The University Of Sheffield.

Functional / Dissociative Seizure (FDS) Severity and the Development of a Patient-Reported Outcome Measure (PROM) for Adults with FDS

Laura Whitaker

A thesis submitted in partial fulfilment of the requirements for the award of Doctor of Clinical Psychology at the University of Sheffield (DClinPsy)

Clinical and Applied Psychology Unit

Department of Psychology

The University of Sheffield

June 2024

Declaration

I declare that this thesis is my own work. It is submitted for the Doctorate in Clinical Psychology at the University of Sheffield and has not been submitted to any other University for any other award.

Word Count

Abstracts

Lay Summary: 500

Systematic Review: 250

Empirical Study: 246

Systematic Review

Excluding abstracts, references and figures/tables: 8000

Including abstracts, references and figures/tables: 11564

Empirical Study

Excluding abstracts, references and figures/tables: 8000

Including abstracts, references and figures/tables: 15862

Total

Excluding abstracts, references and figures/tables: 16000

Including abstracts references and figures/tables: 27426

Lay Summary

Functional / dissociative seizures (FDS) are a common and often debilitating condition. They are often misdiagnosed as epileptic seizures at first, however, they are not associated with the same electrical activity in the brain. Instead, they are considered a dissociative ("switching off") response to triggers inside or outside the body which are perceived as threatening. People who experience FDS are more likely to have complex psychological and physical health difficulties. As such, there is a growing body of evidence to support psychological interventions for FDS, recommended as the treatment of choice. However, assessment and evaluation of treatments are limited by a lack of appropriate tools (outcome measures) developed especially for in people with FDS.

The first part of this thesis was a review of twelve articles to determine what factors are associated with seizure severity in people with FDS. It is important to understand what makes a condition more or less severe as this can help guide treatments. Given that there is no measure of severity specifically developed for FDS, the review also aimed to identify how studies have attempted to measure severity. By looking at the relationships between seizure severity measures and other participant characteristics, we hoped to find out more about the validity of the different severity measures used in people with FDS. Different types of factors had been explored to see if they link with seizure severity. These included trauma, mental health, emotional processes, quality of life, relational factors, illness perceptions, symptom attributions, stigma, and demographics. It was difficult to draw conclusions as studies explored a wide range of different factors. Interestingly, some of the studies examining the same characteristics found different relationships with FDS severity. It is possible that this is explained by the wide variety of methods that were used to measure seizure severity. Perhaps different studies were therefore not measuring the same aspect. This review concluded that there is currently no validated and reliable measure of seizure severity in people with FDS and that the development of such a measure would therefore be of interest.

In the second part of this thesis, two research studies were completed. Overall, these aimed

to develop a self-report FDS outcome measure of seizure severity. In the first study, individuals with lived experience of FDS and professional experts took part in group discussions about FDS severity. This revealed three main themes related to FDS severity including 'lack of control' over seizures, 'distressing physical symptoms', and the 'lasting effects and impact of FDS'. These findings led to the development of a list of questions designed to assess FDS severity. In the second study, a larger group of people with FDS and professional experts were asked in a series of surveys to tell us which questions they considered most important to measure FDS severity. This led to a candidate self-report outcome measure of FDS severity with supplementary sections concerning seizure frequency and duration, and also a symptom checklist to cover the range of symptoms people with FDS may experience.

Acknowledgements

Firstly, I would like to thank my research supervisors Dr Gregg Rawlings, Dr Chris Gaskell and Prof Markus Reuber. It goes without saying it would not have been possible to complete this project without their extensive knowledge and invaluable guidance. Beyond this, I am incredibly grateful for the containing support and inspiration, continual learning opportunities, and very thankfully, their speedy responsiveness. To my placement supervisors, clinical tutor and the incredible friends I have made during training – thank you for the continued understanding and support – with a special shoutout to Emily who has been there from day one.

I would like to share a special thanks to FND Hope for their helpful feedback on this project, kind words of support and help with recruitment. I extend this to the individuals at the Clinical Neuropsychology Division of the BPS and the International League Against Epilepsy for their support and help with recruitment. Most importantly, a massive thank you to the participants who generously took the time to take part and share their incredible insights.

On a personal note, thank you to my family and friends at home who have offered a space to laugh and unwind throughout the doctorate, and endless words of encouragement to get this “novel” wrote! To Fliss and Alby, watching you grow and sharing your smiles and giggles has provided countless boosts to keep going. To my mum and dad, I am unbelievably privileged to call you my parents and forever grateful for your unconditional love and support. Your belief in me is the reason I am here, and I’m so very thankful for every last bit of your help along the way.

Last (but certainly not least) to my Yorkshire family. To Otis, sat by my side for every word wrote and every remote meeting attended. Undeniable proof that life (and a doctorate) is better with a dog. Finally, to my partner Jack, I feel so incredibly lucky that our paths have crossed on this journey and despite the odds, I have met my best friend. I am so proud of everything we have achieved together, and I cannot wait for everything that is to come. Thank you for your unwavering encouragement, love, and advice. Mostly, thank you for providing infinite reasons to laugh and smile, every day of the last few years.

Table of Contents

Preface **Page**

Declaration……... **ii**

Word Count…….. **iii**

Lay Summary……... **iv-v**

Acknowledgments…… **vi**

Section One: Systematic Review

Title……... **1**

Abstract…… **2**

Introduction……... **4**

Methods……. **6**

Results……... **11**

Discussion……. **29**

References……. **37**

Appendices…… **45**

Section Two: Empirical Study

Title……... **68**

Abstract…… **69**

Introduction……... **71**

Methods……. **75**

Results……... **83**

Discussion……. **105**

References……. **113**

Appendices…… **121**

Section One: Systematic Review

Psychosocial Correlates of Seizure Severity in Adults with Functional / Dissociative Seizures (FDS): A Systematic Review

Abstract

Objectives: The review aimed to 1) identify and systematically examine factors associated with seizure severity in adults experiencing FDS, and 2) examine and report how FDS severity has been measured in these studies.

Methods: A systematic search was performed in July 2023 (rerun in April 2024) using four databases: PsycInfo, MEDLINE, CINAHL and Cochrane Reviews. Inclusion criteria focused on quantitative studies exploring psychosocial correlates of FDS severity in adults published in a peer reviewed journal after 1990. Eligible studies were subjected to quality assessment using an adapted version of the Appraisal Tool for Cross-Sectional Studies (AXIS) or the CASP Cohort Study Checklist.

Results: Twelve articles were included; eleven cross-sectional (meeting at least 11/17 on quality assessment) and one cohort (9/12 on quality assessment). Findings were narratively synthesised and grouped thematically (based on the number of studies contributing to the theme). Significant associations were found within domains of trauma, mental health, emotional processes, relational, illness perception and symptom attribution and demographic factors. Effect sizes ranged from weak to moderate. Eleven different methods / measures had been used to assess seizure severity (and associated concepts of intensity, impact and bothersomeness). None were standardised for use with FDS.

Conclusions: No studies primarily aimed to explore correlates of seizure severity thus data was minimal and inconsistent. The variety of seizure severity measures likely exacerbated inconsistencies and a lack of convergent validity was demonstrated. It would be beneficial for future research to develop a measure of FDS severity to address the limitations of this review.

Practitioner Points:

- Reduction of seizure severity is an important treatment goal in psychological interventions for FDS and a common outcome in research.
- Traditionally, FDS severity has been measured using tools developed for epilepsy seizure severity. However, FDS and epileptic seizures are fundamentally different.
- Eleven different methods / measures were used to assess seizure severity and its associated concepts. Of significant correlations found, only weak to moderate effect sizes were demonstrated and inconsistencies were found across studies. A lack of convergent validity was demonstrated in measures used to assess FDS severity.
- A notable gap in the literature was highlighted in studies examining factors associated with FDS severity. This is an area for future research with a reliable and validated measure. Such a measure does not currently exist; it is therefore important this is developed to address the current inconsistencies. This would aid in developing the evidence-base for FDS.

Keywords: functional/dissociative seizures, seizure severity, outcome measures, review, adult.

Functional / dissociative seizures (FDS), also referred to as psychogenic nonepileptic seizures (PNES), are episodes of abnormal experiences and observable behaviour superficially resembling epileptic seizures or syncope (Rawlings & Reuber, 2016). They are not, however, associated with ictal electroencephalographic (EEG) discharges observed in epileptic seizures or the pathophysiological changes underpinning syncope (Reuber, 2008). Video electroencephalograph (vEEG) is recognised as best practice for accurate diagnosis (LaFrance et al., 2013). FDS have been conceptualised as involuntary experiential or behavioural responses to adverse internal or external triggers (Brown & Reuber, 2016) and manifest as periods of reduced self-control associated with a range of motor, sensory, and mental and emotional features (Reuber & Rawlings, 2016). The most recent community-based study of the epidemiology of FDS suggested a prevalence of 23.8 per 100,000 and incidence of 3.1 per 100,000 per year (Villagrán et al., 2021).

Many psychotherapeutic approaches have been explored for FDS with Cognitive Behavioural Therapy (CBT) having the most substantial evidence base (LaFrance et al., 2013; Hingray et al., 2018). Psychological treatments, like CBT, target seizure frequency, severity, and symptoms commonly co-existing with FDS (Lopez & LaFrance, 2022) and, non-seizure-related outcomes (Gaskell et al., 2023). Therefore, knowledge of what is associated with seizure severity could aid in understanding what is related to greater outcomes in this population and guide interventions. Moreover, assessment of symptom severity can be an important factor to monitor in response to treatments provided, and to evaluate outcome.

There is considerable heterogeneity in the experiences and symptoms associated with FDS (Reuber & Rawlings, 2016). This suggests it could be important to understand what symptoms, or combination of symptoms, patients consider most troublesome, and to what extent the symptomatology of FDS is associated with severity of the condition (Nicholson et al., 2019). Patient-reported outcome measures (PROMs) are commonly used to assess patients' experiences of their symptoms and their perception of condition severity (Meadows, 2011). Such measures have long been established in a range of psychological conditions such as depression (e.g. PHQ-9; Kroenke et

al., 2001), anxiety (e.g. GAD-7; Spitzer et al., 2006) and various neurological conditions including epilepsy (e.g. Liverpool Seizure Severity Scale 3; LSSS-3; Baker et al., 1998).

Seizure severity is established as an important outcome variable in the evaluation of epilepsy treatment (Cramer & French, 2001). Reliable and valid epileptic seizure severity measures have been developed such as the LSSS-3 as mentioned, the National Hospital Seizure Severity Scale (NHS-3; O'Donoghue et al., 1996), and the Seizure Severity Questionnaire (SSQ; Cramer et al., 2002). These were developed in recognition of seizure severity being of equal or greater importance than seizure frequency in determining psychological and social well-being of patients with poorly controlled epilepsy (Baker et al., 1991). Researchers have made considerable efforts to explore FDS severity, however, in the absence of a condition-specific PROM, studies have commonly used measures validated for use in epilepsy. However, FDS and epileptic seizures are fundamentally different; self-reported symptoms can be clearly distinguished with patients with FDS reporting greater heterogeneity and symptom frequency associated with loss of consciousness (Reuber et al., 2016). This is important because treatments differ for these conditions and outcome measures developed for epilepsy are unlikely to be suited to FDS.

A previous systematic review found seizure frequency and/or freedom was the most frequently reported outcomes of symptom change in FDS. However, there was variability in how these measures were defined and a lack of data for their reliability and validity (Pick et al., 2020). This review endorsed the relevance of monitoring seizure duration, severity, and specific seizure symptoms, as well as event frequency in FDS. A large-scale randomised controlled trial (RCT) examining the effectiveness of CBT for adults with FDS highlighted limitations of seizure frequency as a preferred outcome measure for FDS (Goldstein et al., 2020). In this RCT, there was no significant improvement in seizure reduction however significant improvements were found in a range of secondary outcomes (i.e. health-related quality of life (HRQoL), psychosocial functioning, psychiatric symptoms, psychosocial distress, and somatic burden). Further, a systematic review evaluating correlates of HRQoL in adults with FDS found that seizure frequency reduction was not

associated with improved HRQoL (Jones et al., 2016). Rawlings et al. (2017b) recognised the complexity between FDS seizure frequency and HRQoL suggesting other psychosocial or psychiatric factors may relate more closely to HRQoL than seizure frequency. Finally, a recent RCT favoured seizure severity due to limitations in the high variability of seizure frequency, differing definitions of when to count seizure-like symptoms, and a lack of valid scales or instruments to measure frequency (Senf-Beckenbach, 2022).

Identifying what influences seizure severity in FDS is therefore essential to guide and evaluate assessments, treatments and monitor outcomes. Moreover, given the uncertainty around the validity of measuring seizure severity (particularly with measures for epilepsy); the demonstration of convergent validity (i.e. through clear correlations between seizure severity measures and other relevant measures of functioning, wellbeing, or treatment outcome) would help the practitioner gain a better understanding of the seizure severity measures available or, confirm the need for development of a new measure. Therefore, this review primarily aims to systematically examine psychosocial factors associated with FDS severity in adults. A secondary aim is to identify how FDS severity has been measured in these studies.

Method

The review was completed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) and was pre-registered on the international prospective register of systematic reviews (PROSPERO) on the 19th July 2023: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=445143.

Search Strategy

Four electronic internet databases were searched for relevant articles: PsycInfo (via

Ovid), MEDLINE (via Ovid), CINAHL (via EBSCO) and Cochrane Reviews from 1990 to 28th July 2023 (search date). No new articles were found when this was repeated on 12th April 2024 (for papers published since). Databases and search terms (Table 1) were selected in-line with recent relevant systematic reviews in FDS (Jones et al., 2016; Gaskell et al., 2023); with review by clinicians with expertise in the field (co-authors). Search term combinations included terms related to *diagnosis*, *severity,* and *correlates*. No language restrictions were applied on searches.

Search results were exported into Rayyan (Ouzzani et al., 2016), a web-based software that collates references and supports the screening of titles and abstracts (by tracking included and excluded articles). Duplicates were removed and an initial screen of titles and abstracts against pre-defined eligibility criteria based on the Population, Intervention, Comparison, Outcomes framework (PICO; Miller & Forrest, 2001) was completed (Table 2). Remaining articles were subject to a full-text review against the eligibility criteria (see Appendix A for excluded papers at full-text screen). If it was unclear from the title / abstract screen whether eligibility criteria were met; the study was included for full-text review to avoid erroneous exclusion.

Table 1

Search Terms

Concept	Key Words
Diagnosis	Functional OR dissociative OR hysteri* OR pseudo* OR unintended (seizure*); Nonepileptic OR psychogenic (seizure* OR attack*); Nonepileptic Attack Disorder
Severity	Sever* OR difficult* OR intensit* OR distress* OR frequenc* OR duration OR burden* OR bother* OR cluster
Correlates	Correlate* OR correlation* OR assoc* OR predict* OR influence* OR impact* OR determinant* OR outcome* OR variable* OR factor* OR relat* OR regression

For reliability checks, a second reviewer (JI) screened 25% of randomly selected articles at the title and abstract screen; and 27.5% at full-text. Interrater reliability was calculated using Cohen's kappa coefficient (Landis & Koch, 1977). This indicated moderate agreement at the first

stage (k = 0.54, agreement = 94.81%) and substantial agreement at the second (k = 0.63, agreement = 93.94%). A pre-determined consensus threshold was set at 80% (i.e. 80% or more was considered reliable). Following discussion, a 100% consensus was reached for articles reviewed by both reviewers. The web-based programme 'Citation Chaser' (Haddaway, Grainger & Gray, 2021) was used to conduct backwards and forward searches of included articles.

Following the above steps, the eligibility criteria were refined to exclude studies that reported solely upon seizure frequency/freedom as a measure of seizure severity (see Appendix B). Having gained a sense of the types of outcomes used across studies, it was apparent seizure frequency and freedom were far less related to the severity of FDS. Given the limitations highlighted regarding seizure frequency reduction or freedom as a measure of FDS severity (e.g. Goldstein, 2020; Green et al., 2016), the authors agreed that studies exclusively using these measures were beyond the scope of this review.

Table 2

Eligibility Criteria

	Inclusion	Exclusion
Purpose	Provides insight into correlates of FDS severity. Focuses primarily on FDS and report on severity related to the immediate pre-ictal (beginning), ictal (middle), and post-ictal (end) phases of FDS.	FDS not the primary focus. Reports solely on severity related to wider impact of FDS and quality of life.
Population	Individuals aged 16 years and over with a diagnosis of FDS. Control samples will be used as comparisons where available (findings will need to be clearly distinguishable).	Children and adolescents (younger than 16 years). Full samples in which >50% participants did not have FDS. Findings reported in such a way that those related to the FDS population and comparison groups could not be distinguished.
Study Design	Quantitative studies	Qualitative studies, case studies, single case experimental designs.
Outcomes	Reported an association between any variable related to FDS severity (e.g. Pearson's *r*, Spearman's rank-order, Cohen's *D*, Regression, ANOVA). Any measure / method used to assess FDS severity.	
Other	Studies published from 1990 to present.	Not published in English. Full text not available. Grey literature.

Quality Assessment

Most eligible studies were quality assessed using the Appraisal Tool for Cross-Sectional Studies (AXIS; Downes et al. 2016). As one study was a cohort design, this was assessed using the CASP (2018) Cohort Study Checklist. Both are validated tools and were supplemented with FDS-specific quality criteria from a previous systematic review of FDS (Brown & Reuber, 2016). Strengths of the AXIS include a comprehensive assessment of each aspect of the study design, risk of bias and quality of the study reporting that can be used across disciplines (Downes et al., 2016). Neither tool provides a numerical scale to assess overall study quality and therefore assessment was based on the performance of individual items. The AXIS included evaluation of seventeen quality assessment components: study aims, design, sample size justification, sample representativeness / vEEG

diagnosis, selection bias, validity of measures, significance reporting, data analysis, methods, results, internal consistency, discussion, limitations and ethics (Appendix C). The CASP Cohort Study Checklist included twelve items across three broader domains focused on validity of the results, content of the results and implications (Appendix D). Items were coded as 'yes' (criteria met), 'no' (criteria not met) or 'unclear' (Appendix E).

To ensure reliability, a second reviewer assessed approximately 25% of the included articles (JI). The initial level of agreement was not calculated however discrepancies were discussed until 100% consensus was achieved.

Data Extraction and Synthesis

A data extraction form was developed by the first author and co-author (GR) in-line with review aims and previous reviews conducted in the field. For each study, the following information was extracted and summarised by the lead author: author(s), country and year(s) of publication, study design, setting, sample size, population characteristics (including descriptive statistics), seizure severity measure, correlated variables or alternate effect sizes (e.g. regression, ANOVA), data analysis, outcome measure of associated variables, and quality assessment. As data was only extracted by one author, some information may have been missed due to human error. This is a limitation for which a second person may have enhanced accuracy. That said, one paper was reviewed by both LW and GR to ensure all relevant data was collected. Moreover, the data extraction form was reviewed on two occasions by the co-authors to ensure no relevant or expected data was missed. Summary tables are provided in the results section and appendices. A meta-analysis was not appropriate due to the heterogeneity of outcomes. A narrative synthesis was performed to provide an overall summary of findings addressing the research questions. Correlates were grouped according to similar themes. Those with most data are presented first.

Results

Search Results

A PRISMA flow diagram (Page et al., 2021) depicts the systematic search process (Figure 1). The initial search equated to 1155 unique articles, of which 120 were identified for full-text review. Of these, one was not available in English and one could not be accessed. Seventy studies did not meet inclusion criteria and were excluded. Initially, 48 articles were included. Backwards and forward searches led to an additional 14 articles. This resulted in 62 studies for inclusion. Refinement of the eligibility criteria (removal of seizure frequency/freedom) led to further exclusion of 50 studies. Subsequently, 12 papers were included for quality assessment and data extraction. For context, findings in relation to seizure severity measures are presented first followed by the narrative synthesis of factors related to FDS severity. Associations with FDS severity are summarised according to the following categories: trauma, mental health (anxiety, depression, general psychological difficulties, stress, dissociation), emotional processes, HRQoL, relational factors, illness perceptions and symptom attribution, stigma, and demographics.

