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# Exploring Illness Perceptions, Quality of Life, and Experiences of Acceptance and Commitment Therapy Among People with Functional Neurological Disorder

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Submitted in partial fulfilment of the requirements for the degree of  
Doctorate in Clinical Psychology

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## Contents

|                                                                |          |
|----------------------------------------------------------------|----------|
| <b>List of Tables.....</b>                                     | <b>3</b> |
| <b>List of Figures.....</b>                                    | <b>3</b> |
| <b>Acknowledgements.....</b>                                   | <b>4</b> |
| <b>Chapter 1: Systematic Review</b>                            |          |
| Abstract.....                                                  | 6        |
| 1. Introduction.....                                           | 7        |
| 2. Methods.....                                                | 10       |
| 3. Results.....                                                | 15       |
| 4. Discussion.....                                             | 25       |
| 5. References.....                                             | 31       |
| <b>Chapter 2: Major Research Project</b>                       |          |
| Plain language summary.....                                    | 40       |
| Abstract.....                                                  | 41       |
| 1. Introduction.....                                           | 42       |
| 2. Methods.....                                                | 45       |
| 3. Results.....                                                | 51       |
| 4. Discussion.....                                             | 61       |
| 5. References.....                                             | 67       |
| <b>Appendices</b>                                              |          |
| 1.1. PRISMA 2020 Statement .....                               | 72       |
| 1.2. Search terms, search strings, and search sensitivity..... | 75       |
| 1.3. Risk of bias assessment.....                              | 83       |
| 1.4. Data extraction form.....                                 | 87       |
| 2.1. COREQ.....                                                | 88       |
| 2.2. 15-point quality checklist for thematic analysis.....     | 91       |
| 2.3. Approval letters (Wales REC & NHS R&D).....               | 94       |
| 2.4. Intervention description and protocol.....                | 100      |
| 2.5. Study documents.....                                      | 102      |
| 2.6. Interview schedule.....                                   | 102      |
| 2.7. Record of analysis.....                                   | 103      |
| 2.8. Information power framework.....                          | 119      |
| 2.9. Approved MRP proposal and subsequent versions .....       | 120      |
| 2.10. Data analysis plan.....                                  | 120      |
| 2.11. Data availability statement.....                         | 120      |

## List of Tables

### Chapter 1: Systematic Review

|                                            |    |
|--------------------------------------------|----|
| Table 1: Overview of selected studies..... | 18 |
|--------------------------------------------|----|

|                                                          |    |
|----------------------------------------------------------|----|
| Table 2.: Associations reported in selected studies..... | 20 |
|----------------------------------------------------------|----|

### Chapter 2: Major Research Project

|                                       |    |
|---------------------------------------|----|
| Table 1: Participant information..... | 47 |
|---------------------------------------|----|

|                                     |    |
|-------------------------------------|----|
| Table 2: Themes and sub-themes..... | 51 |
|-------------------------------------|----|

## List of Figures

### Chapter 1: Systematic Review

|                                    |    |
|------------------------------------|----|
| Figure 1: PRISMA Flow Diagram..... | 15 |
|------------------------------------|----|

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## **Chapter One: Systematic Review**

A Systematic Review of Illness Perceptions and Quality of Life Among People  
with Functional Neurological Disorder

Prepared in accordance with the author requirements for *Psychology &  
Health*

[Author Guidelines](#)

## Abstract

**Title:** A Systematic Review of Illness Perceptions and Quality of Life Among People with Functional Neurological Disorder.

**Background:** Specialist interventions for functional neurological disorder (FND) require further development, particularly regarding how quality of life (QoL) can be enhanced. Illness perceptions are associated with QoL across a range of physical health conditions and may influence clinical outcomes, but it remains unclear whether this extends to FND. This systematic review examined the relationship between illness perceptions and QoL among people with FND.

**Methods:** Eligible studies were English-language primary quantitative studies, published in peer-reviewed journals or identified as unpublished research from 1980 onwards, involving adults aged 16 years or older and exploring associations between illness perceptions and QoL. Search terms associated with FND were informed by Raynor and Baslet's (2021) historical overview of terminology. PubMed, CINAHL, and PsycINFO were searched to November 2025, with backward and forward searches completed to May 2026. Following screening and data extraction, studies were appraised using Joanna Briggs Institute (JBI) critical appraisal tools. A narrative synthesis was conducted.

**Results:** Of 10,250 records retrieved, five UK specialist-service studies involving 420 participants met eligibility criteria; study designs and FND populations varied. Four studies were rated as having a high risk of bias and one as having a moderate risk of bias for the review question. Greater perceived illness threat was tentatively suggested to be associated with poorer QoL. Emotional representations showed the most consistent negative associations, whereas findings for other illness perception domains were weaker or inconsistent.

**Discussion:** Findings should be interpreted cautiously because of the limited number of eligible studies and the methodological limitations of the included studies, but they suggest that routine assessment of illness perceptions may help inform interventions for FND.

**Registration and funding:** Registered with PROSPERO (CRD420251122454). Completed as part of an NHS Education for Scotland-funded Doctorate in Clinical Psychology; no specific project funding was received.

## 1. Introduction

Functional neurological disorder (FND) is a condition where individuals experience neurological symptoms, which are associated with altered brain functioning rather than structural disorder (National Institute for Health and Care Excellence, 2024). These symptoms can affect motor, sensory, cognitive, and perceptual systems. Accordingly, FND can present with a wide range of symptoms, including limb weakness, seizure-like episodes, visual disturbance, sensory changes, gait abnormalities, and cognitive difficulties such as impaired attention (Hallett et al., 2022). Until recently, FND was typically identified through a diagnosis of exclusion, made only once alternative medical explanations had been eliminated (Aybek & Perez, 2022). This approach frequently led to delayed diagnosis, excessive investigations, and heightened uncertainty for patients and clinicians. It also contributed to stigma surrounding FND, including experiences of symptom minimisation, inequitable treatment access, fragmented care, and alienating diagnostic processes (McLoughlin et al., 2024). Recent National Neurosciences Advisory Group (NNAG, 2023) and Centre for Sustainable Delivery (CSD, 2023) guidance therefore represents an important response to historically problematic practice, providing frameworks for specialist multidisciplinary FND care, including psychological input, to reduce stigma and service inefficiency. However, specialist service provision remains highly variable across the UK (British Psychological Society, 2024), partly reflecting the historical absence of national frameworks and shortages of specialist clinicians. Although emerging FND-specific interventions show promise, trials have shown inconsistent improvements in quality of life (QoL; Goldstein et al., 2020; Nielsen et al., 2024), a priority clinical outcome for people with FND (Rutten et al., 2025). Understanding how QoL can be enhanced consistently therefore remains a key research gap with implications for clinical pathways.

QoL is a multifaceted construct. It refers to people's perception of their position in life within their cultural context and value systems and is influenced by physical and psychological health (World Health Organization, 1998). It is typically operationalised across domains including physical and psychological health, autonomy, relationships, beliefs, and occupation (Pequeno et al., 2020). The 36-item Short-Form Health Survey (SF-36; Ware and Sherbourne, 1992) and EuroQol five-dimension, five-level questionnaire (EQ-5D-5L; Herdman et al., 2011; see also Devlin and Brooks, 2017) are among the most frequently

used QoL measures (Pequeno et al., 2020). Although these instruments overlap, the SF-36 provides broader domain coverage, assessing physical functioning; bodily pain, role limitations related to physical and emotional problems, general health perceptions, vitality, social functioning, and mental health. By contrast, the EQ-5D-5L excludes direct equivalents for general health perceptions or vitality and captures social functioning and role limitations indirectly through its usual activities domain. Both measures have been used to examine associations between QoL and variables suggested to influence QoL, including illness perceptions, which are increasingly recognised as relevant in FND (e.g. Dempster et al., 2015; Foxwell et al., 2013; Joos et al., 2024).

Illness perceptions refer to beliefs about a health condition that shape how people interpret symptoms and manage illness. Within the Common-Sense Model of Self-Regulation (CSM), Leventhal and colleagues (1980) proposed that responses to health threats are guided not by medical information alone, but by personal illness representations formed through experience, appraisal, and the perceived outcomes of attempts to manage illness (Leventhal et al., 1992). These representations comprise five core illness representation domains: identity, timeline, consequences, causes, and control/cure. They are dynamic, such that coping responses and their perceived outcomes can reinforce or revise how the illness is understood over time. Later developments have elaborated how illness representations are maintained and updated (Leventhal et al., 2016; Hagger & Orbell, 2022). The Illness Perception Questionnaire (IPQ; Weinman et al., 1996), Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002), and Brief Illness Perception Questionnaire (BIPQ; Broadbent et al., 2006) operationalise the CSM and, like the SF-36 and EQ-5D-5L, have been widely used to explore relationships with QoL.

Examining relationships between illness perceptions and quality of life in a range of health conditions, Dempster et al. (2015) systematically reviewed 26 studies involving e.g. alopecia, cancer, irritable bowel disease, Parkinson's, Huntington's disease, epilepsy, arthritis, and psoriasis. They reported that perceived consequences and emotional representations of illness were consistently associated with QoL, as well as with depression and anxiety, such that more threatening perceptions were associated with poorer mental health outcomes and quality-of-life outcomes. However, their findings require caution. Their quality appraisal focused narrowly on external validity and did not meet PRISMA 2020

reporting standards (Page et al., 2021). Additionally, measures of mood and anxiety may overlap with emotional representations (Broadbent et al., 2015). Nevertheless, their results align with recent systematic reviews focusing on multiple sclerosis (Luca et al., 2022) and epilepsy (Rizou et al., 2025), which also reported associations between illness perceptions and QoL. Both reviews excluded patients with FND, therefore, it remains unclear whether the findings generalise to an FND population. Emerging evidence suggests that illness perceptions may differ in individuals with FND. Joos et al. (2024) compared patients with FND to patients recovering from stroke and those with psychosomatic disorders. They reported that patients with FND typically display lower illness coherence and lower confidence in personal and treatment control by comparison. A further review would help clarify how illness perceptions relate to quality of life and help services better tailor care to the needs of patients with FND.

To the best of our knowledge, no systematic review has explored the relationship between illness perceptions and quality of life in people with FND so far. The aim of the current systematic review is therefore to synthesise and appraise the available evidence regarding the relationship between illness perceptions, as defined by Leventhal et al. (1980; 1992; 2016), and quality of life among people with FND.

## **2. Method**

This review was registered on Prospero (record CRD420251122454). The Population, Exposure, and Outcome (PEO) framework (Moola et al., 2015) was used to structure the systematic literature search and to define eligibility criteria. The review was originally designed with the intention of conducting a meta-analysis. Rayyan, a software platform for systematic reviews, was used to provide a contained workspace for title and abstract screening, full-text screening, and data extraction and to assist with duplicate identification; automated tools were not used to make eligibility decisions. Rayyan's filtering functions were also used to assist in identifying records that clearly did not meet eligibility criteria, such as animal and non-English language studies, which were subsequently reviewed by the first reviewer before exclusion. The first reviewer screened all titles and abstracts after duplicate removal and re-screened a random 20% sample of titles and abstracts after duplicate removal to enhance methodological rigour. A second reviewer independently screened a random 20% sample of titles and abstracts after duplicate removal and completed data extraction and critical appraisal for all included studies. Full-text screening was completed by the first reviewer.

### **2.1. Eligibility Criteria**

To be included in this review, papers were required to meet the following criteria:

- Written in the English language and sampling adults (16 years or older). The definition of adult was based on the Mental Capacity Act (Mental Capacity Act, 2005), which informs operating procedures of UK research committees and health services (British Psychological Society, 2021).
- Published (peer reviewed journals) or unpublished research (e.g. student thesis).
- Primary research with a quantitative design.
- Reported association between illness perceptions and QoL (this was not required to be the primary research focus of the selected papers).
- Illness perceptions were conceptualised in line with the CSM (Leventhal et al., 1980;1992; 2016; Hagger & Orbell, 2022) and the construct of QoL was defined in line with Devlin and Brooks (2017) and Ware and Sherbourne (1992).
- Published from 1980 onwards, as this was year of CSM's first publication.

- Studies using terminology associated with FND were included. Terminology varied according to publication date, as earlier studies may have referred to FND using alternative terms.

## 2.2. Search Strategy

Databases used to identify suitable studies were CINAHL, PsycInfo and PubMed. They were last searched in November 2025, with supplementary searching completed in May 2026. This involved backward citation searching of included papers' reference lists and forward citation searching using ResearchRabbit (Cole & Boutet, 2023), a citation-based literature discovery tool. No additional eligible studies were identified through supplementary searching. The academic supervisor and a librarian from the University of Glasgow were consulted regarding the search strategy. The search terms related to FND, illness perceptions and QoL. FND-related search terms were informed by a historical overview of terminology used to describe the condition (see Raynor & Baslet, 2021). Boolean operators were used for searching, with the synonyms for each concept combined with "OR" and concepts combined with "AND". Proximity and asterisk operators were also applied. Subject headings were adapted for each database. Examples of the full search performed is presented in Appendix 1.2. The following keyword search terms were used:

- "functional neurological disorder\*" OR "fnd" OR "functional neurological symptom\*" OR "conversion symptom\*" OR "conversion disorder" OR "psychogenic" OR "psychogenic non?epileptic seizure\*" OR "non?epileptic" OR "NES" OR "pseudoseizure\*" OR "hysteria" OR "functional seizures" OR "seizure\*" OR "dissociative seizures" OR "non?organic" OR "motor FND" or "functional weakness" OR "functional tremor" OR "functional movement disorder" OR "functional cognitive disorder" OR "persistent perceptual postural dizziness" OR "dystonia". ti, ab.
- "outcome\*" OR "QoL" OR "Quality of Life" OR "health?related quality of life" OR "HRQOL" OR "distress" OR "coping" OR "symptom\*" OR "severity" OR "mental?health" OR "well?being" OR "mood" OR "health status" OR "life quality". ti, ab.
- "illness ADJ3 perception\*" OR "illness ADJ3 representation\*" OR "illness ADJ3 belief\*" OR "illness ADJ3 appraisal\*" OR "disease ADJ3 perception\*" OR "disease

ADJ3 representation\*" OR "disease ADJ3 belief\*" OR "disease ADJ1 appraisal\*" OR "common?sense model" OR "CSM" OR "attitude\*" OR "identit\*" OR "illness ADJ3 understanding\*". ti, ab.

### **2.3. Selection Process**

All research papers identified through the search strategy were screened for duplicates. The title and abstracts of the remaining papers were screened, with potential eligible studies undergoing further full-text screening. Papers meeting eligibility criteria following full-text screening were selected for quality appraisal and data extraction. The first author subsequently re-screened a random 20% of titles and abstracts after duplicate removal to check the original screening decisions. A second, independent researcher also independently screened a random 20% sample of titles and abstracts after duplicate removal (N = 2,050). It was agreed that any disputes would be resolved by a third, independent researcher.

### **2.4. Data Extraction**

Following retrieval of relevant papers, data extraction was completed by the lead researcher. The Cochrane data extraction form (Higgins et al., 2024) was used, with information collected on study design, participant characteristics, outcome measures, statistical information and key findings. A second researcher independently conducted data extraction for all included studies.

### **2.5. Critical appraisal and risk of bias**

Methodological quality of the included papers was appraised using the design-appropriate critical appraisal tools from the Joanna Briggs Institute (JBI; Barker et al., 2024; Moola et al., 2020). These tools ask between 8 and 12 questions, with each item requiring a response of either yes, no, unclear or not applicable. Because this review focused on baseline or observational associations between illness perceptions and QoL, the relevance of individual JBI items was judged against the review question. Intervention-specific items, such as those concerning treatment allocation or post-intervention change, contributed less to risk-of-bias judgements when they were unrelated to the extracted associations. Overall judgements considered the JBI appraisal alongside concerns relevant to the review question,

including control of confounding, sample size in relation to the analyses, adjustment for multiple comparisons, completeness of statistical reporting, and sample representativeness. Ratings were based on the presence and likely impact of these concerns for the review question. A second researcher independently appraised all included studies. Disagreements were resolved through discussion, with appraisal criteria clarified during piloting before final ratings were agreed.

## **2.6. Data Synthesis**

It was initially planned to conduct a meta-analysis using a random-effects model to aggregate effect sizes examining the relationship between illness perceptions and quality of life. However, following consultation with academic supervisors, it was decided that effect sizes reported in the included papers could not be combined and so, a meta-analysis was not completed. A key issue was the use of different measures of illness perceptions across the included studies: the IPQ, IPQ-R, and BIPQ. The IPQ and IPQ-R conceptualise sub-domains as independent constructs and therefore do not support aggregation into a single overall score. Similarly, the BIPQ assesses distinct but related dimensions of illness perceptions using individual items, which are intended to be interpreted separately, although some studies report an overall threat score. Comparability at the domain level was further limited by incomplete alignment across measures. The IPQ-R extends the IPQ through the introduction of additional domains and refinement of existing constructs, while the BIPQ assesses domains using single-item indicators. Collectively, these methodological differences meant that a meta-analysis was not considered the most appropriate approach. A narrative synthesis was conducted to systematically summarise patterns and relationships across studies, adhering to guidance from Popay et al. (2006). Interpretations of relationships between illness perceptions and domains of quality of life were informed by established guidance on conducting power analysis (Cohen, 1988). Due to included papers reporting different correlation coefficients (e.g. Pearson, Spearman), coefficients were transformed using Fisher Z-transformation. This was to aid interpretation on a standard metric. Direction of coefficients were also standardised. For example, Rawlings et al. (2017) re-oriented BIPQ scores so higher values meant more threatening illness perceptions. Similarly, for this review, the scores described by Saunders et al. (2024) as the IPQ protective domains (e.g. personal

control, treatment control and coherence) were reversed to align with threat-related domains (e.g. consequences, identity, concern and emotional representations).

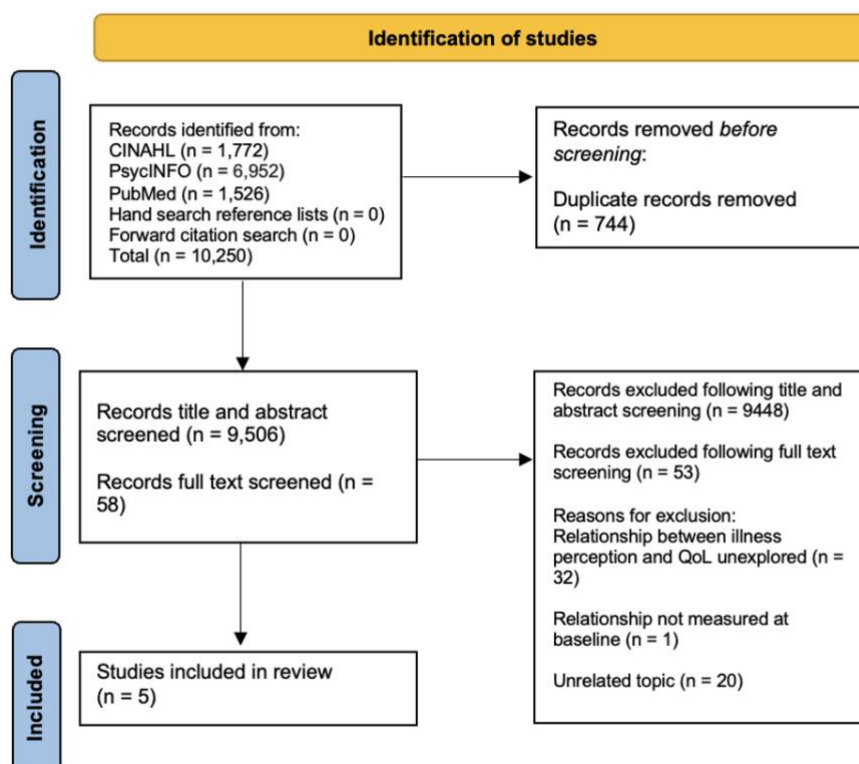
### 3. Results

#### 3.1. Study selection

The studies included for review were retrieved through the search process outlined in Figure 1, which followed the PRISMA 2020 statement (Page et al., 2021). Overall, 10,250 studies were returned, with 744 duplicates identified and removed with the assistance of the Rayyan software. Following the principal researcher's initial screening, a random 20% of titles and abstracts screened by the principal researcher, and a separate random 20% sample were independently screened by a second reviewer. Within the second reviewer's 20% title and abstract screening sample, reviewers disagreed on 10 records prior to discussion. All disagreements were resolved through discussion, and consultation with a third reviewer was not required. Disagreements concerned FND terminology and whether studies should proceed to full-text screening. An intervention study by Williams et al. (2018) initially appeared to meet inclusion criteria because it reported an association between illness perceptions and quality of life (QoL). However, the association was derived from a pre–post intervention context rather than baseline or observational data, and the study was therefore excluded.

**Figure 1**

*PRISMA flow diagram*



### **3.2. Study characteristics**

Table 1 presents the selected studies, which were published between 2010 and 2024 and were conducted in the UK, predominantly within specialist services for neurological conditions; Rawlings et al. (2017) also recruited through epilepsy and FND charities. Two studies used a cross-sectional design (Novakova et al., 2015; Rawlings et al., 2017), while the remaining three employed a quasi-experimental design (Bailey et al., 2024), a cohort design (Saunders et al., 2024) and a case control design (Stone et al., 2010). Sample sizes ranged from 45 to 166, resulting in an overall sample size of 420 participants. No study had the primary aim of examining the relationship between illness perceptions and QoL and reporting of associations were supplementary.

### **3.3. Assessment of illness perceptions and quality of life in selected papers**

The BIPQ was used in two selected papers (Novakova et al., 2015; Rawlings et al., 2017). The IPQ-R, a revised version of the original IPQ, was used in Bailey et al. (2024). The original IPQ was used by Saunders et al. (2024), while Stone et al. (2010) used an adapted version of the original IPQ. All three measures have robust psychometric properties. Moss-Morris et al. (2002) demonstrated strong psychometric properties of the IPQ-R, including good internal consistency and test-retest reliability, consistent with those reported for the original IPQ. A subsequent meta-analysis of the IPQ-R's psychometric properties found acceptable internal consistency across diverse populations and health conditions, while also highlighting the need for adaptation to suit different illness contexts (Rivera et al., 2024). Comparable findings have been reported for the BIPQ, alongside medium to large associations with the IPQ-R. In a later systematic review, Broadbent et al. (2015) concluded that the BIPQ demonstrates strong psychometric properties across a wide range of illness, cultures, and age groups.

For the assessment of quality of life, Saunders et al. (2024) used the EQ-5D-5L (Herdman et al., 2011), and Rawlings et al. (2017) used an adapted epilepsy-specific measure, The Quality of Life in Newly Diagnosed Epilepsy Instrument – six dimensions (NEWQOL-6D; Mulhern et al., 2012). The remaining papers (Bailey et al., 2024; Novakova et al., 2015; Stone et al., 2010) used the SF-36. The SF-36 has been widely reported as a robust and well-validated measure for research and clinical use (Ware, 2000). Similarly, a systematic review

by Feng et al. (2021) described the EQ-5D-5L as having excellent psychometric properties. In a comparative study, Mulhern et al. (2017) found the psychometric properties of the EQ-5D-5L and the NEWQOL-6D to be broadly comparable, with the NEWQOL-6D also demonstrating good internal validity. However, evidence for the NEWQOL-6D remains comparatively sparse and is largely derived from a single clinical population, which limits ability to generalise findings and draw further conclusions about its psychometric properties.

### **3.4. Critical appraisal and risk of bias**

Overall, the studies were initially judged to have a low to moderate risk of bias for their original study aims and research questions. However, because this review focused on baseline or observational associations between illness perceptions and QoL, risk of bias was reassessed in relation to this review question. JBI items concerning intervention allocation or post-intervention change were therefore marked as not applicable where baseline associations were extracted. For this review question, four studies were rated as having a high risk of bias and one a moderate risk of bias. Ratings reflected limited control of confounders, sample sizes relative to the analyses, absence of adjustment for multiple comparisons, and incomplete statistical reporting. Moderate risk was assigned where relevant confounders were addressed through adjusted analyses despite other limitations; high risk was assigned where review-relevant associations were unadjusted alongside additional methodological concerns. Overall ratings reflected the likely impact of each bias domain on the review findings. A second, independent reviewer completed critical appraisal and data extraction for all selected studies. During piloting, involving one study, initial independent agreement was reached on seven of the nine appraisal items (78%). Disagreements concerned the likely impact of recruitment procedures on risk of bias, and the appropriateness of certain statistical analyses. These included whether the absence of control group was relevant when only baseline associations were of interest and whether correlational analyses adequately considered conceptual overlap between illness perception domains and measures of depression and anxiety. These discrepancies were discussed and the appraisal criteria were clarified before final ratings were agreed for all studies.

