kinds of comments really make things harder."*

Sharon describes how her family struggles to understand her condition, often minimizing it by expecting quick fixes:

> *"And your family going, 'oh, is there no tablets for you? Can you not do this? Can you not do that?' No. There's no tablets for it. There's no quick fix for this. There's no—'oh, but you look so well. Why is that?' And you get the, 'ah, sure, you look all right.'"*

Stories were told expressing frustration at the expectations placed on them due to their outwardly non-disabled appearance:

> *"You're not a quadriplegic. You're not... Do you know what I mean? Those are what people perceive as a disability. So for the wider public, they're never going to understand, they're not going to understand until they've got FND, like I said, we can't walk around with signs on our, on our, on our heads saying what, what we have and what we don't have."* (Damian)

Some spoke of feeling that their age playing a role in the perceptions; Maya, 30, noted that "*sometimes I'm very conscious that people will see a young person like me and that, you know, I don't have any physical deformities, so they probably think like, She's fine. Like, you know, what is this? She's just trying to play up or something like that.*" Similarly, Ross, 36, observed stark differences in public understanding towards his uncle with Parkinson's, stating *"he's a lot more able than me. But because I have FND, it's like people just push you to one side."* These contrast highlights the different social pressures participants navigated alongside their symptoms.

Several participants described internalising shame and blame in relation to their FND diagnosis. Nicola questions whether she is exaggerating her condition. She describes engaging in constant monitoring and being highly self-critical, which in turn left her to wonder *"like, maybe I'm an attention seeker. Maybe I'm the hypochondriac."* Several participants described their inclination to downplay symptoms and push themselves to carry on, even when unwell. These narratives suggest an internalised sense of responsibility for their illness. Christine's account was particularly marked by shame. She openly questioned the reality of her symptoms, describing a persistent feeling that she was somehow causing them herself. She also expressed incredulity with more unusual symptoms shared in FND peer groups:

> *"I would judge somebody with FND! I go on the site and I see some people's wacky symptoms and I think yeah, that's really, you know, is that real or you know? And then I think well, people will look at me and think exactly, you know, like the seizures"*

This sense of illegitimacy extended into her personal life, where she felt like a burden and made comparisons to her sister, whose cancer diagnosis she viewed as a more deserving condition. These accounts illustrate how the vagueness surrounding FND could easily translate into an internalisation of doubt and shame.

Despite feeling misunderstood or invisible to wider society, many participants described feeling seen and supported in their social circles and often highlighted how affirming relationships played a role in them coping with the condition. Maya spoke of the importance of her close friend who treated her *"like a normal person"*. She described this and other friendships as essential to her managing mental health through being encouraged to remain socially engaged. Similarly, Rebecca shared her reflections on the unexpectedly positive reactions of her social circle:

> *"My friends have been lovely, you know. More, more often than not, my friends just kind of say, just, you know, be stress-free, take some time out your life, try and enjoy it, don't stress about work. You know, whereas, like I say, I expected a bit of a fight, I expected to have to defend myself as to why I'm not at work anymore. I expected to have to defend myself as well, if I have to leave a party after an hour or whatever."*

Within families, experiences were more mixed, but positive examples stood out. Tariq shared that his sister had taken it upon herself to research FND extensively and now understood the condition even better than he did. Kirsten described a similarly supportive environment with her parents, and described her partner's teasing of her speech difficulties as affectionate and bringing a sense of normalcy to their relationship:

> *"[he] will make jokes about, like, the way that the stutter goes and things. Like, there is some-something I was trying to say something and then it came out BMBM and the word didn't even have an "N" it. I just, it came out that way. So every now and then, he'll just sort of do that song, or he'll pretend that he's like singing, or something... And it's like, I find it quite amusing."*

These accounts underscore the significance of close support networks. Alongside feeling seen by others, an important experience for some participants was of *seeing themselves* in FND. This could emerge through engagement with support groups and spaces, where individuals described recognition. Lorraine, spoke of community as crucial in coming to terms with her diagnosis:

> "*I didn't really get much further until it fell in with the [redacted] Support Group and I sort of found like I'd found my people kind of thing, you know. That's only when things started to become more understandable or more relatable. Maybe that's a better word, more relatable to my diagnosis, you know, and that made the difference for me. You know, it was just having other people there who I could bounce opinions off.*"

Recognition was described as empowering, with several participants also describing a sense of purpose in the opportunity to support others. Rebecca reflected on her progress by observing the differences to those newly diagnosed joining online groups. Advocacy emerged alongside this, with participants attempting to raise awareness about FND and challenge existing misconceptions. Ross described writing to his MP, and others shared that taking part in this research project felt like a way to contribute public and clinical discourse around FND:

> *"It might not—I—I might not get anything from it within my lifetime. But if things like this help people in the future, then it's 100% worth it."* (Ross)

### ***Performative Narrative Analysis – Not a Malingerer***

Damian was diagnosed with FND two years ago, following a sudden onset of symptoms including seizures, tremors, and speech difficulties. Formerly a chef, he is currently signed off work and living apart from his family due to the impact of his condition.

In his wider narrative, Damian alludes to early life trauma, though he now describes himself as being in a very happy phase of life, with a young family of his own. His stories are marked by resilience yet he also expresses frustration over the lack of follow-up from healthcare professionals. The story below emerged in the middle part of the interview and appeared spontaneously after several descriptions of dismissive encounters with medical professionals:

> *People that have known me a long time, they know that I still don't stop now. I do things every day. I'm doing things, I can't do half the things I used to be able to do, but I don't sit on my bum ever. So people will say, even when I have a seizure, anyone will say "I've never seen a man after a seizure just get up and carry on like you do". Even though it kills me off, I jump into my responsibilities as father and as a partner straight away. So yeah. Yeah, I don't think anyone's giving me any negative, no one has said to me "that looks fake Damian. Why? Why is…" Do you know what I'm trying to say? They, they just don't see that in me at all. They, they know that I struggle but they also know that when my legs are shaking, that I'm still trying to walk from A to B and get them a cup of tea or coffee if they're a guest in my house. Do you know what I mean? They won't say, they might say, "Damian, do you want me to do it?" But they know that I'm pig headed and I'll say "no, you're going to get half a cup of tea by the time it gets back to you but I'm doing it". Do you know what I mean? It's one of them.*
>
> \- Damian

In this story, Damian positions family and friends as witnesses to his struggle. In saying, *"no one said to me 'that looks fake Damian',"* he highlights how disbelief has not occurred among his close network in contrast to medical professionals who have repeatedly questioned or dismissed him. Damian constructs his identity as someone who, despite visible physical struggle, refuses to be perceived as passive. He repeatedly uses action-oriented phrases *"I still don't stop," "I do things every day," "I jump into my responsibilities"* to perform a narrative of embodied effort, re-establishing control and resisting the disabled subject position as weak or idle. Damian's act of making tea, though a mundane task, privileges the recognition of effort in domestic life over the external judgments of medical professionals. His repeated emphasis on what others "know" about him constructs a circle of legitimacy, whose belief in his suffering and effort serves as a counterweight the wider culture of doubt that often surrounds FND. Their recognition affirms his moral identity: as someone who is not a malingerer.

### *3.3.5 Stories of Embodied Reinterpretation*

Participants' accounts illustrate how the FND diagnosis can lead individuals to reflect on their health histories, sometimes making connections with previous injuries or ongoing physical issues to their FND. Rebecca fearing her FND is a result of pushing her body too far. Kirsten wonders if years of chronic pain wore her body down, eventually morphing into FND. Alison links her condition to the toll of unattended physical injuries sustained while working as a paramedic. Andre also points to the impact of long-term strain as part of the pathway to his diagnosis:

> "*I've had a lot of aches and pains over the years and I didn't think much of them, tried to resolve them but nothing really seemed to work. And so you just live – because you are told 'everybody has aches and pains.'"*

These stories reflect the theme of embodied reinterpretation, where participants revisit physical experiences imbuing symptoms with new significance the lens of FND diagnosis. Some participants spoke of FND diagnosis also leading to a reappraisal of past mental health symptoms, such as anxiety or depression. For some participants this process took on a selfblaming tone, implicitly linking personal failure to take care of themselves with the onset of symptoms. However, for others, the diagnosis brought a renewed understanding to their physical realities. Lorraine, for example, expressed relief in realising that unexplained past symptoms of tremors in her hands could be part of the FND profile:

> "*I realised, well, that's where that's coming from. So it's sort of things that were happening that I had already had investigated. I realised well that what they're telling me must be what is going on because it fits in with what's been happening beyond just having a weakness in the left side.*"

Similarly, Tariq, who had lived with panic attacks for many years, reflected that the FND diagnosis allowed him to reinterpret these episodes as part of a broader, interconnected condition. He began to question his anxiety and panic disorder symptoms, marking a shift in how he understood his mental health history:

> *"You feel breathless so you feel this sense of impending doom. You know, claustrophobia, noises. But I've always had that then sometimes I thought maybe my anxiety, generally anxiety disorder and my panic disorder has morphed into FND. Sometimes I thought that is that possible?"*

Several participants made sense of themselves – and their FND – through the lens of newly identified neurodivergence. Christine, for example, described herself as coming from a "ticky family" and reflected on whether her long-undiagnosed dyslexia might have contributed to the development of FND:

> *"I recently found out I am dyslexic. And I know I've always struggled with things, some things people find really easy, I cannot do, like, especially to do with writing or which is a lot of things, a lot of things like. So I know that, I found my brain works slightly different,*

> *so I find things a struggle that other people don't, which causes stress in ways that other people aren't stressed. You know... So maybe that brings on FND symptoms?"*

Kirsten described currently undergoing an autism assessment and feeling a strong resonance with the concept of autistic burnout, suggesting it played a role in the onset of her FND. Angela also spoke of recognising previously unmet sensory needs, noting that she was stroking a soft toy during the interview as a way of regulating her nervous system. These stories describe embracing of neurodivergence as meaningful to their FND. Through this lens, they develop new understandings of their bodies and begin to employ strategies that support improved functioning.

Participants told stories of how their FND diagnosis disrupted a reliable or predictable bodily experience. Many spoke of how the fluctuating nature of symptoms made it difficult for them to plan ahead. Loss of bodily autonomy was expressed in diverse ways. Kirsten describes *"I, like, almost as if I was a puppet, stood up, and then all the strings are sort of gone";* whereas Sharon spoke of FND as an external thing takes her over, and Maya articulated a full disconnection from her internal world, marked by a numbness. For some, the instability of experience extends beyond physical symptoms to unpredictable emotional experiences. Angela, for instance, described a new emotional volatility, shifting rapidly between crying and laughing. Below, Nicola reflects on how emotional state directly shapes her physical symptoms:

> *"I remove myself from the situation now. So, so that my symptoms don't get worse and I won't end up with a limp. If I find myself starting to be like 'that person really, really goads me' — like most people do, the only difference is I can't hide it. You know, a person that doesn't have FN— well, for me, a person that doesn't have FND can be*

*annoyed and put on their fake smile and walk away. I can put my fake smile on and then hop away (laughs).”*

Participants described how the shattering of interoception, their ability to sense and interpret internal bodily signals, could be profound. As Damian vividly puts it, *"it’s like I’ve had a car crash and I've completely smashed my brain to pieces and, and I don't know how to get it back together again.”* These ruptures necessitated a process of reinterpreting bodily signals and developing strategies to navigate daily life. For Martin and his wife, they collaboratively develop strategies such as *“just wearing sunglasses and it helped to cut out light and a lot of the information. And then after time we were able to drive without having to wear glasses. It was just getting the brain used to driving again”* Likewise, Rebecca described using physio techniques such as skating to retrain her brain’s automatic movements by *“tapping into a different, you know, a different signal that that's the same movement, but your body doesn't understand it as the same movement. So it's like it more automatic movement, if you like so skating's more automatic than walking.”*

Participants spoke of employing mobility aids, including walkers and wheelchairs, to adapt to their functioning. Seven out of the fifteen participants mentioned learning about ‘spoon theory’ as a way to pace their exertions, though reported its effectiveness variably. Several described using apps and wearable technologies such as smartwatches to monitor their energy levels. Stories within this theme highlight the disintegration of familiar bodily awareness but also the active, often creative processes of re-learning and reconfiguring their relationships with their bodies in order to live with FND.

### ***Performative Narrative Analysis – Rearranging the Furniture***

Andre’s identity as a scientist shaped how he has approached his FND journey – with rigorous investigation and reflection. In his narrative, Andre describes FND as *“the mother of* *all nervous breakdowns".* He attributes its onset to physical stressors, environmental misalignments, overlooked injuries and lifelong socio-cultural pressures. His narrative is saturated with the psychological toll of invisibility within medical systems. His detailed observations span biomechanics, neuroscience, race, psychology, and social inequality. Andre's narrative style is *stream-of-consciousness meets lived-analysis*. His storytelling is often layered and non-linear, weaving personal anecdotes, scientific insights and social critique seamlessly. This story emerged towards the end of the interview process, where Andre described his various processes of arriving at adaptations to his FND limitations.

> *You can't control it because the idea of FND, you know, is that if you connect with your body too much, then… problem. But me, um, in that journey, I decided to go back to basics and like the very beginning. There's mum and dad not there to wipe your nose, or rub it better. If they rub a sore better, let's call it a distraction technique for the child (laughs). And so suddenly you're actually having to relearn how to do everything again from scratch.*
>
> *So I started wearing sandals for a year and a half. It was almost the best thing ever because I started using my toes for balance a lot more. Somebody's neurologist said that your body, the body's in a constant state of learning, all the time. And so you might see, your muscle patterns don't actually stay the same. So I likened it to living in a house where somebody's constantly rearranging the furniture. Physically, in your own body, that's what's actually happening. It's constantly being rearranged, despite the fact, visually, everything's still in the same place. So you, so you know, that's why some people, for instance, can walk through their house with the lights off, because you suddenly pick up on a sense, the smell, the textures and sensations, which is the coldest room. How do you know it's the coldest room? Because it is cold. But if*

> *somebody blindfolded you and moved you around the house? Yeah, I'm in this room because, you know, this is the coldest room based on this environment - you've made interpretations, but with FND suddenly all those senses that you have, and habits, functional habits that you've picked up over the years suddenly now gone.*
>
> \- Andre

Andre opens with the idea that *"you can't control it because... if you connect with your body too much, then… problem."* This reflects the common paradox in FND discourse: the more one focuses on bodily control, the awareness itself becomes pathological. He disrupts this with a counter-response: returning to the beginning, framed through a metaphor of childhood: *"There's mum and dad not there to wipe your nose, or rub it better."* This metaphor positions recovery as a kind of re-parenting. His laugh functions performatively; it signals self-awareness and disarms potential scepticism by acknowledging the simplicity of the metaphor. Andre's reference to wearing sandals is symbolic of his bottom-up approach to re-learning bodily function, it becomes its own scientific method that relies on micro-adjustments to feel and respond.

The metaphor of furniture being rearranged is a powerful analogy to help others understand what FND *feels* like. The house suggests familiarity, while the rearranged furniture signifies internal disorientation. Here, Andre layers the metaphor to highlight his loss of sensory mapping, *"Some people... can walk through their house with the lights off"* noting how most people take interoception for granted. His story works to successfully ground the experience of displacement within one's own body in terms that the listener can emotionally understand.

Throughout this extract, Andre uses metaphor and narrative structure to validates FND as a profound disruption of bodily learning, and to fill gaps where clinical language fails to capture the lived experience of FND. He positions himself as a scientist of his own body whose observations are credible and meaningful. Andre reclaims his recovery as a process of re-education, emphasising sensory attention and physical relearning as treatment. His narrative invites a broader, more nuanced understanding of healing that incorporates experimentation and recognises the intelligence of the body itself.

### 3.4 Chapter Summary

This chapter presents an overview of the symptoms and timelines of the 15 participants living with FND. Relevant contextual information is presented with careful consideration for patient anonymity. The results presented through Thematic Narrative Analysis identifies and explores four narrative types. Performative Narrative Analysis then underscores how narrators crafted these story types in response to the ambiguity surrounding FND.

## 4 Discussion

### 4.1 Chapter Overview

This chapter interprets the findings through sociological and narrative theory, examining how participants construct meaning in the response to an FND diagnosis. The four narrative types identified in findings are delineated and examined using Goffman's (1974) frame analysis and Frank's (1995) illness narrative typologies as interpretive frameworks. Later sections reflect critically on processes and contribution of the study. Strengths and weaknesses of the methodological and analytical approach are acknowledged. Directions for future research are indicated along with key clinical implications for service provision and policy. The researcher outlines her plans for dissemination and offers a reflective account of the work, emphasising the co-construction of knowledge and affirming her commitment to transparency and fidelity to the patient's voice.

## 4.2 Summary of Findings

Four narrative types were identified in the analysis. *Stories of Biographical Disruption* capture the (usually/frequently) sudden onset of symptoms, loss of identity, and rupture of temporal continuity. *Stories of Inadequate Explanations* reflect participants' struggles with unclear diagnosis experiences, lack of medical guidance, and their own attempts to make sense of their condition. *Stories of Stigma and Validation* examine experiences of dismissal by healthcare professionals and broader society, while also emphasising the importance of validation from peers and community. *Stories of Embodied Reinterpretation* show how participants re-evaluate past injuries, mental health symptoms, and neurodivergence, adopting adaptive strategies to retrieve their bodily experience in light of their diagnosis. Though these four narrative types often overlapped and participants' storytelling moved between them rather than following a linear path.)

### *4.2.1 Biographical Disruption: Frame Breaks & Contrastive Framing*

As the appropriated moniker implies, narratives within this type compellingly illustrate Michael Bury's (1982) concept of *Biographical Disruption*, with which he refers to the profound disturbance that chronic illness can cause in the continuity of an individual's life 'biography'.

Findings in the present study contain many depictions of the sudden and inexplicable onset of FND symptoms. These findings confirm findings that individuals with FND often experience a profound loss of bodily control (Dosanjh et al., 2021), or being overpowered or trapped in their bodies (Bazydlo & Eccles, 2024; Thompson et al., 2013), which could lead to disorientation and helplessness (Nielsen et al., 2020). This study's findings would confirm another consistent finding across FND studies as one of role loss, through work and/or meaningful activities, framed as a cascade of functional and social decline (Dosanjh et al., 2021; Nielsen et al., 2020; Rawlings et al., 2018).