Study Characteristics

Twelve studies were published up to April 2024 (Table 3). Eleven were cross-sectional and one a cohort design. Most recruited from outpatient settings ($k = 10$; note that, 'k' refers to number of studies) including specialist epilepsy/seizure clinics, neurology, neuropsychology and/or neuropsychiatry clinics, and a specialist FDS referral centre. Two of these additionally recruited from membership-led organisations for individuals experiencing seizures, one via the social media of seizure organisations and one recruited a sample from the local community. Two studies recruited from inpatient epilepsy monitoring units. Eight studies were conducted in the UK, two the USA, and one study each from Germany and Turkey. Two studies shared an overlapping data set however were

both included as they reported unique outcomes. One of these predominantly focused on patients (Green et al., 2016) and the other on carers of a proportion of those patients (Wardope et al., 2019).

Samples of individuals with FDS were relatively small and ranged from 23 to 368 with a total of 1055 individuals with FDS taking part across studies. Participants with FDS were predominantly female except for one study in which most were male. Across studies, the average age range (mean or median) of participants with FDS was 27.2 to 50.0. Ethnicity was only reported in eight studies, all of which included a predominantly 'White' or 'White British' sample.

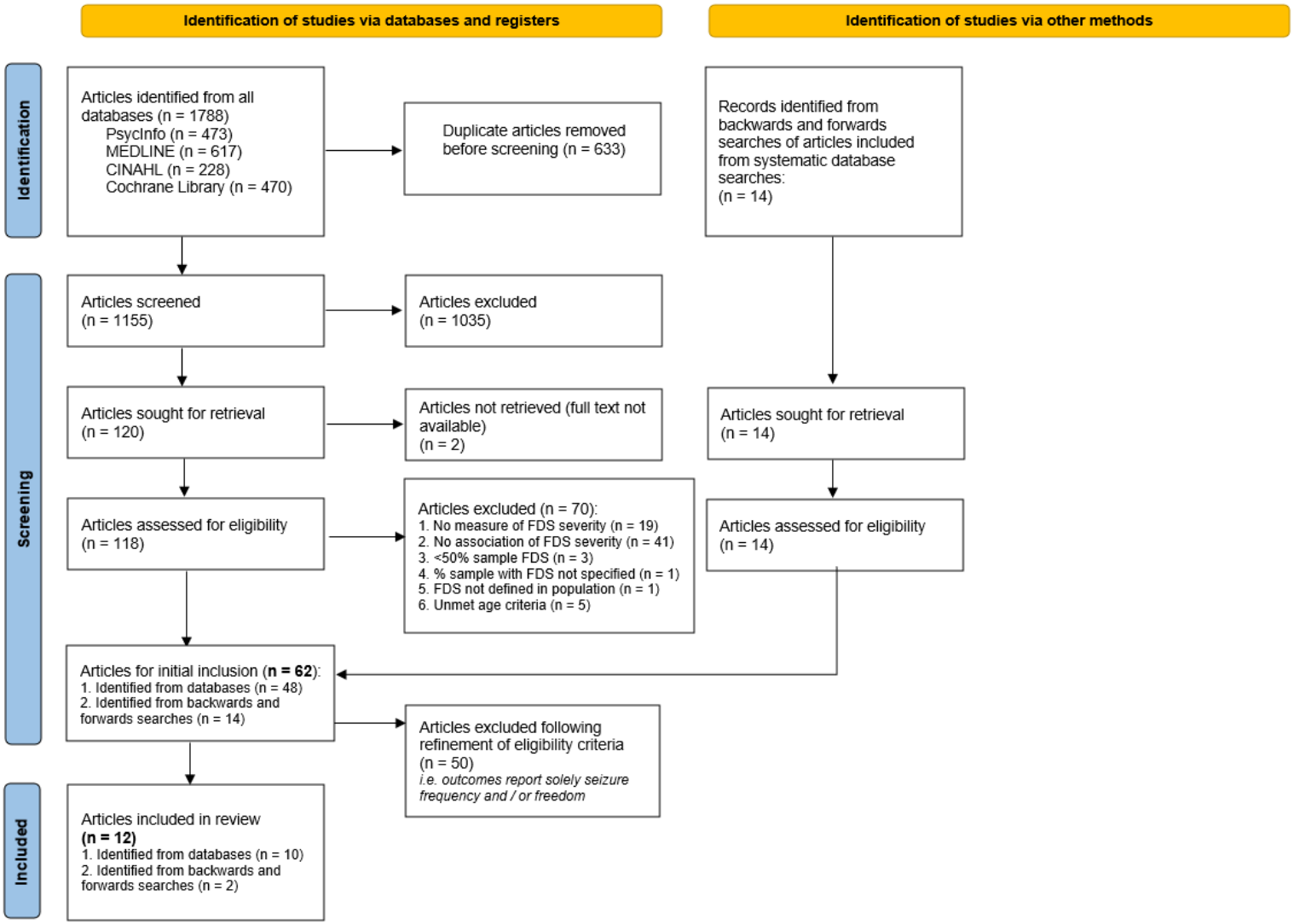
Nine studies included control samples ($k = 9$). Of these, five compared findings with a sample of people with epilepsy (Chen et al., 2018; Green et al., 2016; Rawlings et al., 2017a; Rawlings et al., 2017b; Reuber et al., 2003) with one grouping participants with FDS based on physical versus psychological attribution of symptoms (Chen et al., 2018). Two studies used healthy controls for comparison (Pick et al., 2017; Urbanek et al., 2014) and one used trauma-matched controls (Roberts et al., 2023). This study also had refined subsamples with vEEG confirmation of FDS. Another study compared a sample of patients with FDS and their carers to patients with epilepsy and their carers (Wardrope et al., 2019). Three studies recruited only participants with FDS (Goldstein et al., 2023; Korucuk et al., 2018; Selkirk et al., 2008). One of these grouped individuals according to whether they had or had not reported a history of sexual abuse (Selkirk et al., 2008).

Four studies restricted participant inclusion criteria to vEEG-confirmed FDS. Five studies referred to some FDS participants having received vEEG confirmation but only three reported how many. One of these included additional participants with confirmed diagnosis through alternative imaging or routine EEG methods. Four studies referred to high diagnostic certainty based on diagnoses from neurologists and clinical information. Three studies only required participants to self-declare diagnosis. In two of these, self-reports were confirmed via GPs or clinical information and one study used questions to corroborate diagnosis.

Nine studies reported correlation analyses, three regression analyses, one study reported an ANOVA and two used t-tests.

Figure 1

PRISMA Diagram: Flowchart of the Search and Selection Process



Quality Appraisal

All cross-sectional studies had clear aims, appropriate study design, adequately described findings, distinguished between target populations and were justified in the authors' discussions. Limitations were discussed in all but one study (Selkirk et al., 2008). Nine studies sufficiently described statistical methods however methodological limitations included lack of an acceptable sample size (k = 7) and inclusion of participants without vEEG-confirmed diagnosis (k = 9). Seven studies did not report consecutive or random samples which may indicate possible selection bias, and six studies did not describe attrition rates or non-responders. Nine cross-sectional studies used reliable, validated or previously trialled measures to assess the associated variables however none used a validated measure of FDS severity. Six studies did not use multivariate analysis indicating risk of confound variables. All studies gained ethical approval (Appendix E).

The cohort study (Chen et al., 2018) addressed a focused issue, used an appropriate recruitment strategy (including vEEG diagnosis), included confounding factors in the design / analysis, completed an appropriate follow-up and reported precise and reasonable results fitting with the evidence-informed discussion and offering implications. Limitations of the cohort study included lack of validated or previously trialled measures (including FDS severity) to accurately measure exposure and outcome, and use of a sample that limited generalisability of the findings (Appendix E).

Table 3

Summary of Study and Sample Characteristics

No	Study	Country	Design	Sample Frame	N	Gender	Age Mean (SD) / Median (IQR)	Ethnicity	% vEEG
1	Chen et al. (2018)	USA	Cohort	Epilepsy Monitoring Unit	FDS PHY SA (*N* = 32)	75.0% M	Mean 50.0 (10.8)	NR	100%
					FDS PSY SA (*N* = 40)	62.5% M	Mean 44.4 (12.4)		
					Epilepsy (*N* = 26)	80.8% M	Mean 51.7 (13.9)		
2	Goldstein et al. (2023)	UK	Cross-sectional	OP Neurology / Specialist Epilepsy Clinics	FDS (*N* = 368)	72.0% F	Median 35	90% W	53%
3	Green et al. (2016)	UK	Cross-sectional	OP Seizures Clinics	FDS (*N* = 23)	82.6% F	Mean 37.74 (13.34)	95.7% WB	NR
					Epilepsy (*N* = 72)	52.5% F	Mean 45.21 (15.76)	98.6% WB	
4	Korucuk et al. (2018)	Turkey	Retrospective Cross-sectional	IP vEEG Monitoring Unit, Centre for Epilepsy	FDS (*N* = 41)	75.6% F	Mean 27.2 (12.2)	NR	100%
5	Pick et al. (2017)	UK	Cross-sectional	Neuropsychiatry OP Clinic / local community	FDS (*N* = 40)	80.0% F	Median 40 (23)	80.0% W	68%
					Controls (*N* = 43)	81.4% F	Median 36 (2)	65.1% W	

6	Rawlings et al. (2017a)	UK	Exploratory Cross-sectional	OP Neurology Clinics/ membership-led organisations for seizures	FDS (*N* = 47) Epilepsy (*N* = 78)	91.4% F 67.9% F	Median 37 (23) Median 41 (24)	NR	NR
7	Rawlings et al. (2017b)	UK	Exploratory Cross-sectional	OP Neurology Clinics/ Membership-led organisations for seizures	FDS (*N* = 45) Epilepsy (*N* = 62)	91.1% F 69.4% F	Median 38 (22) Median 39.5 (22)	NR	NR
8	Reuber et al. (2003)	Germany	Cross-sectional	Specialist Epilepsy Centre	FDS (*N* = 98) Epilepsy (*N* = 63)	81.6% F 38.1% F	Mean 36.7 (15.4) Mean 38.4 (10.0)	NR	100%
9	Roberts et al. (2023)	USA	Cross-sectional	Neurology / Neuropsychology Clinics / social media of epilepsy and FDS organisations	**FDS Total** (*N* = 89) FDS/HighPTS (*N* = 51) FDS/LowPTS (*N* = 38) **Controls** (*N* = 216) High PTS (*N* = 91) Low PTS (*N* = 125) Stricter FDS Criteria (*N* = 53)	 78.5% F 89.5% F 87.9% F 85.6% F 	 Mean 37.2 (12.6) Mean 40.8 (12.7) Mean 32 (6.9) Mean 35.9 (8.5) 	 82.4% W 92.1% W 57.1% W 56.0% W 	59.5% 100%

10	Selkirk et al. (2008)	UK	Exploratory Cross-sectional	Specialist Referral Centre for FDS	FDS (*N* = 176) *SAB* Reported (n = 64) / NR (*N* = 112)	74% F	NR	NR	100%
11	Urbanek et al. (2014)	UK	Cross-sectional	OP Neuropsychiatry Clinics	FDS (*N* = 56) Controls (*N* = 88)	64.3% F 70.5% F	Mean 39.2 (13.6) Mean 27.2 (9.3)	89.3% WB 78.4% WB	NR
12	Wardrope et al. (2019)	UK	Cross-sectional	OP Seizure Clinics	FDS Carers (*N* = 16) Epilepsy Carers (*N* = 66) See Green et al. (2016) for Pt demographics.	41.2% F 56.1% F	Mean 44.2 (10.5) Mean 57.5 (10.6)	88.2% WB 98.5% WB	NR

Note, PHY = Physical; PSY = Psychological; SA = Symptom Attribution; M = Male; F = Female; OP = Outpatient, IP = Inpatient; NR = Not Reported; WB = White British; W = White; SAB = Sexual Abuse; PTS = Post-traumatic Stress; Pt = Patient.

Seizure Severity Measures

Although a secondary aim, seizure severity measures are reported first (Table 4) to allow the reader to better interpret psychological correlates. Note that unless stated, no psychometric properties were reported for the measures. The most frequently used measure ($k = 4$) was the LSSS-3 (Baker et al., 1998). Two of these studies reported on seizure severity of the same sample of individuals with FDS (Green et al., 2016; Wardrope et al., 2019). One study reported that the LSSS-3 had good internal consistency in patients with epilepsy (Rawlings et al., 2017b). Two studies referred to the measure being widely used in patients with FDS (Green et al., 2016; Rawlings et al., 2017b).

Three studies measured seizure severity based on the presence or absence of specific symptoms resulting in a total score (Pick et al., 2017; Reuber et al., 2003; Selkirk et al., 2008). The measure used by Pick et al. (2017) was adapted from a previously developed seizure symptoms questionnaire (Goldstein & Mellers, 2006). This specifically asked participants to self-report on the most recent and most severe seizure. This study reported good internal consistency (Cronbach's $\alpha = 0.62 – 0.88$) across the five subscales (chest/abdomen, autonomic arousal, cognitive, mental state, general) of seizure symptoms (Pick et al., 2017). Reuber et al. (2003) defined a seizure severity index of 0-7 based on a sum score of seizure symptoms (loss of consciousness, incontinence, tongue-biting, seizure-related injury, seizure duration > 30 minutes, recurrent seizures, and intensive care treatment) as retrieved from clinical records. Selkirk et al. (2008) used a severity index of 0-5 adapted from that used by Reuber et al. (2003). This was based on self-report of patients and an eyewitness (usually a relative or partner).

Three studies used a selection of single-item self-report Likert scales. Two studies specifically measured 'seizure severity' with one using a four-point scale to measure severity in the past year (Roberts et al., 2023); the other using a seven-point scale to measure severity in the past four weeks (Urbanek et al., 2014). Both scales ranged from '*very mild*' to '*very severe*'. Urbanek et al. (2014) also measured 'seizure bothersomeness' in the past four weeks on a seven-point Likert scale ranging from '*no bother at all*' to '*very bothersome*'. Chen et al.'s (2018) study measured

‘seizure intensity’ on a five-point Likert relating to extent of disruption caused by seizures to self and/or others. One study also measured ‘seizure impact’ (Roberts et al., 2023) using the Impact of Epilepsy Scale (IES; Jacoby et al., 1993). This was reported to have a Cronbach’s alpha of $\alpha = 0.91$ in epilepsy.

One study involved patients self-reporting their total number of ‘severe seizures’ in the past month (Goldstein et al., 2023). No definition was provided as to what classified ‘severe seizures’. The other study reported seizure duration (Korucuk et al., 2018); median ictal duration (minutes) and percent of FDS exceeding two minutes.

Table 4

Summary of Measures / Methods to assess FDS Severity and Related Variables

Measure	Description	Psychometric Properties	Study Included
Seizure Severity (LSSS-3)	Self-report 12-item measure quantifying severity 0-100 (past four weeks). Higher scores indicate greater severity.	Cronbach's α = 0.72–0.96 in epilepsy (Rawlings et al., 2017b)	Green et al. (2016) Rawlings et al. (2017a) Rawlings et al. (2017b) Wardrope et al. (2019)
Seizure Severity	Single question *"*Overall, how severe have your seizures of seizure-like episodes been in the past year?". (1) *"very mild"* (2) *"mild"* (3) *"severe"* (4) *"very severe".*	NR	Roberts et al. (2023)
Seizure Severity	Rated how severe seizures were in past four weeks on 7-point Likert scale ranging from *"very mild"* to *"very severe".*	NR	Urbanek et al. (2014)
Severe Seizure Frequency	Total number of "severe seizures*"* in past month recorded via seizure diary or single question.	NR	Goldstein et al. (2023)
Seizure Severity Index (Total Symptoms)	Score totalled (0-7) based on a clinical history of specified seizure symptoms. Included ictal loss of consciousness, incontinence, tongue biting, other seizure-related injury, seizure duration greater than 30 minutes, recurrent seizures and intensive care treatment for seizures.	NR	Reuber et al. (2003)
Seizure Severity Index (Total Symptoms)	Score totalled (0-5) based on history specified seizure symptoms. Included Score totalled (0-7) based on a clinical history of specified seizure symptoms. Included ictal loss of consciousness, incontinence, tongue biting, other seizure-related injury, seizure duration greater than 30 minutes.	NR	Selkirk et al. (2008) (adapted from Reuber et al., 2003)

Total Seizure Symptoms	Presence / absence of each symptom assessed for most recent and most severe seizures. Total score of 0-26 produced. Higher scores indicate more symptoms. Symptoms include chest/abdomen, autonomic arousal, mental state, cognitive phenomena, and general seizure symptoms.	Cronbach's α = .621 – .883 across subscales	Pick et al. (2017) (adapted from Goldstein & Mellers, 2006)
Seizure Intensity	Rated 5-point Likert "how strongly seizures disrupt self or others' usual activities" related to progress. Ranged from (1) *"much worse — more than twice as bad as before"* to (5) *"much better — less than half as much as before".* Each seizure scored on 5-point Likert. Ranged from (1) *disrupts self or others' activities more than twice as usual"* to (5) *"disrupting self or others' activities less than half as usual."*	NR	Chen et al. (2018)
Seizure Impact (IES)	Eight items assessing seizure impact in multiple domains.	Cronbach's α = 0.91 in epilepsy	Roberts et al. (2023)
Seizure Bothersome	Rated how bothersome seizures were in past four weeks on 7-point Likert scale ranging from *"no bother at all"* to *"very bothersome".*	NR	Urbanek et al. (2014)
Seizure Duration	Median ictal duration (minutes) and % FDS > 2 minutes duration.	NR	Korucuk et al. (2018)

Note, NR = Not Reported.

Factors Associated with Seizure Severity

Tables presenting measures used to assess correlated variables and an overview of key findings are presented in the appendices (Appendix E and F respectively).

Trauma

Four studies explored trauma. Individuals with FDS in a high trauma subsample were found to have greater seizure impact (IES; Jacoby et al., 1999) than individuals with low trauma; however, this was a nonsignificant trend (Roberts et al., 2023). Note that, the high trauma and low trauma subsamples were grouped by total post-traumatic stress disorder (PTSD) score using the PTSD symptom checklist (PCL-5; Blevins et al., 2015). The low trauma FDS subsample however was found to have greater seizure severity (rated from very mild to very severe on a four-point Likert scale) than the high trauma subgroup (p = .032). Similarly, comorbid PTSD (documented in clinical record) in a different study was not found to be a significant predictor of improvement in seizure intensity related to how much the seizures disrupt self and/or others (Chen et al., 2018). Two studies indicated a positive correlation between seizure severity and trauma. One found greater seizure severity (p = .001) in patients with FDS and a history of sexual abuse than without when measuring seizure severity on a total severity index (Selkirk et al., 2008). Moreover, relative risk (RR) of specific 'severe' seizure symptoms was reported. These patients were more likely to have seizure-related injury (RR = 1.81, p = .006) and urinary incontinence during seizures (RR = 1.82, p = .008). The other study (Pick et al., 2017) reported a positive correlation between total ictal cognitive (cognitive symptoms during a seizure) and total PTSD symptoms during most recent FDS (r_s = .524, p = .005) as measured by the Post-traumatic Diagnostic Scale (PDS; Foa et al., 1997). Moreover, total ictal symptoms (symptoms during a seizure) were positively correlated with re-experiencing (e.g. flashbacks, nightmares) of most recent FDS (r_s = .506, p = .007). No other significant or nonsignificant correlations were reported.

Mental Health

Anxiety

Two studies reporting directly on associations between seizure severity and anxiety produced conflicting results. One study found severe seizure frequency positively correlated with anxiety (Goldstein et al., 2023) with a small effect size ($r = 0.225$, $p < .001$). In the second study, no significant correlation between seizure severity (LSSS-3) and anxiety was found in individuals with FDS (Green et al., 2016). Whilst the studies used different measures of seizure severity, the GAD-7 (Spitzer et al., 2006) was used in both. The second study further observed that seizure severity did not significantly predict anxiety in a regression model. When using the same measures in an epilepsy control group, a positive association with a large effect size was found between seizure severity and anxiety ($r = 0.74$, $p < .01$), and greater seizure severity was a significant predictor of increased anxiety symptoms in a regression model *(*$\beta = 0.30$*,* $p < .05$*).* Of note, individuals with FDS were found to have higher seizure severity ($p = .049$) and significantly higher anxiety ($p = .003$) compared to individuals with epilepsy, with significantly more of the FDS group reaching clinically significant anxiety *(*$p = .001$).