**Table 1***Overview of selected studies*

| <b>Author</b>   | <b>Year</b> | <b>Location and setting</b>                                            | <b>Study design</b> | <b>Population</b>   | <b>Sample size</b> | <b>Mean age</b> | <b>Primary aim</b>                                                                                                                                                                                                                          |
|-----------------|-------------|------------------------------------------------------------------------|---------------------|---------------------|--------------------|-----------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Bailey et al.   | 2024        | London, UK, outpatient neuropsychiatry service                         | Quasi-experimental  | FND                 | 166                |                 | To explore illness perceptions, stigma and treatment engagement in functional neurological disorder, and to assess whether multidisciplinary group education improves understanding and engagement.                                         |
| Novakova et al. | 2015        | Yorkshire, UK, neurology psychotherapy service                         | Cross-sectional     | PNES                | 50                 | 39.0            | To investigate emotion-processing styles in patients with psychogenic non-epileptic seizures compared with healthy controls, and to explore how emotion-processing deficits relate to psychological distress, symptoms and quality of life. |
| Rawlings et al. | 2017        | Sheffield, UK, outpatient neurology clinic; Epilepsy and FND charities | Cross-sectional     | PNES                | 45                 | 38.0            | To examine and compare the relative contribution of psychological factors, illness perceptions, clinical variables and demographics to health-related quality of life in patients with epilepsy and psychogenic nonepileptic seizures.      |
| Saunders et al. | 2024        | London, UK, inpatient rehabilitation unit                              | Cohort              | FND                 | 52                 | 40.0            | To evaluate clinical and functional outcomes of specialist inpatient multidisciplinary rehabilitation for severe functional neurological disorder and identify admission factors predicting treatment response.                             |
| Stone et al.    | 2010        | Edinburgh, UK, outpatient neurology service                            | Case control        | Functional weakness | 107                | 39.1            | To determine the incidence and clinical, psychiatric and illness-belief characteristics of patients with recent-onset functional weakness, and to compare these with patients with weakness due to neurological disease                     |

*Note.* Empty cells indicate missing data within paper.

### **3.5. Heterogeneity of selected studies**

As described in Table 1, the selected studies differed in their research aims and methodological design. Potential intervention-related influences on the reported associations were controlled for, as associations between illness perceptions and quality of life were calculated using baseline, pre-intervention, or non-intervention data. Bailey et al. (2024) collected data pre-intervention, Novakova et al. (2015) and Rawlings et al. (2017) used cross-sectional designs, Saunders et al. (2024) recorded variables at admission to an inpatient rehabilitation unit, and Stone et al. (2010) did not deliver an intervention. Therefore, although the studies differed in design, the associations can be interpreted as broadly cross-sectional. Participants were recruited from UK specialist neurology, neuropsychiatry, psychotherapy, and inpatient rehabilitation services, with Rawlings et al. (2017) additionally recruiting through epilepsy and FND charities. Although all were specialist services, they differed in meaningful ways, such as outpatient and inpatient settings and between broader FND samples and subgroups, such as NES and functional weakness. These differences need considering when interpreting variation in associations between illness perceptions and QoL.

### **3.6. Results of synthesis**

Table 2 summarises the findings from the five included studies examining associations between illness perceptions and QoL, including three studies that focused specifically on mental and physical health domains of QoL measures. Overall, illness perceptions and QoL appeared to be associated, with small to large effect sizes reported. The direction and magnitude of these associations varied by illness perception and QoL domain. Across studies, more negative illness perceptions were generally associated with poorer QoL, although the strength of these associations differed across domains. Where mental and physical health domains of QoL measures were used, associations tended to be larger for mental health than physical health, particularly in studies using the SF-36. However, these findings were largely informed by two studies examining associations across most illness perception domains and overall QoL, whereas the remaining three studies had a narrower focus, exploring specific aspects of the illness perceptions–QoL relationship. Associations across studies varied in magnitude: of the 21 reported associations, four were negligible,

seven were small, six were medium, and four were large. Nine of the 21 associations (43%) were statistically significant. Therefore, all findings should be interpreted cautiously. The results for each illness perception domain and its association with QoL are presented below.

**Table 2**  
*Associations reported in selected studies*

| Illness perceptions       | Bailey et al., 2024<br>(IPQ-R – SF-36) | Novakova et al., 2015<br>(BIPQ – SF-36) |                         | Rawlings et al., 2017<br>(BIPQ – NEWQOL-6D) | Saunders et al., 2024<br>(IPQ – EQ-5D-5L) | Stone et al., 2010<br>(IPQ – SF-36) |
|---------------------------|----------------------------------------|-----------------------------------------|-------------------------|---------------------------------------------|-------------------------------------------|-------------------------------------|
|                           | MH                                     | MH                                      | PH                      |                                             |                                           | PH                                  |
| Overall IP score          |                                        | $\rho = -0.69$<br>(-.86)**              | $\rho = -.44$<br>(-.47) | $\rho = -.42$ (-.44)**                      |                                           |                                     |
| Identity                  |                                        |                                         |                         | $\rho = -.14$ (-.14)                        | $\rho = .05$ (.05)                        |                                     |
| Timeline                  |                                        |                                         |                         | $\rho = -.32$ (-.33)*                       | $\rho = -.00$ (-.00)                      |                                     |
| Timeline: Cyclical        |                                        |                                         |                         |                                             | $\rho = .09$ (.09)                        |                                     |
| Consequences              |                                        |                                         |                         | $\rho = -.28$ (-.28)                        | $\rho = -.17$ (-.17)                      |                                     |
| Personal Control          |                                        |                                         |                         | $\rho = -.31$ (-.32)*                       | $\rho = -.22$ (-.22)                      |                                     |
| Treatment Control         |                                        |                                         |                         | $\rho = .18$ (.18)                          | $\rho = .14$ (.14)                        |                                     |
| Coherence                 |                                        |                                         |                         | $\rho = -.23$ (-.23)                        | $\rho = -.49$ (-.53)***                   |                                     |
| Emotional Representations | $r = -.54$ (-.60)***                   |                                         |                         | $\rho = -.54$ (-.60)*                       | $\rho = -.30$ (-.31)*                     |                                     |
| Causes                    |                                        |                                         |                         |                                             | $\rho = -.05$ (-.05)                      | $\rho = .38$ (.40)***               |

*Note.* Fisher z–transformed effect sizes (ES) are shown in brackets to provide a standardised metric for comparing study outcomes. ES interpretation follows Cohen (1988): small = .10–.29, medium = .30–.49, large  $\geq .50$ . All studies reported Spearman correlations except Bailey et al. (2024), which used Pearson coefficients. Abbreviations under each author indicate the measures used. Studies using the SF-36 drew on one or two subdomains rather than the full scale. MH = mental health; PH = physical health. \* $p \leq 0.05$ ; \*\* $p \leq 0.01$ ; \*\*\* $p \leq 0.001$

### **3.6.1. Identity**

The illness identity score reflects the extent to which individuals associate specific symptoms with their illness. Only two of the included studies explored the identity domain and its association with QoL (Rawlings et al., 2017; Saunders et al., 2024). Across these studies, evidence for an association between illness identity and QoL was limited and inconclusive. Rawlings et al. (2017) reported a small negative association, suggesting that higher illness identity scores tended to be associated with lower QoL, whereas Saunders et al. (2024) reported a negligible association. However, neither association was statistically significant, limiting the extent to which this pattern can be interpreted as evidence of a relationship between illness identity and QoL. Rawlings et al. (2017) were rated as having moderate risk of bias, partly due to limited statistical power and the absence of adjustment for multiple comparisons. Saunders et al. (2024) were rated as high risk of bias due to limited reporting of statistical information, including confidence intervals and adjustment for multiple comparisons. The studies also differed in clinical setting and sample composition, including patients with NES and inpatients with broader FND presentations. These differences limit the generalisability of findings to the broader FND population. It is unclear if the differing samples explain variation in reported associations. These study limitations apply to the remaining domains reported by Rawlings et al. (2017) and Saunders et al. (2024) and are therefore not repeated in each subsequent domain subsection.

### **3.6.2. Timeline: chronic-acute and cyclical**

Rawlings et al. (2017) and Saunders et al. (2024) explored the association between the timeline domain and QoL, with this domain capturing beliefs about whether the illness is chronic or acute and whether it follows a predictable pattern. Findings differed across timeline dimensions. Rawlings et al. (2017) showed a statistically significant, medium negative association between chronic timeline beliefs and QoL, suggesting that stronger beliefs about FND as chronic were associated with lower QoL. Saunders et al. (2024) reported negligible, non-significant associations for both chronic-acute and cyclical timeline beliefs.

### **3.6.3. Consequences**

There appeared to be some consistency between Rawlings et al. (2017) and Saunders et al. (2024) in their findings on the association between QoL and beliefs about the expected impact FND will have on physical, social, and psychological wellbeing and daily life. Both studies reported small, non-significant negative associations, suggesting limited evidence that stronger beliefs about the consequences of FND were associated with lower QoL. Although the association reported by Rawlings et al. (2017) was numerically larger than that reported by Saunders et al. (2024), this difference should be interpreted cautiously given the non-significant findings and differences in study context.

### **3.6.4. Personal control**

Personal control reflects beliefs about the extent to which individuals can influence or manage their FND symptoms. Saunders et al. (2024) reported a non-significant small association between lower personal control and lower QoL. Rawlings et al. (2017) reported a medium-sized, statistically significant association in the same direction. This suggests a broadly similar direction of association across studies, although the magnitude and statistical significance differed.

### **3.6.5. Treatment control**

Treatment control reflects beliefs about the extent to which treatment can influence or manage symptoms. Across the two studies examining this domain, greater optimism about treatment was associated with higher QoL, although both associations were small and not statistically significant. Rawlings et al. (2017) reported a numerically larger association than Saunders et al. (2024), but this difference should be interpreted cautiously and not as evidence of a population-level difference.

### **3.6.6. Coherence**

Coherence reflects the extent to which individuals understand their illness and its causes and has been suggested to be relevant to QoL among people with FND by previous research. The studies by Rawlings et al. (2017) and Saunders et al. (2024) differed in their findings related to the coherence domain. Rawlings et al. (2017) reported a small, non-significant association between lower coherence and lower QoL, while Saunders et al. (2024) reported

a larger and statistically significant association in the same direction. This suggests that coherence may be relevant to QoL, although this pattern was driven mainly by the finding reported by Saunders et al. (2024).

### **3.6.7. Emotional representations**

The emotional representation domain assesses the emotional responses elicited by illness, such as fear, distress, and anger. Across studies, emotional representations showed a consistent negative association with QoL, although the size of the association and the QoL domains assessed varied. Among the NES sample, there was a large and statistically significant association between heightened emotional responses and lower QoL (Rawlings et al., 2017). In the broader sample (Saunders et al., 2024), the association was medium and also statistically significant.

This association was also reported by Bailey et al. (2024). They showed a large and statistically significant association between heightened emotional responses and lower QoL as measured by the mental health domain of the SF-36. This suggests that emotional representations may be particularly closely related to psychological aspects of QoL. Like Rawlings et al. (2017) and Saunders et al. (2024), Bailey et al.'s findings should be interpreted cautiously because they did not adjust for repeated correlational tests or control for confounding variables. The measurement of emotional representations and the mental health QoL domain may also involve conceptual overlap, as both may capture aspects of emotional distress. This overlap may partly explain the strength of the association between them, limiting confidence that the association reflects entirely distinct constructs.

### **3.6.8. Causes**

The causes domain explores beliefs about the perceived origins of illness, which are typically assessed through a list of possible causes. Stone et al. (2010) adapted the cause list in the IPQ to assess the extent to which individuals attributed functional weakness to stress. They reported a medium, positive association between stress attribution and the physical health domain of the SF-36, suggesting that stronger attribution of symptoms to stress was associated with better physical functioning or less reported physical disability. However, this finding should be interpreted cautiously because of concerns about confounding variables, appropriateness of statistical analysis, and incomplete reporting of statistical information.

The study's focus on functional weakness also limits the applicability of findings to the broader FND population. Saunders et al. (2024) had also reported an association between causal beliefs and QoL and found a negligible and non-significant association. It was unclear how Saunders et al. (2024) adapted the IPQ.

### **3.6.9. Overall illness perception score**

The study by Novakova et al. (2015) provided an overall illness perception score for the BIPQ. Novakova et al. (2015) interpreted this score as indicating the extent to which someone experiences their condition as threatening. This overall score showed a medium negative association with the physical health domain of the SF-36 (non-significant) and a large negative association with the mental health domain (statistically significant). This suggests that greater perceived illness threat was associated with poorer QoL, particularly in relation to mental health. Although Novakova et al. (2015) acknowledged limitations, their study contained similar limitations to those noted in the Identity sub-section and was rated as high risk of bias, so findings should be interpreted cautiously. Similarly, Rawlings et al. (2017) also reported a medium association, which was statistically significant, suggesting that greater perceived illness threat was associated with poorer quality of life. Unlike previous subsections, these findings refer to global perceived illness threat rather than specific illness perception domains.

## 4. Discussion

This review sought to explore the relationship between illness perceptions and quality of life (QoL) among patients with FND. Five studies were included in the synthesis and involved 420 participants recruited from specialist neurological services. Illness perceptions were assessed using the BIPQ, IPQ and IPQ-R, while QoL was assessed using the SF-36, NEWQOL-6D and EQ-5D-5L. No study had the primary aim of examining illness perceptions and QoL, with associations instead reported as secondary outcomes. Overall risk of bias was determined as moderate to high.

The findings indicate that associations with QoL varied across illness perception domains. The most consistently reported associations with QoL were observed for emotional representations and the overall illness perceptions score of the BIPQ, interpreted as perceived threat, suggesting that the emotional impact and perceived threat of FND may be particularly relevant to QoL, especially within mental health domains. Emotional representations showed the most consistent negative association with QoL and reached statistical significance across studies. Personal control showed a small to medium negative association with QoL, although this pattern was less consistent across samples. Treatment control showed small, non-significant positive associations, suggesting greater treatment control weakly corresponded with better QoL. Identity also showed weak and non-significant associations, with no clear pattern across studies. Timeline and coherence showed significant associations in one study each, but these patterns were not consistent across studies. Moreover, the cause domain was distinctive in showing a positive association with physical health. This may reflect societal stigma and a preference for non-stress-based explanations for FND (see Stone et al., 2010), although direct comparison with other cause-domain findings is limited by differences in how causal beliefs were operationalised. Overall, the synthesis suggests that the way people make sense of FND may be associated with QoL.

In relation to broader literature, the findings are consistent with interpretations of intervention trials (Goldstein et al., 2020; Nielsen et al., 2024) suggesting that symptom severity alone may not explain changes in QoL. They also appear to extend findings from Dempster et al. (2015), whose systematic review identified illness identity, perceived consequences, and emotional representations as being strongly associated with QoL,

whereas personal and treatment control and coherence were not. This pattern was partially mirrored by the present review, where emotional representations and the overall illness perception score were significantly associated with QoL, while treatment control showed weaker and non-significant associations. However, the present review diverged from Dempster et al. in relation to personal control and coherence. Personal control was significantly associated with QoL in Rawlings et al. (2017), although not in Saunders et al. (2024), while coherence was significant in Saunders et al. (2024) but not in Rawlings et al. (2017). Dempster et al. (2015) also did not report associations for timeline or cause domains whereas the current synthesis reported significant associations for these domains in individual studies. Together, these findings suggest that how distressing, chronic, controllable, or meaningful individuals perceive their FND may be related to QoL. However, the role of control beliefs appears domain-specific, with personal control possibly being clinically relevant, whereas treatment control showed weaker associations.

The present findings can be considered alongside Joos et al. (2024), who identified low illness coherence and personal control within their FND sample. Although their study examined between-group differences rather than associations with QoL. The present findings suggest that emotional representations, and more tentatively lower illness coherence, may be associated with poorer QoL, particularly where FND is experienced as emotionally burdensome or threatening. Although this review did not directly examine associations between stigma, illness perceptions, and QoL, wider stigma literature (e.g. McLoughlin et al., 2024; Foley et al., 2024) may help contextualise why these emotional representations matter. Stone et al.'s (2010) finding that greater physical disability was associated with reduced enthusiasm for stress-based causal explanations for FND, which are often experienced as delegitimising or as implying inauthenticity, may be consistent with the possibility that illness perceptions are not just individual beliefs but may be influenced by social contexts.

#### **4.1. Limitations of the evidence and review's strengths**

The review's findings should be considered in relation to several limitations. Confidence in the magnitude and reliability of the observed associations is limited because effect sizes varied by illness perception domain, measure, and sample, and the evidence was largely

correlational. The literature exploring illness perceptions and quality of life in FND remains limited, with only a small number of eligible studies identified. This limitation was compounded by inconsistent reporting of domain-level associations across studies. Three included studies reported only selected associations relevant to the review question (Bailey et al., 2024; Novakova et al., 2015; Stone et al., 2010), meaning that most domain-level comparisons between illness perceptions and QoL were informed primarily by two studies (Rawlings et al., 2017; Saunders et al., 2024). These two studies were rated as moderate and high risk of bias in relation to their ability to answer the current review's research question. Saunders et al. (2024) did not control for confounding variables such as depression and anxiety, and both Saunders et al. (2024) and Rawlings et al. (2017) may have been underpowered due to small sample sizes. This increases the risk of Type 2 errors, while the absence of adjustment for multiple comparisons may increase the risk of Type 1 errors (Chen et al., 2017). There were also concerns regarding how generalisable the findings from both studies are. Rawlings et al. (2017) recruited through both NHS services and charities, with charity-recruited participants relying on self-reported diagnosis. This may limit the validity of the diagnosis and limit how comparable participants were across recruitment routes. For Saunders et al. (2024), the population was highly specific, involving a cohort of inpatients who were described as having severe and chronic FND. They may not be representative of a broader FND population. Finally, confidence was further limited by the partial and inconsistent use of psychometric instruments across studies, which restricted interpretation of illness perceptions and QoL.

These psychometric limitations restricted nuanced analysis of how specific illness perception domains related to QoL. For instance, three studies did not examine associations between identity or timeline domains and QoL, despite prior inconsistencies in findings for these domains. Additionally, two studies (Rawlings et al., 2017; Novakova et al., 2015) derived a total illness perception score from the BIPQ (Broadbent et al., 2006) and interpreted it as overall illness threat. However, the BIPQ was designed to assess distinct cognitive and emotional domains. While defensible in some contexts, using a total score may obscure domain-specific associations and remains contentious (Broadbent et al., 2015). Interpretation is further complicated by overlap between the emotional representation domain and measures of psychological wellbeing, including mental-health-related domains

of QoL measures, such as the mental health domain of the SF-36. This may support the BIPQ's construct validity, but the association between emotional representations and mental-health-related QoL may partly reflect shared variance in emotional distress or psychological wellbeing rather than a relationship between entirely distinct constructs. For example, a person experiencing greater emotional distress may report both more negative emotional representations and poorer mental-health-related QoL, limiting confidence that the observed association reflects an independent relationship between the two constructs. Ideally, studies would have examined whether emotional representation domains remained independently associated with mental-health-related QoL after accounting for broader psychological distress, including depression and anxiety, and whether similar associations were found with less emotionally overlapping QoL domains, such as physical functioning. The findings should therefore be interpreted cautiously.

Despite the limitations of the evidence, the review had key methodological strengths. It adhered to PRISMA 2020 reporting guidance (Page et al., 2021), enhancing transparency and reproducibility. A second independent reviewer conducted 20% of title and abstract screening and completed data extraction and critical appraisal for all selected papers. Although second reviewer involvement did not extend to full-text screening, independent screening of 20% of titles and abstracts, alongside second reviewer data extraction and critical appraisal for all included studies, may have reduced the risk of erroneous exclusion and biased appraisal. However, more extensive title/abstract screening and independent full-text screening would have strengthened methodological rigour (Cherry et al., 2023).

#### **4.2. Deviations from the Original PROSPERO Record**

The search strategy presented in the Prospero record (uploaded on 21.08.25) was designed to capture studies exploring how illness perceptions influence outcomes relevant to FND management (e.g., symptom improvement and QoL), with a planned meta-analysis. However, as the research question was refined, the focus narrowed to the relationship between illness perceptions and a more tightly defined construct of QoL. Following amendments to the research question, search strategy, and eligibility criteria, all searches were re-run and full screening was repeated to minimise selection bias. Screening was conducted a third time after identifying an error in the publication year criterion. Studies

were initially limited to those published from 1992, but this was corrected to 1980, the year the Common-Sense Model was first introduced. A meta-analysis was ultimately not conducted due to the heterogeneity in the psychometric instruments used.

### **4.3. Implications**

Given the tentatively suggested relationship between illness perceptions and QoL, an outcome important to patients (Rutten et al., 2025), routine assessment of illness perceptions upon entering clinical settings may be sensible. The BIPQ may be preferable because of its brevity compared to the 38-item IPQ-R and 35-item IPQ, although domain-level interpretation may be more informative than relying on a total threat score. Regarding assessing QoL, Pick et al. (2020) recommended the SF-36 for routine use in research and clinical practice. This was due to its capacity to provide detailed subdomain scores (physical functioning, role limitations, social functioning, mental health, and general health and vitality), which were examined in this review. Routinely using these measures would strengthen the evidence base by increasing available data on the illness perceptions-QoL relationship and clarify whether perceptions differ among FND subtypes.

The review identified variation in the strength of associations between illness perceptions and QoL across different FND samples but did not assess whether levels of perceived threat differed between FND subtypes. Any differences in perceived threat across FND subtypes therefore remain uncertain. Nevertheless, the clinical implications of this review may be relevant across a range of FND presentations rather than being limited to particular subtypes. Routinely exploring illness perceptions may represent good clinical practice, particularly where beliefs about coherence, control, emotional burden, or perceived threat appear to affect adjustment, engagement, or QoL. Clinicians may also need to adapt appropriately. This may include allocating additional time to explore illness perceptions and their influence on FND management. This may involve offering clear, early explanatory models of FND to enhance illness coherence and explicitly validate experiences of delegitimisation, and using psychologically informed strategies (e.g., tailored patient information, cognitive restructuring and behavioural experiments) to increase perceived control and reduce perceived symptom threat. Collectively, these adaptations support the development of more responsive specialist FND interventions and services.

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**Ethics**

Not applicable.

**Declaration of competing interests**

None.

## 5. References

- Aybek, S., & Perez, D. L. (2022). Diagnosis and management of functional neurological disorder. *BMJ*, 376, o64. <https://doi.org/10.1136/bmj.o64>
- Bailey, C., Agrawal, N., Cope, S., Proctor, B., Mildon, B., Butler, M., Holt, K., Edwards, M., Poole, N., & Nicholson, T. R. (2024). Illness perceptions, experiences of stigma and engagement in functional neurological disorder (FND): Exploring the role of multidisciplinary group education sessions. *BMJ Neurology Open*, 6, e000633. <https://doi.org/10.1136/bmjno-2024-000633>
- Barker, T. H., Habibi, N., Aromataris, E., Stone, J. C., Leonardi-Bee, J., Sears, K., Hasanoff, S., Klugar, M., Tufanaru, C., Moola, S., & Munn, Z. (2024). The revised JBI critical appraisal tool for the assessment of risk of bias for quasi-experimental studies. *JBI Evidence Synthesis*, 22(3), 378–388. <https://doi.org/10.11124/JBIES-23-00268>
- British Psychological Society. (2021). Code of human research ethics. <https://explore.bps.org.uk/content/report-guideline/bpsrep.2021.inf94>
- British Psychological Society. (2024). Functional neurological disorder: Neuropsychological and psychological management in children and adults (Briefing paper). <https://www.bps.org.uk/guideline/functional-neurological-disorder-neuropsychological-and-psychological-management-children>
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, 60(6), 631–637. <https://doi.org/10.1016/j.jpsychores.2005.10.020>
- Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S., & Petrie, K. J. (2015). A systematic review and meta-analysis of the brief illness perception questionnaire.

*Psychology & Health*, 30(11), 1361–1385.

<https://doi.org/10.1080/08870446.2015.1070851>

Centre for Sustainable Delivery. (2023). Functional neurological disorder (FND). Right Decisions.

<https://www.rightdecisions.scot.nhs.uk/neurology-pathways/functional-neurological-disorder-fnd/>

Chen, S. Y., Feng, Z., & Yi, X. (2017). A general introduction to adjustment for multiple comparisons. *Journal of Thoracic Disease*, 9(6), 1725–1729.

<https://doi.org/10.21037/jtd.2017.05.34>

Cherry, M. G., Boland, A., & Dickson, R. (2023). *Doing a systematic review: A student's guide* (3rd ed.). Sage.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Routledge.

<https://doi.org/10.4324/9780203771587>

Cole, V., & Boutet, M. (2023). ResearchRabbit. *Journal of the Canadian Health Libraries Association*, 44(2), 43–47. <https://doi.org/10.29173/jchla29699>

Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping in physical health conditions: A meta-analysis. *Journal of Psychosomatic Research*, 79(6), 506–513.

<https://doi.org/10.1016/j.jpsychores.2015.10.006>

Devlin, N. J., & Brooks, R. (2017). EQ-5D and the EuroQol Group: Past, present and future.

*Applied Health Economics and Health Policy*, 15(2), 127–137.