Participants' narratives of symptom onset and identity loss can be understood as *frame breaks*, moments where their pre-existing frames of "being healthy," "being competent," or "living a coherent life" collapse (Goffman, 1974). Goffman's (1959) notion of *disrupted involvement* also applies here: participants are forcibly pulled out of previously stable social roles (e.g., employee, parent), with FND functioning as the *disruptive event* that renders old frames obsolete.

With the collapse of these experiential frames, participants' accounts often shift into what Frank (1995) characterises as *chaos narratives*. These narratives are characterised by disorientation – a lack of coherent plot – as participants struggle to articulate themselves or locate their experiences within a longer-term life trajectory. Such narrative typologies have been noted in other writing on FND, which identifies chaos storytelling, framed as 'feeling lost', within the illness experience (Bazydlo & Eccles, 2024; Rawlings et al., 2018).

A novel finding in the present study was the prevalence of contrasts between participants' pre- and post-illness selves expressed across several domains. Participants often spontaneously highlighted aspects of their former identity, positioning themselves as physically capable, *"a very, very fit person",* (Angela); sociable, *"really outgoing."* (Craig); or professionally competent *"there wasn't anything I wouldn't tackle in work"* (Martin). By bringing in accounts of who they *used* to be, participants may be attempting to preserve a coherent sense of self in the face of present, or ongoing, disruption. Their illness thereby becomes the anomaly in their personal/medical history. And these retrospective self-portraits often served to demonstrate that their current limitations are not representative of who they "really" are. In doing so, participants engage in what Frank (1995) terms *narrative repair* – a means of recovering identity from *narrative wreckage* (Frank, 1995). This can be understood through Goffman's concept of *contrastive framing*. By anchoring their sense of self in a past that contrasts with their present experience, individuals juxtapose their former, competent selves with their current, impaired selves.

There might be specific reasons persons with FND feel inclined to perform their identity in this way. Previous literature has highlighted how patients with FND struggle to achieve medical legitimacy due to their to a failure to adopt Parsons's (1951) recognised *'sick role'* (McLoughlin et al., 2024; Peacock et al., 2023). Parsons's (1951) role outlines how society views and manages illness by defining specific expectations for the sick individual; he theorised that adopting the "*sick role"* requires a legitimate diagnosis and a culturally sanctioned pathway to exemption from normal roles. This would align with a societally understood *frame of normal illness* (where symptoms lead to a diagnosis and treatment). There is evidence to suggest that in FND this frame is violated. Participants' accounts of prolonged diagnostic journeys revealed a sense of medical liminality, *"left in limbo,"* as Nicola put it, unable to fully inhabit the role of the sick person or be perceived as such by others. This experience was compounded by interactions with healthcare professionals that framed them as puzzling or illegible cases, such as Tariq recalling being termed, *"the mystery man."* Participants like Craig, who underwent various referrals - which deferred his FND diagnosis by approximately a decade –was left without a socially sanctioned status that legitimises his withdrawal from normal responsibilities. As such, contrastive framing functions to legitimize their experience and enable the reconstruction of a frame capable of accommodating altered capacities.

Performatively, this framing can be understood to operate on three interrelated levels, micro, moral, and macro in demonstrating how individuals perform their stories in ways that are personally expressive, socially strategic, and culturally resonant. Firstly, the act can be understood as tailored to the interview context. Participants may be intuitively trying to frame their stories in ways that elicit empathy or recognition from the interviewer. In drawing attention to their past abilities, they can ensure the interviewer fully grasps the extent of their loss and their desire to be seen beyond the illness. While this process was likely unconscious for most participants, it was my felt experience as the researcher of being persuaded of the legitimacy of their suffering. In Craig's case, he articulates this intention explicitly, stating *"...just for you to know that since I started to have the, before I had the problems I was really outgoing..."* Secondly, such performances serve a broader function of *moral positioning*. Frank (1995) argues that illness stories are moral narratives through which individuals can assert their credibility and worth in the face of vulnerabilities. Christine's story demonstrates this process. Through highlighting how others noticed changes in her, she shifts the moral burden away from herself. Her account constructs her as a responsible subject who resisted medicalisation until it was undeniably necessary. Finally, offering contrast between "then" and "now" becomes a social positioning tool, placing themselves as responsible, active, and contributing members of society prior to illness. These narratives can serve a pre-emptive defence against a wider imagined, judgemental audience. This would also be understood through a dramaturgical lens (Goffman, 1959), highlighting how patients manage social impressions by framing their experiences in ways that counteract anticipated stigma.

Participants' narrative strategies can be understood as adaptive responses to the ambiguity they face in the lack of a clear diagnosis experience or clear treatment pathway. This study highlights the social dimensions of FND and the performative work individuals do to reconstruct meaning and identity in the wake of biographical disruption brought on by their symptoms.

### *4.2.2 Inadequate Explanations: Frame Void, Frame Fatigue & Keying*

In this narrative type, participants describe encountering failed or thin explanatory frames in their clinical encounters. The inadequacy of medical frames leads participants to oscillate between diagnostic frame acceptance and ambivalence. Frame analysis helps trace these movements and the affective labour involved when institutional frames fail.

Participants' accounts revealed significant lack of clarity in the whole course of their FND diagnosis, with most describing the experience as confusing. Participants accounts reveal *frame void* – an absence of a structured, coherent explanation to meaningfully situate the diagnosis. Such findings echo previous literature which described patients receiving an FND diagnosis with minimal elaboration (Loewenberger et al., 2021; Thompson et al., 2013). The effect of such poorly delivered diagnosis created confusion and often a feeling of being brushed off (Wyatt et al., 2014). This study builds on those accounts by applying Goffman's concept of *keying* to show how not only the content but also the tone of delivery influences how the FND diagnostic frame is received – both in the moment and thereafter. Participants described the manner in which clinicians communicated the diagnosis was rarely warm or empathetic; their interactional tone or *key* often lacked affective attunement. Goffman adopts the term *keying* to describe the way social actors reinterpret situations through established conventions, much like a melody changes mood or tone when played in a different musical key (Goffman, 1974). In the present study, participants were regularly sent to a website with little in-person elaboration; the diagnostic act was therefore keyed as dismissive or offloaded, rather than authoritative or supportive. For many patients, this act reframes and undermines the authority of the diagnosis, as a bureaucratic handoff rather than a serious medical event.

This lens can explain why the same clinical frame can land differently depending on the relational context. For example Kirsten, who is offered a follow-up appointment, experiences a more engaging, participatory key, she sees the website not as a brush-off, but an invitation to reflect. Martin's diagnosis story is striking for the absence of a coherent frame *or* key. He is left wondering, is this discharge? Diagnosis? Dismissal? Without an appropriate key (e.g., closure, care), he is completely lost. Goffman (1974) suggests that meaning collapses when both frame and key are unclear, which fits Martin's experience of narrative and spatial disorientation.

All participants encountered the psychological or trauma-based explanation for FND that located the origin of their symptoms in past psychological distress. This clinical frame emerged as a *contested key*. For some, such as Craig and Alison, the trauma narrative failed to resonate. They were unable to identify personal experiences that aligned with the information being given to them leading to a feeling of dissonance. This misattunement left them uncertain as to how to engage with the diagnosis, leading them to question of whether the trauma frame was intended as therapeutic or pathologizing. Other participants engaged tentatively with this frame, but their narratives suggest efforts to retroactively construct meaning, mining their histories for moments that could fit the explanation being offered. This interpretive labour did not come naturally but was motivated by a pressure to conform to a clinician's scripts. Only two participants fully accepted the trauma discourse frame. For Lorraine and Tariq, this framing aligned with their lived experience of early trauma. It is important to note that when biographical events and clinical framing align, the trauma discourse does function as a meaningful interpretive resource. However, for many FND patients it remains a problematic key. This would support previous FND literature, where dissatisfaction with psychological framing has been a dominant theme (Dosanjh et al., 2021; Nielsen et al., 2020). Wyatt et al. (2014) has also noted the discomfort some patients expressed in retroactively constructing trauma narratives that felt artificial or imposed. The present study expands the literature by showing how the expectation to accept a trauma frame can in itself become a source of doubt and conflict.

Participants encountered a neurological frame for understanding FND, most commonly communicated through versions of a "hardware/software" metaphor which frames FND as a problem of brain function rather than structure. Many found this frame intuitive to understand as it validated their experiences, and found reassurance in its positioning of their symptoms as real without implying damage. Participants broadly preferred neurological explanations for FND. This aligns with Loewenberger et al. (2021), who found that patients were more receptive to explanations accompanied by metaphors to enliven the diagnosis and make it feel both accessible and credible.

However, the present study highlights a growing scepticism toward generic metaphors that risk becoming depersonalised. Rebecca's narrative demonstrates an awareness of *frame fatigue* – the experience of being repeatedly subjected to a previously meaningful frame that has since become hollow. Her reaction *"is that just something textbook that everybody says now?"* reflects cynical performance (Goffman, 1959), where she begins to doubt the utility of the frame being offered. In response, many participants reframed the metaphor, drawing on personal or professional knowledge to make it meaningful – *a computer with too many tabs open*, or applied technical analogies from engineering and science. Findings showed that the neurological frame was more broadly accepted than the psychological one. However, it often required participants to rework it for it to feel authentically useful, indicating that explanatory frames must evolve to retain their meaning.

The neurologist Jon Stone (2016) outlines what he considers a good diagnosis of FND: that it be delivered as a positive, evidence-based explanation rooted in specific clinical signs, that validates the reality of symptoms, and is conveyed with empathy and clarity. Crucially, it should also offer a hopeful path forward through treatment options and follow-up, making the diagnostic encounter itself a therapeutic intervention. Narratives in this paper would suggest that current practice falls short of achieving this.

But while Goffman (1974) draws on a musical analogy to define "key" as the tonal shift that alters how a frame is interpreted, one could take up the metaphor differently; as a unique opening device; as in who *holds the keys to the relevant knowledge*? In this extended metaphor, keying is not only about mood or mode, but about epistemic authority, and accessibility, surrounding who has the right to define what counts as a valid explanation. The present study suggests that participants frequently interpret the inadequacy of explanations provided by healthcare professionals (outsourcing to websites, pre-authored scripts of trauma aetiology, repetition of metaphors), as a gestures of gatekeeping. They expressed feeling a pressure to accept explanations rather than co-construct meaning of their FND experiences. This is compounded when the lack of treatment pathways creates a feeling of being *locked out* of the medical system they rely on.

### *4.2.3 Stigma & Validation: Frame Negotiations*

Participants shared powerful narratives of stigmatising experiences of FND. Through Goffman's (1974) lens, the narratives in this theme can be understood as acts of *frame negotiation*, where individuals with FND push back against dominant interpretive schemas in an attempt to move the frame from stigma toward validation (although not always successfully). In doing so, they seek to renegotiate the wider frame through which FND is seen.

**Table 7**

*Frame Negotiation in FND Narratives*

| Framing Dimension | Default Frame (Stigma) | Participant Counter-Frame (Validation) |
|---|---|---|
| **Clinical interpretation** | Psychogenic, dismissible, uncertain | Complex, embodied, effortful |
| **Agency** | Passive recipient of diagnosis | Active reframer and educator |
| **Disability visibility** | “You look fine” = “You are fine” | Hidden symptoms require recognition |
| **Moral identity** | Malingerer, hypochondriac | Resilient, responsible, misunderstood |
| **Relational context** | Clinician and public doubt | Family, friends, and peer group support |
| **Voice** | Silenced or disbelieved | Advocacy and self-definition |

Consistent across participant narratives were stories of medical misrecognition, many described being misdiagnosed dismissed or treated as time-wasters, especially when encountering professionals who lacked knowledge in managing FND. This supports existing literature, where stigma has been repeatedly highlighted (Bazydlo & Eccles, 2024; McLoughlin et al., 2024).  Findings here align with Foley et al.’s (2022) meta-synthesis of the experiences of stigma in FND in showing that stigma could even be more acute post-diagnosis and lead to new forms of dismissal, such as having subsequent symptoms attributed automatically to FND. Many of the present study's participants did not use the word 'stigma' themselves, instead often rekeying these experiences as a "lack of understanding". This suggests some participants work to maintain a neutral or hopeful relational frame. This rekeying of clinical stigma into something more tolerable emphasises the emotional labour required to maintain trust in clinicians.

Participants often spoke of reversed epistemic roles, having to teach clinicians about FND or enter clinical spaces armed with defensive explanations. Wyatt et al. (2014) noted how undermining of patients' authority over their symptoms can foster adversarial relationships with clinicians, Foley et al.'s (2022) review found that participants often felt a lack of power in clinical encounters. For the present study's participants, this role reversal was both a source of pride and fatigue. Individuals were denied credibility as knowers of their condition, yet describe increasing confidence in educating clinicians about FND. This constant narrative self-defence is experienced as a burden, enforced by structural failures in clinician education and the lack of continuity in care.

The issue of invisibility also emerged powerfully in narratives. Several participants attributed stigmatising experiences to their 'healthy' appearance or absence of visible, predictable or stable symptoms. This would affirm previous FND findings in highlighting how patients feared not being believed due to symptom variability and invisibility (Loewenberger et al., 2021). Goffman (1963) proposes two types of spoiled identity, dependent on the concealability of the stigmatised trait. The *discredited* refer to individuals whose trait is primarily visible, such as race/ethnicity, gender, or physical disability, whereas the *discreditable* are those with a trait primarily invisible, such as mental illness or sexuality. For FND, patients are at risk of being both the *discredited* and *discreditable* patient. This was managed by switching terminology, such as Martin using “neurological issues” in place of “FND” to avoid confusion or disbelief. Thompson et al. (2013) also found that patients used simplified language to manage impressions. This aligns with Corrigan et al.’s (2013) concept of *strategic disclosure*: how people calculate the risks of naming their condition. Such framing strategies are experienced as exhausting, connected to deeper concerns around being believed.

Findings strongly support prior work around moral identity and resistance to the “malingerer” frame. Participants accounts suggest they feel a need to evidence authenticity through effort, they frequently presented themselves as active and hardworking. This mirrors Peacock et al. (2023), where patients rejected accusations of faking by highlighting resilience. Similarly, Rawlings et al. (2018) noted how patients worked to construct coherent, linear written narratives to legitimise symptoms and avoid being seen as disingenuous. Where this study expands is in noting participants’ use of mundane, everyday acts, such as Damian’s making tea, as moral signifiers used to discredit the doubting frame. Seen through the dramaturgical lens (Goffman, 1963), this is a negotiation of identity through gestures and audience management. Participants like Damian manage the presentation of self by mobilising everyday effort as an embodied counter-claim, which suggests that in the absence of external validation, participants draw on behaviours to assert legitimacy.

Not all attempts to reframe experiences of stigma were successful or possible for every participant. For some, an inability to secure external recognition led to these negative judgments turning inward, fuelling self-doubt. Internalised stigma and self-surveillance featured prominently in narratives. Several participants questioned whether their symptoms were real or whether they might be “attention seeking.” This mirrors McLoughlin et al. (2024), where participants expressed self-doubt; and, further, Bazydlo and Eccles (2024) who titles this as the “intrapersonal battle,” a tug-of-war between self-belief and culturally induced shame. Several participants spoke of judging others in FND support groups while fearing similar judgment. This offers an example of *reflexive stigma,* the internalisation of cultural suspicions, which are then projected outward. Findings expand on previous literature by highlighting how stigma could be sustained within the FND community itself, where a vast symptom heterogeneity can fuel suspicion of other’s experiences.

A crucial counter to stigma was found in the form of validation, with participants repeatedly describing friends, family, or support groups as sites of recognition. These functioned as relational frames that could confirm their experiences of suffering and witness resilience. Lorraine’s experience in FND groups reflects Dosanjh et al. (2021), who describe how collective identity formation as fostering adaptation to FND. Rawlings et al. (2018) also found that support groups helped individuals feel less anomalous. Peacock et al. (2023) would support the findings of peer recognition as crucial to sustaining a coherent illness identity in FND. As importantly however, participants in the present study emphasised the role of emotional intimacy, being teased or simply treated “normally” by those close to them. Ahmed (2004) explores how emotions are shaped by, and also help reproduce, social norms. Emotional labour, defined as the work of managing feelings to meet social expectations, is central to how people maintain belonging and legitimacy. Applied here, arguably participants’ need for their peer recognition reflects emotional labour done to secure legitimacy in the face of widespread medical and societal dismissal. When peers affirmed their experiences, it emotionally re-positions them from ‘problem patients’ to ‘recognised persons’. Emotional intimacy functioned as their counter-narrative to stigma, allowing participants to sustain coherent identities beyond the patient role.

Finally, these findings show how participants reclaimed meaning through advocacy for FND. Ross's reflection that his participation *"might help someone in the future"* echoes previous findings (Bazydlo & Eccles, 2024; Peacock et al., 2023), where engagement in research was framed as a therapeutic act. In this study, advocacy was used to reframe participant's identity, from passive sufferer to active contributor who capable of influencing FND discourse. This frame shift also allows participants to situate their suffering within a larger arc of social change, even if the benefits to them might be limited. This aligns with Nancy Fraser's (2000) concept of recognition justice, calling for the social affirmation of marginalised identities. Through advocacy, participants can challenge the cultural misframings of FND, increase its visibility and be recognised as credible and valuable social actors.

### *4.2.4 Embodied Reinterpretation: Body as the Frame*

The FND diagnosis prompted participants to reinterpret prior bodily experiences, such as chronic pain, tremors, panic attacks within a new bodily narrative. This reframing has been noted by Peacock et al. (2023) who found that for some patients engaged in "post hoc sense-making," which could transform past physiological experiences once dismissed as vague or imagined. Wyatt et al. (2014) findings were also confirmed in the present study to show how for some patients trauma becomes retrospectively meaningful through the FND diagnostic lens.