Depression

One study (Green et al., 2016) explored the association between seizure severity (LSSS-3) and self-reported symptoms of depression in individuals with FDS but found no significant correlation. Moreover, seizure severity was not a significant predictor of depression in a hierarchical regression. Attachment anxiety was the only significant predictor of depression in the FDS group after controlling for demographics, seizure severity and seizure frequency, and attachment avoidance, with greater attachment anxiety associated with higher levels of depression. This finding can be compared to patients with epilepsy in the same study in which a positive correlation between seizure severity and depression was observed with a medium effect size ($r = 0.36$, $p < .01$). This was supported by a multivariate analysis in which epileptic seizure severity was a significant predictor of depression ($\beta = 0.31$*,* $p < .01$) alongside attachment avoidance, with greater seizure severity and more

avoidant attachment traits associated with more depression symptoms in epilepsy. As already noted, seizure severity was significantly higher in this FDS group compared to the epilepsy group. Symptoms of depression were also significantly higher (p = .004) in the FDS group.

Psychological Difficulties

One study (Reuber et al., 2003) associated higher seizure severity in individuals with FDS with increased psychological difficulties (f = 3.488, p = .002) as measured by an adapted German version of the Symptom Checklist-90 (SCL-90-R; Schmitz, 2000). Psychological difficulties broadly included somatisation, obsessive-compulsive, interpersonal sensibility, depression, anxiety, anger-hostility, phobic-anxiety, paranoid ideation, and psychoticism. This association did not remain significant when other scores were introduced as covariates (somatisation and dissociation).

Stress

One study explored the relationship between seizure severity (a four-point Likert scale from *very mild* to *very severe* seizures in the past year) and seizure impact (IES; Jacoby et al., 1993) with perceived stress (Roberts et al., 2023). As noted, this study had an overall FDS sample which was further divided into high-trauma and low-trauma subsamples (Blevins et al., 2015). The FDS sample also had a refined sample of individuals who had a vEEG-confirmed diagnosis. No significant association was shown between seizure severity and perceived stress in the full FDS sample or any of the subsamples (high trauma, low trauma, vEEG confirmed). Weak to moderate effect sizes were however found when exploring the association between seizure impact and perceived stress. A positive association was found between seizure impact and perceived stress in the full sample of individuals with FDS (r_s = .37, p < .001) and in the vEEG subsample (r_s = .44, p < .01). Moreover, seizure impact was positively associated with perceived stress in the low trauma subsample (r_s = .35, p <.05), however, not the high trauma subsample.

Dissociation

Two studies explored dissociation. One study (Reuber et al., 2003) explored dissociative phenomena using an adapted German version of the Dissociative Experiences Scale (DES; Spitzer et al., 1998). This produced a mean DES score and a DES-T score (the latter using a more robust subscale to assess 'pathological dissociation'). A positive correlation was found between seizure severity (as measured by a total seizure severity index) and the mean DES score ($f = 2.186$, $p = .043$) but not the DES-T score. A positive correlation was also found between seizure severity and somatisation ($f = 2.388$, $p = .028$). However, none of these associations remained significant when the other scores were introduced as covariates.

Likewise, a second study (Pick et al., 2017), similarly using a total symptom questionnaire to measure seizure severity, found no significant association between with somatic dissociation. Depersonalisation was found to be positively associated with total ictal symptoms of most recent seizure ($r_s = .497$, $p = .002$) and total ictal mental state symptoms ('mental state' symptoms during a seizure) for most recent ($r_s = .649$, $p < .001$) and most severe seizures ($r_s = .616$, $p < .001$). That is, greater depersonalisation (i.e. a feeling of detachment from one's own body such that you feel outside yourself and observing your own actions, feelings or thoughts from a distance) was associated with increased seizure symptoms of most recent seizures and with increased mental state symptoms of most recent and most severe seizures. For reference, 'mental state' symptoms referred to five items on the seizure questionnaire, four of which related to aspects of dissociation in some form. A positive association was found between derealisation and total ictal mental state symptoms for most recent ($r_s = .606$, $p < .001$) and most severe seizures ($r_s = .501$, $p = .002$). This meaning, derealisation (i.e. a feeling that the world is unreal) was associated with increased mental state symptoms of more recent and most severe seizures. Identity dissociation (i.e. unstable identity states, experiencing more than one 'self') was found to positively correlate with total ictal cognitive symptoms in most severe seizures ($r_s = .459$, $p = .005$).

Emotional Processes

Two studies explored emotional processes. Seizure severity was explicitly measured in both studies however Roberts et al., (2023) used a four-point Likert scale based on seizure severity in the past year and Urbanek et al., (2014) used a seven-point Likert scale of seizure severity in the past four weeks. Moreover, seizure impact (IES; Jacoby et al., 1993) was only measured by Roberts et al., (2023) and 'seizure bothersomeness' was only measured by Urbanek et al., (2014).

One study found no association between seizure severity or seizure impact with emotional avoidance (Roberts et al., 2023). Emotional understanding was explored in both studies. One study found greater seizure severity was associated with increased difficulty understanding emotions (r_s =.029, p = .039) though this was a weak effect size, and no significant association was found with 'seizure bothersomeness' (Urbanek et al., 2023). No association was found between seizure severity or seizure impact with emotional awareness difficulties (Roberts et al., 2023).

For 'emotional regulation' no association was found between seizure severity and emotional regulation difficulties in one study (Roberts et al., 2023). However, a positive correlation was found with seizure impact (r_s = .29, p <.05). This continued to be a significant association in the refined vEEG subsample (r_s = .30, p <.05). Though only weak effect sizes were found, increased difficulty regulating emotions was therefore associated with increased seizure impact in individuals with FDS and this remained significant when a stricter diagnosis criterion was applied. However, no significant association was found between seizure severity and 'seizure bothersomeness' with tendency to control emotions by Urbanek et al. (2014). Similarly, neither seizure severity nor seizure impact correlated with expressive suppression in a full sample of individuals with FDS however, a negative association was found between seizure severity and expressive suppression in an overall vEEG refined subsample (r_s = -.38, p <.05) and in a high trauma FDS vEEG subsample (r_s = -.46, p <.05) with weak and moderate effect sizes respectively (Roberts et al., 2023). This meant higher seizure severity was associated with a reduced tendency to hide outward emotional displays and at subsample level, this only remained a significant association in the high trauma vEEG FDS group. This study

also found no association between seizure severity and seizure impact with situational reappraisal in the overall FDS sample. However, a significant negative association with a moderate effect size was found with seizure severity in the FDS high trauma subgroup (r_s = -.40, p <.01). This remained a significant moderate effect in the high trauma FDS subgroup of patients with vEEG diagnoses (r_s = -.40, p <.05). That is, higher seizure severity in the high-trauma FDS group was associated with a reduced tendency to use situational reappraisal (i.e. think about a situation differently).

Finally, neither seizure severity nor 'seizure bothersomeness' were found to be associated with affect intensity. However, a positive correlation was found between both seizure severity (r_s = .309, p = .027) and 'seizure bothersomeness' (r_s = .372, p <.01) with beliefs about emotions as overwhelming and uncontrollable, shameful and irrational, invalid and meaningless, useless, damaging and contagious and seizure bothersomeness; both demonstrating medium effect sizes.

HRQoL

Two studies explored HRQoL and found no significant association to FDS severity (Green et al., 2016; Rawlings et al., 2017b). Rawlings et al. (2017b) additionally explored this in a multivariate analysis and found seizure severity did not predict a significant amount of variance in HRQoL in FDS with only psychological distress and illness perceptions (specifically personal control) significant predictors. However, a weak negative association was found between seizure severity and HRQoL in individuals with epilepsy in both studies; Rawlings et al. (2017b) reported a Spearman's correlation coefficient of r_s = -.29 (p =.05) and Green et al. (2016) a Pearson correlation coefficient of r = -.34 (p <.01). Notably, the FDS groups in both studies scored significantly lower on HRQoL relative to the epilepsy groups.

Relational

Two studies explored how relational factors are associated with seizure severity. Roberts et

al. (2023) found no significant association between seizure severity or seizure impact with perceived social support, loneliness, comfort with social touch, or frequency of sleep-touch in individuals with FDS. Seizure severity was not associated with physical affection with partner however, a weak negative association was found between seizure impact in the vEEG refined overall FDS sample (r_s = -.38, p <.05) and specifically, the vEEG FDS high-trauma subsample demonstrated a moderate negative association (r_s = -.51, p <.05).

The second study focused on seizure severity of in relation to aspects of carer mental health and HRQoL (Wardrope et al., 2019). Seizure severity was negatively associated with mental wellbeing of carers for epilepsy (r_s = -.356, p = 05) with a weak effect size, but not FDS. The difference in these associations were significant with opposite trends demonstrated (p = .034). No significant associations were found between seizure severity and carer anxiety, carer depression, or carer physical wellbeing in the FDS or epilepsy groups. Correlates of FDS carers versus epilepsy carers in relation to depression were however significantly different (p = .049), and again, showed opposite trends.

Illness Perception and Symptom Attribution

One study explored changes in symptom attribution and illness perception in relation to seizure intensity (Chen et al., 2018). In the FDS groups, the physical attribution group was associated with greater improvement in seizure intensity relative to the psychological attribution group at a 3-month (U = .228.5, p =.002) and 6-month follow-up (U = .155.5, p =.007). Moreover, physical symptom attribution was the only significant predictor of seizure intensity improvement at 3-month (p = .003) and 6-month (p = .013) follow-ups when explored in a multivariate analysis. Extent of change in symptom attribution (pre- vs post-diagnosis) of the physical group toward greater psychological roles was weak to moderately associated with improvement in seizure intensity at a 3-month (r_s = .380, p =.05) and 6-month follow-up (r_s = .448, p =.037). Extent of change toward less severe illness perception of adverse consequences from seizures was also weak to moderately

associated with seizure intensity improvement at both the 3-month (r_s = .396, p =.041) and 6-month follow-ups (r_s = .516, p =.014) in the FDS physical attribution group. No significant associations were found between change in illness perception or change in symptom attribution with seizure intensity improvement in the FDS psychological attribution or epilepsy groups.

Stigma

Self-reported stigma was observed as higher in the FDS sample compared to epilepsy (p = 0.04) however, there was no significant association between seizure severity and perceived stigma in individuals with FDS (Rawlings et al., 2017a).

Demographics

One study found an association between female gender and a greater FDS median duration (p = .016) compared to males (Korucuk, et al., 2018). Moreover, FDS in females were more likely to exceed two minutes (p = .025). Another study found gender, age, and education did not significantly predict seizure intensity improvement (Chen et al., 2018).

Discussion

This systematic review aimed to examine factors associated with FDS severity in adults and establish how seizure severity had been measured within the included studies.

No study used a measure of seizure severity validated in the FDS population. This matches conclusions of similar reviews that highlighted the lack of measures validated for FDS (Pick et al., 2020) and the overuse of epilepsy-based measures as key shortfalls of FDS research (Jones et al., 2016). The current review found a high degree of heterogeneity in measures used, with only the LSSS-3 (Baker et al., 1998) being used in more than one study. Whilst the LSSS-3 may have items relevant to FDS severity, it remains that it was developed for use in epilepsy. Given that different health conditions have unique features related to severity (Meadows, 2011), it is likely that relevant

items for assessing FDS severity have been missed. This limits the findings of research using measures designed for epilepsy.

The extent of heterogeneity of measures was unexpected given only twelve studies were included. Moreover, the measures employed varied in their approach to assessment. Eight studies explicitly referred to a measure of 'seizure severity', of which four used the LSSS-3. This 12-item self-report measure (over the past four weeks) markedly differs from the single-item severity scales used in two other studies, both of which differed in point scales (4-point versus 7-point) and temporal coverage (past year versus past four weeks). An appropriate timeframe is a practical consideration of outcome measure development to enable accurate recall of symptoms whilst allowing for 'time averaging' to ensure one bad day or bad week of symptoms does not lead to overestimation of the problem (Kroenke et al., 2015).

The seizure severity indexes used (Reuber et al., 2003; Selkirk et al., 2008) had some overlap with seizure severity measures developed for epilepsy given the inclusion of specific symptoms, presumably considered clinically relevant to assess severity (though this was not reported) differing to the single-item measures. Whilst single-item measures may be desirable (i.e. more efficient administration) there reliability is more uncertain (Zimmerman et al., 2006). Moreover, they provide limited information to clinicians that may be relevant to guide treatment. This is important as a single-items may fail to recognise the subjective experiences of this highly heterogenous population (Reuber & Rawlings, 2016). The seizure severity indexes in studies differed in terms of number of items included (range = 5 – 7). Furthermore, one index was based on patient and eyewitnesses self-report (Selkirk et al., 2008) whereas the other was from reviewing clinical records (Reuber et al., 2003). Similarly, the measure used by Pick et al. (2017) included varied seizure symptoms to produce a total score. This measure included 26 items across five domains. A greater number of items may be more representative of FDS symptom heterogeneity. This measure did not provide a specific timeframe instead reporting on most recent and most severe seizures.

This review found other outcomes related to severity, which included seizure – intensity, bothersomeness, and impact. Similarly to the single-item scales assessing 'seizure severity'; 'seizure intensity' was measured on a self-report, five-point Likert scale (Chen et al., 2018) and 'seizure bothersomeness' was rated on a seven-point self-report Likert based on seizures in the past four weeks (Urbanek et al., 2014). Similarly to the LSSS-3 (developed for use in epilepsy), 'seizure impact' was measured on the IES (Jacoby et al., 1993), an eight-item self-report measure.

One study measured the frequency of severe seizures (Goldstein et al., 2023). As greater severe seizure frequency correlated with anxiety, this may suggest there remains value in understanding seizure frequency. The remaining measures included median ictal duration and percentage of FDS exceeding greater than two minutes. Longer ictal duration of FDS has been established as a distinguishing feature from epileptic seizures (Leibetseder, 2020) and may be an important factor relevant to severity.

Factors Associated with FDS Severity

Only a small number of articles were identified exploring factors associated with FDS severity. There was heterogeneity in correlates explored, limiting the ability to draw generalisable conclusions. Of the significant associations found, all were weak, small or moderate effect sizes in FDS. Much of the available data represented secondary analyses and was not reflective of the main study aims. Nevertheless, the fact studies have attempted to explore these associations suggests this is an important phenomenon to understand.

Associations between seizure severity and trauma were inconsistent. Two studies, with limited sample sizes, were suggestive of no association (a low-trauma subgroup had higher seizure severity than a high-trauma subgroup and PTSD did not predict of seizure intensity improvement). Whereas two other studies (using total symptom measures) indicated positive correlations (both with sufficient sample sizes).

No significant association was found generally with psychological difficulties after accounting for covariates ($N = 98$) or with anxiety when FDS severity was measured by the LSSS-3 ($N = 23$). A positive correlation was found however between severe seizure frequency and anxiety in a larger sample with sufficient power ($N = 368$). Similarly, no association was found between seizure severity (LSSS-3) with depression or HRQoL in people with FDS ($N = 45$) however, there were positive correlations between epilepsy seizure severity with anxiety and depression ($N = 72$), and HRQoL ($N = 62$). This may reflect that the LSSS-3 was developed and validated for epilepsy or that FDS subsamples may be underpowered comparable to epilepsy samples. Importantly however, the varied comorbidities experienced by individuals with FDS must be considered. Higher rates of anxiety, depression, PTSD, and complex personality, chronic pain, sleep problems, migraines, asthma and head injury are found in people with FDS compared to the general population (Popkirov et al., 2019). Therefore, seizure severity may be less relevant than overall wellbeing, relative to patients with epilepsy. One study explored perceived stress and found no significant association with FDS severity yet a positive correlation with seizure impact in individuals with FDS. This remained significant in a low trauma subgroup however and not a high trauma subgroup.

Nonsignificant associations were predominantly found between FDS severity and dissociation. No significant association was found with dissociation or somatization (after controlling for covariates or with a more robust measure of 'pathological' dissociation). This study was however underpowered. Similarly, another study with a sufficient sample size found no association between seizure severity and somatic dissociation. Though, different measures were used to measure severity, both fundamentally included a total symptom score. One of these specifically explored depersonalisation and derealization; both were positively associated with total "mental state" symptoms of most recent and most severe seizures. This was somewhat unsurprising given four of the five items assessing "mental state" related to dissociation. Additionally, positive associations were found between total seizure symptoms of most recent seizure with depersonalisation and, total cognitive symptoms of most severe seizures with identity dissociation

in the study with a sufficient sample size. Goldstein and Mellers (2006) suggest dissociation could unintentionally protect individuals with FDS from distressing physical arousal symptoms related to feelings of panic. Therefore, dissociation may relieve distressing symptoms which could contribute to seizure severity.

Different emotional processes were explored in two studies (both with insufficient sample sizes). Consistently, greater seizure severity and seizure bothersomeness were associated with increased negative beliefs about emotions. However, no associations were found between seizure severity with emotional regulation difficulties and emotional avoidance or, seizure impact and emotional avoidance. Greater seizure severity was associated with difficulty understanding emotions, but there was no association with bothersomeness or, between seizure severity and impact with emotional awareness difficulties. No associations were found between seizure severity or bothersomeness with tendency to control emotions or affect intensity; or between seizure severity and impact with expressive suppression in the FDS full sample. Negative associations were however found for seizure severity with expressive suppression in the vEEG subsample and high trauma vEEG subsample. Therefore, when stricter sample criteria were applied (vEEG), greater seizure severity (but not impact) was associated with a reduced tendency to hide outward emotional displays. However, at subsample level, this only remained significant in the high trauma vEEG FDS group. Higher seizure severity in the high-trauma FDS group was also associated with reduced tendency to use situational reappraisal (i.e. think about a situation differently).

No significant associations were found between seizure severity or seizure impact with perceived social support, loneliness, comfort with social touch, or frequency of sleep-touch in one study (with an insufficient sample size). Associations were however found between greater seizure impact and less physical affection with partner in a vEEG refined overall FDS sample and specifically, a vEEG FDS high-trauma subsample but no associations were found with FDS severity.

Change in symptom attribution of FDS to physical causes (from psychological

attribution) was associated with seizure intensity improvement. Seizure severity was not however associated with perceived stigma. Female gender was associated with seizure duration in one study. A different study found gender did not predict seizure intensity improvement (or other demographic variables). Of these, none reported a sufficient sample size.

Critique

Included studies had not primarily aimed to explore associations with seizure severity so relevant data was scarce. Therefore, limited conclusions can be drawn related to factors associated with seizure severity. Arguably, grey literature could have been searched to increase the data available. That said, the findings highlight an important research gap. Additionally, it demonstrates very limited evidence of convergent validity of seizure severity measures used in previous studies of patients with FDS (notably, even less from longitudinal studies). The quality assessment also revealed that seven studies did not include a sufficient sample size or failed to report a power analysis likely impacting the lack of significant findings across studies.

This review included a range of different concepts to define seizure severity (i.e. severity, intensity, bothersomeness, impact) due to the lack of a consistent measures assessing severity.
It is unclear to what extent these accurately measured the same concept. This may have contributed to variability in the findings, likely exacerbated by different approaches used to measure seizure severity (i.e. Likerts, total symptom counts, severity frequency). Caution was taken however when interpreting findings and drawing conclusions. Furthermore, although not optimal, refinement of the eligibility criteria reduced the possibility of further variability in the findings.

The quality appraisal conducted was arguably limited due to providing no overall interpretation of each studies' quality and thus, the overall quality of studies in this review. As noted, the AXIS and CASP Cohort Study Checklist do not provide a numerical scale (Downes et al., 2016). Greenland and O'Rourke (2001) have critiqued the use of quality numerical scales as items are

nonlinear, and therefore difficult to weight in an overall quality assessment leading to risk of biases. Adapting this to fit with FDS studies was considered a strength of the tool used.

A further limitation of this review was that most studies included were from predominantly Western countries conducted with mostly White participants. Moreover, some of the studies failed to report ethnicities. The findings are therefore less generalisable the data are not geographically or ethnically diverse.