<https://doi.org/10.1007/s40258-017-0310-5>

Feng, Y. S., Kohlmann, T., Janssen, M. F., & Buchholz, I. (2021). Psychometric properties of the EQ-5D-5L: A systematic review of the literature. *Quality of Life Research*, 30(3), 647–673. <https://doi.org/10.1007/s11136-020-02688-y>

- Foley, C., Kirkby, A., & Eccles, F. J. R. (2024). A meta-ethnographic synthesis of the experiences of stigma amongst people with functional neurological disorder. *Disability and Rehabilitation*, 46(1), 1–12. <https://doi.org/10.1080/09638288.2022.2155714>
- Foxwell, R., Morley, C., & Frizelle, D. (2013). Illness perceptions, mood and quality of life: A systematic review of coronary heart disease patients. *Journal of Psychosomatic Research*, 75(3), 211–222. <https://doi.org/10.1016/j.jpsychores.2013.05.003>
- Goldstein, L. H., Robinson, E. J., Mellers, J. D. C., Stone, J., Carson, A., Reuber, M., Medford, N., McCrone, P., Murray, J., Richardson, M. P., Pilecka, I., Eastwood, C., Moore, M., Mosweu, I., Perdue, I., Landau, S., Chalder, T., & CODES Study Group. (2020). Cognitive behavioural therapy for adults with dissociative seizures (CODES): A pragmatic, multicentre, randomised controlled trial. *The Lancet Psychiatry*, 7(6), 491–505. [https://doi.org/10.1016/S2215-0366\(20\)30128-0](https://doi.org/10.1016/S2215-0366(20)30128-0)
- Hagger, M. S., & Orbell, S. (2022). The common sense model of illness self-regulation: A conceptual review and proposed extended model. *Health Psychology Review*, 16(3), 347–377. <https://doi.org/10.1080/17437199.2021.1878050>
- Hallett, M., Aybek, S., Dworetzky, B. A., McWhirter, L., Staab, J., & Stone, J. (2022). Functional neurological disorder: New phenotypes, common mechanisms. *The Lancet Neurology*, 21(6), 537–550. [https://doi.org/10.1016/S1474-4422\(21\)00422-1](https://doi.org/10.1016/S1474-4422(21)00422-1)
- Herdman, M., Gudex, C., Lloyd, A., Janssen, M., Kind, P., Parkin, D., Bonser, G., & Badia, X. (2011). Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Quality of Life Research*, 20(10), 1727–1736. <https://doi.org/10.1007/s11136-011-9903-x>

- Higgins, J. P. T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M. J., & Welch, V. A. (Eds.). (2024). *Cochrane handbook for systematic reviews of interventions* (Version 6.5, updated August 2024). Cochrane. <https://www.cochrane.org/handbook>
- Joos, A., Popkirov, S., Lahmann, C., Jöbges, M., Herrmann, C., Maner, P., Schörner, K., Birke, G., & Hartmann, A. (2024). Illness perception in functional neurological disorder: Low illness coherence and personal control. *BMJ Neurology Open*, 6(1), e000648. <https://doi.org/10.1136/bmjno-2024-000648>
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common-sense representation of illness danger. In S. Rachman (Ed.), *Medical psychology* (Vol. 2, pp. 7–30). Pergamon Press.
- Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect–cognition interactions. *Cognitive Therapy and Research*, 16(2), 143–163. <https://doi.org/10.1007/BF01173486>
- Leventhal, H., Phillips, L. A., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): A dynamic framework for understanding illness self-management. *Journal of Behavioral Medicine*, 39(6), 935–946. <https://doi.org/10.1007/s10865-016-9782-2>
- Luca, M., Eccles, F., Perez Algorta, G., & Patti, F. (2022). Illness perceptions and outcome in multiple sclerosis: A systematic review of the literature. *Multiple Sclerosis and Related Disorders*, 67, 104180. <https://doi.org/10.1016/j.msard.2022.104180>
- McLoughlin, C., McWhirter, L., Pisegna, K., Tijssen, M. A. J., Tak, L. M., Carson, A., & Stone, J. (2024). Stigma in functional neurological disorder (FND): A systematic review. *Clinical Psychology Review*, 112, 102460. <https://doi.org/10.1016/j.cpr.2024.102460>
- Mental Capacity Act 2005, c. 9. <https://www.legislation.gov.uk/ukpga/2005/9/contents>
- Moola, S., Munn, Z., Sears, K., Sfetcu, R., Currie, M., Lisy, K., Tufanaru, C., Qureshi, R., Mattis, P., & Mu, P. (2015). Conducting systematic reviews of association (etiology): The Joanna

- Briggs Institute's approach. *International Journal of Evidence-Based Healthcare*, 13(3), 163–169. <https://doi.org/10.1097/XEB.0000000000000064>
- Moola, S., Munn, Z., Tufanaru, C., Aromataris, E., Sears, K., Sfetcu, R., Currie, M., Qureshi, R., Mattis, P., Lisy, K., & Mu, P.-F. (2020). Chapter 7: Systematic reviews of etiology and risk. In E. Aromataris & Z. Munn (Eds.), *JBI manual for evidence synthesis*. JBI. <https://synthesismanual.jbi.global>
- Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology & Health*, 17(1), 1–16. <https://doi.org/10.1080/08870440290001494>
- Mulhern, B., Rowen, D., Jacoby, A., Marson, T., Snape, D., Hughes, D., Latimer, N., Baker, G. A., & Brazier, J. E. (2012). The development of a QALY measure for epilepsy: NEWQOL-6D. *Epilepsy & Behavior*, 24(1), 36–43. <https://doi.org/10.1016/j.yebeh.2012.02.025>
- Mulhern, B., Pink, J., Rowen, D., Borghs, S., Butt, T., Hughes, D., Marson, A., & Brazier, J. (2017). Comparing generic and condition-specific preference-based measures in epilepsy: EQ-5D-3L and NEWQOL-6D. *Value in Health*, 20(4), 687–693. <https://doi.org/10.1016/j.jval.2016.03.1860>
- National Institute for Health and Care Excellence. (2024). Functional neurological disorder: Diagnosis. Clinical Knowledge Summaries. <https://cks.nice.org.uk/topics/functional-neurological-disorder/diagnosis/diagnosis/>
- National Neurosciences Advisory Group. (2023). Optimal clinical pathway for adults with functional neurological disorder. <https://www.nnag.org.uk/optimal-clinical-pathway-adults-fnd-functional-neurological-disorder>
- Nielsen, G., Stone, J., Lee, T. C., Goldstein, L. H., Marston, L., Hunter, R. M., Carson, A., Holt, K., Marsden, J., Le Novere, M., Nazareth, I., Noble, H., Reuber, M., Strudwick, A. M.,

- Santana Suarez, B., Edwards, M. J., & Physio4FMD Study Group. (2024). Specialist physiotherapy for functional motor disorder in England and Scotland (Physio4FMD): A pragmatic, multicentre, phase 3 randomised controlled trial. *The Lancet Neurology*, 23(7), 675–686. [https://doi.org/10.1016/S1474-4422\(24\)00135-2](https://doi.org/10.1016/S1474-4422(24)00135-2)
- Novakova, B., Howlett, S., Baker, R., & Reuber, M. (2015). Emotion processing and psychogenic non-epileptic seizures: A cross-sectional comparison of patients and healthy controls. *Seizure*, 29, 4–10. <https://doi.org/10.1016/j.seizure.2015.03.007>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, 372, n71. <https://doi.org/10.1136/bmj.n71>
- Pequeno, N. P. F., Cabral, N. L. A., Marchioni, D. M., Lima, S. C. V. C., & Lyra, C. O. (2020). Quality of life assessment instruments for adults: A systematic review of population-based studies. *Health and Quality of Life Outcomes*, 18(1), 208. <https://doi.org/10.1186/s12955-020-01347-7>
- Pick, S., Anderson, D. G., Asadi-Pooya, A. A., Aybek, S., Baslet, G., Bloem, B. R., Bradley-Westguard, A., Brown, R. J., Carson, A. J., Chalder, T., Damianova, M., David, A. S., Edwards, M. J., Epstein, S. A., Espay, A. J., Garcin, B., Goldstein, L. H., Hallett, M., Jankovic, J., ... Nicholson, T. R. (2020). Outcome measurement in functional neurological disorder: A systematic review and recommendations. *Journal of Neurology, Neurosurgery, and Psychiatry*, 91(6), 638–649. <https://doi.org/10.1136/jnnp-2019-322180>

- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC Methods Programme (Version 1).
- Rawlings, G. H., Brown, I., & Reuber, M. (2017). Predictors of health-related quality of life in patients with epilepsy and psychogenic nonepileptic seizures. *Epilepsy & Behavior*, 68, 153–158. <https://doi.org/10.1016/j.yebeh.2016.10.035>
- Raynor, G., & Baslet, G. (2021). A historical review of functional neurological disorder and comparison to contemporary models. *Epilepsy & Behavior Reports*, 16, 100489. <https://doi.org/10.1016/j.ebr.2021.100489>
- Rivera, E., Levoy, K., Park, C., Villalobos, A., Martin, P., Jung Kim, M., & Hirschman, K. B. (2024). Internal consistency reliability of the revised illness perceptions questionnaire: A systematic review and reliability generalization meta-analysis. *Journal of Health Psychology*, 29(7), 734–746. <https://doi.org/10.1177/13591053231221351>
- Rizou, I., Papavasiliou, A., van Middendorp, H., & De Gucht, V. (2025). The role of illness perceptions in epilepsy throughout the lifespan: A systematic review. *European Journal of Paediatric Neurology*, 60, 1–14. <https://doi.org/10.1016/j.ejpn.2025.10.013>
- Rutten, S., Bradley-Westguard, A., Nicholson, T. R., & Pick, S. (2025). Outcome measurement in functional neurological disorder: A qualitative study on the views of patients, caregivers and healthcare professionals. *Journal of Neurology*, 272, 189. <https://doi.org/10.1007/s00415-025-12912-9>
- Saunders, C., Bawa, H., Aslanyan, D., Coleman, F., Jinadu, H., Sigala, N., & Medford, N. (2024). Treatment outcomes in the inpatient management of severe functional neurological disorder: A retrospective cohort study. *BMJ Neurology Open*, 6, e000675. <https://doi.org/10.1136/bmjno-2024-000675>

- Stone, J., Warlow, C., & Sharpe, M. (2010). The symptom of functional weakness: A controlled study of 107 patients. *Brain*, 133(5), 1537–1551. <https://doi.org/10.1093/brain/awq068>
- Ware, J. E., Jr. (2000). SF-36 health survey update. *Spine*, 25(24), 3130–3139. <https://doi.org/10.1097/00007632-200012150-00008>
- Ware, J. E., Jr., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care*, 30(6), 473–483.
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology & Health*, 11(3), 431–445. <https://doi.org/10.1080/08870449608400270>
- Williams, I. A., Howlett, S., Levita, L., & Reuber, M. (2018). Changes in emotion processing following brief augmented psychodynamic interpersonal therapy for functional neurological symptoms. *Behavioural and Cognitive Psychotherapy*, 46(3), 350–366. <https://doi.org/10.1017/S1352465817000807>
- The WHOQOL Group. (1998). The World Health Organization Quality of Life Assessment (WHOQOL): Development and general psychometric properties. *Social Science & Medicine*, 46(12), 1569–1585. [https://doi.org/10.1016/S0277-9536\(98\)00009-4](https://doi.org/10.1016/S0277-9536(98)00009-4)

## **Chapter Two: Major Research Project**

Acceptance and Commitment Therapy for Functional Neurological Disorder:  
Exploring Experiences of Psychological Group Intervention Within a  
Neuropsychology Service.

Prepared in accordance with the author requirements for *Psychology &  
Health*

[Author Guidelines](#)

## Plain Language Summary

**Title:** Acceptance and Commitment Therapy for Functional Neurological Disorder

**Background:** Functional Neurological Disorder (FND) is a condition where the brain struggles to properly send and receive signals to different parts of the body. People living with FND can report not being able to do daily tasks, being upset, and not working. An NHS health board developed an ACT group intervention for people with FND. This project wanted to know what people thought of the group and what was helpful about it.

**Aims and Questions:** The project wanted to know if the group was helpful for people and if it was helpful, what parts of the group helped most. Through meetings, what people thought of the group was explored, as well whether their thinking about FND changed or not.

**Methods:** Meetings were with people who went to the group. They had to have gone to all the group's meetings. Those people were sent a letter and called to ask if they would like to meet and talk. They were told about what the project was trying to do and how they could quit the study at any time.

The meetings helped us know what helped and didn't help, when learning how to live with FND. The meetings involved talking with a mental health worker and answering questions. People were met online and in-person.

**Main Findings and Summary:** Ten people took part, and most said they found the group helpful, but in different ways. Three main ideas came out of the interviews. First, living with FND could affect how people saw themselves. Some people felt fear, loss, shame, or cut off from life. Second, the group helped when people felt safe, heard, believed, and less alone. Some tasks helped people think about what they cared about and take small steps, but some tasks felt too hard or not helpful. Third, change was not the same for everyone. Some people felt more hope, some felt they could cope better with FND, and some still felt stuck and needed more help.

The findings suggest that the group helped most when people felt safe and not alone, and when it helped them focus on what mattered to them. The findings also suggest that the group will not suit everyone. This was a small study. It only heard from people who had stayed to the end, so it may not show what the group was like for those who left early or had a worse time

## **Abstract**

Functional neurological disorder (FND) is associated with distress, disability, stigma, and difficulties accessing validating care. Acceptance and commitment therapy (ACT) may be helpful for people with FND, but little is known about how patients experience ACT interventions. This study explored patients' experiences of an ACT group intervention for FND and considered what participants experienced as helpful or unhelpful, and how their accounts resonated with ACT processes and illness-perception concepts. Ten patients who had attended the intervention completed semi-structured interviews, analysed using an inductively oriented reflexive thematic analysis. Three themes were developed: 'FND as eroding sense of self'; 'Group as validation and exploration'; and 'Healing as divergent realities'. Participants experienced the group as validating and linked it with reconnection with meaningful activity, although accounts of change were varied. Findings highlight the importance of validation and safe relationships, careful pacing of experiential exercises, and stepped, matched, multidisciplinary care in ACT-informed FND interventions.

## Introduction

Functional neurological disorder (FND) is characterised by neurological symptoms associated with disrupted brain functioning, commonly affecting motor, sensory, and cognitive processes (National Institute for Health and Care Excellence, 2024). Living with FND can entail considerable societal and personal costs, including high service use, increased disability, loss of identity, and experiences of stigma (Bailey et al., 2025; O'Mahony et al., 2023). McLoughlin et al. (2024) highlighted the multifaceted nature of stigma, describing how people with FND (pwFND) can feel ashamed, blamed, and embarrassed by their condition. This was linked to experiences of feeling dismissed as unreliable informants regarding their health, and to perceptions that FND is, within healthcare services, an illegitimate illness. Such experiences may contribute to delayed diagnosis and protracted treatment pathways (McLoughlin et al., 2024). Not being believed or understood has been described as constituting forms of testimonial and hermeneutic injustice (Byrne, 2020), which have similarly been identified across other stigmatised conditions. These experiences of stigma, alongside associated reductions in quality of life (McLoughlin et al., 2024), highlight the importance of targeted training of healthcare professionals to improve the diagnostic process as well as the continued development of specialist FND interventions and services (British Psychological Society (BPS), 2024). Given the disbelief and alienation often reported by pwFND, such development should be conducted in partnership with people with lived experience, rather than relying solely on professionally led accounts of what is needed or useful, as recommended by Bailey et al. (2025).

Acceptance and commitment therapy (ACT) has been cautiously suggested as beneficial in managing the broader impacts of chronic health conditions, including symptom-related worry and comorbid mental health difficulties (Graham et al., 2016; Konstantinou et al., 2023). ACT may be particularly suited to such presentations as it does not directly target alleviation of symptoms which may be intractable in chronic conditions (Curvis & Methley, 2022). Furthermore, whereas therapies such as CBT may aim to refute negative cognitive appraisals, ACT takes the stance that, in the context of poor health, these appraisals may be reasonable responses. There is preliminary evidence for ACT's usefulness for pwFND. In a clinical case series applying ACT to pwFND, Graham et al. (2018) reported large pre-post effect sizes for mental health and psychosocial functioning outcomes ( $d = 1.70$  and  $d = 1.02$ ),

suggesting ACT may be promising for people living with FND. However, caution is required because the study lacked a control condition, did not control for confounders (e.g. placebo effects), and did not measure treatment fidelity. Similarly, in a small feasibility RCT of ACT for functional cognitive disorder, Poole et al. (2025) reported small improvements in psychological flexibility (PF) and larger improvements in self-reported symptom improvement and comorbid anxiety. Their findings also require caution because the comparator group was loosely defined usual-care, and the study may have been statistically underpowered. Clinically, improvements in symptom interference, psychosocial functioning, wellbeing, and quality of life, even when symptoms persist, may arise because PF has been enhanced through ACT. However, PF's relevance to pwFND remains unclear, and few, if any, published studies have explored this directly. Related qualitative research on pwFND's experiences of psychological services has suggested that trusting therapeutic relationships were especially valued, with less apparent emphasis on technical aspects of services or interventions, such as PF (Staton et al., 2024). This suggests a need to consider not only PF, but also how pwFND make sense of and manage their condition, including through illness perceptions.

The Common-Sense Model of Self-Regulation (CSM; Hagger & Orbell, 2022; Leventhal et al., 2016) describes how individuals' illness interpretations shape self-management. Across numerous health conditions, Dempster et al. (2015) suggested that IPs were strongly associated with mental health and quality of life outcomes and predicted engagement with interventions. There has since been increasing focus on IPs among pwFND, with Bailey et al. (2024) and Joos et al. (2024) suggesting that symptom coherence and perceived control, both aspects of the CSM, are associated with decreased treatment adherence. There appears to be scarce research exploring psychological interventions targeting IPs among pwFND, particularly in relation to ACT. Both Karekla et al. (2019) and Graham et al. (2022) argue that ACT may be helpful in addressing unhelpful IPs and understanding how ACT may relate to IPs would support developing specialist interventions for pwFND.

A helpful way of supporting the development of specialist interventions is through qualitative research. Kazdin (2007) discussed how qualitative accounts of psychological interventions can support intervention development through fine-grained analysis of therapeutic processes. This can highlight how participants make sense of helpful and

unhelpful aspects of interventions, supporting the development of approaches more closely tailored to patients' needs and therefore more acceptable, engaging, and meaningful. Given the importance of not relying solely on professionally led accounts of what might be helpful, a qualitative approach, foregrounding patient experience, may benefit efforts to understand ACT for pwFND, particularly because there appears to be limited published research exploring how pwFND experience ACT.

An NHS neuropsychology service piloted an ACT group intervention for pwFND, which consisted of eight two-hour weekly sessions delivered by two clinicians. The primary aim of the present study was to explore how patients experience the ACT group intervention using an inductively oriented reflexive thematic analysis (RTA). This was intended to increase understanding of patients' experiences and to support further development of psychological interventions, such as ACT, for pwFND. A further aim was to explore tentative responses to more theory-informed and applied questions through reflexive engagement with patients' perspectives. The intention was to explore how participants' accounts resonated with, complicated, or exceeded ACT and illness-perception concepts and consider their relevance after foregrounding patients' perspectives.

The primary research question was:

- How do patients experience the ACT group intervention?

The secondary research questions were:

- What did participants experience as the most helpful and unhelpful aspects of the group intervention?
- How, if at all, did participants' qualitative accounts of the group intervention and any change correspond with psychological processes targeted by ACT?
- How did participants retrospectively account for their perceptions of FND across the period before and after the group intervention?

## **Methods**

### **Ethics**

This study received ethical approval (Wales Research Ethics Committee, REC Reference: 25/WA/0115; Appendix 2.2) in April 2025. The participating NHS health board's management approval was granted by their Research and Development Department (Reference: L24096; Appendix 2.2) in May 2025.

### **Design**

This qualitative study explored patients' experiences of the ACT group intervention, through semi-structured interviews.

### **Intervention**

The intervention began with an individual meeting with a clinical psychologist to develop a neuropsychological formulation of the patient's FND using contemporary biopsychosocial models and to establish personalised intervention goals. The subsequent closed-group intervention consisted of eight weekly, in-person, two-hour sessions held at an accessible community venue and facilitated primarily by two ACT-trained clinical psychologists. Sessions linked formulation and goals with ACT exercises, involving present-moment awareness, acceptance, cognitive defusion, values clarification, committed action, and between-session tasks. Additional detail provided in Appendix 2.3.

### **Procedures**

#### **Inclusion and exclusion criteria**

Eligibility for the intervention was assessed by a clinical psychologist using the following criteria:

- be 16 years of age or older.
- have a diagnosis of FND provided by a neurologist.
- be in agreement with the FND diagnosis and not seeking an alternative explanation.
- have sufficient English language proficiency and cognitive capacity to engage.
- present no substantial risk of harm to self or others.

- have no comorbid acquired or progressive brain condition.
- not be currently engaged in another psychological intervention.
- consent to participate in the ACT group intervention.

To participate in the present interview study, patients were required to:

- have attended at least two sessions of the intervention.
- have no severe hearing impairment.

### **Recruitment**

During the intervention, patients were informed of potential future research and provided written consent to be contacted by the NHS neuropsychology service. Sampling was purposeful because patients were recruited for their direct experience of the intervention. The field supervisor, a clinical psychologist, assigned all eligible patients (N = 57) random numbers. Patients were initially contacted in ascending order by the field supervisor and another service clinician, with random ordering intended to promote fairness. As recruitment progressed, limited demographic variability emerged. Therefore, males and non-completers were selectively contacted within the existing numerical order. Despite this adjustment, recruitment was shaped by participant availability and responsiveness, influencing whose experiences are represented. Patients who verbally consented to receive further study information from the PI (a trainee clinical psychologist from the University of Glasgow and NHS) were posted an information sheet and consent form (Appendix 2.4), then telephoned approximately a week later to confirm receipt and to enquire about participation. Of 13 patients contacted, one declined and two did not attend their interviews. No reasons for non-participation were provided. Overall, N = 10 patients participated, with completed consent forms stored securely on NHS premises.

### **Sample**

Demographic information is summarised below to support transferability while minimising the risk of jigsaw identification. Participant and intervention-related information is presented in Table 1. Nine participants were female and one was male. Participants were aged 28 to 74 years (M = 46.5), with FND symptom duration ranging from 2.5 to 13 years (M = 5.2), which was calculated at interview. Three participants were employed part-time, three

were in full-time employment, three were unemployed, and one was retired. Four participants reported high school as their highest level of education, while six reported college or university education. Eight participants were receiving disability-related benefits or support, with seven reporting comorbid conditions. These included osteoporosis; asthma, anxiety, and depression; endometriosis; cervical myelopathy; spinal issues; hearing loss; chronic fatigue syndrome; and arthritis and coeliac disease. Most participants were married, with two living with their partner and one single.

**Table 1**  
*Participant information*

| <b>Cohort no.</b> | <b>Interview no.</b> | <b>Participants</b> | <b>Intervention status</b> |
|-------------------|----------------------|---------------------|----------------------------|
| 2                 | 1                    | Jesse               | Completed                  |
| 1                 | 2                    | Alex                | Completed                  |
| 4                 | 3                    | Jamie               | Completed                  |
| 5                 | 4                    | Brodie              | Completed                  |
| 4                 | 5                    | Charlie             | Completed                  |
| 4                 | 6                    | Ashley              | Completed                  |
| 4                 | 7                    | Robin               | Completed                  |
| 2                 | 8                    | Fran                | Completed                  |
| 1                 | 9                    | Jules               | Completed                  |
| 3                 | 10                   | Morgan              | Completed                  |

*Note.* Participant names are pseudonyms.  
Interviews conducted July–September 2025.  
Completion = attendance at ≥6 intervention sessions. Cohort dates: 1 = February–April 2023; 2 = August–October 2023; 3 = March–May 2024; 4 = August–October 2024; 5 = April–June 2025.

### **Sample size**

Braun and Clarke (2021) recommend using the concept of information power (Malterud et al., 2016), not data saturation, to guide sample size decisions in qualitative research (Appendix 2.7). Following recruitment of 10 participants, sample adequacy was reviewed in academic supervision using information power as a guiding framework. The decision on sample size reflected the specificity of the sample (e.g. shared experience), interview depth,

the scope of research questions, and the coherence of the analytic narrative developed across the dataset.

## **Materials**

An interview schedule (Appendix 2.5) was created to enhance consistency across interviews and was informed by Elliott's chapter on psychotherapy change process research (Elliott, 2012). The schedule facilitated reflection on significant events during the intervention and its helpful and unhelpful aspects. During development, initial versions included questions explicitly referencing ACT strategies and illness perceptions domains, but these were revised before data collection to support a more inductive exploration of participants' experiences.

The schedule was developed in consultation with academic supervisors, clinicians within the NHS neuropsychology service, a clinical lead for a specialist FND psychology service in NHS Fife, and experts by experience. Three experts by experience, recruited through FND Hope, were consulted in June 2025 and informed adaptations to the language and delivery of the schedule. For example, experts by experience cautioned that 'illness perception(s)' could be misinterpreted as implying symptoms were inauthentic. In response, questions explicitly referencing illness perceptions domains were reworded or removed to reduce theory-laden language. During interviews, greater attention was given to validating participants' experiences. A demographic questionnaire was completed following interviews to support consideration of transferability.

## **Data collection**

Ten one-to-one semi-structured interviews were conducted by the principal investigator between July and September 2025, each lasting between 45 and 90 minutes. Based on cohort completion months, the approximate interval between intervention completion and interview ranged from 1 to 29 months. Interviews were retrospective, with participants reflecting on their experiences before, during, and after the intervention. Eight interviews were conducted via NHS Attend Anywhere (video consultation software), and two were completed in person at participants' local health centres. No repeat interviews were conducted. All interviews were audio-recorded on an NHS-encrypted device, with recordings stored securely on an NHS server. The PI anonymised and transcribed recordings verbatim.

Anonymised transcripts were stored and accessed securely on NHS and University of Glasgow servers, and recordings securely disposed of at end of study. Due to time constraints, transcripts were not shared with participants for review.