What the present study terms 'reappraisal' is well discussed in Rimmon-Kenan's (2002) essay on illness and narrative identity, in which she terms it *'Narrating the past in the light of the present'*. She discusses how some narrators may highlight aspects of their past that previously seemed insignificant, draw new connections between events, or shift the emphasis between what is central and peripheral. Individuals who once viewed their lives as steadily progressing may, after the onset of illness, come to see their story as split into a "before" and "after" with an unbridgeable gap between them. In focusing on earlier moments or crisis that they managed to overcome; over time they can bridge this gap to reconstruct a new narrative identity. Drawing on Goffman's (1974) concept of *keying*, participants reinterpret past bodily events once framed as “just stress” or “imagined”, within a clinical narrative that lends legitimacy. Situating FND in life story that contains other sufferings, the rekeyed frame allows participants to tell a story in which FND is not a rupture, but a continuation. To revisit the metaphors, they can successfully change the key of the wider musical score, and *unlock* new meanings in their past experiences. This reconfigured and re-embodied frame allows space for hope, the belief that this too can be overcome. Using Frank’s (1995) typologies, what may have initially been experienced as a *chaos* or thwarted *restitution* narrative transforms into a *quest* narrative where, paradoxically, a form of stability emerges through a repeated cycle of crisis and survival. FND diagnosis can act as a hermeneutic shift, supporting new bodily coherence across time. Findings suggest therefore, that FND recovery is not just future-oriented (symptom control) but retrospective (narrative repair).

The present study offers a novel extension by showing how participants actively linked late-identified neurodivergence, such as autism and dyslexia, with the development and experience of FND. While previous research has commonly foregrounded trauma and psychiatric histories as explanatory frameworks, neurodevelopmental difference has not typically featured in participants’ meaning-making processes. These findings expand the psychosocial lens to include neurodivergence as a potential contributor to the cumulative load that shapes how FND is experienced. By incorporating neurodiversity into their personal FND narratives, participants may be drawing on existing reframing work from within the neurodiversity movement – consciously or unconsciously. This work that has sought to reject the idea that neurological differences are deficits or disorders that need to be fixed (Walker, 2021), instead reframing as part of the natural variation in how human brains function. Aligning with this perspective, narrators such as Kirsten, Angela and Christine can reconfigure their past *and therefore present* through a lens that affirms difference rather than medicalises it. This suggests that identity-based frameworks may be just as critical to narrative integration in FND as traditional biopsychosocial models.

Participants described disconnection impairment to their interoception abilities. Terms like “numbness,” “puppet,” or “shattered brain” illustrate a collapse in participants’ sense of bodily connection and coordination. Andre’s “rearranged furniture” metaphor conveys sensory disorientation in his own corporeal surroundings, that is: in his otherwise familiar and reliable body. His reflection that “*if you connect with your body too much, then… problem”* highlights the paradox of many FND patients: heightened bodily awareness with misinterpretation of those sensations. Pick et al. (2017) noted PNES patients connect physiological states with seizure onset, yet struggled to articulate these sensations. Rawlings and Reuber’s (2016) synthesis of PNES has also hypervigilance towards their bodies and perceiving internal signals as threatening, suggesting a breakdown in interoceptive mapping. These findings support the view that interoceptive disruption is a hallmark of FND.

Elsewhere, theoretical models of predictive processing suggest that the brain operates as a Bayesian inference engine (Seth, 2013), continuously generating predictions or "priors" about bodily states based on incoming sensory data. Edwards et al. (2013) have applied this lens to FND, suggesting these priors may become maladaptive, causing the brain to misinterpret interoceptive signals. This may result in either *hypo-awareness* (e.g., numbness, shutdown) or *hyper-awareness* (e.g., exaggerated distress or misattribution), both of which were reflected in the present study’s narratives. The metaphorical and sensory language used

– navigating a house with the lights off, disconnection from their limbs, a need for sensory recalibration through movement – suggests a fundamental breakdown in predictive bodily self-modelling.

Findings show how emotional instability was often described as entangled with physical symptoms. Angela's mood shifts or Nicola's "limp" emerging from stress illustrate a porous boundary between emotions and sensations, where misattuned interoception causes overwhelm. PNES literature highlights patients describing emotional bottlenecks, and the body stepping in to speak when emotions are suppressed (Rawlings & Reuber, 2016). As McLoughlin et al. (2024) have suggested, alexithymia in FND may stem from interoceptive missatunement, especially where historical trauma has eroded a patient's ability to trust in their internal states.

These narratives resonate strongly with the neurocognitive and affective model of FND proposed by Jungilligens et al. (2022). Their paper suggests that in FND, individuals may struggle to construct *emotion concepts*, when internal signals cannot be matched to an emotional category, they become dysregulated leading to somatic expression as the default outlet. Nicola's experience, where her emotional response (annoyance) rapidly spills into a bodily manifestation (limp). From Jungilligens et al. (2022) view, this speaks to blurred boundary between affect and motor output. Likewise Angela, who experiences rapid shifts between crying and laughing, exemplify overactivation of affective systems without the stability of emotional regulation. These findings support Jungilligens et al. (2022) argument that FND can involve a failure of the brain to predict and prepare for internal states when emotional cues are misinterpreted. Recovery may, therefore, involve acquiring more refined emotional nuance or granularity – what Jungilligens et al. (2022) call the "acquisition of new emotion concepts." Adaptation to FND might require emotional-literacy practices alongside physical retraining.

Findings show how participants described adaptive, creative methods to attempt to retrain their bodily understanding such as ‘skating’ or wearing sandals to enhance proprioceptive feedback, or regulating sensory input through toys or sunglasses. These can be understood as active experiments in re-embodiment and “bottom-up” neural retraining. Evidence of these behaviours has been found in previous literature with participants “testing out” new body strategies (Dosanjh et al., 2021) and developing “new rules” (Nielsen et al., 2020), often improvisational and non-clinical. In many cases, these practices emerged as necessity in the absence of formal neurorehabilitation pathways. Findings suggest however, that for some, this self-directed trial and error is an empowering process, driven by embodied curiosity. Pols’ (2013) concept of “tinkering” in chronic illness is relevant here. Rather than following linear recovery protocols, patients engage experimental adjustments to their environments and bodies. Through tinkering, they gain their own first-hand practical knowledge, learned through experience; through feedback to sensation. These strategies can be overlooked in formal care models, yet they highlight the embodied, or instinctual, intelligence of the affected individuals. Participants reclaimed agency through improvisation, finding their own pathways through functioning with FND.

This study also found that participants employed a range of techniques to track or soothe their physiological states. These included the use of technology, pacing techniques, and sensory regulation items (such as soft toys). These tools helped to manage symptoms and support interoceptive recalibration. A 2025 systematic review on motor and sensory FND noted increasing use of self-monitoring apps, wearable technologies, and frameworks like ‘Spoon Theory’ to manage exertion (Bailey et al., 2025). These adaptations can be seen as forms of externally scaffolded interoception, where technological supports provides structure to externalise the process, when internal cues felt unreliable or inaccessible.

### *4.2.5 Attending to Co-Construction*

While the agency of each participant is central in shaping their own narrative, so too are the conditions under which those stories are told and retold through this research project (Riessman, 1993). It would be misleading to claim that the results presented here constitute a definitive or objective truth about participants' experiences of living with FND. Rather, the narratives that emerge are shaped by the dialogic space between participant and researcher. What is offered here is my interpretation of those stories, understandings forged through co-construction, shaped by my theoretical lens and clinical identity.

Narrative inquiry is always touched by ethical relationality (Sattar et al., 2021), and it is therefore vital to be transparent about the circumstances under which knowledge is produced. The boundaries I drew in the analysis, and the representations I constructed, were influenced by my disciplinary background, evolving academic interest, and personal ethical commitments (Riessman, 2008). Throughout this thesis, I have sought to be honest about these influences and to acknowledge the inevitable subjectivity in how I interpreted and represented participants' accounts. Ultimately, this study offers a version of participants' lived realities as they were expressed by them, and as they were heard and made sense of by me.

## 4.3 Strengths and Limitations

The following section seeks to reflect critically on the strengths and limitations of the present study. As a qualitative narrative inquiry guided by a constructivist-relativist paradigm, the study did not seek to produce generalisable truths but to illuminate lived experiences of individuals diagnosed with FND. It is important therefore to acknowledge the nature of the knowledge produced.

One of the study's strengths lies in its sampling strategy; it recruited a demographically diverse group of participants across a range of ages, religions and regions within the UK. Similarly, by recruiting beyond specialist FND clinics, I was able to include voices not typically represented in clinical research. Findings thereby have broader relevance, and may, in turn enhance any resonance with those without access to consistent or specialist care. By contrast, a limitation of the study is that the majority of participants identified as White British, despite efforts to maximise diversity. The study therefore reflects cultural norms and dynamics predominantly shaped by these perspectives. This homogeneity may limit the transferability of the findings, particularly for individuals whose illness experiences are shaped by different sociocultural or spiritual frameworks.

The study was open to individuals with all types of FND. The term "Functional Neurological Disorder" was used inclusively, rather than recruiting to specific subtypes, such as Functional Motor Disorder (FMD) or Psychogenic Non-Epileptic Seizures (PNES). This open framing supported the inclusion of participants with a wide range of presentations and illness experiences, rather than privileging the narratives of individuals whose symptoms align neatly with recognised subcategories. While this inclusive approach offered breadth of experience, it also introduced a layer of heterogeneity that could complicate thematic categorisations. Participants varied in their positions on the timeline of their condition, with symptom onset ranging from 1 to 13 years prior and diagnosis occurring between 3 months to 7 years ago. This range reflects practical choices and is acknowledged in interpreting the scope of the study.

The richness of data collection is a major strength of this study. The use narrative interviews, with semi-structured open-ended questions provided participants with the opportunity to tell their stories in their own words. It captures many nuances that could have been lost in more structured and constricting formats. Participants were encouraged to guide the interview process by choosing whether to receive questions in advance or scheduling breaks, reinforced the person-centred values of the study. The resulting data were highly textured and emotionally resonant stories, in keeping with the aims of narrative research (Riessman, 2008).

Nevertheless, the narrative form also presents specific limitations. Storytelling is selective by nature; participants may have chosen to omit or adapt parts of their stories to fit perceived expectations in the context of the interview (Frank, 1995). Through triangulation with a performative analysis lens however, the research was able to explore these omissions. Performative elements of the analysis may have been limited by the use of video interviews, which impairs access to non-verbal cues such as body language and facial expressions. This decision was guided by practical reasons to expand accessibility and inclusivity, yet it can be understood as introducing a constraint on the data completeness.

Rigour in qualitative research cannot be assessed through traditional metrics of objectivity. Instead, the trustworthiness of this study is demonstrated through transparency and fidelity to the subject matter (Levitt et al., 2017). Multiple strategies were employed, such as triangulation through thematic and performative narrative analysis, maintenance of a reflexive journal, and an audit trail documenting analytic decisions. Additionally, I invited participants to reflect on early interpretations. These methods supported a grounded and sensitive data analysis.

The interpretive process was conducted solely by myself. While this ensured coherence and depth, it can be said to lack inter-rater triangulation. The absence of a second coder means that interpretations are shaped by my positionality as a White British woman, trainee clinical psychologist, and someone with lived experience of illness. I recognise this position as a lens that shaped my interpretations (Finlay, 2011), acknowledging that other researchers might have seen different emphases or tensions within the same narratives. Throughout though, I attempted to balance ethical witnessing (Frank, 1995) with analytic distance. Yet I still recognise the potential for over-identification. To mitigate this, I engaged in practices of distanciation and appropriation (Ricoeur, 1976) – revisiting transcripts, discussing in supervision, and employing theoretical frameworks to structure my interpretations. Despite efforts, narrative inquiry is understood to bear the marks of the researcher. It is also possible that narrative typologies or thematic frameworks may have imposed too much structure on complex accounts, obscuring nuance in favour of clarity. I acknowledge the risk of categorising participants' lived experiences into *types* that cannot fully capture complexity of participants' lives.

The goal of this study is to offer insights that are *transferable*. Transferability as defined by Lincoln and Guba (1985) to be contextually rich, meaningfully resonant, and theoretically illuminating. Through thick description and the inclusion of extensive participant quotations, I aimed to provide contextual detail to allow readers to decide whether these findings might be relevant to their own settings. Frank's (1995) concept of *narrative truth* also guided this process. Participants' were not required to evidence their diagnosis; therefore stories may not be verifiable in a factual sense, but they hold significance in how they illuminate meaning-making in illness. Transferability is partly constrained by the specificity of the sample and setting. All participants were UK-based and share a broad cultural frame in which medical narratives about FND are understood within biopsychosocial models. The findings may be less applicable in communities where FND is conceptualised differently or where access to care is mediated through more differing systems or support structures (e.g. private healthcare). Additionally, an emphasis on verbal, storied expression necessarily limits insight of non-narrative forms of meaning-making that might also be significant for some individuals living with FND.

The study is underpinned by an epistemological pluralism that draws upon three pillars – interpretivism, social constructionism, and symbolic interactionism. These frameworks facilitated a nuanced analysis that attends to both individual meaning-making and sociocultural discourses that might have shaped illness narratives (Berger & Luckmann, 1966; Goffman, 1974). Such frameworks are particularly appropriate for FND, which exists at the intersection of neurology, psychiatry, and subjective experience. However, my epistemological stance also introduces limitations. Interpretivism privileges the participant's voice, it risks underplaying structural factors such as systemic ableism, racism, or economic marginalisation. Although elements of these were present in participants' stories, my analysis did not explicitly employ an intersectional lens which might have offered depth to the critique.

My use of narrative frameworks such as Frank's (1995) typologies and Goffman's (1974) frame analysis assumes that individuals have a degree of intentionality in how they tell their stories. While useful heuristics, these frameworks risk overlooking the chaotic, unconscious, or dissociative elements that can characterise illness experience. There is always a tension between the clarity these models can provide and the complexity they may inadvertently obscure.

The present study offers rich insights into the storied experiences of individuals diagnosed with FND. Its strengths lie in the depth of data, commitment to participant-centred methodology and its epistemological integrity. At the same time, by reflecting critically on study, I hope to present an honest appraisal of the limits of what this research can claim. My hope is that the value of this work lies in its invitation to listen differently to the stories of FND, and to approach every illness narrative with greater curiosity and humility.

### 4.4 Suggestions for Further Research

This study highlights several avenues for further research that could deepen knowledge of FND and inform more responsive clinical practice. These suggestions are grounded in the lived experiences as storied by participants.

The present findings suggest that participants' understandings of their FND and its shaping of their identity may evolve over time, often beginning with confusion and gradually shifting toward personal adaptations and work towards narrative repair. A key limitation of cross-sectional studies is their inability to capture the evolving nature of patients' experiences and understandings over time. The prevalence of *contrastive framing* and *retrospective reappraisal*, where participants anchor identity in the past or reconstruct present meaning through lens of diagnosis indicates a need for longitudinal research designs that might capture how these processes unfold. Initiating such research at the point of diagnosis would allow for a clearer view of how explanatory frames are internalised or reworked, and map how relationships with clinical information, their bodies and clinicians shift. This could seek to uncover potential psychological adjustment trajectories and identify therapeutic and educational intervention opportunities.

Participants in this study often rekeyed dismissive or invalidating clinical encounters as reflecting a lack of understanding or confidence in working with FND. While some described feeling dismissed many stopped short of labelling these experiences as outright stigma, suggesting a more nuanced appraisal of their clinician's abilities. However, repeated patient perceptions of clinicians as uncertain or gatekeeping raises questions about how FND is understood and treated by professionals. Previous studies (Stone et al., 2002) have identified diagnostic ambivalence among clinicians, but more in-depth, contemporary qualitative research is needed to examine how these attitudes manifest in practice and influence tone or *key* in which information is transmitted and received by patients, and the impact this might have on therapeutic engagement. Integrating clinician perspectives with patients' accounts could illuminate and address gaps in knowledge and ultimately help reduce the relational burden currently carried by patients.

This study highlights how the importance of language in shaping how participants appraise their FND diagnosis. The risk of overuse of metaphors such as "hardware/software" can lead to what is termed here as frame fatigue. Future research might use discourse analysis (Fairclough, 2013) to explore how FND is presented in written materials, such as online resources as well as clinic letters and materials. Such analysis could indicate which metaphors or explanatory phrases foster trust and understanding, and which may alienate or oversimplify. A better grasp of the affective and rhetorical tone of explanations could improve how clinicians tailor communication to individual patient needs and meet them at each stage of acceptance.

A novel and under-researched finding in this study was the centring of late-diagnosed neurodivergence, (including autism, ADHD, and dyslexia) in several participants' narratives. These individuals reframed their FND experiences through a neurodiversity lens, suggesting that traditional FND explanations did not always encompass their experiences. Broader cultural shifts recognise neurodevelopmental difference as a source of sensory, cognitive, and emotional variation rather than deficit. Future research could seek to explore how neurodivergent traits may interact with FND symptoms. This research would need to be sensitive to diagnostic overshadowing, service exclusion, or trait misrecognition common within neurodivergent populations (Walker, 2021). An exploration of neuro-diversity frameworks could offer more flexibility in FND care, improving accessibility for a wider range of patient lived experiences.

## 4.5 Clinical Implications

The findings of this study have highlighted many clinical implications for improving the care of individuals living with FND. These implications span diagnostic practices, clinician training, improvements to service provision.

### *1. Recognise Biographical Disruption and Identity Work.*

Findings indicate that FND onset results in profound biographical disruption. Participants in this study articulated their losses beyond the practical (mobility, employment, independence), in relation to their sense of self. The prevalence of stories of frame breaks and narrative work through contrastive framing and negotiations indicate that FND patients are consistently engaged in acts of identity repair, to compensate for societal and medical delegitimization experienced. Therapeutic approaches should incorporate narrative reconstruction as part of recovery, as illness experiences often involve disruptions to one's sense of self and require the development of revised personal narratives (Bury, 1982; Charmaz, 1991). Findings strongly suggest that validating patients' identities and helping them reframe current capacities may help mitigate distress and foster adaptation to FND, and can encourage alternative, empowering self-stories (White & Epston, 1990; Stone et al., 2020).

A recurrent theme in participants' accounts was the burden of educating clinicians about FND, which align with existing researchers calls for improved clinician training (Pick et al., 2019). Training should foreground the lived experience of FND, incorporating narrative medicine approaches to enhance clinician understanding and empathy, and to ensure treatment approaches are aligned with patient perspectives (Stone et al., 2020). Charon (2006) argues for the introduction of *narrative competence*, the ability to recognise and be moved by the stories of others, as a clinical skill essential to empathetic and effective care. Encouraging clinicians to reflect on their own assumptions or biases about FND may improve relational dynamics and reduce diagnostic inertia. This study's findings underline the presence of stigma noted in previous studies (McLoughlin et al., 2023). Participants in this study consistently engage in frame negotiations, working to shift dominant interpretations of FND from stigmatised to validated as a legitimate condition. The stories they tell in describing their experiences serve social functions. Clinicians should be sensitive to the performative labour that patients may bring to the consultation space, for example, overtly expressing stories of effort, competence, or resilience as a form of self-protection. Recognising this in the patient-clinician dynamic could prevent misreading patients as defensive or resistant to treatment (Stone, 2016). Integrating principles from trauma-informed care and cultural humility may reduce epistemic injustice and help to affirm FND patients as credible narrators, and even experts, of their experience (Fricker, 2007).