Notably, all but one study used cross-sectional designs meaning causal relationships cannot be established. Sample sizes were limited thus caution should be taken when drawing conclusions of any findings. Only four studies required all FDS participants to have vEEG-confirmed diagnosis. Notably, one study demonstrated differences in findings when stricter diagnostic criterion was applied. Nevertheless, whilst this is considered the gold standard, a high level of diagnostic certainty was sought in most studies. This may have aided recruitment and increased sample sizes in some studies given delays in vEEG diagnosis.

Implications

There is very limited evidence of convergent validity of the seizure severity measures used in patients with FDS. Given the many differences between patients with epilepsy and FDS it seems inappropriate simply to use measures developed for a different condition. Since improvement of seizure severity may be a treatment target for patients, validity of existing measures of seizure severity could be tested in FDS populations, however, probably best would be the development of new measures, starting with qualitative work seeking to explore which aspects people with FDS most closely associate with "severity". This will be essential to ensure any measure developed is relevant. Such a measure would be of value in both future research and clinical practice.

Future research should attempt to explore associations with seizure severity in adults with FDS using and reporting on a standardised measure. Longitudinal or experimental study designs would be beneficial to establish causal relationships in larger FDS samples. Participants with vEEG

confirmed diagnosis should be sought where possible, given this may influence results. There is a need to examine correlates associated with seizure frequency given this is the most reported outcome in FDS studies and the body of evidence found during the searches of this review. This would aid in further understanding the complexities of seizure frequency.

There may be clinical value related to the insights as to what influences seizure severity, however, these findings are limited and not generalizable. Healthcare services and clinicians should take a person-centred approach to supporting people experiencing FDS and help them to recognise individual factors influencing their seizure severity (which may include factors in this review). Importantly, seizure severity should be considered alongside other difficulties the individual may be experiencing.

Conclusion

This review aimed to identify what constructs are associated with seizure severity in the FDS population. Findings however were scarce and limited by the lack of a validated FDS severity measure. Moreover, studies varied greatly in measures and methods used to assess FDS severity, somewhat surprising given the small number of studies included. This review provides insights into how severity has been measured in this population which will be of value when considering the need for development of a standardised measure of FDS severity.

References

Baker, G., Smith, D., Jacoby, A., Hayes, J., Chadwick, D. (1998). Liverpool seizure severity scale revisited. *Seizure, 7,* 201–205. http://dx.doi.org/10.1016/S1059-1311(98)80036- 8.

Baker, G. A., Smith, D. F., Dewey, M., Morrow, J., Crawford, P. M., & Chadwick, D. W. (1991). The development of a seizure severity scale as an outcome measure in epilepsy. *Epilepsy Research*, *8*(3), 245–251. https://doi.org/10.1016/0920-1211(91)90071-M

Blevins, C. A., Weathers, F. W., Davis, M. T., Witte, T. K., & Domino, J. L. (2015). The Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5): Development and Initial Psychometric Evaluation. *Journal of Traumatic Stress*, *28*(6), 489–498. https://doi.org/10.1002/jts.22059

Brown, R. J., & Reuber, M. (2016a). Towards an integrative theory of psychogenic nonepileptic seizures. *Clinical Psychology Review*, 47, 55–70. https://doi.org/10.1016/j.cpr.2016.06.003

Brown, R. J., & Reuber, M. (2016b). Psychological and psychiatric aspects of psychogenic non-epileptic seizures: A systematic review. Clinical Psychology Review, 45, 157– 182. https://doi.org/10.1016/j.cpr.2016.01.003

*Chen, D. K., Majmudar, S., Ram, A., Rutherford, H. C., Fadipe, M., Dunn, C. B., & Collins, R. L. (2018). Change in illness perception is associated with short-term seizure burden outcome following video-EEG confirmation of psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *83*, 186–191. https://doi.org/10.1016/j.yebeh.2018.03.007

Cramer, J. A., Baker, G. A., & Jacoby, A. (2002). Development of a new seizure severity questionnaire: initial reliability and validity testing. *Epilepsy Research*, *48*(3), 187–197. https://doi.org/10.1016/S0920-1211(02)00003-7

Cramer, J. A., & French, J. (2001). Quantitative Assessment of Seizure Severity for Clinical Trials: A Review of Approaches to Seizure Components. *Epilepsia (Copenhagen)*, *42*(1), 119–129. https://doi.org/10.1046/j.1528-1157.2001.19400.x

Downes, M. J., Brennan, M. L., Williams, H. C., & Dean, R. S. (2016). Development of a critical

appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open, 6*(12), e011458. https://doi.org/10.1136/bmjopen-2016-011458

Foa, E. B., Cashman, L., Jaycox, L., Perry, K. (1997). The validation of a self-report measure of posttraumatic stress disorder: The posttraumatic diagnostic scale. *Psychological Assessment*, *9*(4), 445–451. https://doi.org/10.1037/1040-3590.9.4.445

Freyberger, H. J., Spitzer, C., Stieglitz, R.-D., Kuhn, G., Magdeburg, N., & Bernstein-Carlson, E. (1998). Fragebogen zu dissoziativen Symptomen (FDS): Deutsche adaptation, reliabilität und validität der Amerikanischen Dissociative Experience Scale (DES). *Psychotherapie Psychosomatik Medizinische Psychologie, 48*(6), 223–229.

Gaskell, C., Power, N., Novakova, B., Simmonds-Buckley, M., Reuber, M., Kellett, S., & Rawlings, G. H. (2023). A meta-analytic review of the effectiveness of psychological treatment of functional / dissociative seizures on non-seizure outcomes in adults. *Epilepsia, 64*(7), 1722-1738. https://doi.org/10.1111/epi.17626

Goldstein, L. H., Carson, A., McCrone, P., Murray, J., Pilecka, I., Mosweu, I., Perdue, I., Abe, A-M., Allroggen, H., Alvares, D., Angus-Leppan, H., Aram, J., Armstrong, R., Atalaia, A., Bagary, M., Baldellou Lopez, M., Bennett, M., Black, T., Blackburn, D., … Callaghan, H. (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

Goldstein, L. H., & Mellers, J. D. C. (2006). Ictal symptoms of anxiety, avoidance behaviour, and dissociation in patients with dissociative seizures. *Journal of Neurology Neurosurgery and Psychiatry, 77*(5), 616-621. https://doi.org/10.1136/jnnp.2005.066878

*Goldstein, L. H., Vitoratou, S., Stone, J., Chalder, T., Baldellou Lopez, M., Carson, A., & Reuber, M. (2023). Performance of the GAD-7 in adults with dissociative seizures. *Seizure*, *104*, 15–21. https://doi.org/10.1016/j.seizure.2022.11.011

*Green, B., Norman, P., & Reuber, M. (2017). Attachment style, relationship quality, and

psychological distress in patients with psychogenic non-epileptic seizures versus epilepsy. *Epilepsy & Behavior*, *66*, 120–126. https://doi.org/10.1016/j.yebeh.2016.10.015

Greenland, S., & O'Rourke, K. (2001). On the bias produced by quality scores in meta-analysis, and a hierarchical view of proposed solutions. *Biostatistics (Oxford, England)*, *2*(4), 463–471. https://doi.org/10.1093/biostatistics/2.4.463

Haddaway, N. R., Grainger, M. J., & Gray, C. T. (2022). Citationchaser: A tool for transparent and efficient forward and backward citation chasing in systematic searching. *Research Synthesis Methods*, *13*(4), 533–545. https://doi.org/10.1002/jrsm.1563

Hingray, C., El-Hage, W., Duncan, R., Gigineishvili, D., Kanemoto, K., LaFrance, W. C., Marinis, A., Paul, R., Pretorius, C., Téllez-Zenteno, J. F., Wiseman, H., & Reuber, M. (2018). Access to diagnostic and therapeutic facilities for psychogenic nonepileptic seizures: An international survey by the ILAE PNES Task Force. *Epilepsia*, *59*(1), 203–214. https://doi.org/10.1111/epi.13952

Jacoby, A., Baker, G., Smith, D., Dewey, M., Chadwick, D. (1993). Measuring the impact of epilepsy: the development of a novel scale. *Epilepsy Research, 16*(1), 83-88. https://10.1016/0920-1211(93)90042-6

Jones, B., Reuber, M., & Norman, P. (2016). Correlates of health-related quality of life in adults with psychogenic nonepileptic seizures: A systematic review. *Epilepsia, 57*(2), 171–181. https://doi.org/10.1111/epi.13268

*Korucuk, M., Gazioglu, S., Yildirim, A., Karaguzel, E. O., & Velioglu, S. K. (2018). Semiological characteristics of patients with psychogenic nonepileptic seizures: Gender-related differences. *Epilepsy & Behavior*, *89*, 130–134. https://doi.org/10.1016/j.yebeh.2018.10.032

Kroenke, K., Monahan, P. O., & Kean, J. (2015). Pragmatic characteristics of patient-reported outcome measures are important for use in clinical practice. *Journal of Clinical Epidemiology, 68*(9), 1085–1092. https://doi.org/10.1016/j.jclinepi.2015.03.023

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression

severity measure. *Journal of General Internal Medicine*, 16, 606-613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

LaFrance, W. C., Baker, G. A., Duncan, R., Goldstein, L. H., & Reuber, M. (2013). Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: A staged approach: A report from the International League Against Epilepsy Nonepileptic Seizures Task Force. *Epilepsia (Copenhagen)*, *54*(11), 2005–2018. https://doi.org/10.1111/epi.12356

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33*(1), 159. https://doi.org/10.2307/2529310

Leibetseder, A., Eisermann, M., LaFrance, W. C., Nobili, L., & Oertzen, T. J. (2020). How to distinguish seizures from non-epileptic manifestations. *Epileptic Disorders, 22*(6), 716–738. https://doi.org/10.1684/epd.2020.1234

Lopez, M. R., & LaFrance, W. C. (2022). Treatment of Psychogenic Nonepileptic Seizures. *Current Neurology and Neuroscience Reports*, *22*(8), 467–474. https://doi.org/10.1007/s11910-022-01209-3

Meadows, K. A. (2011). Patient-reported outcome measures: an overview. *British Journal of Community Nursing*, *16*(3), 146–151. https://doi.org/10.12968/bjcn.2011.16.3.146

Miller, S. A., & Forrest, J. L. (2001). Enhancing your practice through evidence-based decision making: PICO, learning how to ask good questions. *Journal of Evidence Based Dental Practice, 1*(2), 136–141. https://doi.org/10.1016/s1532-3382(01)70024- 3

Nicholson, T. R., Carson, A., Edwards, M. J., Goldstein, L. H., Hallett, M., Mildon, B., Nielsen, G., Nicholson, C., Perez, D. L., Pick, S., Stone, J., and the FND-COM (Functional Neurological Disorders Core Outcome Measures) Group, & FND-COM group collaborators. (2020). Outcome Measures for Functional Neurological Disorder: A Review of the Theoretical Complexities. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *32*(1), 33–42. https://doi.org/10.1176/appi.neuropsych.19060128

O'Donoghue, M. F., Duncan, J. S., & Sander, J. W. A. S. (1996). The National Hospital Seizure

Severity Scale: A further development of the Chalfont Seizure Severity Scale. *Epilepsia, 37*(6), 563-571. https://doi.org/10.1111/j.1528-1157.1996.tb00610.x

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan-a web and mobile app for systematic reviews. *Systematic Reviews, 5*(1), 210. https://doi.org/10.1186/s13643-016-0384-4

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. *PLOS Medicine*, *18*(3), e1003583. https://doi.org/10.1371/JOURNAL.PMED.1003583

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

Popkirov, S., Asadi-Pooya, A. A., Duncan, R., Gigineishvili, D., Hingray, C., Miguel Kanner, A., LaFrance, W. C., Pretorius, C., & Reuber, M. (2019). The aetiology of psychogenic non-epileptic seizures: risk factors and comorbidities. *Epileptic Disorders*, *21*(6), 529–547. https://doi.org/10.1684/epd.2019.1107

*Pick, S., Mellers, J. D. C., & Goldstein, L. H. (2017). Dissociation in patients with dissociative seizures: relationships with trauma and seizure symptoms. *Psychological Medicine*, *47*(7), 1215–1229. https://doi.org/10.1017/S0033291716003093

*Rawlings, G. H., Brown, I., & Reuber, M. (2017a). Deconstructing stigma in psychogenic

nonepileptic seizures: An exploratory study. *Epilepsy & Behavior*, *74*, 167–172. https://doi.org/10.1016/j.yebeh.2017.06.014

*Rawlings, G. H., Brown, I., & Reuber, M. (2017b). 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

Rawlings, G., & Reuber, M. (2016). What patients say about living with psychogenic non-epileptic seizures: A systematic synthesis of qualitative studies. *Seizure, 41*, 100-111. https://doi.org/10.1016/j.seizure.2016.07.014

Reuber, M. (2008). Psychogenic nonepileptic seizures: answers and questions. *Epilepsy & Behaviour, 12*(4), 622-635. https://10.1016/j.yebeh.2007.11.006

*Reuber, M., House, A. O., Pukrop, R., Bauer, J., & Elger, C. E. (2003). Somatization, dissociation and general psychopathology in patients with psychogenic non-epileptic seizures. *Epilepsy Research*, *57*(2), 159–167. https://doi.org/10.1016/j.eplepsyres.2003.11.004

Reuber, M., Chen, M., Jamnadas-Khoda, J., Broadhurst, M., Wall, M., Grünewald, R. A., Howell, S. J., Koepp, M., Parry, S., Sisodiya, S., Walker, M., & Hesdorffer, D. (2016). Value of patient-reported symptoms in the diagnosis of transient loss of consciousness. *Neurology, 97*(6), 625-633. https://doi.org/10.1212%2FWNL.0000000000002948

Reuber, M. & Rawlings, G. (2016). Nonepileptic seizures – subjective phenomena. *Handbook of Clinical Neurology, 139,* 283-296. https://doi.org/10.1016/B978-0-12-801772-2.00025-4

*Roberts, N. A., Villarreal, L. D., & Burleson, M. H. (2023). Socioemotional self- and co-regulation in functional seizures: comparing high and low posttraumatic stress. *Frontiers in Psychiatry*, *14*, 1135590–1135590. https://doi.org/10.3389/fpsyt.2023.1135590

Schmitz, N., N. Hartkamp, J. Kiuse, G. H. Franke, G. Reister, & W. Tress. (2000). The Symptom Check-List-90-R (SCL-90-R): A German validation study. *Quality of Life Research*, *9*(2), 185–193. https://doi.org/10.1023/A:1008931926181

*Selkirk, M., Duncan, R., Oto, M., & Pelosi, A. (2008). Clinical differences between patients with

nonepileptic seizures who report antecedent sexual abuse and those who do not. *Epilepsia, 49*(8), 1446–1450. https://doi.org/10.1111/j.1528-1167.2008.01611.x

Senf-Beckenbach, P., Hoheisel, M., Devine, J., Frank, A., Obermann, L., Rose, M., & Hinkelmann, K. (2022). Evaluation of a new body-focused group therapy versus a guided self-help group program for adults with psychogenic non-epileptic seizures (PNES): a pilot randomized controlled feasibility study. *Journal of Neurology*, *269*(1), 427–436. https://doi.org/10.1007/s00415-021-10652-0

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder: The GAD-7. *Archives of Internal Medicine (1960)*, *166*(10), 1092–1097. https://doi.org/10.1001/archinte.166.10.1092

Spitzer, C., Freyberger, H. J., Stieglitz, R., Carlson, E. B., Kuhn, G., Magdeburg, N., & Kessler, C. (1998). Adaptation and psychometric properties of the German version of the dissociative experience scale. *Journal of Traumatic Stress*, *11*(4), 799–809. https://doi.org/10.1023/A:1024457819547

*Urbanek, M., Harvey, M., McGowan, J., & Agrawal, N. (2014). Regulation of emotions in psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *37*, 110–115. https://doi.org/10.1016/j.yebeh.2014.06.004

Villagrán, A., Eldøen, G., Duncan, R., Aaberg, K. M., Hofoss, D., & Lossius, M. I. (2021). Incidence and prevalence of psychogenic nonepileptic seizures in a Norwegian county: A 10-year population-based study. *Epilepsia (Copenhagen)*, *62*(7), 1528–1535. https://doi.org/10.1111/epi.16949

*Wardrope, A., Green, B., Norman, P., & Reuber, M. (2019). The influence of attachment style and relationship quality on quality of life and psychological distress in carers of people with epileptic and nonepileptic seizures. *Epilepsy & Behavior*, *93*, 16–21. https://doi.org/10.1016/j.yebeh.2019.01.028

Zimmerman, M., Ruggero, C. J., Chelminski, I., Young, D., Posternak, M. A., Friedman, M.,

Boerescu, D., & Attiullah, N. (2006). Developing brief scales for use in clinical practice: the reliability and validity of single-item self-report measures of depression symptom severity, psychosocial impairment due to depression, and quality of life. *Journal of Clinical Psychiatry*, *67*(10), 1536-1541. https://www.psychiatrist.com/wp-content/uploads/2021/02/12460_developing-brief-scales-clinical-practice-reliability.pdf

Appendix A

Studies Excluded at Full Text Screening Stage

Table A1

Studies Excluded at Full Text Screening Stage

	Author(s) / Date	DOI	Reason for Exclusion
1.	Asadi-Pooya & Farazdaghi (2021)	https://doi.org/10.1016/j.yebeh.2021.108485	No correlate of FDS severity
2.	Asadi-Pooya & Farazdaghi (2021)	https://doi.org/10.1016/j.jpsychores.2021.110514	No correlate of FDS severity
3.	Asmussen et al. (2009)	https://doi-org/10.1016/j.seizure.2009.05.006	No measure of FDS severity
4.	Azar et al. (2010)	https://doi-org/10.1016/j.yebeh.2010.08.027	No correlate of FDS severity
5.	Bahrami et al. (2019)	https://doi.org/10.1016/j.yebeh.2019.06.001	No correlate of FDS severity
6.	Baillés et al. (2004)	https://doi-org/10.1016/j.genhosppsych.2004.04.003	No correlate of FDS severity
7.	Baird et al. (2017)	http://dx.doi.org/10.1016/j.yebeh.2017.04.015	No correlate of FDS severity
8.	Baslet et al. (2010)	http://dx.doi.org/10.1016/j.yebeh.2009.12.008	No correlate of FDS severity
9.	Brown et al. (2013)	https://doi.org/10.1016/j.yebeh.2013.07.019	No correlate of FDS severity
10.	Cohen et al. (2014)	http://dx.doi.org/10.1016/j.yebeh.2014.03.001	No correlate of FDS severity
11.	Deli et al. (2020)	https://doi.org/10.1016/j.yebeh.2020.107684	No correlate of FDS severity
12.	Dhanaraj et al. (2005)	https://doi.org/10.4103/0028-3886.16403	No correlate of FDS severity
13.	Duncan et al. (2006)	https://doi.org/10.1212/01.WNL.0000223320.94812.7A	No measure of FDS severity
14.	Duncan & Oto (2008)	https://doi.org/10.1212/01.wnl.0000326593.50863.21	No measure of FDS severity