### **Data analysis**

An inductively oriented reflexive thematic analysis (RTA; Braun & Clarke, 2021) was selected to analyse interview transcripts. This enabled attention to patterned meaning while retaining reflexive awareness of my role in interpretation. A critical realist, contextual position informed attention to both participants' accounts and their wider social and service contexts. Although the secondary research questions were theory-informed, a deductive or codebook thematic analysis (TA) was less aligned with my aim of rich, reflexive theme development. I conceptualised themes as actively constructed through reflexive engagement with the data, rather than identified within it. Phenomenological approaches were less suited to the study's focus on patterned meaning across accounts, rather than idiographic accounts of lived experience. Psychological flexibility and illness perceptions were not used as coding frameworks, as the primary aim was to foreground participants' experiences; instead, they were considered after theme development to support a cautious, theory-informed discussion of the secondary research questions.

I familiarised myself with the interview content through multiple transcript readings, noting features interpreted as relevant to the research questions, idiosyncratic, or particularly meaningful to participants. I independently coded transcripts at semantic and latent levels, using labels that represented my interpretation of participants' meanings. Codes were clustered into patterns of interpreted shared meaning, with themes revised across extracts, transcripts, and the developing analytic narrative. I then named, defined and refined these themes, considering how they formed a coherent thematic account and interpretative response to the research questions. Reflective discussions with peers and supervisors supported reflexive engagement with my interpretations and attentiveness to participants' accounts. The analysis was managed in NVivo (Version 14) (Lumivvero, 2025). A fuller analytic record and quality and reporting checklists are provided in Appendices 2.1., 2.2., and 2.6.

## **Reflexivity and positionality**

I am a male, CAMHS-aligned trainee clinical psychologist from a working-class and mixed ethnic background, with a young family. These characteristics and my training as a person-centred counsellor, and later CBT and ACT practice in a clinical health psychology service, including work with people with FND, likely shaped the project's design, data collection, analysis, interpretation, and reporting.

Navigating cultural identities and training across clinical traditions may have contributed to my view that knowledge is shaped by cultural, social, political, and economic contexts. This informed a critical realist and contextual stance, including efforts to balance theory with participant perspectives. For example, secondary research questions were theory informed but approached with openness to divergence, while the interview schedule was developed with patient and public involvement and transcripts were analysed inductively.

Time constraints associated with doctoral training alongside parental responsibilities may have shaped the depth and pace of my analytic work. As ethnicity was not self-reported, the sample's ethnic composition cannot be established. I nevertheless perceived participants as White Scottish, which I recognise is not demographic evidence and may reflect my own assumptions about ethnicity. Consequently, inequalities affecting people from marginalised ethnic backgrounds is unexamined in this project.

## Results

Three themes were developed: (1) 'FND as eroding sense of self'; (2) 'Group as validation and exploration'; and (3) 'Healing as divergent realities'. These themes tell a story of people with FND describing safety and skill development within the group, alongside possible restoration of a sense of self, following experiences of stigma, fear, and isolation, while some remained affected by ongoing hardship. Overall, the themes suggest the ACT group intervention felt helpful when it recognised what FND had taken from participants and linked it with reconnection with what mattered, but less helpful when this felt unsafe, unrealistic, or insufficient. An overview of the themes and subthemes is presented below in Table 2.

**Table 2**  
*Themes and subthemes*

|                                   | Themes                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                      |
|-----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------|
|                                   | Theme one: FND as eroding sense of self                                                                                                       | Theme two: Group as validation and exploration                                                                                                                                                                                                                                                                                                  | Theme three: Healing as divergent realities                                                                                          |
| <b>Definitions</b>                | This theme illustrates seemingly shared experiences of hardship prior to the group, which presented living with FND as eroding sense of self. | This theme interprets group as representing safety and comfort from hardship and a space for exploring strategies for managing wellbeing. Group was opportunity to restore sense of self.                                                                                                                                                       | This theme illustrates how the form and sustainability of perceived change were understood in relation to participants' wider lives. |
| <b>Sub-themes and definitions</b> |                                                                                                                                               | <p><b>Listening and validation as soothing:</b> Active listening and communicating understanding seemed common and meant people felt comfortable and relaxed.</p> <p><b>Managing wellbeing through exploration:</b> An active process of exploring strategies seemed present, which involved strategies that resonated more so than others.</p> |                                                                                                                                      |

Note. In the extracts illustrating themes, '...' denotes removed irrelevant text or short pauses.

### **Theme one: FND as eroding sense of self**

This theme illustrates shared experiences of hardship before group attendance, which seemed to threaten participants' sense of self. Sense of self was interpreted broadly, comprising identity, values, abilities, and self-worth. These pre-group experiences appeared to shape how participants entered the intervention. This hardship was multifaceted, with stigma appearing as one notable dimension.

“...people... don't understand my condition, people can be quite judgmental and that's why I close myself off to a lot of people... I let people see what they want to see and that's it... there's only a few people who've actually seen me at my worst and that's my husband and my two boys and my mum. My sister seen my tremors once... and she was inconsolable, she really panicked, she got really upset, so I tend to hide a lot of my symptoms... I don't want to upset anyone else.” (Brodie, Interview 4)

In the above extract, Brodie's reference to people not understanding her condition and being judgmental echoes a seemingly common experience across the sample of having symptoms disbelieved or dismissed as less important compared to conditions with structural pathology. Her response to the anticipated judgement and misunderstanding was to isolate herself. This extract highlights another aspect of stigma, whereby her symptoms were viewed as upsetting – in this instance, by her sister. Although her sister's reaction may reflect concern rather than judgement, it seemed to leave Brodie feeling responsible for managing the emotional impact of her symptoms on others. For Brodie, this meant being unable to be her authentic self and having to hide symptoms. This appeared alongside a narrowing of who could see their struggles and who they could rely on for support. Stigma did not always seem solely relational within the sample. There seemed to be instances of structural stigma alongside isolation:

“...you know... there really is those feelings that you feel... if organising a night out... it needs to be somewhere that is accessible for me... that discounts some options and... then you feel like you're, you become a burden to some people.” (Ashley, Interview 6)

For Ashley, a limited number of accessible venues was a barrier to him socialising and contributed to him viewing himself as burdensome to his friends. The limitations of his built and perhaps social environment contributed to his social isolation, despite him seemingly

wanting connection. Moreover, stigma did not seem to be the only driver of isolation.

Participants described isolation from loss of meaningful occupation:

“Oh, I missed my patients. I used to come in, sometimes 20 minutes before my time just to have a chat. ‘I haven’t seen them for 6 weeks’, ‘who’s that?’, ‘What’s that?’. I would have a pile of work sitting at the back desk... the patients came first... I think I felt my legs had been cut off...” (Alex, Interview 2)

Alex had worked for approximately 50 years and described living to work. Work was meaningful and sociable, and losing employment because of FND left her feeling like her “legs had been cut off”. She was isolated and later described feeling depressed, suggesting that meaningful occupation was important for maintaining her wellbeing and sense of self. Alex was not alone in experiencing living with FND as having a negative emotional impact:

“...I had been clinging onto the hope that, you know, there would be a treatment or a tablet... that would get me back... I will get back to who I was. It hadn’t entered my mind that, that was a door that was maybe closing... yeah, that was a dark place that I went to.” (Charlie, Interview 5)

Charlie described a dawning realisation that a return to life as she knew it was perhaps not possible. It had been upsetting that there was seemingly no curative treatment for her FND symptoms. Her happiness was contingent on being symptom-free and being able to live a certain lifestyle that represented who they were. Robin, like others, seemed to be grieving the various losses that came with living with FND:

“...I spent my time grieving... grieving that I wasn’t Robin that likes the gym, that cooked, and meal prepped...I can’t chop things...” (Robin, Interview 7)

Robin described explicitly grieving a former self and currently being a version of herself that she did not recognise. Robin’s value was represented by completion of these activities. This grieving process seemed anxiety provoking for others.

“It was the worry that... I was going to be housebound; I was going to be in a wheelchair... My partner... I’ve had... like, two years... —you’re worrying... about putting that pressure on him; putting that pressure on my daughter. It’s a... worry that, if you’re not well, what pressures are you putting on other people in your household? ...it was such a concern—like sleepless nights. It was almost like I was grieving my old self.” (Morgan, Interview 10)

Morgan was grieving her old self because her current self was a source of worry. Her symptoms were viewed as threatening to her everyday functioning and the quality of her

relationships, perhaps even threatening her relationship status. This was important because being a parent and partner appeared central to who she was. Morgan's extract perhaps also demonstrates the dual state of grief and fear interpreted among participants. For Jesse, though, fear seemed more singular than entwined with grief.

"I was just adamant that I was dying and I was just like, it was just horrific... they reassured me that I was not well, but it wasn't the end." (Jesse, Interview 1)

Before attending the intervention, Jesse described being terrified of her symptoms because, she thought she was dying. Death may represent the ultimate loss of self. However, these anxieties and fears appeared soothed by the group facilitators.

This theme highlights how experiences of hardship involving stigma, isolation, loss, and fear may collectively position living with FND as a threat to participants' sense of self. These experiences of living with FND may have shaped later experiences of the group. Participants' sense of self appeared to be closely linked to their wellbeing.

## **Theme two: Group as validation and exploration**

In the second theme developed from the interview transcripts, there appeared to be a sense among participants that the group represented safety and comfort following previous hardship and threatening experiences, while also providing a space where their struggles were validated. This seemed to occur in a context where strategies for managing wellbeing were explored. The first sub-theme represents listening and validation as soothing.

### ***Listening and validation as soothing***

Across the interviews, it seemed that being actively listened to by other group members and explicitly communicating understanding of difficulties were comforting and linked to people feeling relaxed. However, simply being present with others who shared similar experiences seemed sufficient to provide relief.

"Fran – 'It was... help to meet other, not other people with the same...'

Interviewer – 'It was helpful ...to meet?'

Fran – 'It was, yes, because you think it is only you.'" (Fran, Interview 8)

Fran described a prominent feature of her FND was losing the ability to speak fluently, which contributed to her loss of employment and feelings of isolation. She also described

continuously questioning why her symptoms presented, being confused by them, and feeling as though she were fabricating them – despite knowing otherwise. Meeting others who shared similar experiences therefore seemed a relief. The presence of people sharing similar experiences validated them. This sense of not being alone anymore seemed common.

“...I felt listened to... Before, I... felt like I was being dismissed all the time... told I had anxiety ...that itself breaks you down as a person when you know there’s something more... So, having people sit and listen to you and understand and validate everything you are feeling... is reassuring...” (Jesse, Interview 1)

For Jesse, the group’s validation seemed linked to restoring the sense of self eroded by earlier stigmatising experiences from health professionals, who were reported as routinely misattributing their symptoms to poor mental health. This validation reassured her that the symptoms were real and present, as she thought they were. This reassurance appeared calming and legitimising. In other interviews, feeling heard seemed calming and conducive to people sharing their experiences.

“...it made you open up and explain your experience... I needed it at that time.” (Jules, Interview 9)

Throughout her interview, Jules reported feeling grateful for the group, partly because she felt listened to by the facilitators. Jules seemed to describe how the intervention helped her open up and explain her experiences at a time when she needed this. This may suggest that being listened to created a sense of validation, which made sharing feel more possible and may have created an opportunity for connection with other people.

“It’s absolutely easier for me to stay at home and never go out again... I can have food delivered, I can have entertainment delivered, streamed... always easier to not leave the house. And, going to the group session... it’s a nice thing, we had tea and biscuits and we talk... I think everyone felt quite down when it came to an end... we do keep in touch.” (Charlie, Interview 5)

Charlie reported appreciation for the connections and relationships developed. These seemed to develop not only through conversation or the sharing of information, but through the ritual of sharing tea and biscuits. For Charlie, the group represented connection and comfort, which seemed important to her, alongside curiosity and exploration.

### ***Managing wellbeing through exploration***

It seemed across interviews that there was an active process of exploring strategies for managing wellbeing. Due to the group's emphasis on trialling different strategies, some strategies seemed to resonate, while others did not. Whether strategies were useful or not seemed to reside in a broader context of expectations for the group and what exploration might lead to.

“Interviewer – ‘...what did you make of the idea of acceptance of symptoms or... the suggestion that you can live well with FND?’

Fran – ‘I think that might be somebody who's not got FND that told you that.’

Interviewer – ‘...tell me more...’

Fran – ‘I just think you learn to live with it, I don't think you live well with it. I think it sounds good, but it sets people up to fail, not correct title.’” (Fran, Interview 8)

During her interview, Fran seemed to describe being increasingly sceptical of the group's purpose as the weeks progressed. This scepticism is demonstrated in the above extract, where she described a seemingly wider belief that living well with FND was not possible and that suggesting otherwise offered false hope. This suggested divergent expectations, disappointment, and hopelessness. It also seemed potentially invalidating, as she reported significant socioeconomic loss because of her FND. Scepticism also seemed accompanied by disengagement with therapeutic exercises offered in the group.

“Interviewer – ‘...did you practice any of them?’

Fran – ‘Well, I was always out anyway, I walk every day... but some of the other people hadn't been going out, so it helped them.’

Interviewer – ‘...did it help you?’

Fran – ‘Sorry.’” (Fran, Interview 8)

For Fran, there seemed to be a latent theme of detachment from the therapeutic exercises, and in this instance she was referring to what was intended to be a self-generated behavioural activation task set by the group facilitators. Fran seemed to be communicating an ambivalence about therapeutic exercises, which were perceived as unhelpful. Elsewhere, there seemed to be contrasting experiences.

“I said I would love a bath... I take a shower all the time because I can’t get in and out... I feel embarrassed to ask my partner and that was on my list and I done it. I would never have taken a bath. ...I’m like Moby Dick trying to get back out... embarrassing but it almost pushed you to... move forward with your diagnosis.” (Morgan, Interview 10)

Earlier in her interview, Morgan described modest, but hopeful, expectations for the group. Here, she described a sense of achievement after completing a task that she set herself. Goal setting and graded tasks appeared to help them through discomfort with her appearance, physical abilities, and asking for help. This gave a sense of moving away from feeling unhappy and stuck. In addition to moving towards their goals, some participants experienced the strategies offered by the group as helping provide perspective.

“...for me, the biggest moment was... the passengers-on-the-bus analogy... thinking, you know, I would never say that to anyone else, even someone I hated. I wouldn’t project that onto them. Why am I letting myself project that onto myself? Why am I accepting that coming from myself? ...just that realisation that I had fallen into that trap, as it were.” (Ashley, Interview 6)

For Ashley, the passengers-on-the-bus experiential exercise, which aimed to build awareness of challenging internal experiences, helped him begin to question how he cared for himself and how his current forms of coping were perhaps lacking compassion or helpfulness and were prejudiced against him. This realisation seemed to represent increasing distance from an unhappy situation and gave a sense of optimism about life with FND. Responses to these exercises varied across interviews.

“...it was on your bus. ...my value was to try and get out on my scooter, my passengers... one of them was pain ...you will take unwell ...my scooter will break down ...the battery will run out of charge ...you need to go out alone because no one wants to go with you. ...the four passengers behind me where shouting that at me... I was still having to drive the bus but... it caught me out... this is what I live with every single day in life ...it was really upsetting; I really did not like that practice at all one bit. ...it was very traumatic.” (Brodie, Interview 4)

Brodie appeared to find it difficult to engage directly with internal experiences that felt upsetting. The exercise represented an unexpected traumatic confrontation, highlighting the potential for adverse experiences in psychological interventions. Rather than supporting transition towards living meaningfully with a chronic condition, it appeared to intensify awareness of her ongoing suffering. Despite this difficult experience, Brodie later described

an ambivalent response to the group. She described continuing to suffer across multiple life domains and described herself as a sufferer but also reported feeling more connected with others and identifying connection as a value.

This second theme illustrates the group as not simply a forum to discuss FND but a place to be seen by others and explore strategies for wellbeing. This validation and exploration seemed to offer an opportunity to restore a sense of self that appeared eroded by experiences of stigma, isolation, loss, and fear.

### **Theme three: Healing as divergent realities**

The final theme captures an interpreted pattern across interviews suggesting that, despite the shared group context, participants' accounts linked perceived change to the wider realities of their lives. Healing, participants' language, was broadly interpreted as involving restoration of what felt meaningful to participants. Healing that felt possible within the group was sometimes difficult to sustain when support receded. Elsewhere, healing took forms compatible with ongoing symptoms, changing identities, or access to practical support.

“...I was at the group and I felt great afterwards, I know how to manage everything... you just go back to what you know. ...it's like I know all the information, I just can't I just do it. ...I'm struggling to... navigate my way through life.” (Jamie, Interview 3)

During the group, Jamie reported achieving small, personalised goals, which she associated with improved confidence, mood, and symptom management. She was doing things that were important to her and living well with FND initially seemed possible. However, several weeks later, she began to struggle again, describing returning to what she knew and being unable to sustain changes. For her, information on symptom management was insufficient; daily life seemed overwhelming, suggesting that learning, development, or healing had been scaffolded by the group. For others, this scaffolding appeared less necessary.

“...it's been liberating, it's like a weight has been lifted. As I said earlier, it's given me hope back. And yes, I might not be going out running marathons... but that doesn't mean... that I can't live an active and healthy lifestyle...”  
(Ashley, Interview 6)

At the time of the interview, several months had passed since Ashley completed the group. Despite ongoing pain attributed to FND, Ashley continued to feel relief and hope and appeared accepting that he might remain unable to complete activities to the extent he desired. He was optimistic that leading a life in line with values, such as being active, while experiencing symptoms, was possible. This meant, for Ashley, mood and symptoms were not wholly dependent on one another, and healing may be possible when its form compatibly relates to his ongoing reality. Similar accounts were offered elsewhere.

“Healing... almost like a sense of ...this is what this is. ... I didn’t realise, how much... I was... holding on to, I was holding onto an older me that wasn’t going to come back... there’s nothing I can change about me not being able to do those things anymore. ...people now see me and they go, ‘you just haven’t changed’ and I’m like but I have changed. You know what I mean... I’m genuinely doing the exact same as what I was doing before, only I’m living with FND.” (Robin, Interview 7)

Robin seemed to be describing a process of letting go of an older version of herself, alongside a renewed sense of purpose and focus on activities she had always done. Outwardly, Robin had not changed but inwardly change seemed significant. She seemed more connected with her values. Healing, for Robin, involved changing her relationship with symptoms and daily activities, while reconnecting with what was meaningful to her. It seemed to involve allowing experiences to be present, rather than rejecting them. For others, perceived healing appeared more closely tied to practical and external support.

“...I felt a new person, I felt I was able to cope... doing that course led me to... a physical therapist... they put me onto a strength and balance course... I now go to a circuit training class at least once a week...” (Alex, Interview 2)

Alex earlier reported improved mood and described feeling ‘like [her] old self’, someone who liked to converse and socialise. Signposting and connection with other professionals seemed particularly important. For Alex, healing appeared to involve accessing practical support more tailored to her needs. In other interviews, healing seemed less about external resources and more about building internal resources.

“Jules – ‘...I’ve not had an episode where I’ve been shaky or where I’ve been in floods of tears, uncontrollable.’

Interviewer – ‘Why do you think that is?’

Jules – ‘Probably because I know how to manage it.’” (Jules, Interview 9)

Jules described no longer experiencing uncontrollable tears, which had reflected her anxiety. Jules had previously discussed feeling panic and fear in response to symptoms. For Jules, healing involved not only symptom management and symptom frequency but also feeling empowered in relation to her difficulties.

This final theme, 'Healing as divergent realities', illustrated a shared pattern in which the form and sustainability of perceived change were understood through the interaction between the intervention and their broader personal contexts.

## Discussion

This study explored how patients experienced the ACT group intervention, including what they experienced as helpful or unhelpful, how their accounts appeared to correspond with psychological processes targeted by ACT, and how they made sense of FND before and after the group. Following an inductively oriented reflexive thematic analysis, three themes were developed: (1) 'FND as eroding sense of self'; (2) 'Group as validation and exploration'; and (3) 'Healing as divergent realities'. These themes tell a story of people with FND describing safety and skill development within the group, alongside possible restoration of a sense of self, following experiences of stigma, fear, and isolation, while some remained affected by ongoing hardship. The discussion first considers how each theme relates to existing literature, before drawing the themes together to address primary and secondary research questions.

In theme one, participants reported experiences of loss, fear, isolation, and stigma. Although these accounts mainly concerned experiences pre-intervention, they are important to understanding how participants experienced the group, because they may have shaped what participants needed and valued. These accounts resonated with themes of testimonial and hermeneutic injustice described by Byrne (2020) and wider, layered experiences of stigma encountered by pwFND (McLoughlin et al., 2024). McLoughlin et al. (2024) described stigma as a process involving intrapersonal, interpersonal, and structural aspects that affect quality of life. They also suggested that clinicians may have an important role in combating stigma and associated distress through validation. Theme two builds on this suggestion by illustrating how validation within the group appeared comforting and linked it with possible restoration of a sense of self.

Theme two further suggested that, in relation to what participants experienced as helpful, validating relationships appeared central. This aligns with Staton et al.'s (2024) suggestion that such relationships are highly valued by pwFND. It also suggests that an empathic group context may support exploration of strategies for reconnecting with meaningful activity and wellbeing, echoing Skourteli and Lennie's (2011) comments on therapeutic relationships as regulating affect and providing a context for exploration. This appeared relevant to participants' engagement with ACT strategies. These strategies generally seemed well received, resonating with favourable findings regarding ACT's

application to FND and other chronic health conditions (Graham et al., 2016; 2018; Konstantinou et al., 2023). However, this study adds complexity by suggesting validation may be as important to patients as ACT strategies themselves. Further nuance regarding unhelpful aspects of the intervention is offered by Brodie's distress following an experiential exercise and Fran's experience of socioeconomic difficulties being invalidated by suggestions of living well with FND. These accounts echo the underreported adverse experiences of psychological interventions discussed by Strauss et al. (2026) and highlight the need for sensitivity to individuals' contexts.

In theme three, varied and contextual experiences of healing resonated with biopsychosocial understandings of illness (Bolton, 2023). This was perhaps demonstrated by Ashley and Robin reporting ongoing physical symptoms as not being a barrier to feeling optimistic and more connected to values, suggesting their symptoms and wellbeing were not mutually exclusive. This also resonated with Conrad and Barker's (2010) argument that illness understandings are mediated through cultural practices. Relatedly, accounts within this theme emphasise the relational nature of the group. Jamie struggled without the group's support, which seemed to scaffold progress. Konstantinou et al. (2023) position quality of life as being supported by learning strategies, but Jamie's account tentatively suggests learning and development were supported by social interaction. The relational and contextual nature of participants' accounts therefore appeared central to how participants experienced the intervention.

Responding to the primary research question, the themes linked perceived helpfulness with validating relationships and feeling understood. These relationships appeared to provide context for participants reconnecting with what was important to them, with ACT strategies seeming linked to that reconnection. For participants, the intervention seemed relational, with its helpfulness perhaps judged by its sensitivity to their contexts. This may represent a difference between participants' priorities and more professionally or theory-led accounts of what is therapeutically important in interventions for pwFND, particularly within the intervention. Having foregrounded participants' experiences, the secondary research questions are considered cautiously in relation to psychological flexibility (PF) and illness perceptions (IPs).

In relation to the secondary question concerning ACT processes, aspects of participants' accounts were interpreted as resembling elements of PF. Ashley appeared to describe becoming more aware and less attached to self-critical thoughts, alongside increased hope and optimism. From an ACT perspective (Hayes et al., 2012), this resembled cognitive defusion and present-moment awareness. Relatedly, Robin described inward change that resonated with mindful engagement with valued activities. Together, these observations suggested that PF may be useful for understanding what participants experienced as helpful or unhelpful. However, this interpretation requires caution. Participants' accounts and language may have been shaped by ACT and PF. Patients may become socialised into therapeutic models, and using therapy-consistent language does not necessarily mean change occurred or that therapy produced change. Self-reported therapy outcomes may also omit key evaluative information (Elliott, 2010). Additionally, my ACT training, theory-informed research questions, and profession may have made ACT-consistent meanings more salient than alternatives. For example, participants may have benefited from feeling validated and safe to explore strategies with facilitators and peers. Such relational processes are not incompatible with ACT but may be less foregrounded in accounts of ACT's application to FND. Overemphasising PF may also obscure the possible relevance of illness perceptions.

In response to the secondary research question concerning how participants retrospectively accounted for their perceptions of FND before and after the group, FND appeared more incoherent and threatening before the intervention. Living with symptoms threatened participants' credibility, relationships, and lives. For example, Morgan described worrying about the impact of FND on her partner and daughter. Jesse similarly described confusion about symptoms being accompanied by fears of death. For Jesse, Morgan, and others, perceptions appeared less threatening and more coherent in retrospective accounts of the period following intervention. These perceptions resonate with the CSM (Hagger & Orbell, 2022; Leventhal et al., 2016) and suggestions that perceived threat and incoherence influence quality of life among pwFND (Bailey et al., 2024). Retrospective accounts of shifting perceptions of FND post intervention suggest that the CSM may help interpret some aspects of what participants experienced as helpful or unhelpful. However, as with PF, considering participants' accounts in relation to IPs requires caution. Transcripts were

inductively coded, and IPs were not used as a coding framework. As a result, coverage of IPs across interviews cannot be reliably assessed. Nevertheless, considered retrospectively rather than as a coding framework, IPs and PF may help make sense of some aspects of what was helpful and unhelpful to participants.

### **Strengths and limitations**

To the author's best knowledge, there is no published qualitative research exploring patient accounts of an ACT for FND group intervention. Strengths included meaningful involvement of experts by experience, highlighting the importance of validating relationships, and tentatively suggesting PF and IPs as helpful for partially understanding patient experiences. The study highlighted potential adverse experiences during intervention, contributing to understanding of how an ACT intervention for pwFND may be experienced and developed further.