### *2. Improve Diagnostic Communication Practices*

The inadequacy of FND diagnosis delivery emerged as a key source of distress and confusion. Participants commonly encountered what this study understands as a diagnostic frame void, a lack of coherent explanation. Even when useful metaphors (e.g., hardware/software) were used, their repetition without context or engagement led to frame fatigue. Clinicians must elaborate on the information that is communicated to patients, but also how this information is shared, paying attention to their emotional tone and relational stance. This study would strongly support best practice guidelines outlined by Stone (2016).

Diagnosis should be delivered with clarity, in an empathic manner and include follow-up planning. Stone, Carson, and Hallett (2016) argue that the way clinicians explain a functional neurological diagnosis is central to treatment, with effective communication including taking the patient seriously, providing a diagnostic label, explaining how symptoms arise, and emphasising the potential for improvement. Best-practice guidelines recommend delivering the diagnosis clearly and empathically, using positive, evidence-based language, arranging concrete next steps, and integrating psychoeducation into the clinical encounter practices (Cope et al., 2021), linked in multiple studies to increased understanding and acceptance (Hall-Patch et al., 2010; Carson et al., 2016). Metaphors or structured scripts may be useful in such conversations, but the meaning of the diagnosis should be co-constructed with each individual.

This emphasis on co-construction is particularly important given the ambivalence many patients feel toward psychological framing. While some participants did find the psychological frame meaningful for their FND, the majority did not experience it as aligned with their experience. Qualitative and clinical studies reflect similar concerns: purely psychological narratives can contribute to feelings of invalidation, and disengagement from care (O’Neal et al., 2021). Clinicians should avoid imposing trauma narratives and instead first take the time to explore whether such interpretations might resonate with each individual. Findings in this study indicate that emphasising patient agency in co-constructing explanatory models fosters engagement and trust in the medical system. If psychological frames are introduced, they should be offered as *possible* lenses for symptom development rather than as concrete explanations of the diagnosis. Emphasising patient agency in constructing explanatory models has been associated with better engagement with treatment pathways and reduced risk of re-traumatisation or invalidation (Cope et al., 2021).

### ***3. Include Neurodiversity Perspectives***

This study's finding that several participants reinterpreted their FND experiences in light of later-identified neurodivergence highlights a notable conceptual gap in dominant FND models, which traditionally foreground neurological and psychiatric histories (Edwards & Bhatia, 2012; Hallett, 2016) but seldom consider neurodevelopmental variation. Growing evidence suggests that autistic traits, sensory-processing differences, and alexithymia are disproportionately represented in FND populations and may shape symptom expression and coping (Nicholson et al., 2021; Palmer et al., 2021). Neurodiversity research argues that neurological differences reflect natural human variation rather than deficits, and that clinical models benefit from incorporating strengths-based, person-centred formulations (Milton, 2012; Singer, 1999). Integrating neurodiversity-informed perspectives into FND assessment may therefore improve therapeutic rapport by aligning clinical explanations with patients' lived experiences and may indicate a broader range of cognitive and sensory approaches is needed for recovery.

### ***4. Move Beyond Mind–Body Dualism***

Participants' accounts highlight the need for a move towards an integrated understanding of FND that recognises both embodied strategies and emotional processes as central to recovery. Many described engaging in iterative, trial-and-error forms of self-management, what Pols (2013) terms "tinkering", reflecting meaningful forms of embodied adaptation but are often undervalued in clinical settings. Research has shown that incorporating patient-generated strategies that acknowledge individuals' embodied intelligence can foster more collaborative and empowering therapeutic relationships (Mol et al., 2010). At the same time, participants reported challenges with interoception and emotional overwhelm, suggesting that emotional-literacy practices may be required as accompanying physical rehabilitation. This is strongly supported by the evidence from chronic illness management suggesting that multidisciplinary care improves patient engagement and outcomes (Boult et al., 2009; Wagner et al., 2001). By supporting patients to strengthen emotional awareness alongside bodily regulation, clinicians can encourage a more integrated, non-dualistic approach that honours the interconnectedness of the emotional and physical experience in FND. This would align with the findings of Palmer et al. (2023) who evaluated an FND multidisciplinary treatment model by involving psychological and physical expertise together, which highlighted vast improvements in patient understanding and outcomes.

### ***5. Address Regional Inequity Through Specialist Pathways***

Participants' accounts of the "postcode lottery" of regional variation in diagnosis, treatment, and follow-up reflect broader patterns documented in illness and health services research, in which geographic and systemic inequalities contribute to inconsistent access to care and variable patient outcomes (Starfield, Shi, & Macinko, 2005; Gulliford et al., 2002). Such disparities are particularly pronounced for conditions such as FND that require specialist, multidisciplinary management (MacKay et al., 2018). This study's findings highlight the need for equitable provision of specialist services that integrate neurology, psychology, and physiotherapy, and that are delivered by clinicians trained in functional disorders. Standardised referral pathways and enhanced primary care awareness are critical to reducing diagnostic delays and promoting consistent care, mirroring broader calls in healthcare research for reforms that address inequities in access and ensure high-quality care across regions (Rosenthal et al., 2013).

### 4.6 Dissemination

The findings from this study will be presented to staff and students on the Clinical Psychology Doctorate Programme at the University of Essex, in the form of a poster presentation. Findings will also be presented within Essex Partnership University Trust (EPUT)'s Trust-wide Special Interest Group on FND in the form of an online presentation.

Participants will be offered the opportunity to read the final report, with a shorter version of the final report to be made available for participants who do not wish to read the full account. A version of the findings is also intended to be shared with the charities FND Hope and support organisations such as FND Matters (Northern Ireland), to enhance the clinical utility of the research. Through disseminating key findings and implications for service provision, it is hoped that this research may inform clinicians and policymakers to provide a more person-centred approach, inspired by patient's own stories.

Finally, I intend to submit the final research for publication in relevant academic journals that are read by a variety of professionals who may interact with persons with FND. Journals such as *Intima: A Journal of Narrative Medicine* and the *Journal of Psychosomatic Research* will be approached to publish the thesis as an academic journal article.

### 4.7 Reflexivity

Reflexivity was a methodological commitment and an ethical necessity in this project. Throughout the study, I engaged in sustained reflection on how my positionality as a trainee clinical psychologist with lived experience of illness influenced every phase of the research, from design to analysis.

Narratives in this study were understood not simply as accounts but performative acts of identity. Participants performed versions of themselves in real time, negotiating their emotions, me as audience and perceived wider audiences. Recognising storytelling as performance required me to attend not only to what was said, but how and why it was being said in that moment. Stories are constructed for an audience (Riessman, 2008), participants adapted their narratives in response to their expectations of the interview space. Interviews therefore were not neutral data-gathering exercises. They were dialogic and relational, shaped by my presence. My identity as a trainee clinical psychologist may have signalled to participants that I was safe or empathic, especially within the contested terrain of FND. In my reflexive journal I noted how some participants mirrored the language I used in follow up questions or prompts. Some participants made reference to their knowledge of psychology, possibly adapting their accounts to suit what they perceived I was looking for. I am conscious that my presence will therefore have co-authored these narratives. I managed these tensions through openness, inviting participants to speak freely, to challenge psychological framings, and to include others in the interview if desired. Nonetheless, power dynamics were always present, and I remain aware to the implications of my dual role as both researcher and clinical trainee (Berger, 2015).

Throughout analysis, I grappled with the ethics of representation of the stories I was telling. Narrative inquiry requires interpretation but this involves choices in emphasis, which can become a form of narrative appropriation. I questioned the lines between analysis and intrusion, particularly when making sense of painful or politically charged content (Fricker, 2007). To navigate this, I invited participants to reflect on early interpretations. I could also separate my own reflections by maintaining a reflexive journal throughout the research process. When including participant quotes, I sought to carefully contextualise quotations. Despite efforts, I concede that this final text is filtered through my own lens, and is necessarily shaped by my analytical choices. I remain aware that no representation of experience can be fully neutral nor complete.

My personal and professional values informed how I engaged with the research project, particularly a commitment to patient dignity. I noticed that I was drawn to moments of patients reclaiming narrative agency and found them to be analytically rich. At times, this may have risked overemphasising resistance, particularly where some patient stories were less resolved. Reflexivity, therefore, demanded constant interrogation of my assumptions, but it also heightened ethical tensions. I questioned whether including certain excerpts served the participants or the argument. I returned to the principles of patient-led research, foregrounding voice and using thick description to resist the risk of reductive readings.

Reflexivity was central throughout this research. It made me more attuned to the ethical stakes of interpretation and illuminated the power of storytelling. At the same time, it has revealed to me the limits of representation of lived experience. My hope is that in honestly reflecting on these tensions, the work remains accountable to those who entrusted me with their stories.

### 4.8 Conclusion

This research study sought to use narrative research practices to explore how people construct meaning in response to receiving an FND diagnosis. It used narrative methods to explore the stories told by the 15 participants who had been diagnosed with FND. The findings in these narratives were further understood using theoretical frameworks of frame analysis (Goffman, 1973) and illness narratives (Frank, 1995).

The study identified four narrative types, *Stories of Biographical Disruption:* in which participants experienced abrupt, disorienting losses of identity and meaning, understood as ‘frame breaks’ and chaos narratives. *Stories of Inadequate Explanation:* in which participants reflected on the vagueness or overused nature of the explanations they were given, conceptualized as ‘frame voids’ and ‘frame fatigue.’ *Stories of Stigma and*

*Validation:* in which participants worked to re-author their stories from the dominant discourses provided, engaging in 'frame renegotiation'. Finally, *Stories of Embodied Reinterpretation:* in which participants reappraised their experiences in light of the FND diagnosis, using their bodies as a site of frame construction.

This thesis contributes to knowledge by offering a nuanced understanding of how individuals with FND construct and perform narratives in response to their diagnosis. It highlights the complex ways in which meaning, legitimacy, and identity are negotiated in the landscape of diagnostic ambiguity and stigmatising attitudes. This study centres the lived, narrative experience of FND, revealing how patients actively work to re-author their stories and in doing so redefine what FND means in the UK. The findings of this works hope to advance the understanding of FND as a socially embedded experience.

This study highlights the need for clear, positively framed explanations of FND that validate patients' experiences. It underscores the importance of continuity of care, collaborative communication, and clinician confidence in delivering the diagnosis. Recognising the emotional and identity disruptions patients face, findings advocate for new greater psychosocial support, narrative-informed practice, and clinical training that foster empathy towards FND patients. Together, these insights call for a shift towards relational, explanatory models that can centre the patient's experience and facilitate meaning-making in clinical care.

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# 6 Appendices

## Appendix A: Summary of Articles included for Systematic Review

### Table A1

*Methodological Data for Studies included in the Systematic Review*

| CASP Score | Authors | Aim(s) | Methodology | Data Collection | Mean Age (range) | Gender Male:Female | FND Subtype | Key Findings |
|---|---|---|---|---|---|---|---|---|
| 10 | Bazyldo & Eccles, (2022) | To explore the lived experiences of individuals with Functional Movement Disorders (FMD) | IPA | 10 Semi-structured interviews (online) | 42 (24-66) | 2:8 | Functional Movement Disorder | Themes of identity reconstruction, struggle for legitimacy, and complexity in navigating medical |
| 10 | McLoughlin et al., (2024) | To explore experiences of stigma in Functional Neurological Disorder (FND) as it manifests from the onset of symptoms, up to diagnosis and subsequently. | Reflexive TA | 15 semi-strucured interviews | 42 (19-68) | 3:11<br>1 non-binary | Functional Neurological Disorder | Stigma emerged from multiple sources including self, others, and healthcare; knowledge and validation reduced stigma. |
| 9 | Nielsen et al., (2020) | To explore the experiences and perspectives of patients with functional motor disorder | Inductive Thematic Analysis | 11 Semi-Structured Interviews | 44 (21-67) | 2:9 | Functional Motor Disorder | Patients experienced burden, dissatisfaction with psychological explanations, abandonment, and powerlessness; emphasized importance of communication and biopsychosocial model. |

**Table A1 (continued)**

| CASP Score | Authors | Aim | Methodology | Data Collection | Mean Age (range) | Gender Male:Female | FND Subtype | Key Findings |
|---|---|---|---|---|---|---|---|---|
| 9 | Peacock et al., (2023) | Examine legitimacy and medicalization experiences in people diagnosed with NEAD. | Narrative Interviews | Free Association Narrative Interviews (FANI) | 50 (34-64) | 0:5 | Non-Epileptic Attack Disorder (NEAD) | Patients struggle to find legitimacy; psychological explanations insufficient for social legitimacy; seek medicalized validation. |
| 8 | Staton et al., (2024) | To explore experiences of accessing UK psychological services, from the perspective of those with FND. | Reflexive Thematic Analysis | 15 semi-structured interviews | 34 (21-54) | 3:12 | Functional Neurological Disorder | FND patients experienced stigma when accessing psychological services, which shaped their perceptions of psychological explanations. Positive therapeutic relationships helped to improve engagement with treatment. |
| 9 | Walsh et al., (2024) | To explore adults' experiences of NEAD across the disorder trajectory, including onset, diagnosis, and living with NEAD | Reflexive Thematic Analysis | 12 semi-structured interviews |  | 1:11 | Non Epileptic Attack Disorder (NEAD) | NEAD described a confusing journey marked by a stigmatising diagnostic process. Supportive communication and ongoing therapeutic relationships were experienced as essential in helping them understand, manage the condition. |

**Table A1 (continued)**

| CASP Score | Authors | Aim | Methodology | Data Collection | Mean Age (range) | Gender Male:Female | FND Subtype | Key Findings |
|---|---|---|---|---|---|---|---|---|
| 9 | Revell et al., (2021) | Develop a cognitive behavioural model of idiopathic drop attacks as a subtype of FND. | Grounded Theory | Interviews and diaries | Not specified (40-71) | 0:7 | Drop Attacks | Proposed CBT model with triggers like stress and dissociation; suggests therapy to address fear-avoidance and reinforcement cycles. |
| 9 | Thompson et al., (2013) | Explore patients' experience of receiving a diagnosis of non-epileptic seizures. | IPA | 8 Semi-Structured Interviews | 20s-60s | 0:8 | Non Epileptic Seizures (NES) | Patients felt confused, left in limbo; those who integrated the diagnosis into their narrative adjusted better. |
| 8 | Dosanjh et al., (2021) | To gain insight into how individuals make sense FMD from symptom onset to post-diagnostic adaptation | IPA | 8 Semi-structured interviews | 50s (20s-70s) Exact ages not given | 1:7 | Functional Movement Disorder | Patients struggled with understanding the disorder and its legitimacy; highlighted a lack of continuity and empathy in care. |
| 8 | O'Connell et al., (2020) | Explore experiences and illness perceptions of patients with functional symptoms admitted to hyperacute stroke wards. | Mixed; Quantitative & Thematic Analysis | Semi-structured interviews | 51 (21-88) | 12:24 | Functional Symptoms Stroke Ward | Patients expressed confusion, distress, and concern about being perceived as time-wasters; lack of guidelines may perpetuate symptoms. |

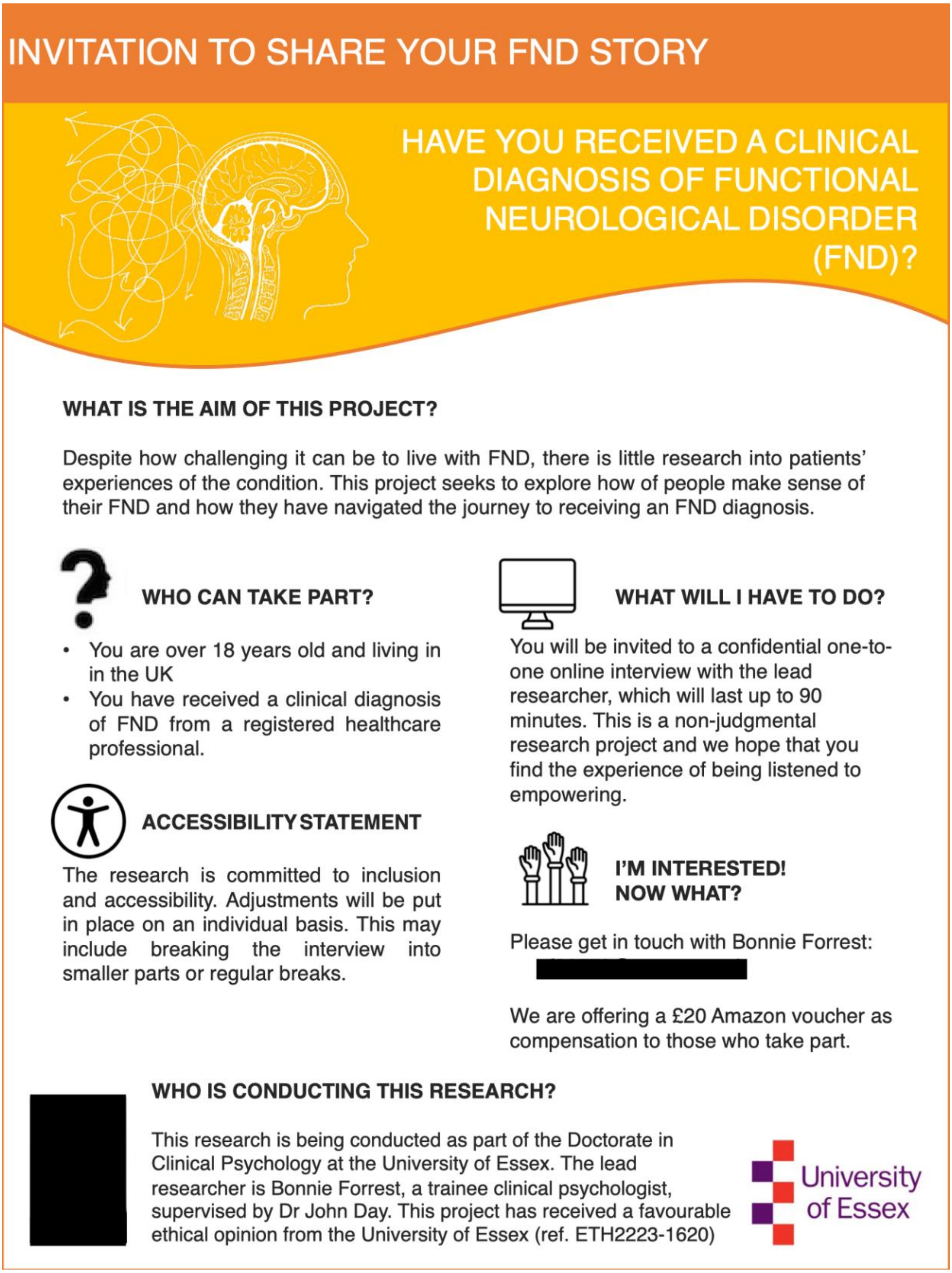
**Table A1 (continued)**

| CASP Score | Authors | Aim | Methodology | Data Collection | Mean Age (range) | Gender Male:Female | FND Subtype | Key Findings |
|---|---|---|---|---|---|---|---|---|
| 8 | Wyatt et al., (2013) | Investigate experiences of adjusting to NEAD diagnosis and psychological therapy. | Thematic Analysis | 6 semi-structured interviews | 47<br>(29-55) | 1:5 | Non Epileptic Attack Disorder (NEAD) | Adjustment to diagnosis impacted therapy engagement; improved understanding of NEAD led to greater acceptance and hope. |
| 7 | Loewenberger et al., (2021) | To explore the preferred terms for functional seizures, and the experience of being diagnosed, from the patient's perspective | Mixed Methods | 39 online survey,<br>13 semi-strucured interviews | Approx. 35<br>(18-46+)<br>Exact ages not given | Survey 7:32<br>Interviews 2:11 | Functional Seizures | Three themes surrounding the experience of being diagnosed: the importance of a shared understanding; feeling alone; and a sense of hope |
| 7 | Chan et al., (2025) | To explore experiences of persons with an FND diagnosis attending A&E. | Mixed Methods | 99 quantitative survey,<br>6 semi-structured interviews | Not collected | Survey 37:62<br>Interviews 0:6 | Functional Neurological Disorder | Patients described their symptom experience in four main themes, with the transcending theme of uncertainty and judgement. A&E attendance was defined as a war on two fronts; with FND and with HCPs. |