15.	Ekanayake et al. (2016)	http://dx.doi.org/10.1016/j.jpsychores.2017.03.018	No measure of FDS severity
16.	Ettinger et al. (1999)	https://doi-org/10.1111/j.1528-1157.1999.tb00860.x	Unmet age criteria (includes aged < 16)
17.	Galimberti et al. (2003)	https://doi.org/10.1007/s00415-003-1009-0	No measure of FDS severity
18.	Gargiulo et al. (2022)	https://doi.org/10.1016/j.seizure.2022.08.002	No measure of FDS severity
19.	Gerhardt et al. (2021)	https://doi-org/10.1016/j.psym.2020.05.014	No measure of FDS severity
20.	Goldstein et al. (2019)	https://doi.org/10.1111/epi.16350	No correlate of FDS severity
21.	Goldstein et al. (2020)	https://doi.org/10.1017/S0033291720001051	No correlate of FDS severity
22.	Griffith et al. (2008)	https://doi-org /10.1016/j.yebeh.2008.06.005	No measure of FDS severity
23.	Gupta et al. (2020)	https://doi.org/10.1016/j.seizure.2020.05.007	Unmet age criteria (includes aged < 16)
24.	Hall-Patch et al. (2010)	https://doi.org/10.1111/j.1528-1167.2009.02099.x	No correlate of FDS severity
25.	Hendrickson et al. (2015)	http://dx.doi.org/10.1016/j.yebeh.2015.07.016	No correlate of FDS severity
26.	Herrero et al. (2020)	https://doi.org/10.1016/j.seizure.2020.07.028	No measure of FDS severity
27.	Hew et al. (2021)	https://doi.org/10.1016/j.yebeh.2021.107987	No correlate of FDS severity
28.	Hoepner et al. (2014)	http://dx.doi.org/10.1016/j.yebeh.2014.04.002	No correlate of FDS severity
29.	Hubsch et al. (2011)	https://doi.org/10.1136/jnnp.2010.235424	No correlate of FDS severity
30.	Ito et al. (2009)	http://dx.doi.org/10.1016/j.yebeh.2009.08.017	<50% sample had FDS
31.	Kanemoto et al. (2023)	https://doi.org/10.1002/epi4.12683	No correlate of FDS severity
32.	Kastell et al. (2022)	https://doi.org/10.1016/j.yebeh.2022.108916	No correlate of FDS severity
33.	Kerr et al. (2018)	http://dx.doi.org/10.1016/j.yebeh.2017.11.035	No measure of FDS severity
34.	Kizilhan et al. (2020)	https://doi.org/10.1192/bjp.2020.2	No measure of FDS severity

35.	Korman et al. (2019)	https://doi.org/10.1016/j.yebeh.2019.03.005	No correlate of FDS severity
36.	LaFrance et al. (2015)	http://dx.doi.org/10.1016/j.yebeh.2015.02.021	No correlate of FDS severity
37.	LaFrance et al. (2020)	https://doi-org /10.1111/epi.16689	No correlate of FDS severity
38.	Massot-Tarrús & McLachlan (2016)	http://dx.doi.org/10.1016/j.yebeh.2016.08.002	<50% sample had FDS
39.	Mayor et al. (2013)	http://dx.doi.org/10.1016/j.seizure.2013.06.008	No correlate of FDS severity
40.	Metin et al. (2013)	http://dx.doi.org/10.1016/j.yebeh.2013.03.023	No correlate of FDS severity
41.	Mousa et al. (2021)	https://doi.org/10.1016/j.yebeh.2021.107867	No correlate of FDS severity
42.	Myers et al. (2018)	https://doi.org/10.1016/j.yebeh.2018.12.027	No correlate of FDS severity
43.	Myers et al. (2021)	https://doi.org/10.1016/j.seizure.2021.04.013	No correlate of FDS severity
44.	Noe et al. (2012)	http://dx.doi.org/10.1016/j.yebeh.2011.12.015	No correlate of FDS severity
45.	Patidar et al. (2013)	https://doi.org/10.4103/0972-2327.112451	Unmet age criteria (includes aged <16)
46.	Proenca et al. (2011)	http://dx.doi.org/10.1016/j.yebeh.2010.11.015	No correlate of FDS severity
47.	Rasker et al. (2021)	https://doi.org/10.1371/journal.pone.0246051	Unmet population criteria (FDS not defined)
48.	Rawlings et al. (2017)	http://dx.doi.org/10.1016/j.seizure.2017.03.015	No measure of FDS severity
49.	Reuber et al. (2016)	http://dx.doi.org/10.1212/WNL.0000000000002948	No measure of FDS severity
50.	Rosales et al. (2019)	https://doi.org/10.1016/j.yebeh.2019.106639	No measure of FDS severity
51.	Russell et al. (2009)	https://doi.org/10.1016/j.yebeh.2009.04.012	No measure of FDS severity
52.	Salehpour et al. (2021)	http://dx.doi.org/10.32598/JGUMS.30.3.761.2	% FDS diagnosis in sample not specified
53.	Salinsky et al. (2018)	https://doi.org/10.1111/epi.14542	No correlate of FDS severity
54.	Salinsky et al. (2020)	https://doi.org/10.1016/j.yebeh.2020.107246	No correlate of FDS severity

55.	Sarudiansky et al. (2020)	https://doi.org/10.1016/j.seizure.2020.04.008	No correlate of FDS severity
56.	Sawant & Umate (2021)	https://doi.org/10.1177/0253717620956460	Unmet age criteria (includes aged <16)
57.	Sawchuk et al. (2019)	https://doi.org/10.1016/j.yebeh.2019.106705	Unmet age criteria (includes aged <16)
58.	Scevola et al. (2013)	http://dx.doi.org/10.1016/j.yebeh.2013.07.012	No measure of FDS severity
59.	Scevola et al. (2021)	https://doi.org/10.1016/j.seizure.2021.09.004	No correlate of FDS severity
60.	Simani et al. (2020)	https://doi.org/10.1016/j.yebeh.2019.106672	<50% sample had FDS
61.	Sobregrou et al. (2023)	https://doi.org/10.1016/j.yebeh.2023.109329	No correlate of FDS severity
62.	Sullivan-Baca et al. (2022)	https://doi.org/10.1016/j.eplepsyres.2022.106995	No measure of FDS severity
63.	Szaflarski et al. (2004)	https://doi.org/10.1016/j.yebeh.2003.10.015	No correlate of FDS severity
64.	Teagarden et al. (2020)	https://doi.org/10.1016/j.yebeh.2020.107160	No correlate of FDS severity
65.	Testa et al. (2007)	https://doi.org/10.1111/j.1528-1167.2006.00965.x	No correlate of FDS severity
66.	Thaller et al. (2015)	https://doi.org/10.1080/13803395.2015.1114072	No measure of FDS severity
67.	Whitehead et al. (2013)	https://doi-org /10.1111/epi.12087	No correlate of FDS severity
68.	Whitehead & Reuber (2012)	http://dx.doi.org/10.1016/j.seizure.2011.09.012	No measure of FDS severity
69.	Wiseman et al. (2016)	http://dx.doi.org/10.1016/j.yebeh.2016.07.033	No correlate of FDS severity
70.	Zhang et al. (2009)	https://doi.org/10.1016/j.yebeh.2009.04.008	No correlate of FDS severity

Appendix B

Studies Excluded Subsequent to Refinement of Eligibility Criteria

Table B1

Studies Excluded Subsequent to Refinement of Eligibility Criteria

	Author(s)	DOI / Reference	Reason for Exclusion
1.	Asadi-Pooya et al. (2019)	https://doi.org/10.1016/j.seizure.2019.02.006	Seizure Freedom
2.	Asadi-Pooya & Bahrami (2019a)	https://doi-org/10.1684/epd.2019.1077	Seizure Frequency
3.	Asadi-Pooya & Bahrami (2019b)	https://doi.org/10.1016/j.seizure.2019.05.012	Seizure Frequency
4.	Asadi-Pooya & Ziyaee (2018)	https://doi.org/10.1016/j.seizure.2018.04.017	Seizure Freedom
5.	Bodde et al. (2007)	https://doi.org/10.1016/j.jpsychores.2006.11.015	Seizure Frequency
6.	Cáceres et al. (2021)	https://doi.org/10.1016/j.yebeh.2020.107766	Seizure Frequency
7.	Dilcher et al. (2020)	https://doi.org/10.1016/j.yebeh.2020.107643	Seizure Frequency
8.	Dimaro et al. (2014)	http://dx.doi.org/10.1016/j.yebeh.2014.02.016	Seizure Frequency
9.	Dimaro et al. (2015)	https://doi.org/10.1016/j.yebeh.2015.03.032	Seizure Frequency
10.	Ettinger et al. (1999)	Ettinger, A. B., Dhoon, A., Weisbrot, D. M., & Devinsky, O. (1999). Predictive factors for outcome of nonepileptic seizures after diagnosis. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *11*(4), 458-463.	Seizure Frequency
11.	Gambini et al. (2014)	http://dx.doi.org/10.1016/j.yebeh.2014.09.076	Seizure Frequency / Seizure Freedom
12.	Goldstein et al. (2022)	https://doi.org/10.1016/j.jpsychores.2022.110921	Seizure Frequency
13.	Grenevald et al. (2021)	https://doi.org/10.1016/j.yebeh.2020.107544	Seizure Frequency

14.	Johnstone et al. (2021)	https://doi.org/10.1016/j.yebeh.2021.107861	Seizure Frequency
15.	Karakis et al. (2020)	https://doi.org/10.1016/j.yebeh.2020.107269	Seizure Frequency
16.	Kuyk et al. (2008)	http://dx.doi.org/10.1016/j.seizure.2008.02.006	Seizure Frequency / Seizure Freedom
17.	Labudda et al. (2020)	https://doi.org/10.1016/j.yebeh.2020.107029	Seizure Freedom
18.	LaFrance et al. (2011)	https://doi.org/10.1111/j.1528-1167.2010.02765.x	Seizure Frequency
19.	LaFrance et al. (2013)	https://doi.org/10.1111/epi.12053	Seizure Frequency
20.	LaFrance & Syc (2009)	https://doi.org/10.1212/WNL.0b013e3181b04c83	Seizure Frequency
21.	Lawton et al. (2009)	https://doi.org/10.1016/j.yebeh.2008.09.029	Seizure Frequency
22.	Martino et al. (2020)	https://doi.org/10.1007/s10072-020-04652-7	Seizure Frequency
23.	Massot-Tarrús et al. (2021)	https://doi.org/10.1016/j.yebeh.2021.108004	Seizure Frequency / Seizure Freedom
24.	Mayor et al. (2010)	https://doi.org/10.1111/j.1528-1167.2010.02656.x	Seizure Frequency / Seizure Freedom
25.	McKenzie et al. (2010)	https://doi.org/10.1212/WNL.0b013e3181c7da6a	Seizure Frequency / Seizure Freedom
26.	Myers et al. (2018)	https://doi.org/10.1016/j.yebeh.2017.10.019	Seizure Frequency
27.	Myers et al. (2020)	https://doi.org/10.1016/j.yebeh.2019.106694	Seizure Frequency
28.	Novakova et al. (2015)	https://doi.org/10.1016/j.seizure.2015.03.007	Seizure Frequency
29.	O'Sullivan et al. (2007)	https://doi.org/10.1016/j.yebeh.2007.04.003	Seizure Frequency
30.	Prigatoni et al. (2002)	https://doi.org/10.1016/S1525-5050(02)00053-7	Seizure Frequency
31.	Reuber et al. (2005)	https://doi.org/10.1111/j.1528-1167.2005.00280.x	Seizure Frequency
32.	Reuber et al. (2011)	https://doi.org/10.1111/j.1528-1167.2011.03162.x	Seizure Frequency
33.	Sakurai & Kanemoto (2022)	https://doi.org/10.1016/j.yebeh.2021.108539	Seizure Frequency

34.	Silva et al. (2001)	https://doi.org/10.1046/j.1528-1157.2001.45299.x	Seizure Freedom
35.	Taylor et al. (2021)	https://doi.org/10.1016/j.yebeh.2020.107578	Seizure Frequency
36.	Tolchin et al. (2019)	https://doi.org/10.1177/1535759719841354	Seizure Frequency
37.	Valente et al. (2021)	https://doi.org/10.1016/j.yebeh.2021.107852	Seizure Frequency
38.	Whitfield et al. (2020)	https://doi.org/10.1016/j.seizure.2020.09.034	Seizure Frequency

Excluded after Forward and Backward Searches

1.	Alkhadi et al. (2024)	https://doi.org/10.1016/j.eplepsyres.2023.107279	Seizure Frequency / Seizure Freedom
2.	Arain et al. (2007)	https://doi.org/10.1016/j.yebeh.2007.07.017	Seizure Freedom
3.	Chalder et al. (2024)	https://doi.org/10.1017/s0033291723003665	Seizure Frequency
4.	Duncan et al. (2016)	https://doi.org/10.1016/j.seizure.2015.12.016	Seizure Freedom
5.	Jungilligens et al. (2023)	https://doi.org/10.1080/13803395.2023.2287778	Seizure Frequency
6.	Kanner et al. (1999)	https://doi.org/10.1212/wnl.53.5.933	Seizure Freedom
7.	Lempert & Schmidt (1990)	https://doi.org/10.1007/BF00319665	Seizure Freedom
8.	Patidar et al. (2013)	https://doi.org/10.4103/0972-2327.112451	Seizure Frequency / Seizure Freedom
9.	Quigg et al. (2002)	https://doi.org/10.1016/S1525-5050(02)00524-3	Seizure Frequency / Seizure Freedom
10.	Uhlmann & Schmid (2023)	https://doi.org/10.1016/j.yebeh.2023.109463	Seizure Freedom
11.	Villagrán et al. (2022)	https://doi.org/10.1016/j.yebeh.2022.108890	Seizure Freedom
12.	Walther et al. (2019)	https://doi.org/10.1111/epi.14682	Seizure Freedom

Appendix C

Quality Appraisal Tool

Table C1

Quality Appraisal Tool Adapted from the AXIS (Downes et al., 2016) and Brown & Reuber (2016)

	Introduction	Yes	No	Don't Know
1.	**Were the aims/objectives of the study clear?** **Yes**, if there is a clear aim/hypothesis that names predictor and outcome variables OR if the study is exploratory, does it state which factors it will explore. **No,** if otherwise.			
	Methodology	**Yes**	**No**	**Don't Know**
2.	**Was the study design appropriate for the stated aim(s)?**			
3.	**Was the sample size justified?** (Index of power) **Yes,** if statement of a formal sample size calculation or a target sample size of 115 or more to detect a relatively small association, that is, correlation coefficient of 0.3, at 5% alpha and 90% power. **No,** if sample less than 115 or if less than stated in formal sample size calculation.			
4.	**Was the target population clearly defined and relevant?** (i.e. FDS participant's diagnoses confirmed by EEG) **Yes,** if vEEG reported for all participants with FDS. If control group have epilepsy, this can be clearly distinguished. **No,** if otherwise.			
5.	**Was there consecutive or random selection of participants?** *(An index of sample and response bias).* **Yes,** if paper stated consecutive or random sample. **No,** if otherwise.			
6.	**Were the outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?** *(an index of valid measurements).* **Yes,** if measure of association(s) compared with seizure severity is validated. **No,** otherwise.			
7.	**Is it clear what was used to determine statistical significance and/or precision estimates?** **Yes,** if standardised slope estimates/correlation coefficients, p-values, and confidence intervals are reported where appropriate. **No,** if otherwise.			
8.	**Did the study use multivariate analysis to establish an association?** (An index of level of confounding risk/variables). **Yes,** if regression/Bayesian statistics/t-tests were reported. **No,** if otherwise.			
9.	**Were the methods (including statistical methods) sufficiently described to enable them to be repeated?**			

	Yes, if repeatable. Including sufficient detail regarding how the questionnaires/measures were administered and by whom, and such details of the statistical analyses that can be repeated. **No**, if otherwise.			
10.	**Was a valid measure used to determine seizure severity?** **Yes,** if a validated measure of seizure severity is used. **No,** if otherwise.			
	Results	**Yes**	**No**	**Don't Know**
11.	**Were the results adequately described?** **Yes,** if the results link back to methods and report both significant and non-significant findings relevant for the research question both in the tables and text. **No,** if otherwise.			
12.	**Did the study address response bias?** **Yes**, if authors reported response rates/attrition and describe nonrespondents. **No,** if otherwise.			
13.	**Were the results internally consistent?** **Yes,** if authors reported the results consistently across the paper. **No,** if otherwise.			
14.	**Were the findings for the target population clearly distinguishable?** **Yes,** if findings related to FDS can be clearly distinguished. **No,** if otherwise.			
	Discussion	**Yes**	**No**	**Don't Know**
15.	**Were the authors' discussions and conclusions justified by the results?** **Yes,** if the authors discussed both relevant significant and non-significant results and did not make overstatements. **No,** if otherwise.			
16.	**Were the limitations discussed?** **Yes,** if limitations are stated. **No**, if otherwise.			
	Ethics	**Yes**	**No**	**Don't Know**
17.	**Was ethical approval or consent from participants obtained?** **Yes**, if stated in the text. **No,** if otherwise.			

Appendix D

Table D1

Quality Appraisal Tool Adapted from the CASP (2018) Cohort Study Checklist and Brown & Reuber (2016)

	SECTION A: ARE THE RESULTS OF THE STUDY VALID?	Yes	No	Don't Know
1	**Did the study address a clearly focused issue?** *A question can be focused in terms of:* ▪ *Population studied* ▪ *Risk factors studied* ▪ *Is it clear whether the study tried to detect a beneficial or harmful effect?* ▪ *Outcomes considered*			
2	**Was the cohort recruited in an acceptable way?** *Look for selection bias which might compromise the generalisability of the findings:* ▪ *Was the cohort representative of a defined population?* ▪ *Was there something special about the cohort?* ▪ *Was everybody included who should have been?* ▪ *Did participants have vEEG diagnosis of FDS?*			
3	**Was the exposure accurately measured to minimise bias?** Look for measurement or classification bias: ▪ Did they use subjective or objective measurements? ▪ Do the measurements truly reflect what you want them to (have they been validated)? ▪ Were all the subjects classified into exposure groups using the same procedure?			
4	**Was the outcome accurately measured to minimise bias?** Look for measurement or classification bias: ▪ Did they use subjective or objective measurements? ▪ Do the measurements truly reflect what you want them to (have they been validated)? Including a measure of FDS severity. ▪ Were the measurement methods similar in the different groups? ▪ Were the subjects and / or outcome assessor blinded to the exposure (does this matter)?			
5	**a) Have the authors identified all important confounding factors?** **b) Have they taken account of the confounding factors in the design and/or analysis?** Look for restrictions in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors.			
6	**a) Was the follow-up of subjects complete enough?** **b) Was the follow-up of subjects long enough?** Consider: ▪ Good or bad effects should have had long enough to reveal themselves ▪ The persons that are lost to follow-up may have different outcomes that those available for assessment ▪ In an open or dynamic cohort, was there anything			

special about the outcome of the people leaving, or the exposure of the people entering the cohort

SECTION B: WHAT ARE THE RESULTS?

7 **What are the results of this study?**

- What are the bottom-line results?
- Have they reported the rate or proportion between the exposed / unexposed, the ratio / rate difference?
- How strong is the association between exposure and outcome (RR)?
- What is the absolute risk reduction (ARR)?

8 **How precise are the results?** Look for the range of the confidence intervals, if given.

9 **Do you believe the results?**

- Big effect is hard to ignore
- Can it be due to bias, chance or confounding
- Are the design and methods of this study sufficiently flawed to make the results unreliable
- Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)

SECTION C: WILL THE RESULTS HELP LOCALLY?

10 **Can the results be applied to the local population?**
Consider whether:

- A cohort study was the appropriate method to answer this question
- The subjects covered in this study could be sufficiently different from your population to cause concern
- Your local setting is likely to differ much from that of the study
- You can quantify the local benefits and harms

11 **Do the results of this study fit with other available evidence?**

12 **What are the implications of this study for practice?**

- One observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making
- For certain questions, observational questions provide the only evidence
- Recommendations from observational studies are always stronger when supported by other evidence.