Alongside strengths, several limitations require consideration. Given limited research on ACT-FND groups, the study was designed broadly to explore patient experience and theory-relevant material. However, a narrower focus may have allowed greater analytic depth, particularly in relation to PF and IPs, prompting reflection on my assumption that research value lay in novelty and breadth over focused, incremental contributions. Interview mode may also have shaped rapport, disclosure, and my noticing of embodied discomfort, while resource constraints potentially shaped the sample.

The sample consisted of ten patients who had completed the intervention, aged 28 to 74 years, and was predominantly female, with one male participant. Ethnicity was not collected, reflecting insufficient consideration of its relevance at design stage, potentially shaped by epidemiological literature foregrounding other characteristics, such as age and sex. I perceived participants as White Scottish, but this was not self-reported and local population data cannot substitute for self-identification. This omission limited assessment of sampling inequalities and transferability, particularly important given inequalities affecting marginalised communities in Scotland (Public Health Scotland, 2023). Attempts were made to recruit more males and non-completers. As all participants had also completed the intervention, the study may underrepresent experiences of males and those who disengaged or experienced it less positively. Although randomised recruitment was intended to be

procedurally fair, it did not address structural factors that may have shaped intervention completion or study participation. More purposeful sampling procedures could have enhanced the study's exploratory nature and diversity. FND sub-type was also not formally collected, although classification may be complicated by the chronic, fluctuating, and comorbid nature of symptoms. This information would have supported readers' consideration of transferability.

## **Implications**

Theoretically, the analysis cautiously suggests that PF and IPs may help understand the intervention experiences of pwFND, although this warrants further exploration. Clinically, and theoretically, participants' accounts suggest that validation and safe relationships were prominent in accounts of perceived change alongside ACT strategies. The intervention protocol may therefore benefit from making relational processes more explicit, supporting consistency in delivery and evaluation. It may also be helpful to acknowledge the potentially challenging nature of experiential exercises, including possible distress. At a service level, participants' accounts highlight the importance of stepped, matched, and multidisciplinary care. Many participants presented with complex difficulties, meaning the intervention may have been too broad to address individual needs fully. Without acknowledging this, patients may feel invalidated. For example, Fran's socioeconomic difficulties suggested psychological intervention addressed only one part of her needs. Situating the intervention earlier within a clinical pathway may therefore be appropriate, provided more intensive individual support remains available. Finally, considering theme three, meaningful occupation could be considered a relevant clinical and service-level outcome for evaluating intervention utility.

## **Future directions**

The findings may inform future quantitative research exploring whether concepts highlighted by the analysis, such as therapeutic relationship quality, psychological flexibility, and illness perceptions, are associated with quality of life, symptom interference, symptom frequency, and mental health outcomes. Prospective research could examine any associations before, during and after intervention, while qualitative research could explore how participants' experiences evolve over the course of intervention, as retrospective accounts may differ when elicited during or closer to intervention. Future research could

purposively address sampling gaps and record clinically established FND subtype to explore variation in experiences. It would also be valuable to explore experiences of individual interventions and whether the importance of relationships remain salient in participants' accounts.

## **Conclusion**

The study primarily aimed to explore how patients experienced the ACT group intervention and to consider theory-informed and applied questions by interviewing ten participants who had attended the intervention. Following reflexive thematic analysis, three themes told a story of people with FND finding safety and developing skills within the group following experiences of stigma, fear, and isolation, while some remained affected by ongoing hardship. Through interpretation, participants seemed to value validation and relationships and the opportunity to reconnect with what was meaningful to them. PF and IPs may offer useful partial lenses for understanding these experiences, but the findings suggest that validating relationships and sensitivity to contexts could be central to intervention development.

## References

- Bailey, C., Agrawal, N., Cope, S., Proctor, B., Mildon, B., Butler, M., Holt, K., Edwards, M., Poole, N., & Nicholson, T. R. (2024). Illness perceptions, experiences of stigma and engagement in functional neurological disorder (FND): Exploring the role of multidisciplinary group education sessions. *BMJ Neurology Open*, 6(1), Article e000633. <https://doi.org/10.1136/bmjno-2024-000633>
- Bailey, C., Tamasauskas, A., Bradley-Westguard, A., Gilli, P., Poole, N., Edwards, M. J., Agrawal, N., & Nicholson, T. (2025). What are the experiences of people with motor and sensory functional neurological disorder? A systematic review and thematic synthesis of qualitative studies. *Disability and Rehabilitation*, 47(1), 1–15. <https://doi.org/10.1080/09638288.2024.2333491>
- Bolton, D. (2023). A revitalized biopsychosocial model: Core theory, research paradigms, and clinical implications. *Psychological Medicine*, 53(16), 7504–7511. <https://doi.org/10.1017/S0033291723002660>
- Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide* (1st ed.). Sage.
- British Psychological Society. (2024). *Functional neurological disorder: Neuropsychological and psychological management in children and adults* (Briefing paper). <https://www.bps.org.uk/guideline/functional-neurological-disorder-neuropsychological-and-psychological-management-children>
- Byrne, E. A. (2020). Striking the balance with epistemic injustice in healthcare: The case of chronic fatigue syndrome/myalgic encephalomyelitis. *Medicine, Health Care and Philosophy*, 23(3), 371–379. <https://doi.org/10.1007/s11019-020-09945-4>

- Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior*, 51(1\_suppl), S67–S79.  
<https://doi.org/10.1177/0022146510383495>
- Curvis, W., & Methley, A. (2022). *Acceptance and commitment therapy and brain injury: A practical guide for clinicians*. Routledge. <https://doi.org/10.4324/9781003024408>
- Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping in physical health conditions: A meta-analysis. *Journal of Psychosomatic Research*, 79(6), 506–513. <https://doi.org/10.1016/j.jpsychores.2015.10.006>
- Elliott, R. (2010). Psychotherapy change process research: Realizing the promise. *Psychotherapy Research*, 20(2), 123–135.  
<https://doi.org/10.1080/10503300903470743>
- Elliott, R. (2012). Qualitative methods for studying psychotherapy change processes. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 69–81). John Wiley & Sons. <https://doi.org/10.1002/9781119973249.ch6>
- Graham, C. D., Gouick, J., Krahé, C., & Gillanders, D. (2016). A systematic review of the use of acceptance and commitment therapy (ACT) in chronic disease and long-term conditions. *Clinical Psychology Review*, 46, 46–58.  
<https://doi.org/10.1016/j.cpr.2016.04.009>
- Graham, C. D., McCracken, L. M., Harrison, A., Walburn, J., & Weinman, J. (2022). Outlining an acceptance and commitment therapy approach to treatment non-adherence. *British Journal of Health Psychology*, 27(1), 1–12.  
<https://doi.org/10.1111/bjhp.12579>

- Graham, C. D., O'Hara, D. J., & Kemp, S. (2018). A case series of acceptance and commitment therapy (ACT) for reducing symptom interference in functional neurological disorders. *Clinical Psychology & Psychotherapy*, 25(3), 489–496.  
<https://doi.org/10.1002/cpp.2174>
- Hagger, M. S., & Orbell, S. (2022). The common-sense model of illness self-regulation: A conceptual review and proposed extended model. *Health Psychology Review*, 16(3), 347–377. <https://doi.org/10.1080/17437199.2021.1878050>
- Hayes, S. C., Pistorello, J., & Levin, M. E. (2012). Acceptance and commitment therapy as a unified model of behavior change. *The Counseling Psychologist*, 40(7), 976–1002.  
<https://doi.org/10.1177/0011000012460836>
- Hill, G., Hynd, N., Price, J., Evans, S., Moffitt, J., & Brechin, D. (2017). *Living well with neurological conditions: An eight-week series of group workshops informed by acceptance and commitment therapy (ACT)* [Group intervention protocol]. South Tees NHS Foundation Trust. <https://goo.gl/aX6qB5>
- Joos, A., Popkirov, S., Lahmann, C., Jöbges, M., Herrmann, C., Maner, P., Schörner, K., Birke, G., & Hartmann, A. (2024). Illness perception in functional neurological disorder: Low illness coherence and personal control. *BMJ Neurology Open*, 6(1), Article e000648.  
<https://doi.org/10.1136/bmjno-2024-000648>
- Karekla, M., Karademas, E. C., & Gloster, A. T. (2019). The common-sense model of self-regulation and acceptance and commitment therapy: Integrating strategies to guide interventions for chronic illness. *Health Psychology Review*, 13(4), 490–503.  
<https://doi.org/10.1080/17437199.2018.1437550>

Kazdin, A. E. (2007). Mediators and mechanisms of change in psychotherapy research.

*Annual Review of Clinical Psychology*, 3, 1–27.

<https://doi.org/10.1146/annurev.clinpsy.3.022806.091432>

Konstantinou, P., Ioannou, M., Melanthiou, D., Georgiou, K., Almas, I., Gloster, A. T.,

Kassianos, A. P., & Karekla, M. (2023). The impact of acceptance and commitment

therapy (ACT) on quality of life and symptom improvement among chronic health

conditions: A systematic review and meta-analysis. *Journal of Contextual Behavioral*

*Science*, 29, 240–253. <https://doi.org/10.1016/j.jcbs.2023.08.004>

Leventhal, H., Phillips, L. A., & Burns, E. (2016). The common-sense model of self-regulation

(CSM): A dynamic framework for understanding illness self-management. *Journal of*

*Behavioral Medicine*, 39(6), 935–946. <https://doi.org/10.1007/s10865-016-9782-2>

Lumivero. (2025). NVivo (Version 14) [Computer software].

<https://lumivero.com/products/nvivo/>

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview

studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753–

1760. <https://doi.org/10.1177/1049732315617444>

McLoughlin, C., McWhirter, L., Pisegna, K., Tijssen, M. A. J., Tak, L. M., Carson, A., & Stone, J.

(2024). Stigma in functional neurological disorder (FND): A systematic review. *Clinical*

*Psychology Review*, 112, Article 102460. <https://doi.org/10.1016/j.cpr.2024.102460>

National Institute for Health and Care Excellence. (2024, September). *Functional*

*neurological disorder*. NICE Clinical Knowledge Summaries. Retrieved May 15, 2026,

from <https://cks.nice.org.uk/topics/functional-neurological-disorder>

- O'Mahony, B., Nielsen, G., Baxendale, S., Edwards, M. J., & Yogarajah, M. (2023). Economic cost of functional neurologic disorders: A systematic review. *Neurology*, *101*(2), e202–e214. <https://doi.org/10.1212/WNL.0000000000207388>
- Poole, N., Cope, S., Vanzan, S., Duffus, A., Williams, T., Mantovani, N., Smith, J. G., Barrett, B., Scicluna, M., Beardmore, S., Edwards, M. J., & Howard, R. (2025). Randomised controlled feasibility trial of online group acceptance and commitment therapy for functional cognitive disorder. *BJPsych Open*, *11*(3), Article e91. <https://doi.org/10.1192/bjo.2025.33>
- Public Health Scotland. (2023, May 30). *Monitoring racialised health inequalities in Scotland: Data and evidence*. <https://publichealthscotland.scot/publications/monitoring-racialised-health-inequalities-in-scotland/monitoring-racialised-health-inequalities-in-scotland-30-may-2023/>
- Skourteli, M. C., & Lennie, C. (2011). The therapeutic relationship from an attachment theory perspective. *Counselling Psychology Review*, *26*(1), 20–33. <https://doi.org/10.53841/bpscpr.2011.26.1.20>
- Staton, A., Dawson, D., Merdian, H., Tickle, A., & Walker, T. (2024). Functional neurological disorder: A qualitative study exploring individuals' experiences of psychological services. *Psychology and Psychotherapy: Theory, Research and Practice*, *97*(1), 138–156. <https://doi.org/10.1111/papt.12504>
- Strauss, B., Rosendahl, J., & Klatte, R. (2026). Adverse experiences in psychological treatments: Where do we stand? *Current Opinion in Psychology*, *67*, Article 102161. <https://doi.org/10.1016/j.copsyc.2025.102161>

## Appendices

### Appendix 1.1: PRISMA 2020 Checklist

| Section and Topic             | Item # | Checklist item                                                                                                                                                                                                                                                                                       | Location where item is reported |
|-------------------------------|--------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|
| <b>TITLE</b>                  |        |                                                                                                                                                                                                                                                                                                      |                                 |
| Title                         | 1      | Identify the report as a systematic review.                                                                                                                                                                                                                                                          | P9                              |
| <b>ABSTRACT</b>               |        |                                                                                                                                                                                                                                                                                                      |                                 |
| Abstract                      | 2      | See the PRISMA 2020 for Abstracts checklist.                                                                                                                                                                                                                                                         | P9                              |
| <b>INTRODUCTION</b>           |        |                                                                                                                                                                                                                                                                                                      |                                 |
| Rationale                     | 3      | Describe the rationale for the review in the context of existing knowledge.                                                                                                                                                                                                                          | P10-12                          |
| Objectives                    | 4      | Provide an explicit statement of the objective(s) or question(s) the review addresses.                                                                                                                                                                                                               | P12                             |
| <b>METHODS</b>                |        |                                                                                                                                                                                                                                                                                                      |                                 |
| Eligibility criteria          | 5      | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.                                                                                                                                                                                          | P13, P16                        |
| Information sources           | 6      | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.                                                                                            | P14                             |
| Search strategy               | 7      | Present the full search strategies for all databases, registers and websites, including any filters and limits used.                                                                                                                                                                                 | P14, P75-82                     |
| Selection process             | 8      | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.                     | P15, P17                        |
| Data collection process       | 9      | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | P13-17                          |
| Data items                    | 10a    | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.                        | P18-19                          |
|                               | 10b    | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.                                                                                         | P18-19                          |
| Study risk of bias assessment | 11     | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.                                    | P19                             |
| Effect                        | 12     | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.                                                                                                                                                                  | P22                             |

| Section and Topic             | Item # | Checklist item                                                                                                                                                                                                                                                                       | Location where item is reported |
|-------------------------------|--------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|
| measures                      |        |                                                                                                                                                                                                                                                                                      |                                 |
| Synthesis methods             | 13a    | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).                                                                 | P15-16                          |
|                               | 13b    | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.                                                                                                                                | P15-16                          |
|                               | 13c    | Describe any methods used to tabulate or visually display results of individual studies and syntheses.                                                                                                                                                                               | P15-16                          |
|                               | 13d    | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.                          | P15-16                          |
|                               | 13e    | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).                                                                                                                                                 | N/A                             |
|                               | 13f    | Describe any sensitivity analyses conducted to assess robustness of the synthesized results.                                                                                                                                                                                         | N/A                             |
| Reporting bias assessment     | 14     | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).                                                                                                                                                              | N/A                             |
| Certainty assessment          | 15     | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.                                                                                                                                                                                | N/A                             |
| <b>RESULTS</b>                |        |                                                                                                                                                                                                                                                                                      |                                 |
| Study selection               | 16a    | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.                                                                                         | P17                             |
|                               | 16b    | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.                                                                                                                                                          | P17                             |
| Study characteristics         | 17     | Cite each included study and present its characteristics.                                                                                                                                                                                                                            | P20                             |
| Risk of bias in studies       | 18     | Present assessments of risk of bias for each included study.                                                                                                                                                                                                                         | P19, P83-86                     |
| Results of individual studies | 19     | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.                                                     | P22                             |
| Results of syntheses          | 20a    | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.                                                                                                                                                                               | P21-26                          |
|                               | 20b    | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | N/A                             |
|                               | 20c    | Present results of all investigations of possible causes of heterogeneity among study results.                                                                                                                                                                                       | P21                             |

| Section and Topic                              | Item # | Checklist item                                                                                                                                                                                                                             | Location where item is reported |
|------------------------------------------------|--------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|
|                                                | 20d    | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.                                                                                                                                 | N/A                             |
| Reporting biases                               | 21     | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.                                                                                                                    | N/A                             |
| Certainty of evidence                          | 22     | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.                                                                                                                                        | N/A                             |
| DISCUSSION                                     |        |                                                                                                                                                                                                                                            |                                 |
| Discussion                                     | 23a    | Provide a general interpretation of the results in the context of other evidence.                                                                                                                                                          | P27-28                          |
|                                                | 23b    | Discuss any limitations of the evidence included in the review.                                                                                                                                                                            | P28-30                          |
|                                                | 23c    | Discuss any limitations of the review processes used.                                                                                                                                                                                      | P30                             |
|                                                | 23d    | Discuss implications of the results for practice, policy, and future research.                                                                                                                                                             | P30-31                          |
| OTHER INFORMATION                              |        |                                                                                                                                                                                                                                            |                                 |
| Registration and protocol                      | 24a    | Provide registration information for the review, including register name and registration number, or state that the review was not registered.                                                                                             | P9                              |
|                                                | 24b    | Indicate where the review protocol can be accessed, or state that a protocol was not prepared.                                                                                                                                             | P9                              |
|                                                | 24c    | Describe and explain any amendments to information provided at registration or in the protocol.                                                                                                                                            | P30                             |
| Support                                        | 25     | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.                                                                                                              | P9, P31                         |
| Competing interests                            | 26     | Declare any competing interests of review authors.                                                                                                                                                                                         | P31                             |
| Availability of data, code and other materials | 27     | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | N/A                             |

## Appendix 1.2: Search terms, search string for each database, and search sensitivity

| Thesaurus terms     |                                                                                                  |                                                                 |                                                                                                                        |
|---------------------|--------------------------------------------------------------------------------------------------|-----------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------|
| Concepts            | PubMed                                                                                           | CINAHL                                                          | PsycInfo                                                                                                               |
| Quality of Life     | "health status"[MeSH Terms]                                                                      | SU health status OR SU psychological, stress                    | SU "quality of life"                                                                                                   |
| FND                 | "seizures"[MeSH Terms] OR "conversion disorder"[MeSH Terms]                                      | SU ("seizures" OR "mental disorders" OR "somatoform disorders") | MA ("seizures" OR "mental disorders")                                                                                  |
| Illness perceptions | "perception"[MeSH Terms] OR "personality"[MeSH Terms] OR "adaptation, psychological"[MeSH Terms] | SU emotion OR SU coping OR self assessment                      | MA ("perception" OR "personality" OR "adaptation, psychological") OR DE "Emotions" OR DE "Demographic Characteristics" |

| Free text terms |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|-----------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Concepts        | PubMed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | CINAHL                                                                                                                                                                                                                                                                                                                                                                                                                                  | PsycInfo                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| Quality of Life | "QoL"[Title/Abstract] OR "quality of life"[Title/Abstract] OR "life quality"[Title/Abstract:~2] OR "health*related quality of life"[Title/Abstract] OR "HRQoL"[Title/Abstract] OR "distress"[Title/Abstract] OR "psychological distress"[Title/Abstract:~2] OR "symptom severity"[Title/Abstract:~2] OR "symptom improvement"[Title/Abstract:~2] OR "mental*health"[Title/Abstract] OR "well*being"[Title/Abstract] OR "mood"[Title/Abstract] OR "health status"[Title/Abstract:~2] OR "physical functioning"[Title/Abstract] OR "role physical" [Title/Abstract] OR "bodily pain" [Title/Abstract] OR "general health" [Title/Abstract] OR "vitality" [Title/Abstract] OR "social functioning" [Title/Abstract] OR "role emotional" [Title/Abstract] OR "mobility" [Title/Abstract] OR "self*care" [Title/Abstract] OR "usual activities" [Title/Abstract] OR "pain" [Title/Abstract] | XB (QoL OR "life N2 quality" OR "health*related quality of life" OR "HRQoL" OR "distress" OR "psychological N2 distress" OR "symptom N2 severity" OR "symptom N2 improvement" OR "well*being" OR "mood" OR "health N2 status" OR "physical functioning" OR "role physical" OR "bodily pain" OR "general health" OR "vitality" OR "social functioning" OR "role emotional" OR "mobility" OR "self care" OR "usual activities: OR "pain") | XB (QoL OR "quality of life" OR "life N2 quality" OR "health*related quality of life" OR "HRQoL" OR "distress" OR "psychological N2 distress" OR "symptom N2 severity" OR "symptom N2 improvement" OR "well*being" OR "mood" OR "health N2 status" OR "physical functioning" OR "role physical" OR "bodily pain" OR "general health" OR "vitality" OR "social functioning" OR "role emotional" OR "mental health" OR "mobility" OR "self*care" OR "usual activities" OR "pain") |
| FND             | "functional neurological disorder*"[Title/Abstract] OR "FND"[Title/Abstract] OR "functional neurological symptom*"[Title/Abstract] OR "conversion symptom*"[Title/Abstract] OR "conversion disorder*"[Title/Abstract] OR "psychogenic"[Title/Abstract] OR "psychogenic non epileptic seizure*"[Title/Abstract] OR "psychogenic                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | XB ("functional neurological disorder" OR "FND" OR "functional neurological symptom*" OR "conversion symptom*" OR "conversion disorder*" OR "psychogenic" OR "psychogenic non epileptic seizure*" OR "psychogenic nonepileptic seizure*" OR "non epileptic" OR "nonepileptic" OR "PNES" OR "pseudoseizure*" OR "hysteria" OR "functional N2                                                                                             | XB ("functional neurological disorder" OR "FND" OR "functional neurological symptom*" OR "conversion symptom*" OR "conversion disorder*" OR "psychogenic"                                                                                                                                                                                                                                                                                                                       |

|                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|---------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                     | <p>nonepileptic seizure*[Title/Abstract] OR "non epileptic"[Title/Abstract] OR "nonepileptic"[Title/Abstract] OR "PNES"[Title/Abstract] OR "pseudoseizure*[Title/Abstract] OR "hysteria"[Title/Abstract] OR "functional seizure"[Title/Abstract:~2] OR "functional seizures"[Title/Abstract:~2] OR "seizure*[Title/Abstract] OR "dissociative seizure"[Title/Abstract:~2] OR "dissociative seizures"[Title/Abstract:~2] OR "non organic"[Title/Abstract] OR "nonorganic"[Title/Abstract] OR "motor FND"[Title/Abstract] OR "functional weakness"[Title/Abstract:~2] OR "functional tremor"[Title/Abstract:~2] OR "functional movement disorder"[Title/Abstract] OR "functional cognitive disorder"[Title/Abstract] OR "persistent perceptual postural dizziness"[Title/Abstract] OR "dystonia"[Title/Abstract] OR "clinical neurology"[Title/Abstract] OR "non epileptic attack disorder*[Title/Abstract] OR "epilepsy"[Title/Abstract] OR "epileptic"[Title/Abstract]</p> | <p>seizure" OR "functional N2 seizures" OR "seizure*" OR "dissociative N2 seizure" OR "dissociative N2 seizures" OR "non organic" OR "nonorganic" OR "motor FND" OR "functional N2 weakness" OR "functional N2 tremor" OR "functional movement disorder" OR "functional cognitive disorder" OR "persistent perceptual postural dizziness" OR "dystonia" OR "clinical neurology" OR "non-epileptic attack disorder*" OR "epilepsy" OR "epileptic")</p>       | <p>OR "psychogenic non epileptic seizure*" OR "psychogenic nonepileptic seizure*" OR "non epileptic" OR "nonepileptic" OR "PNES" OR "pseudoseizure*" OR "hysteria" OR "functional N2 seizure" OR "functional N2 seizures" OR "seizure*" OR "dissociative N2 seizure" OR "dissociative N2 seizures" OR "non organic" OR "nonorganic" OR "motor FND" OR "functional N2 weakness" OR "functional N2 tremor" OR "functional movement disorder" OR "functional cognitive disorder" OR "persistent perceptual postural dizziness" OR "dystonia" OR "clinical neurology" OR "non-epileptic attack disorder*" OR "epilepsy" OR "epileptic")</p> |
| Illness perceptions | <p>"illness representation"[Title/Abstract:~2] OR "illness representations"[Title/Abstract:~2] OR "illness perception"[Title/Abstract:~2] OR "illness perceptions"[Title/Abstract:~2] OR "illness belief"[Title/Abstract:~2] OR "illness beliefs"[Title/Abstract:~2] OR "illness appraisal"[Title/Abstract:~2] OR "illness appraisals"[Title/Abstract:~2] OR "disease perception"[Title/Abstract:~2] OR "disease</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | <p>XB ("illness N2 representation" OR "illness N2 representations" OR "illness N2 perception" OR "illness N2 perceptions" OR "illness N2 belief" OR "illness N2 beliefs" OR "illness N2 appraisal" OR "illness N2 appraisals" OR "disease N2 perception" OR "disease N2 perceptions" OR "disease N2 representation" OR "disease N2 representations" OR "disease N2 belief" OR "disease N2 beliefs" OR "disease N2 appraisal" OR "disease N2 appraisals"</p> | <p>XB ("illness N2 representation" OR "illness N2 representations" OR "illness N2 perception" OR "illness N2 perceptions" OR "illness N2 belief" OR "illness N2 beliefs" OR "illness N2 appraisal" OR "illness N2 appraisals" OR</p>                                                                                                                                                                                                                                                                                                                                                                                                    |