**Table A1 (continued)**

| CASP Score | Authors | Aim | Methodology | Data Collection | Mean Age (range) | Gender Male:Female | FND Subtype | Key Findings |
|---|---|---|---|---|---|---|---|---|
| 6 | Rawlings et al., (2018) | Analyse narratives of people with epilepsy and PNES to identify narrative typologies. | Narrative Analysis | Written Narratives | Median<br>43 | 9:40 | Non Epileptic Attack Disorder (NEAD) | PNES narratives often characterized by feeling lost; contrasted with epilepsy narratives which focus more on tackling adversity. |

## Appendix B: Recruitment Poster



# INVITATION TO SHARE YOUR FND STORY

## HAVE YOU RECEIVED A CLINICAL DIAGNOSIS OF FUNCTIONAL NEUROLOGICAL DISORDER (FND)?

### WHAT IS THE AIM OF THIS PROJECT?

Despite how challenging it can be to live with FND, there is little research into patients' experiences of the condition. This project seeks to explore how of people make sense of their FND and how they have navigated the journey to receiving an FND diagnosis.

### WHO CAN TAKE PART?

- You are over 18 years old and living in in the UK
- You have received a clinical diagnosis of FND from a registered healthcare professional.

### ACCESSIBILITY STATEMENT

The research is committed to inclusion and accessibility. Adjustments will be put in place on an individual basis. This may include breaking the interview into smaller parts or regular breaks.

### WHAT WILL I HAVE TO DO?

You will be invited to a confidential one-to-one online interview with the lead researcher, which will last up to 90 minutes. This is a non-judgmental research project and we hope that you find the experience of being listened to empowering.

### I'M INTERESTED! NOW WHAT?

Please get in touch with Bonnie Forrest:
[redacted]

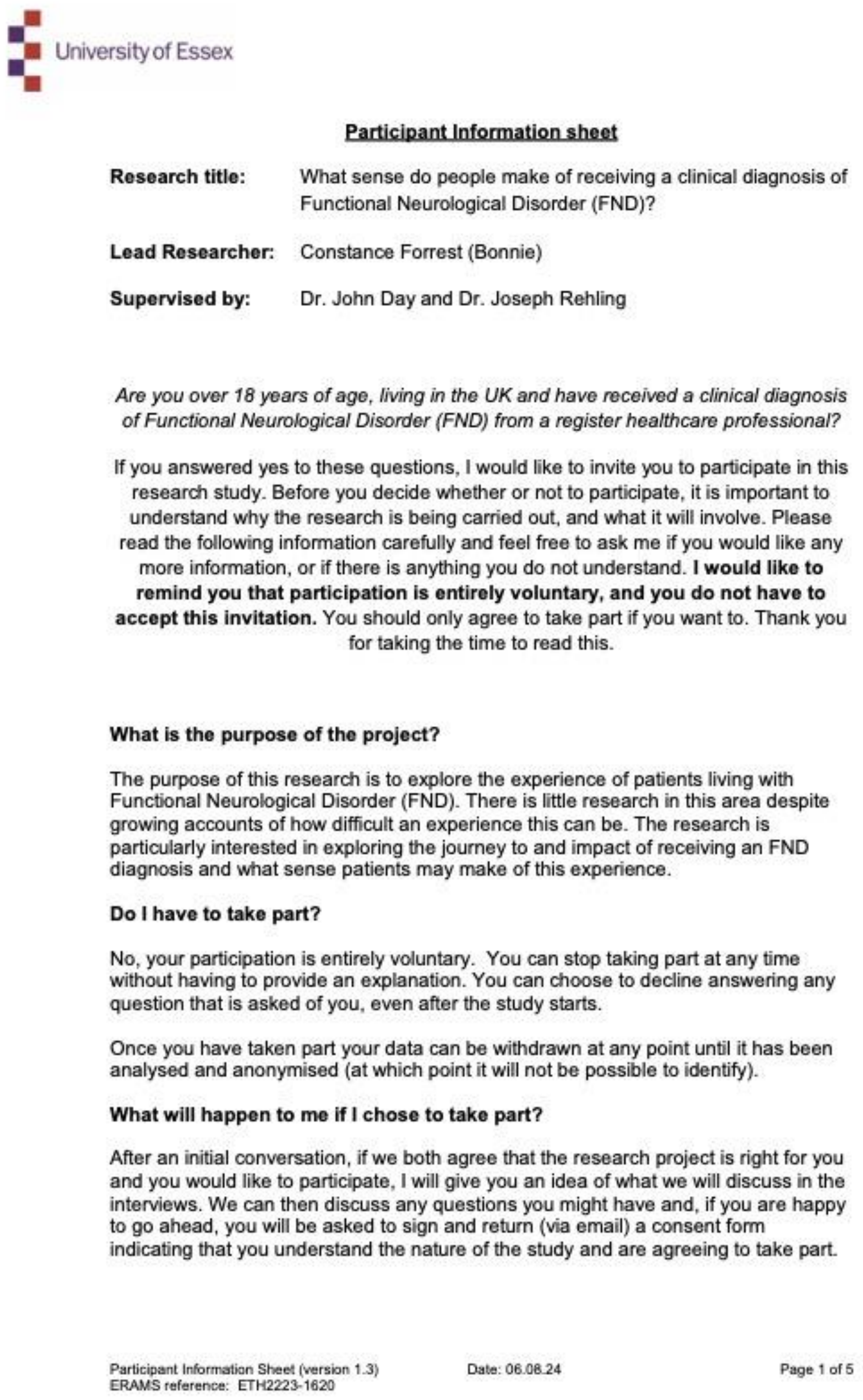
We are offering a £20 Amazon voucher as compensation to those who take part.

### WHO IS CONDUCTING THIS RESEARCH?

[redacted]

This research is being conducted as part of the Doctorate in Clinical Psychology at the University of Essex. The lead researcher is Bonnie Forrest, a trainee clinical psychologist, supervised by Dr John Day. This project has received a favourable ethical opinion from the University of Essex (ref. ETH2223-1620)

# Appendix C: Participant Information Sheet



University of Essex

## Participant Information sheet

| | |
|---|---|
| **Research title:** | What sense do people make of receiving a clinical diagnosis of Functional Neurological Disorder (FND)? |
| **Lead Researcher:** | Constance Forrest (Bonnie) |
| **Supervised by:** | Dr. John Day and Dr. Joseph Rehling |

*Are you over 18 years of age, living in the UK and have received a clinical diagnosis of Functional Neurological Disorder (FND) from a register healthcare professional?*

If you answered yes to these questions, I would like to invite you to participate in this research study. Before you decide whether or not to participate, it is important to understand why the research is being carried out, and what it will involve. Please read the following information carefully and feel free to ask me if you would like any more information, or if there is anything you do not understand. **I would like to remind you that participation is entirely voluntary, and you do not have to accept this invitation.** You should only agree to take part if you want to. Thank you for taking the time to read this.

### What is the purpose of the project?

The purpose of this research is to explore the experience of patients living with Functional Neurological Disorder (FND). There is little research in this area despite growing accounts of how difficult an experience this can be. The research is particularly interested in exploring the journey to and impact of receiving an FND diagnosis and what sense patients may make of this experience.

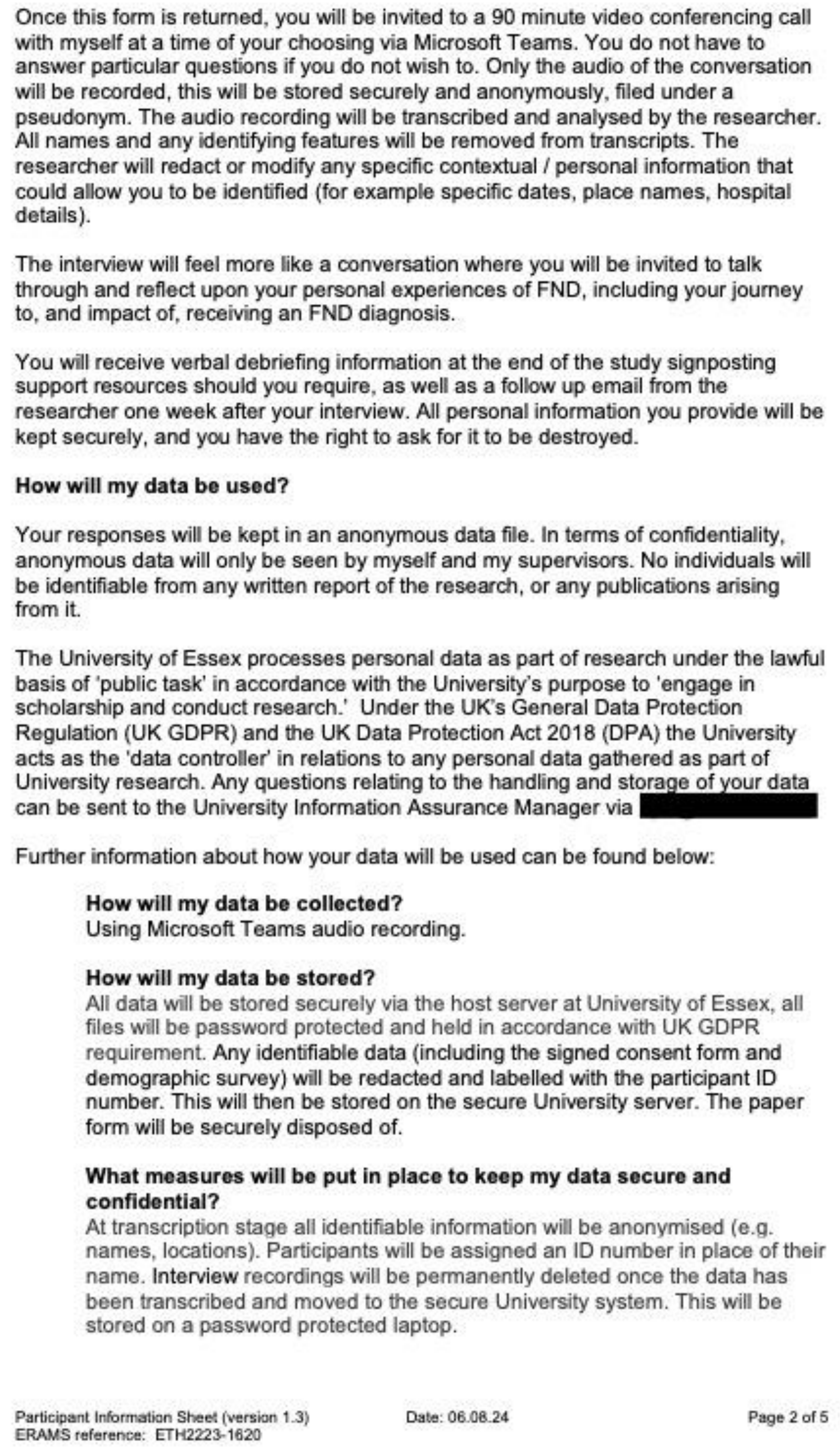
### Do I have to take part?

No, your participation is entirely voluntary. You can stop taking part at any time without having to provide an explanation. You can choose to decline answering any question that is asked of you, even after the study starts.

Once you have taken part your data can be withdrawn at any point until it has been analysed and anonymised (at which point it will not be possible to identify).

### What will happen to me if I chose to take part?

After an initial conversation, if we both agree that the research project is right for you and you would like to participate, I will give you an idea of what we will discuss in the interviews. We can then discuss any questions you might have and, if you are happy to go ahead, you will be asked to sign and return (via email) a consent form indicating that you understand the nature of the study and are agreeing to take part.



Once this form is returned, you will be invited to a 90 minute video conferencing call with myself at a time of your choosing via Microsoft Teams. You do not have to answer particular questions if you do not wish to. Only the audio of the conversation will be recorded, this will be stored securely and anonymously, filed under a pseudonym. The audio recording will be transcribed and analysed by the researcher. All names and any identifying features will be removed from transcripts. The researcher will redact or modify any specific contextual / personal information that could allow you to be identified (for example specific dates, place names, hospital details).

The interview will feel more like a conversation where you will be invited to talk through and reflect upon your personal experiences of FND, including your journey to, and impact of, receiving an FND diagnosis.

You will receive verbal debriefing information at the end of the study signposting support resources should you require, as well as a follow up email from the researcher one week after your interview. All personal information you provide will be kept securely, and you have the right to ask for it to be destroyed.

**How will my data be used?**

Your responses will be kept in an anonymous data file. In terms of confidentiality, anonymous data will only be seen by myself and my supervisors. No individuals will be identifiable from any written report of the research, or any publications arising from it.

The University of Essex processes personal data as part of research under the lawful basis of 'public task' in accordance with the University's purpose to 'engage in scholarship and conduct research.' Under the UK's General Data Protection Regulation (UK GDPR) and the UK Data Protection Act 2018 (DPA) the University acts as the 'data controller' in relations to any personal data gathered as part of University research. Any questions relating to the handling and storage of your data can be sent to the University Information Assurance Manager via [redacted]

Further information about how your data will be used can be found below:

**How will my data be collected?**
Using Microsoft Teams audio recording.

**How will my data be stored?**
All data will be stored securely via the host server at University of Essex, all files will be password protected and held in accordance with UK GDPR requirement. Any identifiable data (including the signed consent form and demographic survey) will be redacted and labelled with the participant ID number. This will then be stored on the secure University server. The paper form will be securely disposed of.

**What measures will be put in place to keep my data secure and confidential?**
At transcription stage all identifiable information will be anonymised (e.g. names, locations). Participants will be assigned an ID number in place of their name. Interview recordings will be permanently deleted once the data has been transcribed and moved to the secure University system. This will be stored on a password protected laptop.

**Will my data be anonymised?**
Yes, your data will be anonymised. This means that your real name and any identifiable information will not be included. A pseudonym will be used for the purposes of the final report and specific contextual / personal information (for example specific dates, place names, hospital details) that could allow you to be identified will be redacted or modified to protect your anonymity.

**How will my data be used?**
Your data will be used for the purposes of this study only with the potential for future publication of the research paper in academic journals.

**Who will have access to my data?**
The lead researcher– Bonnie Forrest and research supervisor(s) – Dr John Day & Dr Joseph Rehling

**Will my data be archived for use in future research projects?**
No.

**How will my data be destroyed?**
Anonymised data will be securely held by the University on an archive/repository (indefinitely), any other data will be permanently deleted as soon as is feasible.

**What is the legal basis for using the data and who is the Data Controller?**

The legal basis for using the data will be your informed consent. This will be a statement signed by all participants. The Data Controller will be the University of Essex. Further details regarding data controls can be directed to the

University Information Assurance Manager [redacted]

**Exceptions to anonymity**

The only exception to maintaining anonymity would be if you disclosed information to suggest yourself or another person were at risk of serious harm or engaging in serious criminal activity. In such cases I may be legally required to disclose your confidential information to the relevant authorities. Such a situation is highly unlikely to occur, but please ask for more information if you have any concerns.

**Are there possible disadvantages and risks in taking part?**

The researcher is aware that FND can be a debilitating experience and therefore has potential to be upsetting topic of conversation. The project does not intend to cause you any distress by the resurfacing of upsetting memories related to your experiences, as such you are not required to answer any questions, nor elaborate on any details of which you do not feel comfortable in sharing. Together we will agree on steps we can take if you feel distressed at any point. This may involve pausing, discussing what may help you feel more comfortable and then deciding if you would like to continue or end the interview.

This research project seeks to explore how you understand your experience of being diagnosed with FND, as well as how this experience may have shaped your understanding of physical and mental health provision in the UK.

I intend to offer you a verbal and written debrief after the interview, a follow up email a week after your interview with the offer of a further phone call, as well as signposting to relevant organisations supporting those affected by FND.