Appendix E

Quality Assessment

Table E1

Quality Assessment using the AXIS Criteria (Appendix C)

	Quality Appraisal Criterion																
Author	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**
Goldstein et al. (2023)	✓	✓	✓	X	✓	✓	✓	X	✓	X	✓	✓	✓	✓	✓	✓	✓
Green et al. (2016)	✓	✓	X	X	✓	✓	✓	✓	✓	X	✓	X	✓	✓	✓	✓	✓
Korucuk et al. (2018)	✓	✓	X	X	X	-	✓	X	✓	X	✓	-	✓	✓	✓	✓	✓
Pick et al. (2017)	✓	✓	✓	X	X	✓	✓	✓	X	X	✓	X	✓	✓	✓	✓	✓
Rawlings et al. (2017a)	✓	✓	X	X	X	✓	✓	X	✓	X	✓	X	✓	✓	✓	✓	✓
Rawlings et al. (2017b)	✓	✓	✓	X	X	✓	✓	✓	✓	X	✓	X	✓	✓	✓	✓	✓
Reuber et al. (2003)	✓	✓	X	✓	X	✓	✓	✓	✓	X	✓	✓	✓	✓	✓	✓	✓
Roberts et al. (2023)	✓	✓	X	X	X	✓	✓	X	X	X	✓	✓	✓	✓	✓	✓	✓
Selkirk et al. (2008)	✓	✓	✓	✓	✓	-	✓	X	✓	X	✓	-	✓	✓	✓	X	✓
Urbanek et al. (2014)	✓	✓	X	X	X	✓	✓	✓	✓	X	✓	X	✓	✓	✓	✓	✓
Wardrope et al. (2019)	✓	✓	X	X	✓	✓	✓	X	✓	X	✓	X	✓	✓	✓	✓	✓

Key	
✓	Yes
X	No
-	N/A

Table E2

Quality Assessment using the CASP: Cohort Study Checklist (Appendix D)

	1	2	3	4	5	6	7	8	9	10	11	12
Chen et al. (2018)	✓	✓	X	X	✓	✓	✓	✓	✓	X	✓	✓

Appendix E

Table E1

Summary of Instruments used to Measure Associated Variables (Grouped According to Themes)

Group	Measure	Studies Included	Brief Description
Mental Health	GAD-7	Goldstein et al. (2023) Green et al. (2016) Wardrope et al. (2019)	Symptoms of anxiety. Higher scores indicate increased symptoms.
	PHQ-9	Green et al. (2016) Wardrope et al. (2019)	Symptoms of depression. Higher scores indicate increased symptoms.
	PSS	Roberts et al. (2023)	Perceived stress.
	SCL-90	Reuber et al. (2003)	Psychological difficulties. Somatization, obsessive-compulsive, interpersonal sensibility, depression, anxiety, anger-hostility, phobic-anxiety, paranoid ideation, psychoticism.
Trauma	PCL-5	Roberts et al. (2023)	PTSD. Symptom checklist to indicate diagnosis.
	PDS	Pick et al. (2016)	PTSD. Subscales: reexperiencing, avoidance, arousal. Higher scores indicate higher severity.
Dissociation	FDS	Reuber et al. (2003)	German adaptation of DES. Dissociative phenomena: mDES score and DES-T score (more robust subscale to assess pathological dissociation).
	MDI	Pick et al. (2016)	Psychological dissociation. Subscales: d*isengagement, depersonalization, derealization, emotional constriction, memory disturbance, identity dissociation.*
	SDQ-20	Pick et al. (2016)	Presence of physical symptoms conceptualized as resulting from somatoform dissociation.

	SOMS	Reuber et al. (2003)	Physical symptoms of somatization disorder.
Emotional Processes	DERS-18	Roberts et al. (2023)	Difficulties in emotional awareness and emotional regulation.
	BEAQ	Roberts et al. (2023)	Experiential avoidance.
	ERQ	Roberts et al. (2023)	Emotional regulation.
	AIM	Roberts et al. (2023)	Affect intensity.
	BAEQ	Roberts et al. (2023)	Beliefs about emotions as overwhelming and uncontrollable, shameful and irrational, invalid and meaningless, useless, damaging, and contagious.
	TAS-20	Urbanek et al. (2014)	Understanding of one's own emotions or 'Alexithymia'. Higher scores suggestive of difficulty.
	CECS	Urbanek et al. (2014)	Tendency to control emotional reactions.
QoL	QOLIE-10-P	Green et al. (2016)	QoL (Epilepsy). Seizure worry, overall QoL, emotional well-being, energy-fatigue, cognitive functioning, physical and psychological effects of AEDs, work, driving, and social function.
	NEWQOL-6D	Rawlings et al. (2017a) Rawlings et al. (2017b)	HRQoL for seizures. Six domains: worries about seizures, depression, memory, concentration, perceived control over events, and stigma. Higher overall score represents better HRQoL.
	SF-12	Wardrope et al. (2019)	HRQoL. Physical wellbeing and mental wellbeing. Higher scores indicate better HRQoL.
Relational	ASQ	Green et al. (2016)	Attachment avoidance and attachment anxiety.
	ISEL	Roberts et al. (2023)	Interpersonal support. Subscales: appraisal, tangible, and belonging.

	PAS	Roberts et al. (2023)	Physical affection.
	Sleep Touch	Roberts et al. (2023)	Single-item *"How much do you and your spouse/partner ordinarily touch each other while sleeping in the same bed?"*
	STQ	Roberts et al. (2023)	Touch-related attitudes and behaviours. Higher scores indicated greater comfort with touch.
	UCLA-R	Roberts et al. (2023)	Loneliness. Higher scores reflect greater loneliness.
Illness Perception	BIPQ	Chen et al. (2018)	One-item *"How much does your illness affect your life?".* Higher scores imply higher severity.
	SA	Chen et al. (2018)	Perception of cause of seizures as physical or psychological.
Stigma	NEWQOL-6D	Rawlings et al.	One-item "*How much do you feel people treat you as an inferior person?".* A lower score indicated better outcome.

Note, GAD-7 = General Anxiety Disorder Questionnaire (Spitzer et al., 2006); PHQ-9 = Patient Health Questionnaire (Kroenke et al., 2001); PSS = Perceived Stress Scale (Cohen et al., 1983); SCL-90 = Symptom Checklist-90-R (Schmitz et al., 2000); PCL-5 = Post-traumatic stress disorder checklist for DSM-5 (Blevins et al., 2015); PTSD = Post-traumatic Stress Disorder; PDS = Posttraumatic Diagnostic Scale (Foa et al., 1997); MDI = Multiscale Dissociation Inventory (Briere, 2002); SDQ-20 = Somatoform Dissociation Questionnaire (Nijenhuis et al., 1996); SOMS = Screening Test for Somatoform Symptoms-2 (Rief et al., 1997); DERS-18 = Difficulties in Emotional Regulation Scale (Victor & Klonsky, 2016); BEAQ = Brief Experiential Avoidance Questionnaire (Gamez et al., 2014); ERQ = Emotional Regulation Questionnaire (Gross et al., 2003); AIM = Affect Intensity Measure (Larsen & Diener, 1987); BAEQ = Beliefs about Emotions Questionnaire (Manser et al., 2012); TAS-20 = Toronto Alexithymia Scale – 20 (Bagby et al., 1994); CECS = Courtauld Emotional Control Scale (Watson & Greer, 1983); QoL = Quality of Life; QOLIE-10-P = Quality of Life in Epilepsy Questionnaire (Devinsky, 1983); AEDs = anti-epileptic drugs; NEWQOL-6D = epilepsy specific QALY measure (Mulhern, 2012); HRQoL = health-related QoL; SF-12 = Short Form 12 Health Survey (Ware et al., 1996); ASQ = Attachment Style Questionnaire (Polek et al., 2008); ISEL = Interpersonal Support Evaluation List – Short Form (Cohen et al., 1983; Russell et al., 1980); PAS = Physical Affection Scale (Burleson et al., 2022; Diamond et al., 2000); STQ = Social Touch Questionnaire (Wilhelm et al., 2001); UCLA-R = UCLA Loneliness Scale (Russell et al., 1980); BIPQ = Brief Illness Perception Questionnaire (Broadbent et al., 2006); SA = Symptom Attribution Scale (Wessely et al., 1989; Powell et al., 1990)

Appendix F

Table F1

Key Findings in Relation to Research Question (Factors Related to FDS Severity)

Study No.	Analysis	Factors Related to FDS Severity / Comparison Groups
1	Mann-Whitney U Ordinal Regression	FDS PHY associated with greater improvement in seizure intensity compared to FDS PSY at 3-M FU (U = 228.5**) and 6-M FU (U = 155.5**). Prediagnosis SA the only significant predictor of FDS PHY improvement in seizure intensity at 3-M** and 6-M* FUs.
	Spearman's Rho	FDS PHY change in SA of seizures to greater psychological roles correlated (weak to moderate degree) with improvement in seizure intensity at 3-M FU (r_s = .380*) and 6-M FU (r_s = 0.448*). FDS PHY change toward less severe illness perception correlated (weak to moderate degree) with improvement in seizure intensity 3-M FU (r_s = 0.396*) and 6-M FU (r_s = 0.516*). No significant correlations between change in illness perception and improvement in seizure intensity in FDS PSY or Epilepsy groups.
2	Pearson's *r*	Higher GAD-7 scores correlated with severe seizure frequency (*r* = .225***).
3	Pearson's *r*	FDS severity not significantly associated with HRQoL (*r* = 0.11), depression (*r* = 0.29) or anxiety (*r* = 0.06). Epileptic seizure severity correlated with HRQoL (r = -.34***), depression (r = .36***) and anxiety (r =.74***).
	Hierarchical regression	*FDS* Demographics, seizure duration (years) and seizure severity non significant predictors of depression (ΔR^2 = 0.26, p = 0.24) and anxiety scores (ΔR2 = 0.12, F(4,17) = 0.60, p = 0.67). Attachment variables and relationship conflict explained 45% of variance in depression scores (ΔR^2 = 0.45)** and additional variance in anxiety scores (ΔR2 = 0.60, F(5,12) = 5.08)**. Final regression model significant (F(7,14) = 5.07)** explaining 72% of variance in

		depression. Only attachment anxiety made significant contribution. Variables in final regression model of anxiety accounted for 72% of variance (F(9,12) = 3.41)*. No significant individual variables.
		Epilepsy Demographics, seizure duration (years) and seizure severity accounted for a significant amount of variance in epilepsy group HRQoL (ΔR2 = 0.13, F(4,67) = 2.58, p = 0.045). Depression increased amount of variance explained (ΔR2 = 0.16, F(1,66) = 15.34, p = 0.001). Attachment scales added no further variance (ΔR2 = 0.01, F(2,64) = 0.43, p = 0.650). Final regression model significant (F(7,64) = 4.04, p = 0.001) explaining 31% of variance in HRQoL. Only depression made a significant contribution. Demographics, seizure duration (years), and seizure severity explained 23% of variance in depression (ΔR2 = 0.23, F(4,65) = 4.73, p = 0.002) but accounted for a non-significant amount of variance in anxiety (ΔR2 = 0.13, F(4,67) = 2.42, p = 0.057). Attachment scores and relationship conflict explained additional variance in the depression model (ΔR2 = 0.16, F(3,62) = 5.46, p = 0.002) and 13% additional variance in the anxiety model (ΔR2 = 0.13, F(2,65) = 5.88, p = 0.005). The variables in the final regression models accounted for 39% of variance in depression scores (F(7,62) = 5.60, p = 0.001) and 26% of the variance in anxiety scores (F(6,65) = 3.81, p = 0.003). Seizure severity and attachment avoidance were significant predictors of depression and anxiety.
4	Student's t test	FDS median duration greater in females*. 87.1% of FDS exceeded two minutes in females compared to 50% in males*.
5	Spearman rank-order Point-biserial correlations	PTSD associated with total ictal cognitive symptoms most recent seizure (*r* = .524). Reexperiencing associated with total ictal symptoms most recent seizure (*r* = .506). Depersonalization associated with ictal mental state symptoms for most recent (*r* = .649) and most severe seizures (*r* = .616) and with total ictal symptoms of most recent seizure (r = .497). Derealization associated with ictal mental state symptoms of most recent (*r* = .606) and most severe seizures (*r* = .501). Identity dissociation associated with ictal cognitive symptoms in most severe seizures (*r* = .459). Somatic dissociation not significantly correlated with any seizure variable.

6	Spearman rank-order	Perceived stigma showed weak nonsignificant trends with seizure severity in the FDS group (rs = -0.07) and epilepsy group (rs = 0.14).
7	Spearman rank-order	Seizure severity not significantly correlated with HRQoL in FDS (r = -.16). Negative correlation found between HRQoL and seizure severity in epilepsy (r = - 0.29*).
	Hierarchical regression	Demographic factors explained 3% of variance (p = 0.5) in FDS HRQoL, condition variables (severity and frequency) accounted for a further 10.9% (p = 0.1) with seizure frequency* but not seizure severity an independent significant predictor of HRQoL. Psychological distress accounted for 24.8%*** and illness perceptions 23.3%*. Personal control* was a significant predictor of HRQoL.
8	ANOVA	High FDS severity associated with high somatization (F = 2.388*), dissociation/mDES (F = 2.186*) and psychological difficulties (F = 3.488**). No associations remained significant when other scores introduced as covariates. DES-T score showed no significant association with seizure severity.
9	Spearman rank-order	FDS-HiPTS greater seizure impact than FDS-LoPTS however this was nonsignificant. FDS-LoPTS greater seizure severity* than FDS-HiPTS. FDS-HiPTS seizure severity associated with situational reappraisal (r = -.40***); remained significant in FDS-HighPTS vEEG group (r = -.40*). Expressive suppression associated with seizure severity (r = -.38**) in FDS-vEEG subgroup and FDS-HiPTS-vEEG subgroup (r = -.46*). Seizure impact associated with perceived stress in FDS-FS (r = .37***) and FDS-LoPTS subsample (r = .35*); remained significant in FDS-vEEG subgroup (r = .44**). Seizure impact associated with emotional regulation difficulties in FDS-FS (r = .29*) and in FDS-vEEG subsample (r = .30*). Physical affection with partner negatively correlated with seizure impact in FDS-vEEG subsample (r = -.38*) and vEEG FDS-HiPTS subsample (r = -.51*).
		FDS-FS: seizure severity not significantly associated with emotional avoidance (r = -.02), emotional awareness difficulties (r =-.02), emotion regulation difficulties (r =-.01), expressive suppression (r =-.21), situational reappraisal (r = -.17), perceived stress (r - .08), social support (r = .01), loneliness (r = -.09), comfort with social touch (r = -.01), physical affection with partner (r = .17), or frequency of sleep-touch (r = .08). Seizure impact not significantly associated with emotional avoidance (r = .13), emotional awareness difficulties (r =-.09), expressive

		suppression (r =-.07), situational reappraisal (r = -.14), social support (r = -.16), loneliness (r = .11), comfort with social touch (r = -.03), physical affection with partner (r = -.21), or frequency of sleep-touch (r = -.21).
10	Student's *t*-test	History of sexual abuse associated with higher mean seizure severity score***. Self-injurious behaviour** and urinary incontinence** significantly more likely during spells.
11	Spearman rank-order	BAEQ total medium correlation with FDS severity (r = .309*) and FDS bothersomeness (r = .372**). Small correlation between TAS-20 and FDS severity (r = .029*) but not FDS bothersomeness. No significant associations found between FDS severity or FDS bothersomeness with AIM or CECS.
12	Spearman rank-order Fisher's z	Seizure severity negatively associated with mental wellbeing in CfE* (rE = -0.356) but not CfFDS (rE = 0.264) and correlates were significantly different*. Seizure severity not significantly associated with anxiety in CfFDS (rE = -0.229) or CfE (rE = 0.173); CfFDS depression (rE = -0.33) or CfE depression (rE = 0.248) or; CfFDS physical well-being (rs = .230) or CfE physical well-being (rs = .168). Depression correlates significantly differed* between CfFDS and CfE.

Note, PHY = Physical Group, PSY = Psychological Group; M = Month, FU = Follow-up, SA = Symptom Attribution, HRQoL = Health-related Quality of Life; PTSD = Post-traumatic stress disorder; FDS-HiPTS = High Trauma FDS Group; FDS-LoPTS = Low Trauma FDS group; FDS-FS = FDS Full Sample; CfE = Carers for Epilepsy; CfFDS = Carers for FDS. * = $p \leq .05$; ** = $p \leq .01$; *** = $p \leq .001$

Appendix G

PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg 2 Pg 3-6
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg 2 Pg 6
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg 7-10
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.	Pg 7
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Pg 7
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.	Pg 7-10
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.	Pg 7-10
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.	Pg 7-10
	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.	Pg 7-10
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.	Pg 9
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Pg 58
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)).	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Pg 9-10
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pg 10
	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.	Pg 10
	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
RESULTS			
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.	Pg 10-11
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Pg 8 Pg44-50
Study characteristics	17	Cite each included study and present its characteristics.	Pg 14-16
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Pg 13
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.	Pg 21-28 Pg 58-61
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Pg 10 Pg 12-13
	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.	Pg 21-28 Pg 58-61
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	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			

Section and Topic	Item #	Checklist item	Location where item is reported
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pg 28-33
	23b	Discuss any limitations of the evidence included in the review.	Pg 33-34
	23c	Discuss any limitations of the review processes used.	Pg 33-34
	23d	Discuss implications of the results for practice, policy, and future research.	Pg 34-35
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.	Pg 10
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg 10
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg 8
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
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

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Section Two: Empirical Study

Development of a Functional Dissociative Seizure Self-Report Severity Questionnaire: a Mixed Methods Design

Abstract

Objectives: Functional / dissociative seizures (FDS) are a debilitating condition for which there are no validated or reliable condition-specific severity measures. Such a measure would be of value for clinical and research applications. The current study aimed to develop a self-report measure of FDS severity.

Design: An exploratory sequential mixed methods design was employed including a qualitative phase followed by a quantitative phase.

Methods: Participants included people with lived experience of FDS and healthcare professionals. Focus groups were conducted to explore FDS severity and the feasibility of developing a measure. Subsequently, a pool of items relevant to FDS severity was developed. This item pool was the basis of a three-round Delphi survey involving a larger sample of experts (lived or professional experience) aiming to reach consensus on items of highest relevance for FDS severity.

Results: Three primary themes emerged relating to FDS severity: (1) Seizure take control and "you can't stop it"; (2) Seizures are "physically tough"; and (3) Seizures leave their mark. 115 candidate items formed the first round of the Delphi, leading to the development of a three-section questionnaire. 35 items that reached consensus were organised into 'Severity' or 'Frequency / Duration' sections. The third section was a symptom checklist.

Conclusions: Consensus of experts by experience and clinicians on items for inclusion in a measure of FDS severity was achieved. A draft 'Functional / Dissociative Seizure Scale' (FDS-S) is now ready for further validation prior to its use in clinical and research practice.

Practitioner Points:

- There is no valid or reliable seizure severity measure developed for FDS; subsequently, research to date has used a variety of alternative methods to assess FDS seizure severity. This has primarily included use of measures developed for epilepsy that have not been validated for FDS populations.
- Seizure severity is an important outcome in the treatment of FDS. A condition-specific measure would be of value to guide, monitor and evaluate the effectiveness of treatment for individual patients and also, service benchmarking.
- Loss of control, physical symptoms and the lasting effects of seizures (including emotional, physical, cognitive factors) are important factors in the perception of seizure severity. Notably, the impact of FDS on quality of life is important to understand the wider severity of the condition.
- The FDS-S is a comprehensive measure developed to assess FDS severity, grounded in the perspectives of a large group of individuals with lived experience of FDS and healthcare professional experts. Subject to further psychometric development and evaluation, the FDS-S will provide a standardised measure for clinical use and in future research.

Key Words: Functional / dissociative seizures, seizure severity, condition-specific measures, outcome, psychological therapy, adults, FDS-S

Functional / dissociative seizures (FDS) are episodes of reduced self-control causing disturbances to normal functioning associated with a range of motor, sensory and mental manifestations (Brown & Reuber, 2016a). FDS superficially resemble epileptic seizures or syncope but are not associated with the same physiological changes which underpin these conditions (Reuber, 2008). FDS populations demonstrate high levels of psychiatric comorbidities, especially post-traumatic stress disorder, complex trauma, anxiety, and depression (Brown & Reuber, 2016b). Additionally, higher rates of complex physical health comorbidities such as pain and fatigue, and worse general health to the extent that, there is an increased risk of premature death (Tan et al., 2023). Moreover, individuals report significantly poorer health-related quality of life (HRQoL) compared to normal populations and other neurological condition such as epilepsy (Marzooqi et al., 2004).

Psychological interventions for FDS are recommended internationally (Hingray et al., 2018). There is however no agreement as to what therapeutic approach achieves the best results in this population (La France et al., 2013). Nevertheless, there is an expanding evidence base. A recent systematic review and meta-analysis revealed psychological interventions are effective at reducing seizure-related (i.e. seizure frequency) and non-seizure-related (i.e. anxiety, depression) patient-reported outcome measures (PROMs; Gaskell et al., 2023; Gaskell et al., 2024).
Despite this, a landmark randomised controlled trial (RCT) exploring the effectiveness of Cognitive Behavioural Therapy (CBT) for adults with FDS ($N = 368$) found no significant treatment effect for the primary outcome of seizure frequency reduction (CODES; Goldstein et al., 2020). However, seizure frequency and freedom are the most reported outcomes across studies evaluating psychological treatments for FDS (Gaskell at al., 2024). This raises the question of the appropriateness of seizure frequency for evaluating FDS treatments. Goldstein et al. (2024) argued seizure frequency may not be as important to people with FDS as seizure impact or bothersomeness.