|  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                               |                                                                                                                                                                                                                                                                                                                                                                |
|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  | perceptions"[Title/Abstract:~2] OR "disease representation"[Title/Abstract:~2] OR "disease representations"[Title/Abstract:~2] OR "disease belief"[Title/Abstract:~2] OR "disease beliefs"[Title/Abstract:~2] OR "disease appraisal"[Title/Abstract:~2] OR "disease appraisals"[Title/Abstract:~2] OR "common*sense model"[Title/Abstract] OR "CSM"[Title/Abstract] OR "attitude*"[Title/Abstract] OR "identit*"[Title/Abstract] OR "illness understanding"[Title/Abstract:~2] OR "illness understandings"[Title/Abstract:~2] | OR "common*sense model" OR "CSM" OR "attitude*" OR "identit*" OR "illness N2 understanding" OR "illness N2 understandings" OR "coping" OR "emotion process*") | "disease N2 perception" OR "disease N2 perceptions" OR "disease N2 representation" OR "disease N2 representations" OR "disease N2 belief" OR "disease N2 beliefs" OR "disease N2 appraisal" OR "disease N2 appraisals" OR "common*sense model" OR "CSM" OR "attitude*" OR "identit*" OR "illness N2 understanding" OR "illness N2 understandings" OR "coping") |
|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

| Search strategy: PsycInfo |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|---------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| #                         | Search terms                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| 1                         | SU "quality of life"                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 2                         | XB (QoL OR "quality of life" OR "life N2 quality" OR "health*related quality of life" OR "HRQoL" OR "distress" OR "psychological N2 distress" OR "symptom N2 severity" OR "symptom N2 improvement" OR "well*being" OR "mood" OR "health N2 status" OR "physical functioning" OR "role physical" OR "bodily pain" OR "general health" OR "vitality" OR "social functioning" OR "role emotional" OR "mental health" OR "mobility" OR "self*care" OR "usual activities" OR "pain")                                                                                                                                                                                                                                                                                                            |
| 3                         | S1 OR S2                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 4                         | MA ("seizures" OR "mental disorders")                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| 5                         | XB ("functional neurological disorder" OR "FND" OR "functional neurological symptom*" OR "conversion symptom*" OR "conversion disorder*" OR "psychogenic" OR "psychogenic non epileptic seizure*" OR "psychogenic nonepileptic seizure*" OR "non epileptic" OR "nonepileptic" OR "PNES" OR "pseudoseizure*" OR "hysteria" OR "functional N2 seizure" OR "functional N2 seizures" OR "seizure*" OR "dissociative N2 seizure" OR "dissociative N2 seizures" OR "non organic" OR "nonorganic" OR "motor FND" OR "functional N2 weakness" OR "functional N2 tremor" OR "functional movement disorder" OR "functional cognitive disorder" OR "persistent perceptual postural dizziness" OR "dystonia" OR "clinical neurology" OR "non-epileptic attack disorder*" OR "epilepsy" OR "epileptic") |
| 6                         | S4 OR S5                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 7                         | MA ("perception" OR "personality" OR "adaptation, psychological") OR DE "Emotions" OR DE "Demographic Characteristics"                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| 8                         | XB ("illness N2 representation" OR "illness N2 representations" OR "illness N2 perception" OR "illness N2 perceptions" OR "illness N2 belief" OR "illness N2 beliefs" OR "illness N2 appraisal" OR "illness N2 appraisals" OR "disease N2 perception" OR "disease N2 perceptions" OR "disease N2 representation" OR "disease N2 representations" OR "disease N2 belief" OR "disease N2 beliefs" OR "disease N2 appraisal" OR "disease N2 appraisals" OR "common*sense model" OR "CSM" OR "attitude*" OR "identit*" OR "illness N2 understanding" OR "illness N2 understandings" OR "coping")                                                                                                                                                                                               |
| 9                         | S7 OR S8                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 10                        | S3 AND S6 AND S9                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

| Search strategy: CINAHL |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|-------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| #                       | Search terms                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| 1                       | SU health status OR SU psychological, stress                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| 2                       | XB (QoL OR "life N2 quality" OR "health*related quality of life" OR "HRQoL" OR "distress" OR "psychological N2 distress" OR "symptom N2 severity" OR "symptom N2 improvement" OR "well*being" OR "mood" OR "health N2 status" OR "physical functioning" OR "role physical" OR "bodily pain" OR "general health" OR "vitality" OR "social functioning" OR "role emotional" OR "mobility" OR "self care" OR "usual activities: OR "pain")                                                                                                                                                                                                                                                                                                                                                    |
| 3                       | S1 OR S2                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 4                       | SU ("seizures" OR "mental disorders" OR "somatoform disorders")                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| 5                       | XB ("functional neurological disorder" OR "FND" OR "functional neurological symptom*" OR "conversion symptom*" OR "conversion disorder*" OR "psychogenic" OR "psychogenic non epileptic seizure*" OR "psychogenic nonepileptic seizure*" OR "non epileptic" OR "nonepileptic" OR "PNES" OR "pseudoseizure*" OR "hysteria" OR "functional N2 seizure" OR "functional N2 seizures" OR "seizure*" OR "dissociative N2 seizure" OR "dissociative N2 seizures" OR "non organic" OR "nonorganic" OR "motor FND" OR "functional N2 weakness" OR "functional N2 tremor" OR "functional movement disorder" OR "functional cognitive disorder" OR "persistent perceptual postural dizziness" OR "dystonia" OR "clinical neurology" OR "non-epileptic attack disorder*" OR "epilepsy" OR "epileptic") |
| 6                       | S4 OR S5                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 7                       | SU emotion OR SU coping OR self assessment                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| 8                       | XB ("illness N2 representation" OR "illness N2 representations" OR "illness N2 perception" OR "illness N2 perceptions" OR "illness N2 belief" OR "illness N2 beliefs" OR "illness N2 appraisal" OR "illness N2 appraisals" OR "disease N2 perception" OR "disease N2 perceptions" OR "disease N2 representation" OR "disease N2 representations" OR "disease N2 belief" OR "disease N2 beliefs" OR "disease N2 appraisal" OR "disease N2 appraisals" OR "common*sense model" OR "CSM" OR "attitude*" OR "identit*" OR "illness N2 understanding" OR "illness N2 understandings" OR "coping" OR "emotion process*")                                                                                                                                                                         |
| 9                       | S7 OR S8                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 10                      | S3 AND S6 AND S9                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

| Search strategy: PubMed |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| #                       | Search terms                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| 1                       | "perception"[MeSH Terms] OR "personality"[MeSH Terms] OR "adaptation, psychological"[MeSH Terms]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| 2                       | "illness representation"[Title/Abstract:~2] OR "illness representations"[Title/Abstract:~2] OR "illness perception"[Title/Abstract:~2] OR "illness perceptions"[Title/Abstract:~2] OR "illness belief"[Title/Abstract:~2] OR "illness beliefs"[Title/Abstract:~2] OR "illness appraisal"[Title/Abstract:~2] OR "illness appraisals"[Title/Abstract:~2] OR "disease perception"[Title/Abstract:~2] OR "disease perceptions"[Title/Abstract:~2] OR "disease representation"[Title/Abstract:~2] OR "disease representations"[Title/Abstract:~2] OR "disease belief"[Title/Abstract:~2] OR "disease beliefs"[Title/Abstract:~2] OR "disease appraisal"[Title/Abstract:~2] OR "disease appraisals"[Title/Abstract:~2] OR "common*sense model"[Title/Abstract] OR "CSM"[Title/Abstract] OR "attitude*" [Title/Abstract] OR "identit*" [Title/Abstract] OR "illness understanding"[Title/Abstract:~2] OR "illness understandings"[Title/Abstract:~2]                                                                                                                                                                                                                                                                                                                                                                                        |
| 3                       | S1 OR S2                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| 4                       | "health status"[MeSH Terms]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| 5                       | "QoL"[Title/Abstract] OR "quality of life"[Title/Abstract] OR "life quality"[Title/Abstract:~2] OR "health*related quality of life"[Title/Abstract] OR "HRQoL"[Title/Abstract] OR "distress"[Title/Abstract] OR "psychological distress"[Title/Abstract:~2] OR "symptom severity"[Title/Abstract:~2] OR "symptom improvement"[Title/Abstract:~2] OR "mental*health"[Title/Abstract] OR "well*being"[Title/Abstract] OR "mood"[Title/Abstract] OR "health status"[Title/Abstract:~2] OR "physical functioning" [Title/Abstract] OR "role physical" [Title/Abstract] OR "bodily pain" [Title/Abstract] OR "general health" [Title/Abstract] OR "vitality" [Title/Abstract] OR "social functioning" [Title/Abstract] OR "role emotional" [Title/Abstract] OR "mobility" [Title/Abstract] OR "self*care" [Title/Abstract] OR "usual activities" [Title/Abstract] OR "pain" [Title/Abstract]                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| 6                       | S4 OR S5                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| 7                       | "seizures"[MeSH Terms] OR "conversion disorder"[MeSH Terms]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| 8                       | "functional neurological disorder*" [Title/Abstract] OR "FND"[Title/Abstract] OR "functional neurological symptom*" [Title/Abstract] OR "conversion symptom*" [Title/Abstract] OR "conversion disorder*" [Title/Abstract] OR "psychogenic" [Title/Abstract] OR "psychogenic non epileptic seizure*" [Title/Abstract] OR "psychogenic nonepileptic seizure*" [Title/Abstract] OR "non epileptic" [Title/Abstract] OR "nonepileptic" [Title/Abstract] OR "PNES" [Title/Abstract] OR "pseudoseizure*" [Title/Abstract] OR "hysteria" [Title/Abstract] OR "functional seizure" [Title/Abstract:~2] OR "functional seizures" [Title/Abstract:~2] OR "seizure*" [Title/Abstract] OR "dissociative seizure" [Title/Abstract:~2] OR "dissociative seizures" [Title/Abstract:~2] OR "non organic" [Title/Abstract] OR "nonorganic" [Title/Abstract] OR "motor FND" [Title/Abstract] OR "functional weakness" [Title/Abstract:~2] OR "functional tremor" [Title/Abstract:~2] OR "functional movement disorder" [Title/Abstract] OR "functional cognitive disorder" [Title/Abstract] OR "persistent perceptual postural dizziness" [Title/Abstract] OR "dystonia" [Title/Abstract] OR "clinical neurology" [Title/Abstract] OR "non epileptic attack disorder*" [Title/Abstract] OR "epilepsy" [Title/Abstract] OR "epileptic" [Title/Abstract] |
| 9                       | S7 OR S8                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| 10                      | S3 AND S6 AND S9                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |

| Search sensitivity                                     |        |                 |                 |
|--------------------------------------------------------|--------|-----------------|-----------------|
| Paper                                                  | PubMed | PsycInfo        | CINAHL          |
| Rawling et al., 2017<br>10.1016/j.yebeh.2016.10.035    | Yes    | Yes             | Yes             |
| Novakova et al., 2015<br>10.1016/j.seizure.2015.03.007 | Yes    | Yes             | Yes             |
| Saunders et al., 2024<br>10.1136/<br>bmjno-2024-000675 | Yes    | Not in database | Not in database |
| Bailey et al., 2024<br>10.1136/<br>bmjno-2024-000633   | Yes    | Not in database | Not in database |
| Stone et al., 2010<br>10.1093/brain/awq068             | Yes    | Yes             | Yes             |

### Appendix 1.3: Risk of bias assessment

| Risk of bias – JBI critical appraisal tool quasi-experimental studies (This paper was the pilot for appraisal process) |                            |                                                       |                                           |                                              |                                                                                                                          |                                  |                                                                                                                                                                                           |                               |
|------------------------------------------------------------------------------------------------------------------------|----------------------------|-------------------------------------------------------|-------------------------------------------|----------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|----------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|
| Study ID                                                                                                               | Temporal precedence (Q1)   | Selection and allocation (Q2)                         | Confounding factors/ Group comparison(Q3) | Administration of Intervention/exposure (Q4) | Assessment, detection, and measurement of the outcome (Q5, Q6, Q7)                                                       | Participant retention (Q8)       | Statistical Conclusion validity*(Q9)                                                                                                                                                      | Overall risk of bias judgment |
| Bailey et al., 2024                                                                                                    | Yes - low concern          | No - high concern                                     | Yes - low concern                         | N/A                                          | Yes - low concern                                                                                                        | No - High concern                | Yes - low concern                                                                                                                                                                         | Moderate risk of bias         |
| In relation present review's question                                                                                  | N/A – baseline association | N/A – no comparator required for baseline correlation | N/A                                       | N/A                                          | Yes – low concern, but some concern about overlap between emotional representations and emotional-wellbeing QoL (Q5 N/A) | N/A for the baseline association | No – high concern. Baseline correlations were unadjusted; no power analysis or correction for multiple correlational tests were report. Bailey et al did not consider conceptual overlap. | High risk of bias             |

| Risk of bias – JBI critical appraisal tool for case control studies |                                                                         |                                                             |                                                                      |                                                                        |                                                                                                                                                                                                                     |                                                                 |
|---------------------------------------------------------------------|-------------------------------------------------------------------------|-------------------------------------------------------------|----------------------------------------------------------------------|------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------|
| Study ID                                                            | Selection and allocation (Q1, Q2, Q3)                                   | Measurement of outcome/exposure (Q4, Q5, Q8, Q9)            | Confounding factors identified (Q6)                                  | Confounding factors controlled for (Q7)                                | Statistical Conclusion validity* (Q10)                                                                                                                                                                              | Overall risk of bias judgment                                   |
| Stone et al., 2010                                                  | Yes - low concern                                                       | Yes - low concern                                           | Yes - low concern                                                    | No – high concern                                                      | Yes, but partially - low concern (statistical analysis was appropriate for group comparison but did not control for confounders or multiple comparisons)                                                            | Moderate risk of bias                                           |
| In relation present review's question                               | Q1 (N/A), Q2 (N/A) Q3- Yes, low concern. Clear neurologist confirmation | Yes – low concern (Q5, Q9, N/A). Appropriate measures used. | Yes - low concern. Psychiatric and other clinical factors identified | No – high concern. The review-relevant association was unadjusted for. | No - high concern. The original between-group comparison was N/A to the review question; the extracted within-group association was supplementary (post-hoc and exploratory), unadjusted and incompletely reported. | High risk of bias (analytic misalignment and confounding-prone) |

| Risk of bias – JBI critical appraisal tool for cohort studies |                                                         |                 |                                                                    |                                                                                                           |                          |                                                                                                                 |                                  |                                                                                                                                                                                 |                                                                             |
|---------------------------------------------------------------|---------------------------------------------------------|-----------------|--------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|--------------------------|-----------------------------------------------------------------------------------------------------------------|----------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|
| Study ID                                                      | Selection (Q1)                                          | Allocation (Q2) | Confounding factors identified (Q4)                                | Confounding factors controlled for (Q5)                                                                   | Temporal precedence (Q6) | Assessment, detection, and measurement of the outcome (Q3, Q7, Q8)                                              | Participant retention (Q9, Q10)  | Statistical Conclusion validity* (Q11)                                                                                                                                          | Overall risk of bias judgment                                               |
| Saunders et al., 2024                                         | Yes – low concern. Selected from appropriate population | N/A             | Yes - low concern                                                  | No – high concern                                                                                         | Yes - low concern        | Yes - low concern                                                                                               | Yes - low concern                | Yes, but partially (statistical analysis was appropriate for group comparison but did not control for confounders or multiple comparisons) - low concern                        | Low risk of bias (analysis was aligned with review Q but confounding-prone) |
| In relation present review's question                         | Yes - low concern. Selected from appropriate population | N/A             | Yes - low concern, mood, symptom duration and comorbidity measured | No – high concern, Depression and anxiety were not controlled in the illness-perception-QoL correlations. | N/A                      | Yes – low concern (Q8, N/A as follow up measures not relevant). But some concern re. overlap between variables. | N/A for the baseline association | No – high concern (only interested in baseline measures, so above analysis not relevant. No power analysis or multiple comparison adjustment. Incomplete statistical reporting) | High risk of bias (analytic misalignment and confounding-prone)             |

| Risk of bias – JBI critical appraisal tool for cross-sectional studies |                   |                                                                                       |                                                                                              |                                                                                                                                    |                                                                                                                                                          |                                                                                            |
|------------------------------------------------------------------------|-------------------|---------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|
| Study ID                                                               | Selection (Q1)    | Setting (Q2)                                                                          | Measurement of outcome (Q3, Q4 and Q7)                                                       | Confounding factors (Q5 and Q6)                                                                                                    | Statistical validity (Q8)                                                                                                                                | Overall risk of bias judgment                                                              |
| Rawlings et al., 2017                                                  | Yes - low concern | No - high concern                                                                     | Yes-low concern                                                                              | Yes-low concern                                                                                                                    | Yes- low concern                                                                                                                                         | Moderate risk of bias                                                                      |
| In relation present review's question                                  | Yes - low concern | Yes - low concern but cautious as some recruited through membership-led organisations | Yes - low concern but caution required re. total BIPQ score used. Appropriate measures used. | Yes (Q5) – confounders identified. Partially, yes (Q6). Regression model adjusted for confounders but not for multiple comparison. | No – high concern. No power sample or adjustment for multiple comparisons. Likely small sample.                                                          | Moderate risk of bias (analysis was aligned with review Q but caution regarding analysis.) |
| Novakova et al., 2015                                                  | Yes - low concern | Yes - low concern                                                                     | Yes - low concern. Appropriate measures used.                                                | No - high concern.                                                                                                                 | Yes, but partially - low concern (statistical analysis was appropriate for group comparison but did not control for confounders or multiple comparisons) | Moderate risk of bias                                                                      |
| In relation present review's question                                  | Yes - low concern | Yes - low concern                                                                     | Yes - low concern. Appropriate measures used.                                                | No - high concern. Neither clearly identified or addressed.                                                                        | No - high concern. The extracted association was post-hoc, exploratory and not adjusted for confounders or multiple comparisons.                         | High risk of bias (analytic misalignment and confounding-prone)                            |

#### Appendix 1.4: Data extraction form

| Study ID              | Intervention | Treatment duration | Group name | Treatment delivery | N of randomised to group | Theoretical basis of group | Description of group | Timing | Providers | Study aims |
|-----------------------|--------------|--------------------|------------|--------------------|--------------------------|----------------------------|----------------------|--------|-----------|------------|
| Rawling et al., 2017  |              |                    |            |                    |                          |                            |                      |        |           |            |
| Novakova et al., 2015 |              |                    |            |                    |                          |                            |                      |        |           |            |
| Saunders et al., 2024 |              |                    |            |                    |                          |                            |                      |        |           |            |
| Bailey et al., 2024   |              |                    |            |                    |                          |                            |                      |        |           |            |
| Stone et al., 2010    |              |                    |            |                    |                          |                            |                      |        |           |            |

| Data extraction form continued. |                    |              |              |                   |                     |        |         |                      |                |             |                  |              |
|---------------------------------|--------------------|--------------|--------------|-------------------|---------------------|--------|---------|----------------------|----------------|-------------|------------------|--------------|
| FND type                        | Start and end date | Participants | Study design | N of Participants | Baseline imbalances | Ethics | Setting | Eligibility criteria | Co-morbidities | Recruitment | Illness severity | Demographics |

| Data extraction form continued. |                          |                  |
|---------------------------------|--------------------------|------------------|
| Outcome measures                | Timepoint of measurement | Statistical info |

## Appendix 2.1. COREQ

| Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist |                                                                                                                                                          |                    |
|------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------|
| Item No                                                                            | Guide Questions/Description                                                                                                                              | Reported on Page # |
| <b>Domain 1: Research team and reflexivity</b>                                     |                                                                                                                                                          |                    |
| <b>Personal Characteristics</b>                                                    |                                                                                                                                                          |                    |
| 1. Interviewer/ facilitator                                                        | Which author/s conducted the interview or focus group?                                                                                                   | Pg 48              |
| 2. Credentials                                                                     | What were the researcher's credentials? E.g., PhD, MD                                                                                                    | Pg 47, 50          |
| 3. Occupation                                                                      | What was their occupation at the time of the study?                                                                                                      | Pg 47              |
| 4. Gender                                                                          | Was the researcher male or female?                                                                                                                       | Pg 50              |
| 5. Experience and training                                                         | What experience or training did the researcher have?                                                                                                     | Pg 50              |
| <b>Relationship with participants</b>                                              |                                                                                                                                                          |                    |
| 6. Relationship established                                                        | Was a relationship established prior to study commencement?                                                                                              | Pg 47              |
| 7. Participant knowledge of the interviewer                                        | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?                                                | Pg 47              |
| 8. Interviewer characteristics                                                     | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic                | Pg 50              |
| <b>Domain 2: study design</b>                                                      |                                                                                                                                                          |                    |
| <b>Theoretical framework</b>                                                       |                                                                                                                                                          |                    |
| 9. Methodological orientation and Theory                                           | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Pg 46, 49          |
| <b>Participant selection</b>                                                       |                                                                                                                                                          |                    |
| 10. Sampling                                                                       | How were participants selected? e.g., purposive, convenience, consecutive, snowball                                                                      | Pg 47              |
| 11. Method of approach                                                             | How were participants approached? e.g., face-to-face, telephone, mail, email                                                                             | Pg 47              |
| 12. Sample size                                                                    | How many participants were in the study?                                                                                                                 | Pg 47              |
| 13. Non-participation Setting                                                      | How many people refused to participate or dropped out? Reasons?                                                                                          | Pg 47              |

| Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist |                                                                                                                                  |                                                            |
|------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------|
| Item No                                                                            | Guide Questions/Description                                                                                                      | Reported on Page #                                         |
| 14. Setting of data collection                                                     | Where was the data collected? e.g., home, clinic, workplace                                                                      | Pg 48                                                      |
| 15. Presence of nonparticipants                                                    | Was anyone else present besides the participants and researchers?                                                                | Pg 48                                                      |
| 16. Description of sample                                                          | What are the important characteristics of the sample? e.g. demographic data, date                                                | Pg 51                                                      |
| <b>Data collection</b>                                                             |                                                                                                                                  |                                                            |
| 17. Interview guide                                                                | Were questions, prompts, and guides provided by the authors? Was it pilot tested?                                                | Pg 48 (Pg 102, appendix 2.5)                               |
| 18. Repeat interviews                                                              | Were repeat interviews carried out? If yes, how many?                                                                            | No, see Pg 48                                              |
| 19. Audio/visual recording                                                         | Did the research use audio or visual recording to collect the data?                                                              | Pg 48                                                      |
| 20. Field notes                                                                    | Were field notes made during and/or after the interview or focus group?                                                          | Pg 49                                                      |
| 21. Duration                                                                       | What was the duration of the interviews or focus group?                                                                          | Pg 48                                                      |
| 22. Data saturation                                                                | Was data saturation discussed?                                                                                                   | Pg 47                                                      |
| 23. Transcripts returned                                                           | Were transcripts returned to participants for comment and/or correction?                                                         | Pg 49                                                      |
| <b>Domain 3: analysis and findings</b>                                             |                                                                                                                                  |                                                            |
| <b>Data analysis</b>                                                               |                                                                                                                                  |                                                            |
| 24. Number of data coders                                                          | How many data coders coded the data?                                                                                             | Pg 49                                                      |
| 25. Description of the coding tree                                                 | Did the authors provide a description of the coding tree?                                                                        | N/A but thematic maps available. Appendix 2.6 (Pg 107-109) |
| 26. Derivation of themes                                                           | Were themes identified in advance or derived from the data?                                                                      | Pg 49                                                      |
| 27. Software                                                                       | What software, if applicable, was used to manage the data?                                                                       | Pg 49                                                      |
| 28. Participant checking                                                           | Did participants provide feedback on the findings?                                                                               | Pg 49                                                      |
| <b>Reporting</b>                                                                   |                                                                                                                                  |                                                            |
| 29. Quotations presented                                                           | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number | Pg 53-61                                                   |

| Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist                                                                                                                                                              |                                                                          |                    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------|--------------------|
| Item No                                                                                                                                                                                                                                         | Guide Questions/Description                                              | Reported on Page # |
| 30. Data and findings consistent                                                                                                                                                                                                                | Was there consistency between the data presented and the findings?       | Pg 53-67           |
| 31. Clarity of major themes                                                                                                                                                                                                                     | Were major themes clearly presented in the findings?                     | Pg 53-61           |
| 32. Clarity of minor themes                                                                                                                                                                                                                     | Is there a description of diverse cases or a discussion of minor themes? | Pg 53-67           |
| Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357 |                                                                          |                    |

## Appendix 2.2. 15-Point quality checklist for thematic analysis process

|               |    |                                                                                                                                                                                                                                                                                                                                            |
|---------------|----|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Transcription | 1. | The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'. <b>Recordings were transcribed verbatim, with each transcript produced in approximately 7 hours. Entire transcripts were not checked against recordings but extracts were (see Appendix 2.6.</b> |
| Coding        | 2. | Each data item has been given equal attention in the coding process. <b>The process was recursive. I revisited codes and re-coded items as necessary so items were not coded superficially.</b>                                                                                                                                            |
|               | 3. | Themes have not been generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive and comprehensive. <b>Attention was paid to ensure there was even coverage across participants and 'texture' of experiences was reported.</b>                                               |
|               | 4. | All relevant extracts for all each theme have been collated. <b>Coded extracts were collated and reviewed for each theme. See Appendix 2.6.</b>                                                                                                                                                                                            |
|               | 5. | Themes have been checked against each other and back to the original data set. <b>In Appendix 2.6., I compare themes against each other to consider whether they are meaningfully different and whether they are meaningfully represented across the dataset.</b>                                                                          |
|               | 6. | Themes are internally coherent, consistent, and distinctive. <b>This was considered, with table in Appendix 2.6. outlining consistency and distinctiveness. Reported analysis attempts to show coherence of themes.</b>                                                                                                                    |

|                |     |                                                                                                                                                                                                                                                                                                                                              |
|----------------|-----|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Analysis       | 7.  | Data have been analysed rather than just paraphrased or described. <b>When analysing, the ‘and, what?’ question was held in mind to support interpretation and move the analysis beyond paraphrasing.</b>                                                                                                                                    |
|                | 8.  | Analysis and data match each other – the extracts illustrate the analytic claims. <b>This was considered during drafting analysis and a self-audit in response to supervisors’ comments was produced and can be seen in Appendix 2.6.</b>                                                                                                    |
|                | 9.  | Analysis tells a convincing and well-organised story about the data and topic. <b>This was considered in Appendix 2.6. when considering how each theme contributes to the research Qs and analysis. There’s also an organising story at the beginning of the results and discussion.</b>                                                     |
|                | 10. | A good balance between analytic narrative and illustrative extracts is provided. <b>When presenting extracts, it was considered that the following analytic commentary should typically contain an acknowledgment of the wider context which the extract is situated in, what the extract is communicating and why that extract matters.</b> |
| Overall        | 11. | Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly. <b>Despite resource constraints reflected upon, sufficient time given to analysis should be evident in methods and Appendix 2.6.</b>                                                             |
| Written report | 12. | The assumptions about Thematic analysis are clearly explicated. <b>Please see Methods.</b>                                                                                                                                                                                                                                                   |

|                                                                                                                 |            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|-----------------------------------------------------------------------------------------------------------------|------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                                 | <b>13.</b> | There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent. <b>I reviewed whether the report demonstrated fit between the stated method and the written analysis. In particular, I checked that the Results foregrounded patient-experience themes rather than ACT or illness-perception categories, and that the Discussion treated PF and IPs as partial, retrospective interpretive lenses rather than as coding frameworks or causal mechanisms.</b> |
|                                                                                                                 | <b>14.</b> | The language and concepts used in the report are consistent with the epistemological position of the analysis. <b>I also reviewed the language used across the Results and Discussion for consistency with the study’s critical realist and reflexive orientation. I amended wording that risked implying causality, verification, or direct mapping onto theory, and used more interpretive phrasing such as “appeared,” “seemed,” “resonated with,” and “was interpreted as.”</b>                                                          |
|                                                                                                                 | <b>15.</b> | The researcher is positioned as <i>active</i> in the research process; themes do not just ‘emerge’. <b>I reviewed whether the report positioned me as active in the analytic process. I therefore used first-person language in parts of the Methods and Discussion, described themes as developed rather than discovered, and documented how my clinical training, theoretical commitments, personal context, and reflexive journaling shaped the analysis.</b>                                                                             |
| Braun, V., & Clarke, V. (2021). Thematic analysis: A practical guide (First ed.). SAGE Publications, Ltd. (UK). |            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

## Appendix 2.2. Approval letters (Wales REC & NHS R&D)



Wales Research Ethics Committee 7  
Carmarthen

email:

07 May 2025

Dr Katja Weides  
School of Health & Wellbeing  
College of Medical, Veterinary and Life Sciences  
Clarice Pears Building, University of Glasgow  
Glasgow  
G12 8TB

Dear Dr Weides

|                         |                                                                                                                                                                                            |
|-------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Study title:</b>     | <b>Acceptance and Commitment Therapy for Functional Neurological Disorder: exploring therapeutic change following a psychological group intervention within a Neuropsychology service.</b> |
| <b>REC reference:</b>   | <b>25/WA/0115</b>                                                                                                                                                                          |
| <b>Protocol number:</b> | <b>350063</b>                                                                                                                                                                              |
| <b>IRAS project ID:</b> | <b>350063</b>                                                                                                                                                                              |

Thank you for your response of 6 May 2025, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

### Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: [Research registration and research project identifiers](#)).