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

I hope you find the conversation interesting and satisfaction in knowing you are contributing to the growing body of research around the experiences of FND patients and which may help to shape future health policy. We are offering you a £20 Amazon voucher as compensation for your time.

**What will happen to the results of this research project?**

The results of this study will be written into a thesis as part fulfilment of the Doctorate in Clinical Psychology at the University of Essex. A version of the final report may be submitted for publication in academic journals such as *Intima: A Journal of Narrative* Medicine and the *Journal of Psychosomatic Research.*

**Who is organising and/or funding this project?**

The research project will be carried out by Constance Forrest, as part fulfilment for the doctorate in Clinical Psychology at the University of Essex, and supervised by Dr. John Day (PhD) and Dr. Joseph Rehling (DClinPsy).

**Who has reviewed the study?**

The study has been reviewed and approved by the Science and Health Ethics sub-committee at the University of Essex.

**What if something goes wrong?**

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact myself, or the research supervisor, Dr. John Day, using the contact details below and we will try to help. If are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach us, then please contact the University's Research Governance and Planning Manager, Dr Mantalena Sotiriadou (e-mail [redacted]). Please include the ERAMS reference which can be found at the bottom of this page.

The University of Essex strives to maintain the highest rigour when processing your personal data, however it is important that you are aware of your right to submit a complaint to the University Data Protection Officer via email at [redacted] or by telephone on [redacted].

**Here are the names and contact details of the researcher conducting this study and their supervisors:**

Researcher:
Constance "Bonnie" Forrest: [redacted]

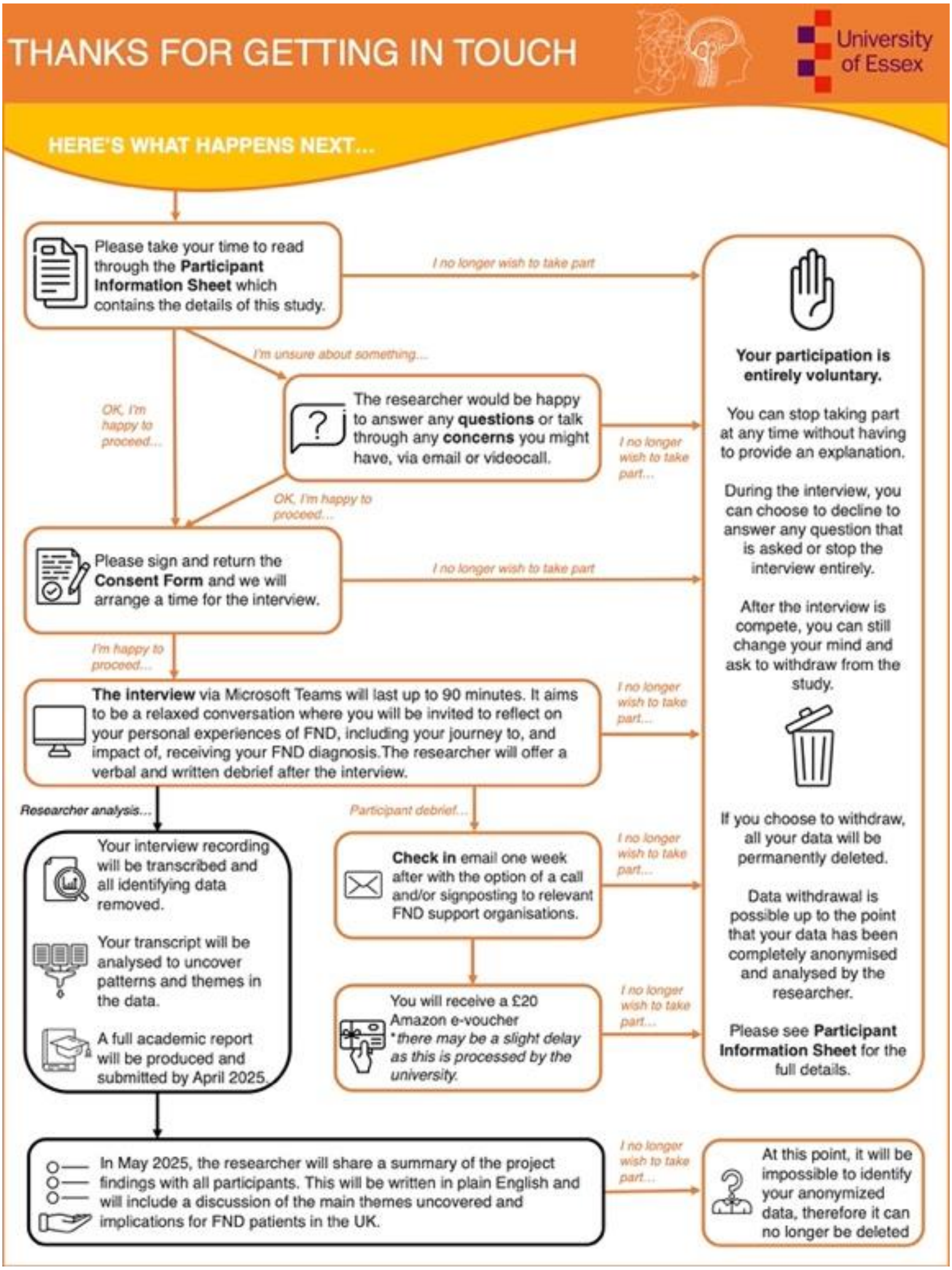
Research Supervisors:
Dr. John Day (PhD) [redacted]
Dr. Joseph Rehling (DClinPsy) [redacted]

School of Health and Social Care, University of Essex, Wivenhoe Park, Colchester, Essex, CO4 3SQ

Tel: [redacted]

**Thank you for considering taking part, please be in touch if you have any questions.**

# Appendix D: Accessible Flowchart Participant Information Sheet



## THANKS FOR GETTING IN TOUCH

University of Essex

### HERE'S WHAT HAPPENS NEXT...

Please take your time to read through the **Participant Information Sheet** which contains the details of this study.

*I no longer wish to take part*

*I'm unsure about something...*

The researcher would be happy to answer any **questions** or talk through any **concerns** you might have, via email or videocall.

*OK, I'm happy to proceed...*

*I no longer wish to take part...*

*OK, I'm happy to proceed...*

Please sign and return the **Consent Form** and we will arrange a time for the interview.

*I no longer wish to take part*

*I'm happy to proceed...*

**The interview** via Microsoft Teams will last up to 90 minutes. It aims to be a relaxed conversation where you will be invited to reflect on your personal experiences of FND, including your journey to, and impact of, receiving your FND diagnosis. The researcher will offer a verbal and written debrief after the interview.

*I no longer wish to take part...*

*Researcher analysis...*

Your interview recording will be transcribed and all identifying data removed.

Your transcript will be analysed to uncover patterns and themes in the data.

A full academic report will be produced and submitted by April 2025.

*Participant debrief...*

**Check in** email one week after with the option of a call and/or signposting to relevant FND support organisations.

*I no longer wish to take part...*

You will receive a £20 Amazon e-voucher **there may be a slight delay as this is processed by the university.*

*I no longer wish to take part...*

**Your participation is entirely voluntary.**

You can stop taking part at any time without having to provide an explanation.

During the interview, you can choose to decline to answer any question that is asked or stop the interview entirely.

After the interview is compete, you can still change your mind and ask to withdraw from the study.

If you choose to withdraw, all your data will be permanently deleted.

Data withdrawal is possible up to the point that your data has been completely anonymised and analysed by the researcher.

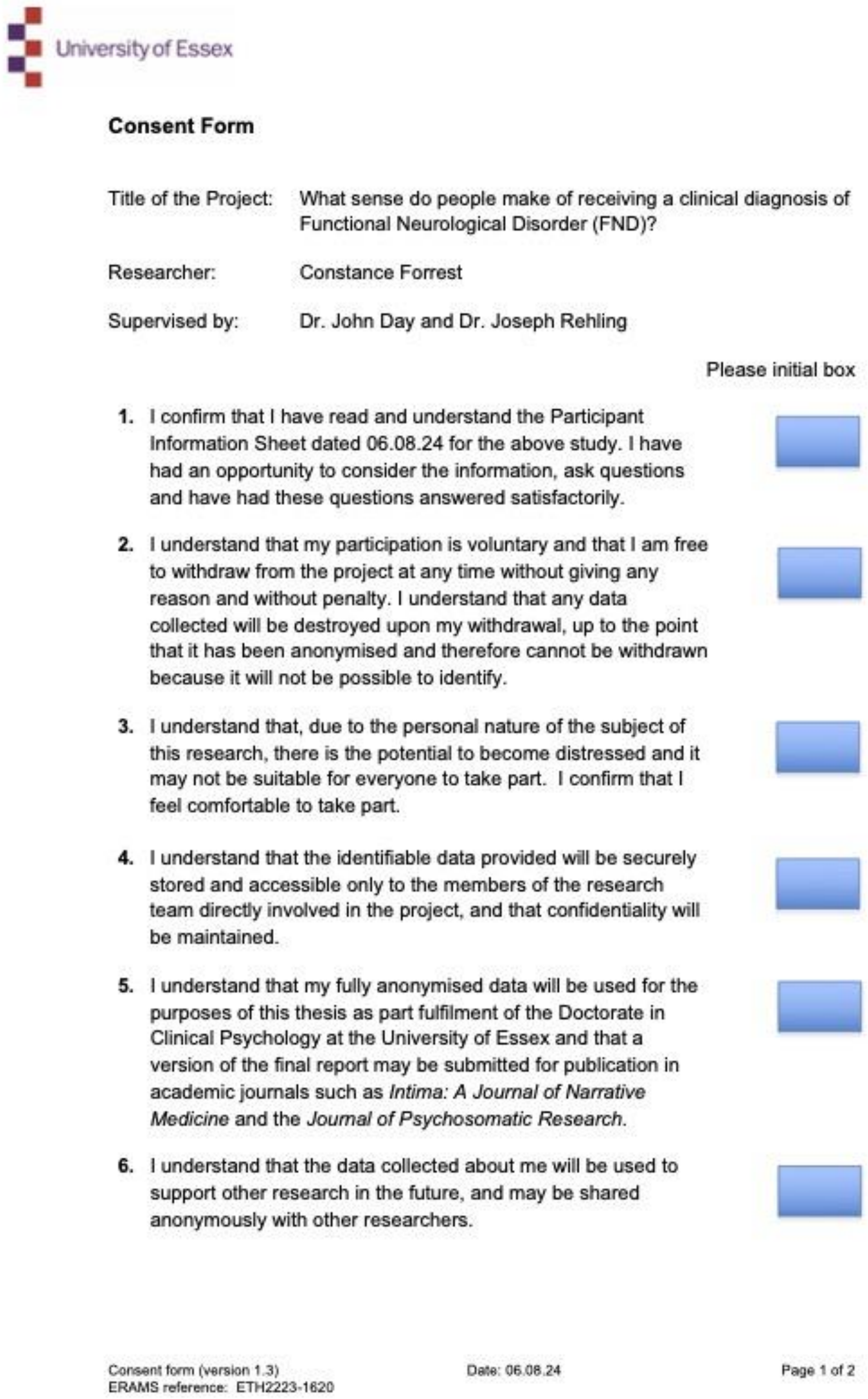
Please see **Participant Information Sheet** for the full details.

In May 2025, the researcher will share a summary of the project findings with all participants. This will be written in plain English and will include a discussion of the main themes uncovered and implications for FND patients in the UK.

*I no longer wish to take part...*

At this point, it will be impossible to identify your anonymized data, therefore it can no longer be deleted

# Appendix E: Consent Form



University of Essex

**Consent Form**

Title of the Project: What sense do people make of receiving a clinical diagnosis of Functional Neurological Disorder (FND)?

Researcher: Constance Forrest

Supervised by: Dr. John Day and Dr. Joseph Rehling

Please initial box

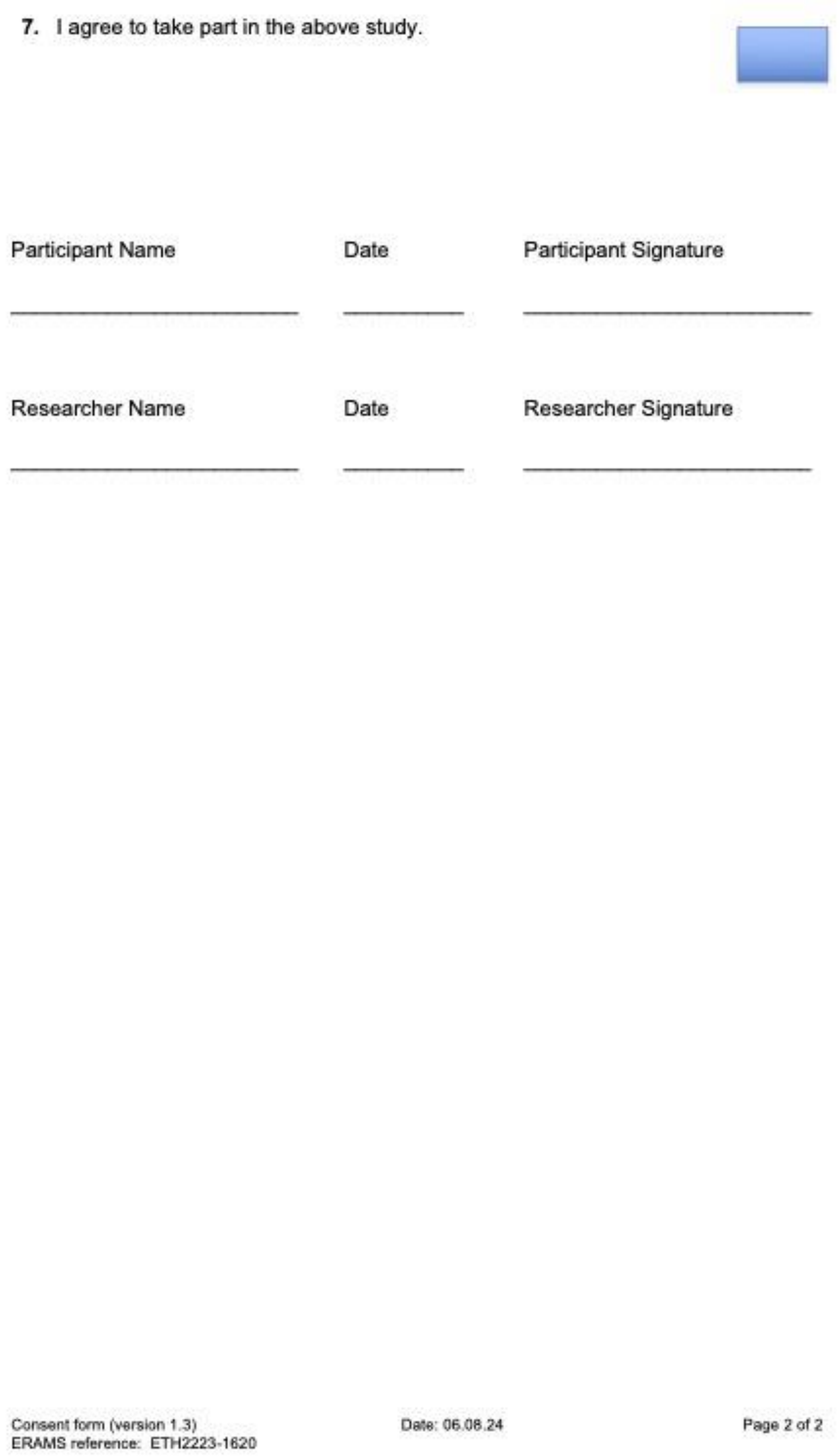
1. I confirm that I have read and understand the Participant Information Sheet dated 06.08.24 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty. I understand that any data collected will be destroyed upon my withdrawal, up to the point that it has been anonymised and therefore cannot be withdrawn because it will not be possible to identify. ☐
3. I understand that, due to the personal nature of the subject of this research, there is the potential to become distressed and it may not be suitable for everyone to take part. I confirm that I feel comfortable to take part. ☐
4. I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. ☐
5. I understand that my fully anonymised data will be used for the purposes of this thesis as part fulfilment of the Doctorate in Clinical Psychology at the University of Essex and that a version of the final report may be submitted for publication in academic journals such as *Intima: A Journal of Narrative Medicine* and the *Journal of Psychosomatic Research*. ☐
6. I understand that the data collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