Notably, the CODES trial (Goldstein et al., 2020) found a significant improvement in

several clinically relevant secondary outcomes following CBT, including outcomes capturing mental health, bothersomeness of seizures and health-related quality of life (HRQoL). The apparent dissociation of seizure frequency and other outcomes is not completely surprising, considering the findings of a systematic review which demonstrated a lack of correlation between seizure frequency and HRQoL (Jones et al., 2016). In another study, psychological factors accounted for a larger variance in HRQoL than condition-related (i.e. seizure frequency, seizure severity) factors (Rawlings et al., 2017). Taking these considerations into account, an opinion statement by a large group of international FND experts argued that measures of the impact of FND (i.e. disability, HRQoL, functioning, and psychological distress) are most relevant across functional neurological disorder (FND) presentations (Nicholson et al., 2020). As such, generic outcome measures, known to be reliable and valid in related populations, can be used to assess the impact of FND (Pick et al., 2020). Nevertheless, measures of the existing core symptoms of FND (i.e. manifestations of the severity of FDS) may be of value (Nicholson et al., 2020).

Unfortunately, to date, no validated condition-specific PROM has been developed for FDS although it has been argued that PROMs are necessary to establish intervention effectiveness from the patient perspective (NHS, 2018). Whilst general measures have their advantages, condition-specific measures are developed with the recognition that different health conditions have specific features relevant to that patient group and the severity of that condition (Meadows, 2011). A PROM developed for people with FDS would be a positive step in ensuring psychological treatments are consistent with therapy goals. The current authors previously conducted a systematic review examining correlates associated with FDS severity (Whitaker et al., 2024). None of the included studies employed a seizure severity measure that is reliable or validated for FDS, limiting the conclusions that could be drawn. This review also demonstrated very limited convergent validity of seizure severity measures used with patients with FDS in the studies.

Of relevance, Whitaker et al. (2024) reiterated that many researchers have attempted to measure seizure severity in this population, suggesting that FDS severity is widely recognised as an

important outcome. However, given the lack of a validated FDS seizure severity measures, most chose seizure severity measures developed for patients with epilepsy. The most commonly used measures of this type are the Liverpool Seizure Severity Scale (LSSS-3, Baker et al., 1998) and the Seizure Severity Questionnaire (SSQ; Cramer et al., 2002). It has long been established that seizure severity is an important aspect of epilepsy and may have a greater effect than seizure frequency or psychosocial outcomes (Baker at al., 1991). Moreover, greater seizure severity has been associated with poorer HRQoL in the epilepsy population (Harden et al., 2007). Given condition-specific measures are more likely to detect clinically relevant changes in response to treatment (Meadows, 2011), it is unlikely measures developed for epilepsy provide a relevant evaluation of FDS severity.

Several studies have demonstrated FDS are highly heterogenous (e.g. Brown et al., 2013; Hingray et al., 2022). Rawlings and Reuber (2016) provided an overview of quantitative and qualitative studies demonstrating insights into the broad range of subjective symptoms associated with FDS. To the researcher's knowledge however, no studies have attempted to explore what people with FDS say influences the severity of this condition.

A seizure severity measure in FDS would help to screen and triage patients contributing to a holistic assessment of the individual and their needs. This would guide interventions and enable patients and clinicians to monitor if seizures are more or less severe overtime. The effectiveness of psychological interventions could be evaluated at an individual level and, more widely across healthcare services to compare treatment outcomes for FDS and share good practice. Moreover, a standardised measure of FDS severity would provide a consistent outcome for use in research studies to understand more about the condition and what is associated with its severity. FDS severity could be studied as part of clinical trials examining the effectiveness of psychological treatment for FDS, both as a direct outcome, or as a potential mediator or moderator variable of other reported outcomes. In turn, this would inform clinical practice ensuring patients receive the most effective treatments which may aid in minimising cost to healthcare services.

Current Study

The aim of the current study was to develop and propose a comprehensive PROM of FDS severity considered relevant by individuals with lived experience. New questionnaires should be developed when (a) there are no existing measures of the constructs, (b) existing measures have insufficient reliability or validity, or (c) existing measures have other practical limitations (Rosellini & Brown, 2021). These points have been addressed above. To develop a rigorous outcome measure, three key developmental phases (item development, scale development, and scale evaluation) collectively consisting of nine steps have been proposed (Boateng et al., 2018). This study sought to achieve the initial phase 'item development' (i.e. generating an initial set of items for an eventual scale). This included two steps: (1) identification of domain(s) and item generation, and (2) content validity (evaluation by experts and the target population). This would produce a measure ready for further quantitative testing and evaluation (prior to use in clinical practice) to achieve the additional phases proposed for the development of an outcome measure (Boateng et al., 2018). As this is an exploratory study, there was no formal hypothesis.

This project uses a mixed-method research approach involving qualitative and quantitative data collection and analysis within the same study (Creswell & Plano Clark, 2018). The combination of qualitative and quantitative methods is recognised as a useful approach for developing quantitative instruments (Onwuegbuzie et al., 2010). An exploratory sequential mixed-method design is recommended for scale development (Creswell & Plano Clark, 2011). This type of mixed-method design has two distinct phases: qualitative followed by quantitative (Creswell & Plano Clark, 2018). The initial qualitative phase involves collation and analysis of qualitative data to explore a phenomenon. A quantitative phase follows in which some aspect of the qualitative findings is utilised to examine trends or associations using quantitative methods (Fetters & Tajima, 2022). This results in the development of a tool grounded in the perspectives of the target population; more likely seen as relevant (Creswell & Plano Clark, 2018).

Methods

Ethical Approval

Ethical approval was obtained from the University of Sheffield Ethics Committee (Appendix A). Participation was voluntary and participants could withdraw at any point. Informed consent was provided prior to taking part.

Design Overview

A mixed methods exploratory sequential design was employed, involving two phases. Phase one involved the collection of qualitative data through two focus groups, with findings informing phase two. Phase two was a three-round Delphi survey, conducted to reach a consensus around proposed FDS severity items for a candidate questionnaire. Phase two was predominantly quantitative with a small amount of supplementary qualitative data. This meant Phase Two was in itself based on a convergent mixed-methods design (questionnaire variant). The questionnaire variant refers to using both open- and closed-ended questions in which qualitative data are collected as an accessory to support quantitative data (Creswell & Plano-Clark, 2018).

Recruitment

Recruitment for both study phases followed the same process. Participants with lived experience of FDS (PwLE) and carers familiar with FND were recruited via third sector organisations for individuals with FDS. Healthcare professionals (HCPs) were approached through professional organisations with a particular interest in FND (see acknowledgements). Recruitment for the focus groups took place in December 2023 and for the Delphi surveys December 2023 to January 2024. Information was circulated about the specific study phase (Appendix B) with a Qualtrics link to a Participant Screening Survey (Appendix C) to determine if prospective participants met the eligibility criteria (see Table 1). Individuals who met this could then access the relevant 'Participant Information Sheet' (Appendix D) and 'Consent Form' (Appendix E) via Qualtrics. FDS diagnoses were

determined through patient self-report. Participants consenting to take part were asked to provide demographic information.

Table 1

Participant Eligibility Criteria

Inclusion Criteria		Exclusion Criteria
▪ Lived experience of FDS (either personally or as a caregiver to an adult experiencing FDS). ▪ Experienced FDS in the last two years. ▪ For *Focus Groups*, reside in the UK (for practical and safety reasons of seizure management).	**OR** ▪ Professional expert in the field of FDS (e.g. Academic, Clinical Psychologists, Psychiatrists, Neurologists, Psychotherapists).	▪ Non-fluent in English. ▪ Co-morbid diagnosis of epileptic seizures (due to potential difficulty distinguishing between different seizure types). ▪ A marked speech difficulty which could pose a significant barrier to engagement in group discussions.
AND ▪ Aged 18 years and over. ▪ Provided informed consent to take part in the study.		

Phase One

Participants

Braun and Clark (2013) recommend a smaller focus group of three to eight participants. This was the desired sample size range for the current study. Smaller groups can be easier to manage, generate rich discussion and provide opportunity for each participant to contribute.

Individuals were invited to take part in either a 'PwLE' or 'HCPs' focus group. Eighteen individuals with lived experience and eighteen HCPs met the eligibility criteria and consented to take part. Prospective participants were consecutively invited to take part until the desired sample was achieved. Of the eighteen individuals with lived experience, one did not respond, six were unavailable, three withdrew due to physical health reasons, and two did not attend. Therefore, the first group consisted of six PwLE. Nine HCPs were unavailable at the arranged time for the focus group and one withdrew resulting in a second sample of eight HCPs.

Data Collection

Two focus groups were conducted remotely via 'Google Meet' in December 2023 and January 2024: PwLE group (2 hours in duration) and a HCPs group (1.5 hours in duration). Discussions aimed to focus on the period immediately before, during, and immediately after FDS (i.e. the prodromal, aura, ictal and post-ictal phases of a seizure). Facilitation of two focus groups was considered sufficient to capture the perspectives of PwLE and HCPs, providing a foundation for the second study phase (with a larger sample).

A semi-structured focus group topic guide (Appendix F) was developed to elicit relevant discussions aiding with development of a scale. Open-ended questions guided discussions predominantly focused on what participants felt made seizures more or less severe and the feasibility / acceptability of an FDS severity measure. On commencing the PwLE group, slides were presented outlining a general PROM (i.e. SF-12; Ware et al., 1996) and a condition-specific PROM (i.e. PHQ-9; Kroenke et al., 2001) to familiarise participants to types of outcome measures and enhance understanding of the research aims.

The topic guide was partly informed by a previous systematic review conducted to examine correlates associated with FDS severity (Whitaker et al., 2024). These findings were included to prompt further discussion if required (see question 4b; Appendix F). To broaden this further, data reporting on correlates associated with seizure frequency were also extracted. These were presented to PwLE in the final ten minutes of the focus group. In-depth discussions had already been generated therefore this has not been required to prompt discussions. Subsequent to this, discussions were minimal and gravitated off topic. This was not presented during the HCP group due to timings.

Data Analysis

Focus groups were video recorded and transcribed verbatim by the main author (and facilitator). Reflexive Thematic Analysis (RTA) was conducted as outlined by Braun and Clark (2006; 2021). Thematic analysis is a suitable approach for two to four focus groups (Braun & Clark,

2013). The analysis was guided by the six-phase process for data engagement, coding, and theme development (Braun & Clark, 2006) outlined in Table 2. Themes are presented in the results sections; participants quotes are represented by quotation marks.

An experiential, inductive approach was taken in that themes and subthemes were grounded in the data to understand the meanings, views and perspectives of participants and their experiences of FDS. It is important to acknowledge, existing knowledge of the literature may have influenced this. RTA is a flexible approach compared to other qualitative analyses and is not tied to a particular epistemological or theoretical perspective (Maguire & Delahunt, 2017).

A central component of RTA is the author's subjectivity which is unavoidable, necessary, and valuable (Braun & Clark, 2021). A full reflexive statement is provided to outline potential biases in the researcher's processes (Appendix G) and a reflexive log (see Appendix H) maintained. The researcher is a White British woman from a working-class background working as a Trainee Clinical Psychologist in an outpatient epilepsy service and inpatient neurorehabilitation service. Therefore, the researcher has more clinical experience with individuals experiencing organic as opposed to functional neurological presentations. She has also previously worked in primary healthcare services in which barriers to accessing support were apparent for individuals with more complex neurological and mental health presentations.

Table 2

The Six Phase Process of Data Analysis

	Phase	Action(s)
1.	Data familiarisation	LW transcribed both focus group video audio files. Each transcript was read and reread. Initial reflections were noted. Transcripts were transported onto NVivo
2.	Systematic coding	Initial codes were generated; recoded and refined as new codes emerged. Throughout this process, data was extracted relevant as potential items for measure. The process was discussed with the coauthors, but interrater reliability was not sought (in-line with RTA).
3.	Generation of initial themes from coded and collated data	Thematic maps were used to aid with collating codes. This led to the development of initial themes and subthemes. Data was grouped due to evident overlap in discussions.
4.	Developing and reviewing themes	Thematic maps were developed and reviewed to refine themes and subthemes. These were shared and discussed with the co-authors GR, CG and MR. This was repeated until there was a general agreement of themes and subthemes best representative of the data and study aims (see Appendix I for reiterations).
5.	Refining, defining, and naming themes	Final refinements to subthemes and themes were made (Figure 1), assigning clear titles to each with definitions.
6.	Write-up	Themes and subthemes were narratively synthesised using participant quotes.

Interim Phase

A list of items was generated for the initial round of a Delphi survey, informed by focus group transcriptions (during familiarisation and coding), correlates of FDS severity in a previous systematic review (Whitaker et al., 2024), and in discussion with the co-authors.

Phase Two

Participants

A Delphi survey includes a group of participants called the “Delphi panel”. A consecutive sample of 121 prospective participants consented to take part. Contact information was not provided by two people resulting in a prospective panel of 119. Recommendations for the size of a Delphi panel vary; it can be dependent on the topic area and resources available (Iqbal &

Pipon-Young, 2009). Kilroy and Driscoli (2006) suggest between 10 and 50 participants is sufficient. A larger sample was intentionally recruited to maintain a sufficient sample at each round and given the heterogeneity of FDS. A response rate above seventy percent is optimal (Sumsion, 1998).

Data Collection Procedure and Analyses

A Delphi survey took place from 9th February to 23rd April 2024. The Delphi method is a widely used method for gathering data from expert respondents to gain a consensus concerning a specific topic (Hsu & Sandford, 2007). It is a flexible methodology with variations in how it is applied. Distinct features include the Delphi panel and a series of sequential questionnaires (at least two) known as 'rounds' (Iqbal & Pipon-Young, 2009). Rounds include generation of ideas, evaluation of items, and re-evaluation based on responses of other 'panellists'. Boateng et al. (2018) suggest Delphi methodology is appropriate to reach consensus on items reflective of the construct a questionnaire aims to measure and to demonstrate content validity.

Three rounds were considered sufficient to achieve consensus (Stone Fish & Busby, 2005), maintain enthusiasm (Iqbal & Pipon-Young, 2009), and limit attrition (Cantrill, Sibbald & Buetow, 1996). Participants were emailed procedural instructions and Qualtrics survey links at each round (accessible for a two-week period). Reminder emails were sent to increase response rates. Participants were only invited to the next round if they completed the previous round.

The procedures and analyses at each round are outlined in Table 3. Analyses occurred following each round and results were shared with participants of prospective rounds (i.e. feedback in Table 3). Consensus thresholds (i.e. items to include and items to exclude) were determined at each round after data collection. These were set to maximise item reduction ensuring only the most relevant items (reaching the highest level of agreement) were prospectively included. Similarly, the methodology was iterated at each phase, based on the results from the previous round. In each round,

participants evaluated items, provided supplementary qualitative data, answered multiple-choice questions, and provided feedback on the practicalities of the questionnaire (see Table 3).

The proposal of a three-section questionnaire was made subsequent to Round One in response to results and qualitative feedback (see results). This formed three sections, including (1) Severity of FDS, (2) Frequency / Duration of FDS, and (3) a Symptom Checklist. Sections one and two were established based on items achieving the highest rankings and greatest level of consensus during the Delphi process. Section three – the symptom checklist – was generated from all data gathered related to the characteristics of FDS (i.e. a symptom or feature of FDS that was not necessarily related to its severity).

Table 3

Procedures and Analyses for each Delphi Round

	Round One	Round Two	Round Three
Procedures	Items ranked on 11-point Likert scale 'how relevant to measure FDS severity' ('0 = *Extremely Irrelevant'*; '5 = *Neither Irrelevant nor Relevant'* to; '10 = *Extremely Relevant'*). Note that, an 11-point scale was selected as it is more powerful in discriminating responses and a midpoint allowed for genuinely neutral responses. Supplementary qualitative feedback sought to contextualise rankings (for sharing with other panellists), suggest item refinements, and to generate additional items. See Appendix J.	Reviewed 'Round One' feedback (rankings and qualitative data; Appendix K). Evaluated 'non-consensus' items and participant generated items from 'Round One'. Stated whether to (1) '*include*' or (2) *'exclude'* each item from the questionnaire. Completed multiple-choice questions: chose sections for inclusion in the questionnaire (*severity, frequency / duration, symptom checklist*) and a preferred timeframe of which the items should relate to (*'one week', 'two weeks', 'four weeks'*). See Appendix L. Supplementary qualitative feedback sought to contextualise responses.	Reviewed 'Round Two' feedback (inclusion versus exclusion percentages and qualitative data; Appendix M) and a candidate questionnaire (Appendix N). To reduce items, selected preferred items from two to three options of included items measuring similar or overlapping concepts. Completed multiple choice questions: chose preferred number of severity section questionnaire items (i.e. ≤ 15; 16-20; 21-30; 31-40 items; or 'other'); assessed a proposed rating system and the questionnaire. See Appendix O. Generated 'seizure characteristics' for a symptom checklist (see results). Supplementary qualitative feedback sought to contextualise responses and to provide item refinements.
Analyses	Scores compiled; median and IQR calculated for each item. Qualitative data cleaned analysed using qualitative content analysis (Bengtsson, 2016).	Frequencies and percentages for each item calculated to establish majorities. Qualitative data screened and categorised into emerging ideas.	Frequencies and percentages calculated to establish the majority option for each item. Qualitative data synthesized and guided final questionnaire refinements.
Consensus threshold	Included items = median of 10.00 and an IQR of 2.00 or less. Excluded items = median of 7.00 or less, or an IQR of 6.00. Non-consensus items progressed to Round Two (see results).	Included items = ≥ 75.00% of the panel in agreement for 'Include'. Items below cut-off excluded (see results).	For sets of item options, the majority choice was included in the questionnaire (see result).

Note, IQR = Interquartile Range.

Findings / Results

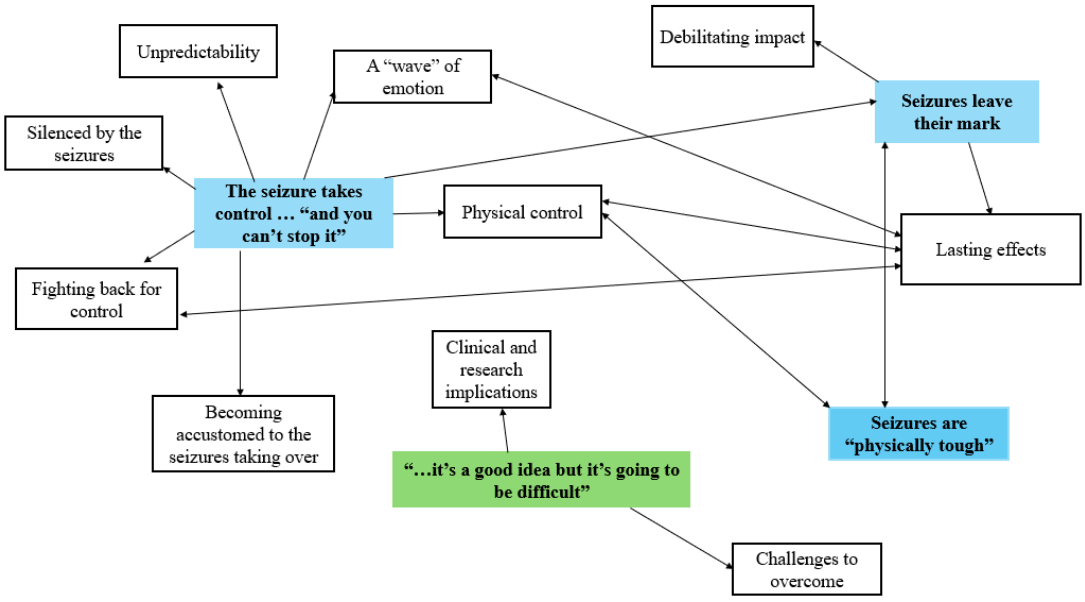
Phase One

The median age of PwLE of FDS ($N = 6$) was 43.0 (IQR = 30.3). Four experienced seizures at least daily; two had seizures "at least once a week" or "weekly". Median age of HCPs ($N = 8$) was 48.5 (IQR = 13.3). HCP roles included a psychotherapist, epilepsy specialist nurses, radiographer, neurology registrar, neurologist, clinical psychologist, and a neurofeedback practitioner with median years of experience of 10.0 (IQR = 4.5). Across both groups, most identified as a White female.