Where a deferral is agreed we expect the sponsor to publish a [minimal record](#) on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform [deferrals@hra.nhs.uk](mailto:deferrals@hra.nhs.uk) and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

### Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, a [minimum research summary](#) will still be published in [the research summaries database](#). At the end of the deferral period, we will publish the [full research summary](#).

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: [Research summaries - Health Research Authority \(hra.nhs.uk\)](#)

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### **After ethical review: Reporting requirements**

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at [Managing your approval - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/managing-your-approval)

### **Ethical review of research sites**

#### **NHS/HSC sites**

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Non-NHS/HSC sites**

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

| <i>Document</i>                                                                               | <i>Version</i> | <i>Date</i>      |
|-----------------------------------------------------------------------------------------------|----------------|------------------|
| Interview schedules or topic guides for participants [Interview schedule]                     | 1.1            | 02 February 2025 |
| IRAS Application Form [IRAS_Form_28032025]                                                    |                | 28 March 2025    |
| Letter from sponsor [Insurance letter]                                                        |                | 28 June 2024     |
| Other [Privacy Notice ]                                                                       | 1.4            | 26 March 2025    |
| Other [Telephone Script]                                                                      | 1.0            | 04 March 2025    |
| Other [updated debrief sheet]                                                                 | 1.3            | 28 April 2025    |
| Other [updated distress protocol]                                                             | 1.1            | 28 April 2025    |
| Other [Response to REC opinion]                                                               | 1.0            | 28 April 2025    |
| Participant consent form [Consent for participation in clinical intervention] (standard form) |                |                  |
| Participant consent form [Consent for future contact] (standard form)                         |                |                  |
| Participant consent form [Updated consent form]                                               | 1.8            | 28 April 2025    |
| Participant information sheet (PIS) [Updated PIS/Invite letter]                               | 2.3            | 28 April 2025    |
| Research protocol or project proposal [Updated proposal]                                      | 4.1            | 28 April 2025    |
| Summary CV for Chief Investigator (CI) [CV_chief investigator and academic supervisor]        |                | 17 December 2024 |
| Summary CV for student                                                                        |                |                  |
| Summary CV for supervisor (student research) [Dr Thomas Campbell - Field Supervisor]          |                |                  |

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### User Feedback

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|                                                                               |
|-------------------------------------------------------------------------------|
| <b>IRAS project ID: 350063 Please quote this number on all correspondence</b> |
|-------------------------------------------------------------------------------|

With the Committee's best wishes for the success of this project.

Yours sincerely

**Sue Byng, Approvals Specialist  
pp. Chair**

*Enclosures:* List of names and professions of members  
who were present at the meeting and those who submitted written  
comments

[After ethical review guidance for sponsors and investigators –  
Non CTIMP Standard Conditions of Approval](#)

*Copy to:* Ms Sinead Traynor

*Lead Nation*  
**Scotland:** [gram.nrspcc@nhs.scot](mailto:gram.nrspcc@nhs.scot)



Dr Katja Weides  
University of Glasgow  
Veterinary and Life Sciences  
Clarice Pears Building  
University of Glasgow  
G12 8TB

R&D Department  
[REDACTED]

Date 23<sup>rd</sup> June 2025

Enquiries to [REDACTED]

Direct Line [REDACTED]

Email [REDACTED]

Dear Dr Weides

**Project title: Acceptance and Commitment Therapy for Functional Neurological Disorder: a mixed methods analysis of a psychological group intervention within a Neuropsychology service.**

**R&D ID: L24096**

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS [REDACTED] as detailed below:

| NAME        | TITLE                         | ROLE                   | NHSL SITE TO WHICH APPROVAL APPLIES |
|-------------|-------------------------------|------------------------|-------------------------------------|
| Lloyd Cheng | Trainee Clinical Psychologist | Principal Investigator | NHS [REDACTED]                      |

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and relevant UK-GDPR and Data Protection 2018 legislation.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.cso.scot.nhs.uk/> or the Research & Development Intranet site: <http://firstport2/staff-support/research-and-development/default.aspx>
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS [REDACTED] Data Protection Office and the Research &



Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality. [REDACTED]

- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS [REDACTED]
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS [REDACTED] but who will be dealing with NHS [REDACTED] patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case, please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,

[REDACTED]

CC.

| NAME               | TITLE                                      | CONTACT ADDRESS | ROLE                   |
|--------------------|--------------------------------------------|-----------------|------------------------|
| Lloyd Cheng        | Trainee Clinical Psychologist              | [REDACTED]      | Principal Investigator |
| Sinead Traynor     | Research Regulation & Compliance Team      | [REDACTED]      | Sponsor Contact        |
| Dr Thomas Campbell | Clinical Psychologist and Field Supervisor | [REDACTED]      | Named Contact          |

### **Appendix 2.3. Intervention description and protocol**

Participants were patients referred to the NHS community Neuropsychology service for FND intervention.

Eligibility criteria included standard criteria for referral to the service: (1) Aged  $\geq 16$ ; (2) An unequivocal diagnosis of FND made by a Neurologist; (3) Accepts the diagnosis and not seeking alternative explanation. Additional criteria for group suitability were assessed in a 30-minute screening session with a clinical psychologist: (4) Sufficient English language proficiency & cognitive ability to engage; (5) No substantial risk of harm to self or others (6) Absence of comorbid organic neurological conditions (7) Not currently engaged in another psychological intervention (8) Provided informed consent to participate in the intervention.

Procedures for FND referrals—typically from neurologists or neuro-rehab clinicians (OT, physiotherapists)—are screened against eligibility criteria 1–3. Accepted cases attend a 30-minute screening during group suitability is assessed against criteria 4-8. Those who meet criteria join the group waiting list, complete a 1:1 neuropsychological assessment and formulation session, then begin the eight-week group programme. The aim was to recruit 12 participants per cohort.

#### **Intervention**

**Assessment & formulation:** A clinical psychologist met individually with each patient to develop a neuropsychological formulation of their FND using contemporary biopsychosocial models. This session provided tailored psychoeducation and established personalized treatment targets for the subsequent group work.

**Group intervention:** The programme comprised eight weekly, in-person sessions (2 hours each, including a 15-minute break) at an accessible community venue. Two ACT-trained clinical psychologists—one with extensive group-therapy experience—adapted an established protocol (for using ACT in organic neurological conditions) (Hill et al., 2017) to FND. Content and materials included exercises, skills, metaphors and home-based practice reflecting traditional ACT protocols. Examples and exercises were modified to reflect FND specific experiences. Each week participants received a companion booklet to reinforce

learning and support ongoing practice. Other materials required included a laptop with projector/smart screen for presenting videos and a small amount of powerpoints slides, flipcharts and marker pens for group discussions, and pens for patients to make notes in their booklets. Sessions were co-facilitated by a minimum of two staff—always at least one clinical psychologist, alongside trainee/assistant psychologists or neuro-specialist OTs. Participants were informed that missing >2 sessions would result in discharge from the programme.

The full protocol for the intervention is **in draft format** and will be refined as the pilot progresses. The protocol can be found here: <https://osf.io/c8gj3/files/hfdgu>

#### **Appendix 2.4. Study documents**

Invite/Study information - <https://osf.io/c8gj3/files/te76r>

Consent form - <https://osf.io/c8gj3/files/2bw5e>

Debrief sheet - <https://osf.io/c8gj3/files/bsk8e>

Demographic questionnaire - <https://osf.io/c8gj3/files/2wsv5>

Privacy notice - <https://osf.io/c8gj3/files/w3dh2>

#### **Appendix 2.5. Interview schedule**

Interviewer's interview schedule - <https://osf.io/c8gj3/files/sgza5>

Participant's interview schedule - <https://osf.io/c8gj3/files/4rtzg>

*Identifying details relating to participating NHS health board, service and service-specific intervention title has been redacted from study documents. The substantive content of the original documents have not been altered.*

## Appendix 2.6: Record of data analysis

The thematic analysis followed Braun and Clarke's (2021) six phase approach. This first phase involved returning to the interview transcripts, which I was familiar with from transcribing interviews verbatim, and repeatedly reading transcripts. I made annotations noting and reflecting on excerpts that seemed noteworthy. This process helped make sense of the data. In the screenshot below, we can see an example of a note during this stage.

L – yeah, of course before the group, really frustrated that

M – yeah in the beginning can't happening to really angry. Anger something happened part in it frustration

L – why anger?

Created: 12 Apr 2026

By: KYLC

For Morgan, acceptance also seemed like an ongoing and non-linear process. There would be times where she would feel more accepting than others. Acceptance was not binary.

Delete

when you're saying fighting them,

're thinking well it g it and you feel, an hour after r does play a big ated a lot.

M – because its taken something away from you. So things I use to be able to do, I can't do now and it's sometimes, its not all the times but see sometimes it does make me angry like it makes you like, why is this doing this to me, why is this to me? The anger kind of bubbles a wee bit and then you just to need think well you know what, it is what it is. And that's probably my biggest motto now, it is what it is. But the anger does bubble sometimes yeah.

Phase two involved coding the transcripts. All transcripts were coded before candidate themes were developed, although coding and theme development remained recursive. In the screenshot below, we can see some codes that I made. This was not a neat, linear process. It involved revisiting codes and transcripts, renaming them, and later reorganising groups of coded extracts (which was moving from phase two into phase three). In the next two screenshots, there is a list of codes that had been organised into groups of codes and an example of a coded extract. These groups of codes were also the beginning of preliminary themes forming.

| Name                                                                                   | Files | References | Created on            | Created... | Modified on           | Modified by |
|----------------------------------------------------------------------------------------|-------|------------|-----------------------|------------|-----------------------|-------------|
| <input type="radio"/> Attributing change to group                                      | 1     | 1          | 9 Apr 2026 at 09:42   | KYLC       | 13 Apr 2026 at 21:27  | KYLC        |
| <input type="radio"/> Care among group helpful                                         | 1     | 1          | 9 Apr 2026 at 10:53   | KYLC       | 9 Apr 2026 at 10:53   | KYLC        |
| <input type="radio"/> Company - as simple as tea and biscuits                          | 2     | 2          | 8 Apr 2026 at 10:48   | KYLC       | 13 Apr 2026 at 21:55  | KYLC        |
| <input type="radio"/> Comparing and sharing symptoms was reassuring                    | 1     | 2          | 6 Apr 2026 at 08:16   | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| ✓ <input type="radio"/> Connection was important, which was why group not being lon... | 2     | 2          | 9 Apr 2026 at 10:58   | KYLC       | 14 Apr 2026 at 10:15  | KYLC        |
| <input type="radio"/> Relationships important, would've liked longer group             | 1     | 1          | 8 Apr 2026 at 13:13   | KYLC       | 8 Apr 2026 at 13:13   | KYLC        |
| <input type="radio"/> Wishing for more time, indicates valuing relationships           | 1     | 1          | 9 Apr 2026 at 11:13   | KYLC       | 9 Apr 2026 at 11:14   | KYLC        |
| ✓ <input type="radio"/> Desire for connection, even when not felt or received          | 1     | 2          | 8 Apr 2026 at 08:27   | KYLC       | 14 Apr 2026 at 10:15  | KYLC        |
| <input type="radio"/> Wanting my connectness but not receiving it                      | 1     | 4          | 9 Apr 2026 at 12:29   | KYLC       | 9 Apr 2026 at 12:30   | KYLC        |
| <input type="radio"/> Everyone is encouraging each other                               | 2     | 2          | 6 Apr 2026 at 12:25   | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| ✓ <input type="radio"/> Group                                                          | 0     | 0          | 11 Apr 2026 at 19:53  | KYLC       | 11 Apr 2026 at 19:53  | KYLC        |
| <input type="radio"/> Group as helping manage other difficulties                       | 1     | 1          | 9 Apr 2026 at 15:25   | KYLC       | 9 Apr 2026 at 15:26   | KYLC        |
| <input type="radio"/> Group as supporting understanding of condition                   | 1     | 2          | 10 Apr 2026 at 14:12  | KYLC       | 10 Apr 2026 at 14:52  | KYLC        |
| <input type="radio"/> Group helping with co-existing difficulties                      | 1     | 1          | 9 Apr 2026 at 14:35   | KYLC       | 9 Apr 2026 at 14:35   | KYLC        |
| <input type="radio"/> Group helping with focusing on what matters                      | 1     | 1          | 8 Apr 2026 at 12:58   | KYLC       | 8 Apr 2026 at 12:58   | KYLC        |
| <input type="radio"/> Group reducing social isolation                                  | 5     | 6          | 7 Apr 2026 at 09:58   | KYLC       | 10 Apr 2026 at 14:58  | KYLC        |
| <input type="radio"/> Group was dedicated time to themselves                           | 1     | 1          | 9 Apr 2026 at 11:12   | KYLC       | 9 Apr 2026 at 11:12   | KYLC        |
| ✓ <input type="radio"/> Groups scaffolds learning                                      | 1     | 2          | 7 Apr 2026 at 12:26   | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| <input type="radio"/> Group scaffolds - remove scaffolding, changes aren't sust...     | 1     | 1          | 7 Apr 2026 at 12:27   | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| <input type="radio"/> Listening to different viewpoints brought connection             | 1     | 1          | 9 Apr 2026 at 12:50   | KYLC       | 13 Apr 2026 at 21:50  | KYLC        |
| <input type="radio"/> Group meant freedom of expression                                | 1     | 1          | 7 Apr 2026 at 09:17   | KYLC       | 13 Apr 2026 at 21:05  | KYLC        |
| <input type="radio"/> Group provided accountability                                    | 1     | 2          | 13 Apr 2026 at 11:04  | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| ✓ <input type="radio"/> I'm not alone anymore                                          | 3     | 3          | 9 Apr 2026 at 10:34   | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| <input type="radio"/> Other people have this, they're still here                       | 1     | 1          | 6 Apr 2026 at 08:16   | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| <input type="radio"/> Relief at shared experience                                      | 2     | 4          | 7 Apr 2026 at 12:04   | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| ✓ <input type="radio"/> Listening and validating as soothing                           | 7     | 19         | 6 Apr 2026 at 08:19   | KYLC       | 14 Apr 2026 at 10:08  | KYLC        |
| <input type="radio"/> Accurate understanding of FND, helped them open up               | 1     | 1          | 14 Apr 2026 at 09:... | KYLC       | 14 Apr 2026 at 09:11  | KYLC        |
| <input type="radio"/> Being seen by group helped rediscover identity                   | 1     | 1          | 9 Apr 2026 at 09:57   | KYLC       | 13 Apr 2026 at 21:46  | KYLC        |
| <input type="radio"/> Comfortable to be who I am                                       | 1     | 1          | 14 Apr 2026 at 09:... | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| <input type="radio"/> I didn't have to explain symptoms in detail - and that was good  | 1     | 1          | 6 Apr 2026 at 11:48   | KYLC       | 14 Apr 2026 at 10:07  | KYLC        |
| <input type="radio"/> I'm not, this is not, important, I feel silly                    | 1     | 1          | 8 Apr 2026 at 15:07   | KYLC       | 14 Apr 2026 at 09:21  | KYLC        |
| <input type="radio"/> No longer just a label, I'm seen                                 | 1     | 1          | 7 Apr 2026 at 09:17   | KYLC       | 13 Apr 2026 at 20:51  | KYLC        |
| <input type="radio"/> Not being seen by others                                         | 1     | 1          | 6 Apr 2026 at 11:49   | KYLC       | 14 Apr 2026 at 09:... | KYLC        |
| ➢ <input type="radio"/> Prior experiences of not being understood, dismissed, not b... | 3     | 7          | 8 Apr 2026 at 09:44   | KYLC       | 14 Apr 2026 at 10:10  | KYLC        |
| <input type="radio"/> Sharing of experiences helped reduce self-stigma                 | 1     | 2          | 9 Apr 2026 at 10:37   | KYLC       | 9 Apr 2026 at 10:38   | KYLC        |

Name

>

Activity pacing helping manage symptoms and mood

○

Despite knowing strategies, gains weren't maintained

○

Distraction as not helpful

✓

○

Experiential exposure exercise as intolerable

○

Horrible to watch

○

Experiential exposure exercise as leading to catharsis

○

Felt like group missed personal touch and this is important to th...

✓

○

Goal setting provides framework for rewarding and hopeful lifes...

○

Setting achievable goals provided hope

○

Goals must be located inward, on values

○

Graded activity as opening up possibilities

○

Graded activity helped to challenge fears and re-engage with a...

○

Graded activity helping with functioning and then mood

○

Grading activity meant managing wellbeing sustainably

○

Harm from psychological intervention

✓

○

Increasing activity helping improve mood

○

Activity needs to be meaningful

○

Non-meaningful activity not increasing wellbeing

○

Need for adaptations to engage with group

○

Perhaps not the most physically accessible

○

Pursuing valued action is sometimes worth suffering symptoms

○

Variety helped engagement

Settina achie...

Graded activi...

Activitv need...

Variety helpe...

Pursuing valu...

○

Pursuing valued action is sometimes worth suffering symptoms

Coding Stripes

Highlight

Code

Annotations

Summary

Reference

Files\\Interview 10 transcript

1 reference coded, 1.78% coverage

Reference 1: 1.78% coverage

M – so you know when they say, so they say in the group, try it, do it and accept that its not going to be 100% the same as what it was before, the experience but you know what, you've done it so if you need to take like 5 days to recover, you have done that, you have experienced life basically. So I think I went to a concert, I went to the james blunt concert and I would never have done that if it hadn't been for the group. And it was all about you've done it now like you know you can do it, leave your baggage behind for one night, do what you've to do and then if you need to lie in bed for a week to recover, do that but push yourself to do things that's basically what they were saying, push yourself. Not too hard but definitely push for basically like your life so whatever your life is, make sure you push yourself to a wee bit more.

Created: 13 Apr 2026

By: KYLC

For Morgan, feeling symptoms or fatigue is worth it if activity was in line with values. The reward must be greater than the cost. Living in line with values was important

Delete

Journaling throughout all the analysis but especially during the coding process was vital. I wanted to ensure I was attentive to what the participants were saying and that I was being thoughtful in how I was interpreting the extracts and that I was attempting inductive coding and not prematurely organising them around theories. ACT processes and illness-perception concepts were part of my awareness of theory

but were not used as coding frameworks to structure coding or theme development; explicit theory-informed interpretation occurred later. Journaling was also important for helping me to pause and reflect throughout the process and consider my analytic decisions in relation to Braun and Clarke's guidance. Below is an extract from my journal.

| Name            | Codes | References | Created on          | Created by |
|-----------------|-------|------------|---------------------|------------|
| Reflexive notes | 0     | 0          | 5 Apr 2026 at 23:44 | KYLC       |

Reflexive notes

Coding Stripes

Highlight

Code

Annotations

Code Panel

Edit

10.04.26

I was feeling anxious in response to the coding. Like how much permission do I have to interpret the transcripts independently. Losing this fear has offered more interpretive freedom and to be more aligned with what the participants are saying.

I think the next step is to put codes into clusters and then review the codes again in the context of those clusters. So, what is this cluster saying?

11.04.26

so, what I'm going to do now is begin to cluster codes together that are broadly of a similar theme. I will then review each cluster and re-code if need and start developing ideas and notes about what those themes are.

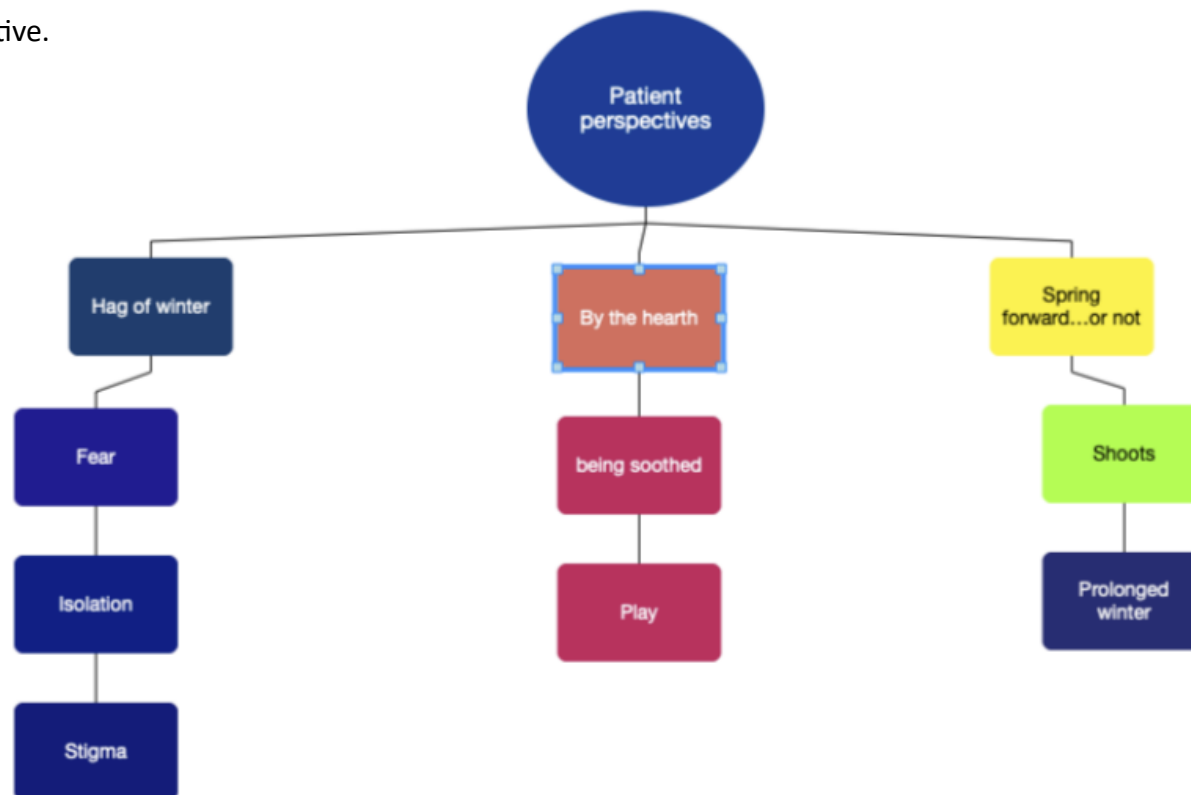
12.04.26

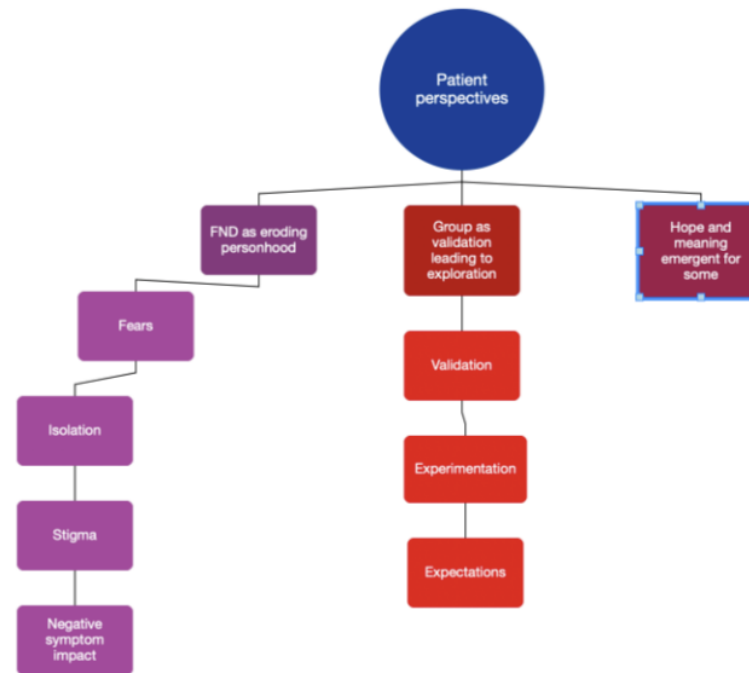
I continued reviewing acceptance and what I did here was re-code so descriptor was more accurate and closer to what the patients' appear to be communicating. I deleted some codes from acceptance that on review, didn't illustrate the candidate theme or was insightful to the research question. I also merged some codes with other codes. So, there is like a preliminary broader theme and then sub-themes (or flavours of that theme). I also annotated the extracts with my interpretation of what was being communicated.