Consent form (version 1.3)
ERAMS reference: ETH2223-1620

Date: 06.08.24

Page 1 of 2

# Appendix E: Consent Form (continued)



**7.** I agree to take part in the above study. ☐

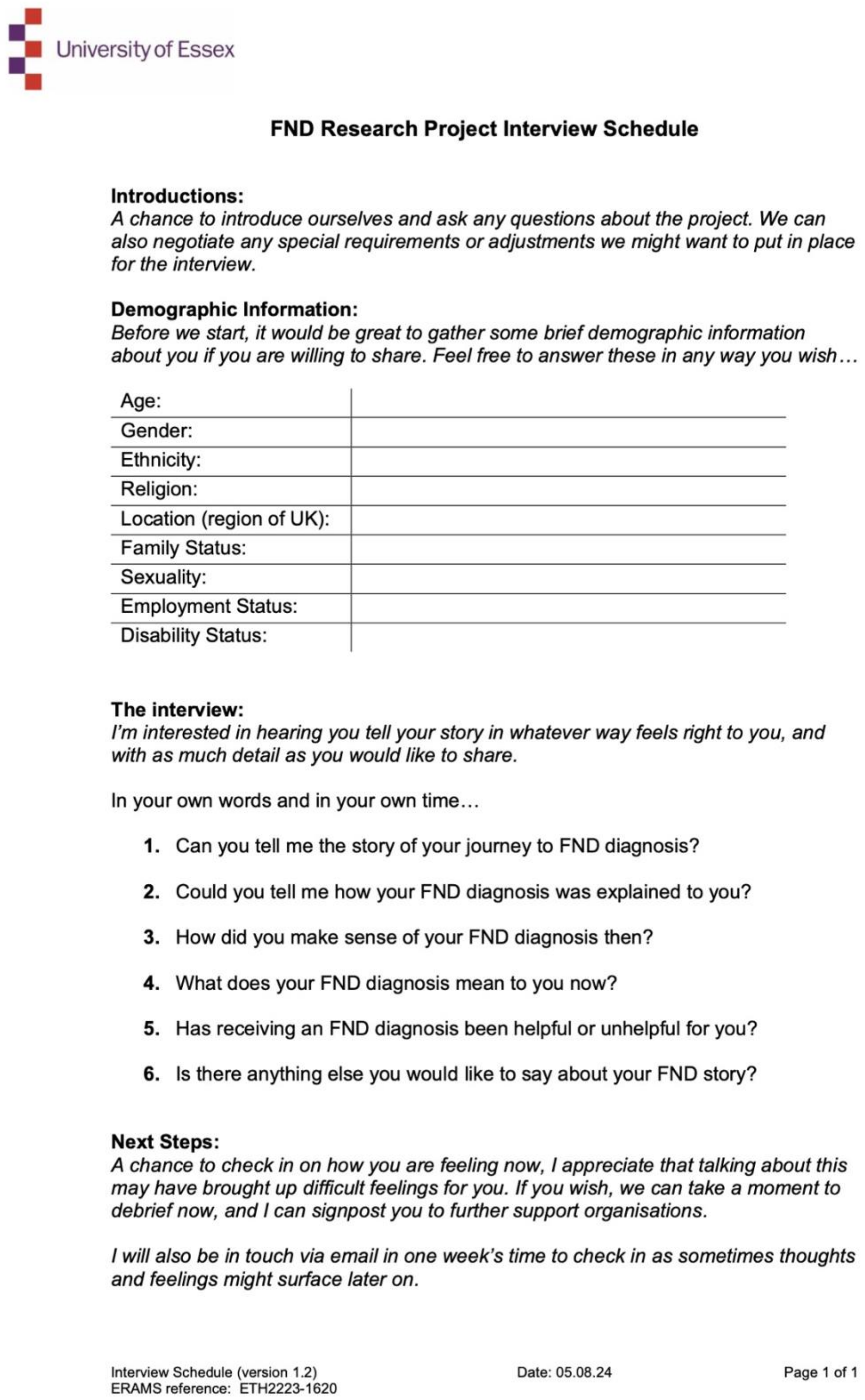
| | | |
|---|---|---|
| Participant Name | Date | Participant Signature |
| ______________________ | __________ | ______________________ |
| Researcher Name | Date | Researcher Signature |
| ______________________ | __________ | ______________________ |

Consent form (version 1.3)
ERAMS reference: ETH2223-1620

Date: 06.08.24

Page 2 of 2

# Appendix F: Interview Schedule



University of Essex

## FND Research Project Interview Schedule

**Introductions:**
*A chance to introduce ourselves and ask any questions about the project. We can also negotiate any special requirements or adjustments we might want to put in place for the interview.*

**Demographic Information:**
*Before we start, it would be great to gather some brief demographic information about you if you are willing to share. Feel free to answer these in any way you wish…*

| | |
|---|---|
| Age: | |
| Gender: | |
| Ethnicity: | |
| Religion: | |
| Location (region of UK): | |
| Family Status: | |
| Sexuality: | |
| Employment Status: | |
| Disability Status: | |

**The interview:**
*I'm interested in hearing you tell your story in whatever way feels right to you, and with as much detail as you would like to share.*

In your own words and in your own time…

1. Can you tell me the story of your journey to FND diagnosis?
2. Could you tell me how your FND diagnosis was explained to you?
3. How did you make sense of your FND diagnosis then?
4. What does your FND diagnosis mean to you now?
5. Has receiving an FND diagnosis been helpful or unhelpful for you?
6. Is there anything else you would like to say about your FND story?

**Next Steps:**
*A chance to check in on how you are feeling now, I appreciate that talking about this may have brought up difficult feelings for you. If you wish, we can take a moment to debrief now, and I can signpost you to further support organisations.*

*I will also be in touch via email in one week's time to check in as sometimes thoughts and feelings might surface later on.*

Interview Schedule (version 1.2) Date: 05.08.24 Page 1 of 1
ERAMS reference: ETH2223-1620

## Appendix G: Example Anonymised Transcript

### FND Interview – Angela

***Researcher: The way I would like to do it, is really just to hand it over to you. I have five-ish questions, but what I'm interested in is just hearing people's stories with as much detail as you're willing to share. So I'll kind of take a step back and just please just feel free to speak until you've run out of words. Please go off on as many tangents as you want to go off on. It's really, it's whatever comes to mind in terms of the question OK?***

***So the firstly in your own words and in your own time, could you tell me the story of your journey to FND diagnosis?***

Angela: OK. Yeah. It all started with a sore throat and a croaky voice and it was three years ago and uh I then developed a cough and just felt really, really tired and I thought I might have COVID because obviously that was a big thing at the time. I thought I might just be getting flu or something. I thought it could be an infection because I had like white spots sort of on my tonsils. I ended up getting some antibiotics because at the time it was all phone appointments because you couldn't see anybody and the antibiotics didn't make any difference. Not COVID I was clear of COVID and then I ended up getting stronger antibiotics and then that was when I just got horrendously tired, I could hardly keep my eyes open and my legs started to go, I was like 'Bambi on ice' was kind of a probably a good term. I was like falling down, I couldn't seem to stand up anymore.

So when I read the what do you call them? The the the things on the… er... I can't always think straight. The things that could go wrong if you're taking the medication. I can't remember what they're called, but anyway, them.

***Researcher: Side effects?***

Angela: That's the one, yeah. So it said if you had extreme fatigue or I think there was like muscle weakness or something or something, it said you know, like stop taking them and contact, you know, your GP immediately. So contacted the GP and they just said Oh well, just stop taking them then. And then after that I couldn't, I couldn't walk properly all the time. Sometimes my right leg was just giving way but and then as time went on it was happening more and more until the point where practically every step I took, I could walk and then I was sometimes falling down. All of the other symptoms were still the same. Then I started getting tremors and God knows what else.

So I ended up seeing or being referred for respiratory because I still have this horrendous cough and then, because my leg was giving way, eventually I got to see the actually got in to see the doctor and then I was referred for an MRI. She said that I'd probably need loads of physio. So I, I decided to try and get ahead of it, so made a private appointment with a physio to see if I could get, you know, tips on how to help things. And when he did an assessment, he said ‘I don't think there's anything to do with your knee’. He said, ‘there's something neurologically going wrong’. So as it turned out, though after my MRI scan on my knee, it turned out I had high knee caps so it was an abnormal MRI but when I went to see somebody about that who the doctor told me to go and see he said ‘no, he said it's just because you're hypermobile’ he said, ‘you know, it's just normal for you’, he said, ‘there is something neurologically going on’.

So then I needed an MRI of my brain and spine which turned out fine as well, apart from the usual stuff for my age. So, but obviously all of the while I was kind of Googling as you do and I think I was quite unusual because I actually came across FND when I was Googling and I was, I thought I think I've got that because everything made so much sense because it didn't make sense that there was so many different things going wrong with me all at the same time whereas FND seemed to make sense for all of it. So I mentioned it to my GP and I said, oh, I think I've got, I think I might have FND. She said that she didn't know anything about it. But anyway because the musculoskeletal person had said that it was neurological I was obviously then referred to a neurologist but I think when I got the appointment through, it was gonna be for about nine months’ time and everything had already been going on for like God knows how long so again, I thought right, I'm going to go private to get the diagnosis and then get back for NHS to get some treatment so I paid privately and the neurologist said ‘yes you have got FND’ and he said that you could take, there was a tablet he was, he said, that he would recommend that might help, but it might not. And he said there's no treatment in in this area for it though, CBT, he said, might help with your anxiety and good luck with it, that was it. Good luck with it.

So I paid over £200, for somebody to give me the official yes, that's what you've got, and that was it. I was just left to get on with it, my GP wouldn't prescribe the medication that he'd suggested because she said it's for people with bipolar or epilepsy and she said you've got neither of those. So I'd, she said, a psychiatrist or somebody like that would have to prescribe, I think, was it called lamotrigine, iamotrigine or something? I don't know. And anyway, when I'd googled that, it didn't seem to be a a thing that would normally be for it because there isn't really medication for FND so I was basically just left. I asked my GP whether I could have physio or, go see a speech therapist to try and get my voice back to normal and basically, she said no and she said I needed a multidisciplinary team but she said, you know, I'll have to see if there's a, multidisciplinary team, the neurologist has already told me there wasn't one and basically, I just never ever heard from her again and I was just left and my walking and fatigue, everything was just getting worse and worse, so I ended up getting OK, social services and I've got like a shower stool and a mobility walker thing. Since then, moved on to a wheelchair for when I'm outside because I was just never getting out at all. I had to surrender my driving licence because of my eyes. Umm, so yeah, it's just been… a bit of a journey really.

***Researcher: Definitely, yeah. And thank you for sharing that, and as you say, you maybe are a little bit unusual because my next question was going to be about how your FND diagnosis was explained to you, but it sounds like maybe you were the one suggesting it to the medical professionals?***

Angela: Yeah, yeah. From what I've gathered for all of all of the people I've spoken to with FND, most of them, had never, ever heard of it and didn't have a clue and didn't necessarily even believe, you know that that it was a thing. But yeah, because I'd, I don't know whether part of it was because of the job that I did, and I've done degrees so I can feel I was used to sort of research and stuff. So yeah, I'm very unusual. I think in that I actually figured out what it was for myself because nobody else seemed to bother really

***Researcher: And then, so I suppose when you did meet with this neurologist who confirmed it for you. It sounds like the way they explained the treatment options and things like that didn't quite make sense to you. Could you tell me a bit more about that process of them confirming and how it was explained?***

Angela: Yeah, it was a lot. To be honest, I I was, I was distraught when I I kind of held it together while I was in there, but when I got back outside, I was literally in tears and I couldn't stop crying for so long because I thought, well, what do you mean there's no treatment like because I knew that psycho, psychotherapy and neuropsychology and neuro-physio and were things that could help and it was just and yeah, I I just thought, well, hang on, what do you mean none in this area? Why? Why isn't there anything? And well, can't I go somewhere else? Can't you do anything and… So yeah, I just found the whole the whole thing really rubbish because I thought so basically I'm now I kind of felt as if I was no further forward other than the fact that I had the official diagnosis and my doctor never, ever got back to me so, and then the next time I did actually speak to her. I was like, oh, well, you know it it's surely - is there nothing that you can do then? She said oh, oh, well, well, no. It's like oh, ok, wow.

***Researcher: Mm hmm.***

Angela: So yeah, it was just a bit, in a way, disbelief and just, and I did feel quite, quite down about everything really because I thought well you know, you basically just left to get on with it, and there's such a stigma around it as well, because some people don't believe it's a thing or believe it's just in your head.

***Researcher: When you were researching and you came across it, and it chimed with you that the FND was what you probably had. How did you make sense of it as a diagnosis, how did you make sense of FND?***

Angela: The, the general thing I kind of got was that all that the most common thing to be described was that, it was like the hardware's fine, but the software's gone a bit wrong and obviously, since then, the more I've like looked and the more I've learnt about it, it's I think it's more like a brain network disorder, so that you, it's to it kind of messes up your self agency and the emotional control or something and from what I've gathered, it's kind of yeah, your brain predicts, predicts everything and basically it's it's predicting the wrong thing and there's a lot of different factors that kind of make it go wrong and keep it going wrong. I did actually look at the there's you can be have predisposing factors or things and when I read, when I read those, it was like Oh yeah. So being hypermobile, having anxiety or depression before, having trauma, and I can't remember some of them - or being, being a bit of a perfectionist. So yeah, it was as I was reading it was a bit like, oh, well, yeah, that's me.

***Researcher: Mm hmm.***

Angela: But umm, I I think one of one of the good ways that somebody described it was that if you imagine a train on a track and if the train has come off the rails slightly? And then the more the more time it's got to be off the rails, the more it digs in so it's harder to drag it, to be able to get it back on the track again, and so yeah, I think I think I understand it quite well how it works but I know that it should be possible with neuroplasticity and everything to kind of retrain my brain to get it things back.

***Researcher: Mhmm.***

Angela: But not yet. As yet I haven't been able to.

***Researcher: This sounds like you've been on quite a journey of research since first hearing about it to where you are now with your understanding of it. What does it mean to you now?***

Angela: Partly I think, probably I think I'm used to it now. Obviously it's been three years, I think I grieved for a very long time because, you know, I had to give up my car, can't drive. Had to, you know, give up my job. I've now retired. I haven't left the house on my own for two years. So if my like if [redacted] isn't here to take me somewhere, well, I'm just in the house but and I think I've I've found it very, very hard, I was, I was actually a very, very fit person. I used to exercise. I used to go for like two or three mile walk every day. I walked fast everywhere, we played tennis, we, you know, I did all this sport and everything whereas now I struggle to do stuff just because of the fatigue. But I'd say I'm kind of, I'm kind of more accepting of just, well, this is how it is and I am trying to obviously improve. I actually joined something in America, and they seem to know what they're doing. I and obviously I'm learning a lot from from that as well because we get like FND education sort of like classes every week so I'm learning more and more. I'm currently like playing with a a soft toy because it's turns out that I've got a sensory needs which I never realised before and that kind of can help so I'm learning more and more things that can regulate my nervous system. Obviously it helps sometimes, but it's still, you know, I'm still, I still can't walk outside, I still, you know, my eyes still shuts and just so yeah, but I think I'm just more used to it now. It kind of it is what it is and I try and get on with life as best I can and try and do things that I enjoy still but obviously you know it's it's totally a change from how I used to live my life and I'll just live it in a different way.

***Researcher: Thank you. Do you think that receiving the FND diagnosis has that been helpful or unhelpful for you?***

Angela: I think it's helpful because at least I know that's what it is and if anyone ever asks you know, like what's wrong with you? And I can say, well, I've got this but on the other hand, because most people have never heard of it, it's like what? So, to be honest, I I often just say actually I've got a neurological condition, I don't, I don't often say that I've got FND because it's more complicated to explain it, and some people think that FND is a made-up thing and it's all in your head which is really annoying. And that, yeah I mean, I'm not really on social media a lot, but you know, yeah, that there are a lot of horrible people on there that say so much awful things about, you know, FND that you know, it's just made up, it's just it's not really a, it's not a real diagnosis, It's just, you know, it's just a made-up thing that people say to make people think that they've got something wrong with them and, and obviously I try to ignore all that because I just think, well, you know, you know, now shut up, because they've proved with FMRI's and you know different things that it is actually a real thing.

***Researcher: Mm hmm. Why do you think that is? And I think you used the word stigma earlier as well. I'm wondering, why do you think there is so much doubt or stigma around FND?***

Angela: The only thing I can think of is that very originally it it used to be called hysteria and conversion disorder and all people just think you know, it's it's just psychological, there's… You know, yeah, you've, you've had a trauma or something and it's it's just a mental thing that you're, that you're you're kind of, you know, are faking it and I think because some of the symptoms don't happen all the time, so like one minute you could look or sound fine but then another minute you know you can't walk or you you know, have spasms or different things. I think people can find it hard to believe. Well, well, you're all right a minute ago so why aren't? Why aren't you like that now? They think that if you've got something wrong with you, it's got to be all the time. Umm, so I think I think that's possibly one of the reasons and just the fact that nobody, nobody's heard of it, so nobody talks about it.

***Researcher: Yeah, it's still quite unknown, isn't it? You mentioned there one of the original understandings or theories was around a trauma and then a conversion into these symptoms. And I suppose before you said that when you'd read the predisposing factors that had been something that had maybe chime with you. Going into or as much detail as you want to, which is to say that you don't have to share your trauma with me at all, but I'm just wondering to what extent that theory kind of made sense to you or fitted with what with your experience or not?***

Angela: Some of it did a little bit because like, I think one of the biggest things it was on about, like, sexual abuse and all of that, that didn't happen. No, there's nothing like that and I was never beaten up as a child or anything but I was, I was often picked on at school and, and then I did have as an adult, I had a couple of relationships that were, you know, slightly abusive. And just, just think like I was once at a friend's house and her partner kind of went off on it and, you know, smashed up the house and started basically throwing her around like a rag doll. And I was just like Jesus. So just some things that have just happened and even I don't know like, you know, friendships that have gone wrong or not like so… not kind of… some things weren't trauma as in physical, but even, I don't know, like things that just going wrong or you know, like moving house a couple of times. It's like stressed, stressful event. So and when I thought about it, it was kind of, well, there have been quite a lot of stressful events in my life. I was very, very stressed at work actually, when when it all started and [redacted] was buying a house and we were going to move in together and so although that was a good a good, that part of it was a good stress. It was still added stress but I say work, I I think work was horrifically stressful and and I I kind of think that was like the final, the final straw really.

***Researcher: Mm hmm mm hmm. So yeah for you that theory that that, yeah, that life, stressful events can contribute towards it, that kind of rings true? Yeah. OK. Interesting.***

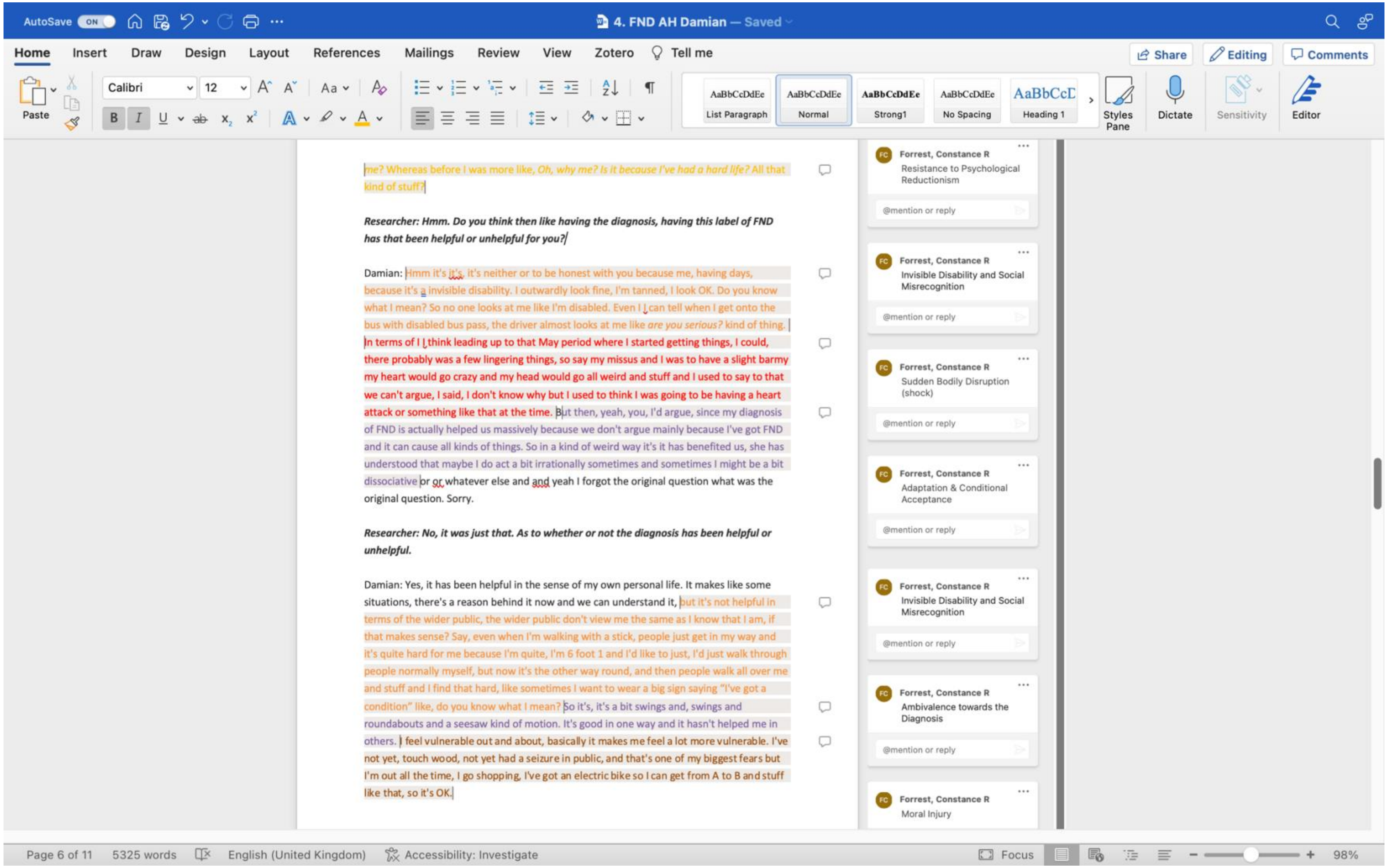
Angela: Hmm yeah.

***Researcher: Alright thank you, I think that's pretty much all of my main questions. I suppose the last one is just like, is there anything else you would want to share about your FND story or how it's impacted you?***

Angela: I think I just wish more people knew that it is a real thing. We're not making it up and it really does impact every aspect of your life. Umm, because even like emotionally, I can laugh for no reason whatsoever, cry just for no reason, cry when I should be laughing, laugh when I should be crying. Just, I don't think there's any area of my life that hasn't actually been impacted by it and it's just such, it's such a hard thing to deal with anyway. What, without kind of most of the world not having a clue or not believing what it is. I think and I just and it's really really annoying that there aren't more treatment options no matter where you live. That there just should be. There should be something.

***Researcher: Absolutely. Well, thank you very much for sharing that.***

# Appendix H: Example of Thematic Coding and Data Analysis



me? Whereas before I was more like, *Oh, why me? Is it because I've had a hard life?* All that kind of stuff?

***Researcher: Hmm. Do you think then like having the diagnosis, having this label of FND has that been helpful or unhelpful for you?***

Damian: Hmm it's it's, it's neither or to be honest with you because me, having days, because it's a invisible disability. I outwardly look fine, I'm tanned, I look OK. Do you know what I mean? So no one looks at me like I'm disabled. Even I I can tell when I get onto the bus with disabled bus pass, the driver almost looks at me like *are you serious?* kind of thing. In terms of I I think leading up to that May period where I started getting things, I could, there probably was a few lingering things, so say my missus and I was to have a slight barmy my heart would go crazy and my head would go all weird and stuff and I used to say to that we can't argue, I said, I don't know why but I used to think I was going to be having a heart attack or something like that at the time. But then, yeah, you, I'd argue, since my diagnosis of FND is actually helped us massively because we don't argue mainly because I've got FND and it can cause all kinds of things. So in a kind of weird way it's it has benefited us, she has understood that maybe I do act a bit irrationally sometimes and sometimes I might be a bit dissociative or or whatever else and and yeah I forgot the original question what was the original question. Sorry.

***Researcher: No, it was just that. As to whether or not the diagnosis has been helpful or unhelpful.***

Damian: Yes, it has been helpful in the sense of my own personal life. It makes like some situations, there's a reason behind it now and we can understand it, but it's not helpful in terms of the wider public, the wider public don't view me the same as I know that I am, if that makes sense? Say, even when I'm walking with a stick, people just get in my way and it's quite hard for me because I'm quite, I'm 6 foot 1 and I'd like to just, I'd just walk through people normally myself, but now it's the other way round, and then people walk all over me and stuff and I find that hard, like sometimes I want to wear a big sign saying "I've got a condition" like, do you know what I mean? So it's, it's a bit swings and, swings and roundabouts and a seesaw kind of motion. It's good in one way and it hasn't helped me in others. I feel vulnerable out and about, basically it makes me feel a lot more vulnerable. I've not yet, touch wood, not yet had a seizure in public, and that's one of my biggest fears but I'm out all the time, I go shopping, I've got an electric bike so I can get from A to B and stuff like that, so it's OK.

**Forrest, Constance R**
Resistance to Psychological Reductionism
@mention or reply

**Forrest, Constance R**
Invisible Disability and Social Misrecognition
@mention or reply

**Forrest, Constance R**
Sudden Bodily Disruption (shock)
@mention or reply

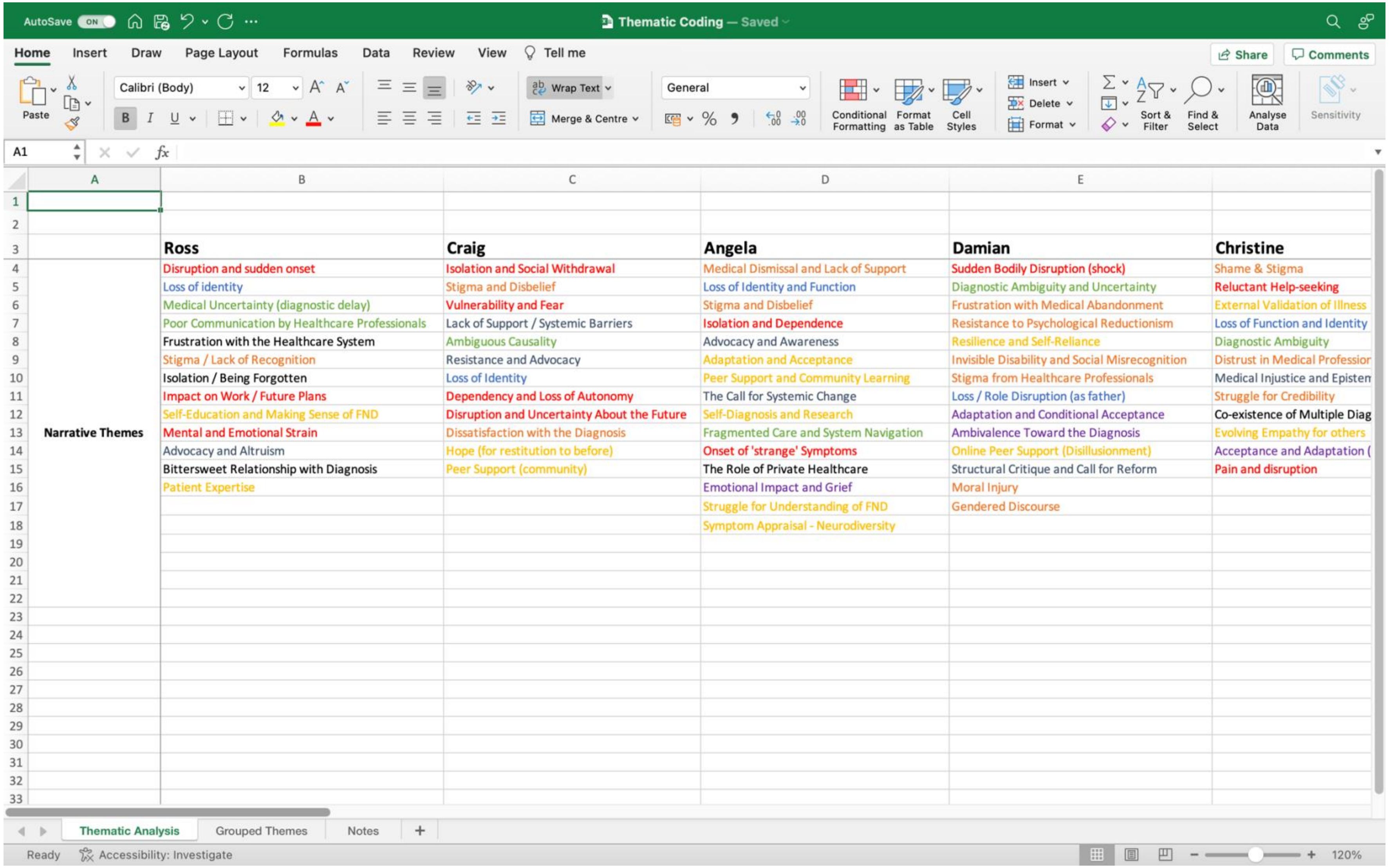
**Forrest, Constance R**
Adaptation & Conditional Acceptance
@mention or reply

**Forrest, Constance R**
Invisible Disability and Social Misrecognition
@mention or reply

**Forrest, Constance R**
Ambivalence towards the Diagnosis
@mention or reply

**Forrest, Constance R**
Moral Injury

## Appendix H: Example of Thematic Coding and Data Analysis (continued)



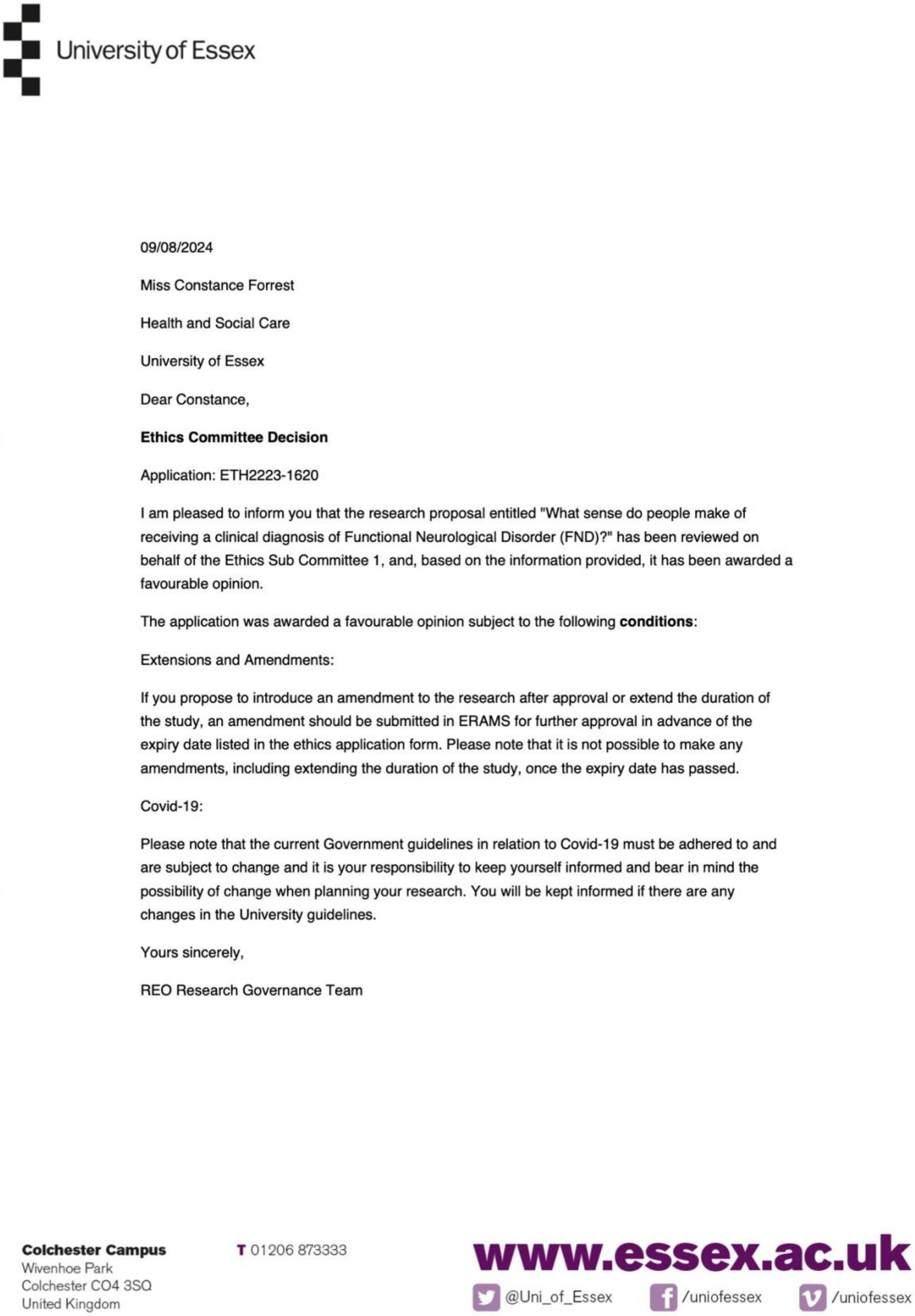
| | Ross | Craig | Angela | Damian | Christine |
|---|---|---|---|---|---|
| **Narrative Themes** | Disruption and sudden onset | Isolation and Social Withdrawal | Medical Dismissal and Lack of Support | Sudden Bodily Disruption (shock) | Shame & Stigma |
| | Loss of identity | Stigma and Disbelief | Loss of Identity and Function | Diagnostic Ambiguity and Uncertainty | Reluctant Help-seeking |
| | Medical Uncertainty (diagnostic delay) | Vulnerability and Fear | Stigma and Disbelief | Frustration with Medical Abandonment | External Validation of Illness |
| | Poor Communication by Healthcare Professionals | Lack of Support / Systemic Barriers | Isolation and Dependence | Resistance to Psychological Reductionism | Loss of Function and Identity |
| | Frustration with the Healthcare System | Ambiguous Causality | Advocacy and Awareness | Resilience and Self-Reliance | Diagnostic Ambiguity |
| | Stigma / Lack of Recognition | Resistance and Advocacy | Adaptation and Acceptance | Invisible Disability and Social Misrecognition | Distrust in Medical Professio |
| | Isolation / Being Forgotten | Loss of Identity | Peer Support and Community Learning | Stigma from Healthcare Professionals | Medical Injustice and Episte |
| | Impact on Work / Future Plans | Dependency and Loss of Autonomy | The Call for Systemic Change | Loss / Role Disruption (as father) | Struggle for Credibility |
| | Self-Education and Making Sense of FND | Disruption and Uncertainty About the Future | Self-Diagnosis and Research | Adaptation and Conditional Acceptance | Co-existence of Multiple Diag |
| | Mental and Emotional Strain | Dissatisfaction with the Diagnosis | Fragmented Care and System Navigation | Ambivalence Toward the Diagnosis | Evolving Empathy for others |
| | Advocacy and Altruism | Hope (for restitution to before) | Onset of 'strange' Symptoms | Online Peer Support (Disillusionment) | Acceptance and Adaptation ( |
| | Bittersweet Relationship with Diagnosis | Peer Support (community) | The Role of Private Healthcare | Structural Critique and Call for Reform | Pain and disruption |
| | Patient Expertise | | Emotional Impact and Grief | Moral Injury | |
| | | | Struggle for Understanding of FND | Gendered Discourse | |
| | | | Symptom Appraisal - Neurodiversity | | |

## Appendix I: Example Performative Narrative Analysis

Christine – Biographical Disruption

| | |
|---|---|
| I was like, really struggling to work, to have energy, getting odd sensations and then I was at work, working for this lady who I had worked for, for a few years. She went on holiday and then she come back and then she said, *'I've got to speak to you'* and she says, *'your face has changed and we think you should see a doctor'*. She *says, 'your face has dropped since last saw you',* which was an odd – she says, *'I want you to go and see your doctor and I'll go with you and I'll explain'*. But I didn't, | **Scene 1**<br>direct speech<br>repetition<br>direct speech |
| I thought I just I was losing weight, so I thought it's me weight that's changed my face and | **Aside** |
| then I was at the dentist and I mentioned, just a check-up, and I mentioned I was noticing I was lisping and I thought it must be an age thing, or maybe with age your teeth move. And he says, *'I think you should see your doctor'*. But I didn't, but the next week he phoned us up and he said, *'have you seen your doctor?'* | **Scene 2**<br>direct speech<br>repetition<br>direct speech |
| Which I thought was really odd, your dentist phoning you up. And I says no, | **Aside** |
| but I made an appointment so I saw me doctor and I said I was feeling… me body wasn't working properly and basically my hands; it's mostly my hands and my brain but my hands weren't doing what I wanted them to do. | **Scene 3**<br>repetition |
| It's like you know, the, it's like my hands are you know, your hands are really cold and you can't do a zip or you can't do laces, you lose your… your dexterity? So, I've lost me dexterity in my hands, so she made me an appointment to see a neurologist. | **Aside**<br>repetition |
| And then I went to work one day and just me body just wouldn't, it just got too, too hard to work. So, I just told the lady *'I've got, I can't do anymore'*. And I got in the car and I drove home. Luckily, it's an automatic and I didn't have the power in my hands and me legs to drive safely but we live very rural area so | **Scene 4**<br>direct speech |
| I got home and I told my husband *'I cannot work anymore'*. And I don't drive anymore. | **Coda**<br>direct speech |

# Appendix J: Ethical Approval



University of Essex

09/08/2024

Miss Constance Forrest

Health and Social Care

University of Essex

Dear Constance,

**Ethics Committee Decision**

Application: ETH2223-1620

I am pleased to inform you that the research proposal entitled "What sense do people make of receiving a clinical diagnosis of Functional Neurological Disorder (FND)?" has been reviewed on behalf of the Ethics Sub Committee 1, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

REO Research Governance Team

**Colchester Campus**
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

**T** 01206 873333

www.essex.ac.uk
@Uni_of_Essex
/uniofessex
/uniofessex