The attention cluster doesn't really seem like a theme and I imagine that I will collapse into and another cluster or part of a broader cluster of meaningful occupation. I've deleted a number of items in this cluster and re-coded others.

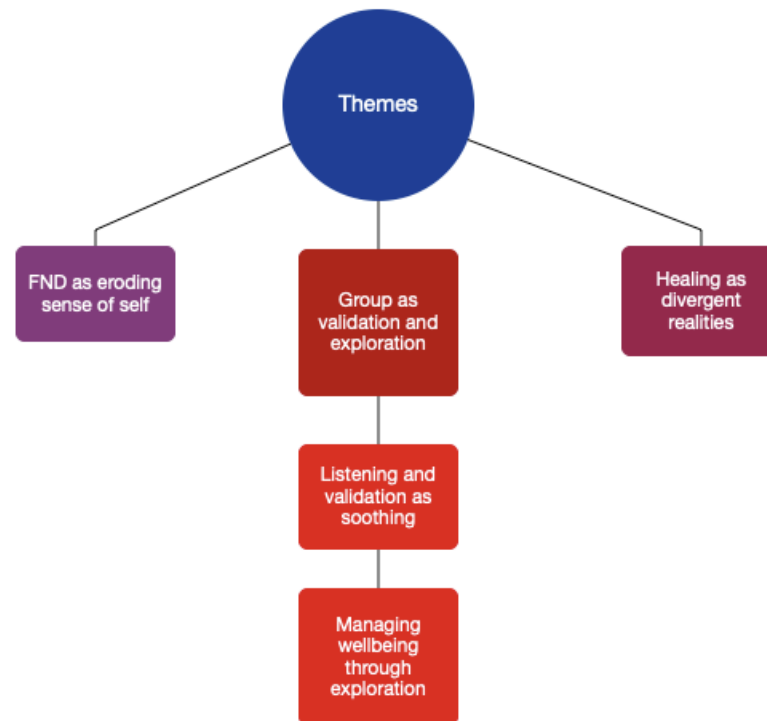
It seems like attention is perhaps like a sub-theme of a larger theme or not a theme at all. It is too narrow or it belongs to mindfulness. I suspect mindfulness, acceptance and behavioural strategies may be related.

Phase three was the start of trying to generate themes. I collated the codes into clusters with these clusters indicating some shared meaning. As I reviewed the clusters, I re-coded as necessary to ensure code labels were appropriately labelled as possible and adding annotations as necessary, which were reflections on possible meanings. Below is a screenshot of an early attempt at generating themes. I had tried to define themes and the underlying concept and ensure I was not developing topic summaries. During this early attempt, I struggled but the use of metaphors helped develop the underlying concepts, which would form later themes. It also helped to take time away from the analysis to reflect on my impressions of the transcripts, extracts and codes and to also simply gain space from the material. It was during this time away that a podcast about life's transitions, spring equinox and old druid traditions prompted me to reflect on how the patients' experiences were possibly an account of a life transition. So, a transition from being in a hard, fallow environment to being in a warm, fertile, nurturing environment, and then venturing from that environment to explore themselves and their lives. This prompted reflection on how my own context, including media, political, and cultural influences, may have shaped theme development and the later emphasis on context within the analytic narrative.





The final phases, four to six, involved reviewing and refining theme names and their definitions. This involved discussing themes with peers and supervisors and how they form an analytic narrative that addressed the research question and how reflective journaling and thinking about the themes and their development corresponded to Braun and Clarke’s guidance. Below is the final thematic diagram; a table of theme definitions and boundaries; a table of sample coded extracts; a table exploring the support and limits of interpretative claims, which was produced in response to supervisors’ comments during drafting the analysis; and a timestamp of included extracts.



|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Expectations (re-coded)</li> <li>Expectations (re-coded)</li> <li>Impact on mood</li> <li>Socially isolated</li> <li>Stigma</li> </ul> </li> <li> <ul style="list-style-type: none"> <li>Being listened to and validated was reassuring and calming</li> <li>Experimenting</li> </ul> </li> <li> <ul style="list-style-type: none"> <li>Acceptance (re-coded)</li> <li>Being curious and noticing more</li> </ul> </li> <li> <ul style="list-style-type: none"> <li>No improvement reported (re-coded)</li> </ul> </li> </ul> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                         |                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>I felt safe and co...</li> <li>I'm not alone any...</li> <li>It was so safe</li> <li>Knowledge excha...</li> <li>Listening and vali...</li> <li>Listening to differ...</li> <li>Patience explainin...</li> <li>They didn't blame...</li> <li>They knew exactl...</li> <li>They understood...</li> <li>They understood...</li> <li>They understood...</li> <li>They'll understand</li> <li>We were just bein...</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>1</li> <li>3</li> <li>1</li> <li>1</li> <li>0</li> <li>1</li> <li>1</li> <li>1</li> <li>1</li> <li>1</li> <li>1</li> <li>1</li> <li>1</li> </ul> | <ul style="list-style-type: none"> <li>1</li> <li>4</li> <li>1</li> <li>1</li> <li>0</li> <li>1</li> <li>1</li> <li>1</li> <li>1</li> <li>1</li> <li>1</li> <li>2</li> <li>1</li> </ul> | <ul style="list-style-type: none"> <li>17 Apr 2026 at 20:...</li> <li>17 Apr 2026 at 12:25</li> <li>17 Apr 2026 at 15:35</li> <li>17 Apr 2026 at 15:25</li> <li>17 Apr 2026 at 12:25</li> <li>17 Apr 2026 at 12:25</li> <li>17 Apr 2026 at 15:33</li> <li>17 Apr 2026 at 20:...</li> <li>17 Apr 2026 at 21:07</li> <li>17 Apr 2026 at 20:...</li> <li>17 Apr 2026 at 21:08</li> <li>17 Apr 2026 at 20:52</li> <li>17 Apr 2026 at 20:...</li> </ul> | <ul style="list-style-type: none"> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> <li>KYLC</li> </ul> |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

| Theme definitions and boundaries    |                                                                                      |                                                                                                                                                |                                                                                       |                                                                                                |                                                                                                              |                                                                                                                                                       |
|-------------------------------------|--------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme name                          | Subtheme                                                                             | What is the central organising concept?                                                                                                        | What is the boundary of this theme?                                                   | Is there enough data?                                                                          | What is unique about this theme?                                                                             | Does it convey something important re. analysis and research Qs?                                                                                      |
| FND as eroding sense of self        |                                                                                      | This theme highlights the various experiences of hardship that people have experienced before the group which have eroded their sense of self. | This theme contains extracts speaking about pre-group experiences of living with FND. | Yes, there were rich extracts across accounts concerning difficult aspects of living with FND. | This theme is unique from others in that it highlights the difficulty of living with FND prior to the group. | This highlights the context in which people entered the group from, which may shape their responses to the group, which is later outlined in Theme 2. |
| Group as validation and exploration | Listening and validation as soothing.<br><br>Managing wellbeing through exploration. | This theme highlights group as representing safety and comfort from hardship and a space for exploring strategies for                          | This theme contains extracts referencing experiences within the group.                | Yes, the pattern was supported by extracts across multiple accounts.                           | This theme is unique from others in that it captures within intervention experiences.                        | Yes, it highlights direct experiences of the intervention, suggesting what was helpful and unhelpful.                                                 |

|                                |  |                                                                                                                                |                                                                                             |                                                                                                                               |                                                                                                                                         |                                                                                                                 |
|--------------------------------|--|--------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
|                                |  | managing wellbeing. Group was an opportunity to restore sense of self.                                                         |                                                                                             |                                                                                                                               |                                                                                                                                         |                                                                                                                 |
| Healing as divergent realities |  | This theme highlights, despite shared intervention context, outcomes are distinctive and need to be understood within context. | This theme contains extracts that speak to perceived change and continuity after the group. | Yes, there were references to various gains from the group. Although, these gains varied in significance and their endurance. | This theme is unique because it contains extracts exploring participants' varied accounts of change and non-change following the group. | This theme highlights people's experience of leaving the intervention and what, if anything, was taken from it. |

| Examples of coded extracts |                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|----------------------------|--------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme                      | Code                                       | Extract                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Theme 1                    | Protracted route to treatment/diagnosis    | Well, for me, because it took so long to get there, it was a sense of: one, relief; but two, actually somebody was taking an interest in me, my case, and my situation. Up until that point, I don't want to speak ill of anyone in the NHS, but it felt like every consultant I went to was trying to wash their hands of me because I wasn't an obvious, straightforward case. It wasn't, 'Oh, he's broken his leg' or 'he's pulled a muscle.' Because it wasn't a quick diagnosis or a quick fix, there wasn't really an interest. So, it was a very frustrating period for a number of years until somebody came along and said, 'Hang on a second, this is FND.' It felt like somebody was finally taking me seriously. Ashley, Interview 6 |
| Theme 1                    | Fearing being judged by others             | Em, I don't know. I honestly don't know, because I know that they would never, ever think she's got a disability, but I just maybe felt they were thinking, 'She's weird.' Robin, Interview 7                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Theme 1                    | Grieving loss of function                  | Yeah, I just cried all the time. I think what frustrated me was when I phoned the doctors and they were saying I've got depression. I was like, 'That's not what it is. It's more frustration.' I felt like I was grieving my old life, and I still get that sometimes. I genuinely felt, at first, that I would be back at the gym in a week, or back in three weeks. We're now three years down the line [laughing]. Jesse, Interview 1                                                                                                                                                                                                                                                                                                        |
| Theme 1                    | Negatively impacted by loss of functioning | I worked all these years... I would still be working if this hadn't happened to me. I now knew my time to give up work... and that put me into a depression again. Alex, Interview 2                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Theme 2                    | Goal setting as hopeful structure          | Definitely. I liked that they used to do a group thing where we would try something every week; something we would hide ourselves from doing, something we maybe wouldn't do before because of the condition. I liked that. It felt like that set us up for tasks. I actually feel like that sets me up every week. On Sunday night, me and my husband go for a walk, and I plan my week. I go, 'I'm going to try this this week because I wouldn't do that before.' Robin, Interview 7                                                                                                                                                                                                                                                          |
| Theme 2                    | Listening and validating as soothing       | It was very reassuring, and I've got to say, yes, it was less worrying. Because during the group, you were with professionals who knew exactly what was happening to you, you weren't making it up. It was real. Jules, Interview 9                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

| Examples of coded extracts |                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|----------------------------|---------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme                      | Code                                        | Extract                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Theme 2</b>             | Pursuing valued action despite symptom cost | So, when they say in the group, 'Try it, do it, and accept that it's not going to be 100% the same as what it was before,' you know what, you've done it. If you need to take five days to recover, you have experienced life. I went to a concert, the James Blunt concert, and I would never have done that if it hadn't been for the group. It was about, 'You've done it now; you know you can do it. Leave your baggage behind for one night, do what you have to do, and then if you need to lie in bed for a week to recover, do that.' Not too hard, but definitely push for your life; whatever your life is, make sure you push yourself a wee bit more. Morgan, Interview 10 |
| <b>Theme 2</b>             | Relief at shared experience                 | I'm still there and I think that, when you're in a room where people have tremors or tics, or go to stand up but can't feel the floor, you're in a room full of people who are having different symptoms. As much as I wouldn't wish it on them, it was nice being in a room with people who knew that sometimes your leg doesn't work, and sometimes that cup you're holding is going to the floor because your brain has decided it doesn't want to hold it anymore. Em, I kind of lost track of your question. Charlie, Interview 5                                                                                                                                                  |
| <b>Theme 3</b>             | Increased sense of purpose and connection   | It gives me purpose, I think that's the main one. Other people's... I don't know, just understanding that everybody's got their own thing going on in life and taking five minutes to listen to somebody can help them massively. It's just five minutes out of your day, and if I can do that for people coming, even if we meet up in a coffee shop or a community hall, if people can take away that they've had a good chat, a good blether, they'll feel better for it. I think that's a massive positive I can take away from the group. That's what I've got from the group. Brodie, Interview 4                                                                                 |
| <b>Theme 3</b>             | Relationships improved, but not overnight   | It was a massive turning point in my life and I don't know if I would have made as much progress without going to it. It changed my way of thinking; it changed how I was living my life for the better. It made my relationships, my friendships, everything so much better. It did take time; it obviously didn't happen overnight. When I came out, I had to work on it, but without the help of the group, like Thomas, Catriona, the group, the guys in the group, I think I would have still been clawing my way back. Brodie, Interview 4                                                                                                                                        |
| <b>Theme 3</b>             | Feeling hopeless after the group            | L – Some days are not great, the symptoms...<br>F – Yeah, really stressful.<br>L – Stressful, yeah.<br>F – Because there's no end. There's nothing for this; it just happened. Fran, Interview 8                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |

| Examples of coded extracts |                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|----------------------------|---------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme                      | Code                            | Extract                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Theme 3                    | Rejecting of group premise      | As it was going on, and they're telling you, 'Don't think this way, think that way. You need to get those bad feelings away and find the good ones,' you're thinking, 'I've sat in a house, freezing, not got any money for the heating because I can't work—because I've got this—and I have tried to get wee part-time jobs, and I can't manage it. So, you can't live well. You can live with it. You need to take the 'well' out of that title. Fran, Interview 8 |
| Theme 3                    | Reverting back to what you know | You just go back to what you know, and that's the frustrating thing. It's not as if I wanted to, or want to, feel like this. Jamie, Interview 3                                                                                                                                                                                                                                                                                                                       |

| Support for and limit of analytic claims |                                                                                                                                                                                                                                                                                  |                                                                                                                                     |                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                          |                                                                                                                               |
|------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|
| Theme                                    | Extract / participant                                                                                                                                                                                                                                                            | Analytic claim made in Results                                                                                                      | What in the extract and wider account supports this claim?                                                                                                                                                                                                                                                              | Limit                                                                                                                                                                                                                                                                                    | Decision                                                                                                                      |
| <b>FND as eroding sense of self</b>      | <b>Jesse:</b> “I was just adamant that I was dying and I was just like, it was just horrific... they reassured me that I was not well, but it wasn’t the end.”                                                                                                                   | FND symptoms could be experienced as frightening and life-threatening before the group, contributing to a threatened sense of self. | Jesse explicitly describes believing they were dying and experiencing this as “horrific.” This supports the interpretation that symptoms were not only confusing but existentially threatening. The later reference to reassurance also links the pre-group fear to the later importance of validation and explanation. | The extract supports fear and threat, but “death may represent the ultimate loss of self” is an interpretive step rather than something Jesse explicitly states.                                                                                                                         | Retained. Used to support the interpretation that FND could be experienced as a threat to self and life.                      |
| <b>FND as eroding sense of self</b>      | <b>Morgan:</b> “It was the worry that... I was going to be housebound; I was going to be in a wheelchair... you’re worrying... about putting that pressure on him; putting that pressure on my daughter... it was such a concern—like sleepless nights. It was almost like I was | FND could erode sense of self through anticipatory loss, worry about dependency, relational strain, and grief for a previous self.  | Morgan links feared functional decline with worry about the impact on their partner and daughter. The phrase “grieving my old self” directly supports the interpretation of identity loss. The extract also supports the analysis of grief and fear as intertwined, rather than separate experiences.                   | The extract supports grief, fear, and relational concern, but does not show whether these concerns were realised or primarily anticipatory. The interpretation should therefore remain focused on perceived threat and anticipated loss. Threat to relationships is interpretative step. | Retained as fits extract and claim. Used to show how FND threatened identity, relationships, and imagined future functioning. |

|                                            |                                                                                                                                                                                                                                                                   |                                                                                                                                                   |                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                         |                                                                                                                                                                                                                 |
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|                                            | grieving my old self.”                                                                                                                                                                                                                                            |                                                                                                                                                   |                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                         |                                                                                                                                                                                                                 |
| <b>Group as validation and exploration</b> | <b>Jules:</b> “...it made you open up and explain your experience... I needed it at that time.”                                                                                                                                                                   | Being listened to in the group could create a sense of validation, making disclosure feel more possible and opening opportunities for connection. | Jules describes the intervention helping them “open up” and “explain” their experience at a time when this was needed. In the surrounding analysis, this is linked to feeling listened to by facilitators, supporting the interpretation that being heard helped make disclosure possible. | The extract supports opening up and need, but does not by itself prove validation or connection. Those are interpretive links drawn from the wider interview context and the subtheme pattern across interviews.        | Retained, but phrased cautiously as “may suggest.” Used to support the subtheme “Listening and validation as soothing,” while recognising that the extract alone does not evidence sustained relational change. |
| <b>Healing as divergent realities</b>      | <b>Jamie:</b> “...I was at the group and I felt great afterwards, I know how to manage everything... you just go back to what you know... it’s like I know all the information, I just can’t I just do it. ...I’m struggling to... navigate my way through life.” | Change could feel scaffolded by the group but difficult to sustain after the intervention ended.                                                  | Jamie describes feeling able to manage during or shortly after the group, but later “going back to what you know” and struggling to navigate life. This supports the interpretation that information or skills alone were insufficient once the group context was removed.                 | This does not prove that the group caused change or that loss of group scaffolding caused relapse. The difficulty may also reflect ongoing life stressors, limited follow-up, symptoms, or broader unmet support needs. | Retained, but phrased cautiously as “suggesting” that learning, development, or healing had been scaffolded by the group. This supports the theme’s focus on fragile and context-dependent change.              |
| <b>Healing as divergent realities</b>      | <b>Alex:</b> “...I felt a new person, I felt I was able to                                                                                                                                                                                                        | Healing may involve connection with                                                                                                               | Alex retrospectively linked feeling “a new person” and more able to cope with subsequent physiotherapy,                                                                                                                                                                                    | The extract and wider dataset support the importance of signposting                                                                                                                                                     | Retained as an example of pragmatic/contextual healing. Wording kept                                                                                                                                            |

|                                       |                                                                                                                                                                                |                                                                                                     |                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                 |                                                                                                                                 |
|---------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------|
|                                       | cope... doing that course led me to... a physical therapist... they put me onto a strength and balance course... I now go to a circuit training class at least once a week..." | practical, tailored, multidisciplinary support, not only internal psychological change.             | strength-and-balance work, and circuit training.                                                                                                                                                                                              | and practical support, but they do not show that the group alone caused improvement.                                                                                                                                            | cautious: For Alex, healing appeared to involve expanded support networks with support more closely tailored to everyday needs. |
| <b>Healing as divergent realities</b> | <b>Jules:</b> "...I've not had an episode where I've been shaky or where I've been in floods of tears, uncontrollable." / "Probably because I know how to manage it."          | Healing could involve a developing sense that symptoms and emotional distress were more manageable. | Jules links reduced episodes of shakiness and uncontrollable crying with knowing "how to manage it." This supports the interpretation that healing involved symptom management, reduced emotional overwhelm, and increased perceived control. | The extract does not prove symptom improvement was caused by the group. "Feeling empowered" may be slightly stronger than the extract alone supports but was interpreted as a reasonable consequence of feeling able to manage. | Retained.                                                                                                                       |

| Timestamp of included extracts in interviews |                     |              |           |                 |
|----------------------------------------------|---------------------|--------------|-----------|-----------------|
| Extract                                      | Recording timestamp | Date checked | Outcome   | Checker         |
| Theme 1, Brodie, Interview 4                 | 18:53-20:04         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 1, Ashley, Interview 6                 | 28:40-29:16         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 1, Alex, Interview 2                   | 09:36-10:01         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 1, Charlie, Interview 5                | 07:19-07:51         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 1, Robin, Interview 7                  | 31:07-31:39         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 1, Morgan, Interview 10                | 05:22-06:09         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 1, Jesse, Interview 1                  | 06:58-07:44         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Fran, Interview 8                   | 14:48-15:03         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Jesse, Interview 1                  | 27:44-28:16         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Jules, Interview 9                  | 21:45-21:49         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Charlie, Interview 5                | 49:36-50:45         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Fran, Interview 8                   | 54:51-55:27         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Fran, Interview 8                   | 01:13:00-01:13:21   | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Morgan, Interview 10                | 56:33-57:04         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Ashley, Interview 6                 | 53:10-55:46         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 2, Brodie, Interview 4                 | 01:09.10-01:10:09   | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 3, Jamie, Interview 3                  | 04:04-04:39         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 3, Ashley, Interview 6                 | 18:40-19:25         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 3, Robin, Interview 7                  | 01:02:11-01:03:48   | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 3, Alex, Interview 2                   | 14:59-16:06         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |
| Theme 3, Jules, Interview 9                  | 29:11-29:21         | 05.05.26     | Confirmed | Kuen-Yuen Cheng |

## Appendix 2.7. Information power framework

This framework was used to reflect on adequacy of sample size.

| Information power item                                                                                                                                                                                     | Justification                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Study aim                                                                                                                                                                                                  | The research aim sat in the middle of the broad–narrow continuum. The primary aim was focused on patients’ experiences of one specific ACT FND group intervention. However, the secondary research questions broadened the study by also considering helpful and unhelpful aspects of the group, ACT processes, and illness-perception concepts. This breadth reduced information power, particularly in relation to the secondary questions.                                                             |
| Broad to narrow                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Sample specificity                                                                                                                                                                                         | The sample had relatively strong specificity for the primary research question because all participants had direct experience of the intervention and all had completed the group and majority were female. However, specificity was reduced by variation in cohort, time since intervention, symptom duration, comorbidities, while missing FND subtype and ethnicity data limited assessment of sample heterogeneity.                                                                                   |
| Sparse to dense                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Use of established theory                                                                                                                                                                                  | The study was partly informed by existing theory, including psychological flexibility and illness perceptions. However, these were not used as coding frameworks, as the primary aim was to foreground participants’ experiences. Theoretical concepts therefore increased information power only partially, supporting cautious discussion of secondary questions rather than systematic theory testing.                                                                                                 |
| None to applied                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Quality of dialogue                                                                                                                                                                                        | Interviews lasted between 45 and 90 minutes and generated detailed accounts of participants’ experiences across the period of before, during, and after the intervention. The PI’s clinical training supported sensitive interviewing, while the interview schedule was developed with supervisory, clinical, and expert-by-experience input. However, interviews were retrospective, and some participants could have been influenced by recall, gratitude, or the wish to present the group positively. |
| Weak to strong                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Analysis strategy                                                                                                                                                                                          | The study used an inductively oriented reflexive thematic analysis to develop shared patterns of meaning across the dataset. A cross-case approach generally requires greater information power than an in-depth case-based analysis. However, the sample provided detailed material across cases to develop shared patterns of meaning relevant to the primary research question. Information power was more limited for detailed analysis of PF and IPs.                                                |
| Cross-case to case-based                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Developed from: Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. <i>Qualitative health research</i> , 26(13), 1753-1760. |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

Overall, the sample was judged to provide adequate information power for the project’s primary aim of exploring patients’ experiences of the ACT group intervention. Information power was more limited for the broader theory-informed secondary questions, which were addressed cautiously through the thematic account rather than through separate deductive analyses.

#### **Appendix 2.8. Approved MRP proposal and subsequent versions**

<https://osf.io/c8gj3/files/gpehd>

#### **Appendix 2.9. Data analysis plan**

<https://osf.io/c8gj3/files/w3gja>

#### **Appendix 2.10. Data availability statement**

The participants have also not consented to their data to be shared with third parties. Please contact the Chief or Principal Investigator should you have any questions regarding the study.