Four main themes and ten subthemes emerged. Three themes reflected participants' perceptions of FDS severity: (1) The seizure takes control … "and you can't stop it"; (2) Seizures are "physically tough"; and (3) Seizures leave their mark. The fourth theme "…it's a good idea but it's going to be difficult" encapsulated views on the feasibility of developing a PROM (presented in Appendix P). Figure 1 depicts a thematic map illustrating links between themes and subthemes. Table 4 presents illustrative quotes referenced throughout the narrative summary of themes.

Figure 1

Thematic Map



Note, *blue = themes related to FDS; green = theme related to development of the measure.*

The Seizure takes Control … "and you can't stop it."

This theme captures the loss of control seizures cause. Throughout discussions, implicit references were made to "the seizure" as a separate entity taking control.

Physical control. Explicit reference was made to physical loss of control during seizures for which a disconnect was implied between the mind and body (Q1). Different "physical symptoms" were discussed to demonstrate the seizures control such as "shaking", "contraction", "drop attacks" and "weakness" as well as "disrupted breathing" and "losing vision". PwLE referred to "panic" evoked from seizures taking control (Q2). In turn, panic gives the seizures more control (Q3). "Vulnerability" and a sense of fear were denoted from the most extreme expressions of physical loss of control which included "paralysis" (Q4) and "incontinence" (Q5).

Silenced by the seizures. Participants described seizures where a person becomes "completely irresponsive as if asleep". They referred to distress evoked from "fully experiencing" seizures due to "preserved awareness". This meant people were aware they lacked control but were unable to say or do anything in response (Q6). This exacerbated vulnerability but could also be frustrating, "…somebody says, '*can't you get up?*' and in your head you're screaming '*of course I can't get up!*' But you can't say it. It's so frustrating…". Such seizures could occur in anxiety-provoking contexts that they cannot escape or respond to (Q7). Sometimes, people with FDS "don't have any awareness" during seizures which could also contribute to severity. Adding to vulnerability was that "a lot of people don't remember what happens" relying on others for accurate accounts (Q8).

Participants made explicit reference to "speech problems" during seizures (e.g. "speech loss", "slurred speech") impacting ability to communicate. PwLE felt "embarrassed" by this which in itself was silencing. It was also distressing when people did not believe symptoms of such a temporary nature (Q9).

A "Wave" of emotion. Participants referred to an "outburst", "wave" and "rush" of "emotion" after seizures inferring a lack of control over emotional responses. This could trigger further distressing emotions (Q10). PwLE gave an impression of seizures taking over their mood. One example of this, in its extremity, was that their mood could drastically switch from "absolutely fine" to "intense sadness" and feeling "suicidal" (Q11). This example encapsulated an ultimate sense of hopelessness against the seizures taking control. One healthcare professional described patients experiencing a "disconnect" between how they are feeling and "what their body is doing" emphasising their lack of control (Q12).

Fighting back for control. PwLE gave the sense of a constant "fight" against seizures. Both groups indicated the importance of "triggers" and "warning signs" to "master" or "control seizures" (Q13). PwLE inferred a sense of triumph when managing to "pinpoint" triggers or recognising warning signs with one stating: "Your brain goes, '*ah, this is what we have to do*'. I know when my legs start to wobble '*right, I need to get on the floor. It's happening.' Let's crack this.*". There was indication to the seizures' persistence in that there would always be "new triggers" or often "no triggers" at all (Q14). Moreover, warning signs only provided temporary control to get to a "safe place", reduce risk of injury and protect a person's "dignity". For some, warning signs without sufficient warning time evoked distress and a reliance on others for support.

There was suggestion to negative consequences associated with trying to take back control of seizures. PwLE resiliently talked about attempts to "downplay", "ignore", or "push through" symptoms. This often however led to "boom and bust" cycles in which seizures inevitably "won". Moreover, attempts to push through and ignore seizures could worsen them (Q15). "Avoidance" was discussed in trying to prevent seizures. Both groups discussed the impact of this on worsened "quality of life" emphasising the wider control of FDS (Q16). PwLE described an ongoing battle as to whether taking back control outweighed consequences (Q17).

Becoming accustomed to the seizures taking control. Some of the PwLE described "getting used to" seizures as opposed to severity reducing (Q18). There was an implicit sense of reduced severity from allowing the seizure to take control (Q19) and "hopefully it'll be over". Further, PwLE who'd had FDS longer seemed somewhat less distressed by symptoms. This was implied by nonchalant descriptions, at times appearing detached from emotion as they listed symptoms, and regularly using humour throughout accounts. In contrast, for a different PwLE newly diagnosed with FDS, talking about symptoms was incredibly difficult triggering seizures (Q20).

Unpredictability. Some seizures could be unsettling and unpredictable (Q21). This linked with taking back control in that seizures remain unpredictable, even when trying to control them (Q22). There was a sense of unpredictability inferred from the unknown of how long seizures would last or how many seizures would be in a cluster. Lack of control evoked fears about seizures worsening which caused "anxiety" or "panic" (Q23). Healthcare professionals discussed unpredictability in relation to low seizure frequency (Q24).

Participants inferred how the unpredictability of seizures meant they could occur in places that are physically unsafe (i.e. risk of "falls", "injury") and as touched upon, psychologically unsafe. One participant with FDS said "…when I say somewhere safe, I really mean just not in front of my classmates because I get embarrassed…". In such instances, warning time could make seizures more predictable and "increases your safety, dignity, and all that stuff that affects your quality of life". Both groups referred to relying on others due to the unpredictability of seizures which could also evoke fear in families (Q25). More generally, there was a sense of FDS as a condition being unpredictable with many unknowns (Q26).

Seizures are "physically tough".

This theme reflected emphasis on the "real", "physical symptoms" from which seizures

could become “violent”. Both groups discussed a range of seizure symptoms such as “lots of pain”, “injuries” (Q27), “choking” (Q28), or “difficulties breathing” (Q29). Almost all participants with FDS described experiences of “stroke-like symptoms” during their “worst seizures” indirectly emphasising the real and severe nature of these symptoms, often resulting in hospital admissions (Q30). Participants emphasised the lasting effects of physical symptoms (see next subtheme) and fears associated with the uncertain longevity of these.

PwLE felt physical symptoms were overlooked comparable to the psychological focus on FDS. There was a sense of frustration related to this as it could lead to barriers accessing support (Q31). Physical symptoms were described as central to FDS; these were what often caused the exacerbation of comorbid diagnoses (both mental health and physical health) and contributed to a “vicious cycle”. Moreover, physical symptoms could be worst, when it was felt mental health was managed (Q32). Additionally, it was felt the psychological elements to seizures (such as, “emotions”, distressing “thoughts”, “panic”, “fear”) came secondary to physical symptoms. That said, both groups emphasised the need for a multidisciplinary approach to treat seizures (Q33).

Seizures leave their mark

This theme represents descriptions of prolonged seizure symptoms and the impact of these more broadly.

Lasting effects. PwLE discussed “recovery time” and said “in a lot of ways this was almost the biggest reflection of how tough a seizure was”. Both groups talked about the consequential effects of seizures once they are over. These exacerbated the recovery period and demonstrated the seizures’ impact beyond the ictal period. Effects after a seizure included the varied prolonged physical symptoms (Q34), “cognitive” difficulties, and the emotional impact (see ‘a “wave” of emotion’ subtheme). Participants made continual reference to “fatigue” and “exhaustion” after seizures (Q35). HCPs discussed the “knock-on-effect” of distressing physical symptoms (Q36) and

fear due to their longevity (Q37). Additionally, “coming round” from seizures triggered anxiety related to the possible uncertainty about what had happened (Q38). Both groups discussed “cognitive difficulties”; feeling “confused”, “out of it”, “disorientated” and “not able to think straight”. This was referred to in relation to making “unsafe choices” (Q39) by PwLE. Both groups suggested a need for “support” from others after seizures as “perceived danger” is impacted (Q40).

Debilitating impact. Despite aiming to focus discussions on severity of the seizures themselves, there was a continual pull in both groups to highlight that FDS are debilitating much more widely (Q41), “impacting patients’ lives… not just the five minutes or thirty seconds”. Participants implied an obvious impact the seizures had, and the lasting effects of seizures more broadly on day-to-day life, relationships, activities and employment. Seizures also evoked fear of more seizures and the understandable use of avoidance to prevent them (Q42).

Table 4

Themes, Subthemes and Illustrative Quotes

Theme	Subtheme	Quote No.	Illustrative Quotes	Participant
The seizures take control and "you can't stop it."	Physical Control	**Q1**	"I think the biggest shock with the seizure was the loss of control. My body has done exactly what I wanted it to do for flipping fifty-five years and then suddenly it's not and that is really, really frustrating."	LE1
		Q2	"…its always interesting people have conflated this idea of panic causing seizures where for me it's seizures causing panic…. They definitely do cause a level of anxiety … it's just that panic of having lost control."	LE4
		Q3	"I find if I panic it makes it worse."	LE2
		Q4	"…although they've been unconscious, they have tears coming down their face and you can see that they're upset… it's quite, it's really sad because you can't do anything… all's I've done is just stand there and been like 'you're okay, you're safe'… so I think that must be quite scary."	HCP5
		Q5	"There's one other thing which is about losing control of your bladder. That really does up your anxiety. If you've had a seizure, where you've lost control of your bladder, then everything becomes much more, that's a real physical symptom, and that makes things a lot worse. That's quite an escalation factor."	LE1
	Silenced by the seizures	**Q6**	"… I know what's going on I can hear what's going on but, I can't do anything about not being there or not being present…"	LE5
		Q7	"I've got some patients that, five, six hours they're lying there, can't move, but they're aware. For a lot of people I speak to, it's when they're aware of what's going on around them but have no control over what their bodies doing. It's the hearing what other people are saying that they find really distressing. So, whether that's a chaotic family whose really highly distressed and panicky or whether sadly it's A&E and they can hear doctors and nurses saying *'oh they're putting it on, their faking it they're wasting our time'*, for a lot of people it's the distress of hearing that and knowing that they just can't get themselves out that situation."	HCP3
		Q8	"…sometimes people aren't necessarily aware… so I always thought I was conscious during my seizures, that was how I experienced them as far as I was concerned. But then people were saying "*oh, such and such happened while you were out*', and I was like *'I'm sorry, it did?*'. … that didn't happen for me, but, until that point I assumed my memory was continuous. I have a memory up to a certain point and then I have another memory. Therefore, people actually aren't even necessarily going to know how conscious they are."	LE4
		Q9	"I feel people don't believe you, other times I can talk quite efficiently. So people think 'what's wrong with you? You can talk other times so you must be acting'. It's the not being believed I find the hardest.".	LE6

A “wave” of emotion	**Q10**	“… when people have spoken to me about their experiences immediately after, for a lot of people they will be quite emotional… that kind of outburst of emotion afterwards and that in itself, a lot of people have told me they experience a lot of embarrassment or shame around that, just that, outpouring of emotion that they don’t feel in control of.”	HCP7
	Q11	“… that kind of feeling like a wash of sadness … I’ve come round and burst into tears before, I’ve come around and my mood has gone from being absolutely fine, cluster of seizures come around, I’m feeling quite frankly suicidal and I know rationally, I’m not. I’ve got my husband here I’ve got my daughter here there’s no way I would act on those thoughts but that is what occurs to me is like it’s happened again, just here’s the answer and it’s not the answer I know that but that’s the extreme place my mind goes to, post seizures. …I can’t do this anymore… make it stop.”	LE3
	Q12	“…often people will say to me that they don’t even feel, emotional ((laughs)), so that kind of disconnect between what they’re actually experiencing between what their body is doing can feel quite separate to them, which I guess might overlap a lot with this like idea of agency within this group of people…”	HCP7
Fighting back for control	**Q13**	“…a lot of people, when I first … meet them, would say that they don’t get any warning signs or don’t have any awareness of a seizure coming on, and part of the work, when I’m working with them, is to help them to start to notice and see that maybe there are some warning signs, so that they get themselves to a safe place, and get into a place where they’re much less likely to injure themselves, and hopefully, also to manage and control the seizures.”	HCP2
	Q14	“**…**the key thing for me is learning my triggers. Erm, I'm starting to recognize these and that's not always going to be possible because there's always new things, but there is a little few triggers you know that I'm starting to learn and can now avoid.”	LE6
	Q15	“You can push yourself and make it worse. Because you’re faking that you’re ‘oh there’s nothing, I can cover this symptom, I can hide that under the rug and I’ll be alright’, and it’s not. You’re just setting yourself up for a bigger flop a little bit further along the lines.”	LE2
	Q16	“… so isolating, how much have you limited yourself from working, how much have you isolated yourself from your social activities, how safe are you keeping yourself as a preventative measure from having a full-blown seizure in public and losing bowel control, losing ability to walk, talk, breathe…”	HCP1
	Q17	“… you want to dig in and you want to go ‘no, it’s not defining me. It’s not going to stop me doing what I had planned for today or the next day or the following week or whatever, ‘I’m going to do it’. But at some point you go ‘okay, it’s won today, so we’ll take it small steps and then we’ll move on.’”	LE5
Becoming accustomed to the seizures taking over	**Q18**	“…it’s excruciating all the pain down my neck and into my shoulder, when it first started happening erm, I would rate it at like nine to a ten. But, like you say now I would put that at a five four five because you get … it’s incredible what you can get used to.”	LE5
	Q19	“…we’ve got some form of resilience as you get used to it… when I first started having my periods with paralysis, I was terrified. It was sort of a ‘oh my God what if this doesn’t go?’ And then over time I’ve got used to the paralysis bits and gone ‘up here we go again’ er, just shut my eyes and	LE2

		when, well my eyes shut regardless, ((laughs)) when I'm having a paralysis seizure, and I just go to sleep and go, well when I wake up hopefully it'll be over.*"*	
		Q20	"…that's where it gets hard to talk. As *soon* as you think about your symptoms. ((pause)). They kick in! ((exhales sharply))."	LE6
	Unpredictability	**Q21**	**"…**sometimes I don't feel I'm going to come out of it and those are the really scary ones. I don't know what's different about some seizures to others… but sometimes I'll be in a seizure and it'll be so deep, and I'll be so pushed into a corner in my head that I don't think I'm ever going to come out of it."	LE1
		Q22	[Explained a seizure trigger] "… it set off a seizure in motion. So, there are certain… its trying to identify the triggers than can set it, but then sometimes I can't really pinpoint what's caused it.".	LE2
		Q23	"Vulnerable is the word that I would use surrounding my seizures because even if I don't panic prior to seizures but while I'm having them, it's the escalation of 'right how many are going to be in this cluster?', 'are they going to progress to the point where I'm paralyzed or the paramedics have been called and I wake up with a tube in my throat?'".	LE3
		Q24	"I've had patients whose anxiety is incredibly high, because they're not having frequent seizures. It almost becomes more familiar and manageable when it's a thing that's happening all the time.".	HCP7
		Q25	"…they're family members are afraid of leaving them alone because of the severity of attacks… just getting that safety that other people can … maybe be very alarmed by the symptoms and even if they're recurrent but people, erm don't have any injuries and recover after each attack and erm it can still cause a lot of distress…"	HCP6
		Q26	"I'm concerned if I'm going to get worse again. Will I go back? Regress? Will it happen where I'm just flat out in the chair and, not know where the heck I am? Then come around and go 'ah yeah it's happened again'. So that's my concern because we don't know ((laughs)), we don't know what's going to happen. We don't know what the future holds for the condition."	LE5
Seizures are "physically tough"		**Q27**	"…I was just thinking about patients I've seen who've ended up with carpet burns and or broken bones from falling down the stairs and other symptoms like that. Well not symptoms but consequences of the seizures."	HCP2
		Q28	"…my very worst one has been where my throat has er tried, erm, I'm choking on nothing because the muscles have spasmed in my throat..."	LE2
		Q29	"I know somebody that had a seizure the other day which was they couldn't breathe during the seizure and that was a real panic thing."	LE1
		Q30	"…and then really things kicked off about a year, just over a year ago. I ended up in A&E with stroke-like symptoms, they thought I'd had strokes, and clear brain scans…"	LE3

		Q31	"…unfortunately, as we know, many doctors then dismiss it as 'oh it's just mental health'. Well actually, I'm sorry but if mental health is causing me paralysis, then my mental health needs to be treated … and I think for a lot of us we've been told 'oh it's just anxiety, it's just stress', I mean honestly if it was just stress, well it's not 'just' stress is it? Because it's affecting us to this extent. … [we have] almost had it fobbed off, dismissed almost as, 'oh it's a mental health condition and therefore we're not going to treat you'".	LE4
		Q32	"…it's a vicious cycle because your mental health, it gets worse when I'm physically less able to things because I'm being disabled by the seizures… because the only treatment a lot of the time, barring physio, it's treated from almost exclusively a psychological perspective, there isn't that much focus on the physical contributors. … I felt like I'd already done all this CBT, I'd already been through years and year of therapy talking about traumas, and I felt like I'd gotten to a really good place with managing my anxiety, my PTSD in that sense. Then all this physical stuff started … you never really get rid of it [mental health] but I felt like I was on top of that at the point my physical health started to decline."	LE3
		Q33	"… it needs tackling from a three-prong attack … it would be in an ideal world if you have your GP for the medication side of things to manage that and keep an eye on that and adjust that for you. Physio for or some sort of physical therapy to help with the motion things, and then as the psychological side of things are helping you deal with that."	LE2
Seizures leave their mark	Lasting effects	**Q34**	"…for some people they have a seizure, and then they've got symptoms that carry on for a lot longer afterwards, like the… paralysis… which ends you up in hospital, you know it's not the seizure that's your ticket to hospital it's the paralysis."	HCP2
		Q35	"I know I'm going to fall asleep for at least an hour, because … the body collapses down, as if to say 'that's it, you've done enough today'…".	LE5
		Q36	"… [the] knock-on effect of the injuries caused after so, with the blindness, with the deafness, with the balance with the falling… because a balance issue doesn't seem like much on paper but if you're falling every week and having teeth knocked out for example, that needs to be I think recorded as an impact of the severity…"	HCP1
		Q37	"I've certainly met a number of people who, their main fear about having seizures are these sort of prolonged neurological symptoms that happen afterwards which might go on for hours or days."	HCP8
		Q38	"…immediately afterwards is the anxiety of 'who saw me?', 'did I lose control?', 'are there people around me?', 'are they responding in a way that I find stressful?'	LE4
		Q39	"…I don't think particularly clearly around a seizure and that can result in me making unsafe choices… I've had to say to my friends, ignore me basically, do not believe me when I've just had a seizure because I'm chatting rubbish. I think I'm fine because my perception, my ability to perceive danger is just affected by the seizure."	LE4

	Q40	"I think there's something quite interesting there about the perceptions of each the patient and the person supporting the patient in that moment of what's going on, how severe it is, how much risk there is cause I think perception of risk is what people would touch on as an element or idea of severity as well and that perception of risk may or may not be accurate ((laughs)) for a lots of reasons…"	HCP7
Debilitating impact	**Q41**	"…it's not only getting a measure of the duration but … seeing that length of time and how that impacts is really important… how we measure how that is impacting your relationship with your work, with your day-to-day life, with your family, if you're living with someone, because, it's important to be aware of how these are impacting patients' lives, not just with those, you know five minutes or thirty seconds, but I think ((pauses)) the impact of what, those seizures are having…"	HCP1
	Q42	"… sometimes that means I avoid things and that affects my quality of life… you avoid doing stuff because you're like '*well if I have a seizure, then this is, not going to be a good place for me to have a seizure*'. I leave class earlier than I really need to … I won't have a seizure in class if I can avoid it, therefore, I will leave like as soon as I start getting the warning symptoms, which is probably good for my health but it's not very good for my academics. …I don't want to risk having a seizure in front of people …"	LE4

Integration

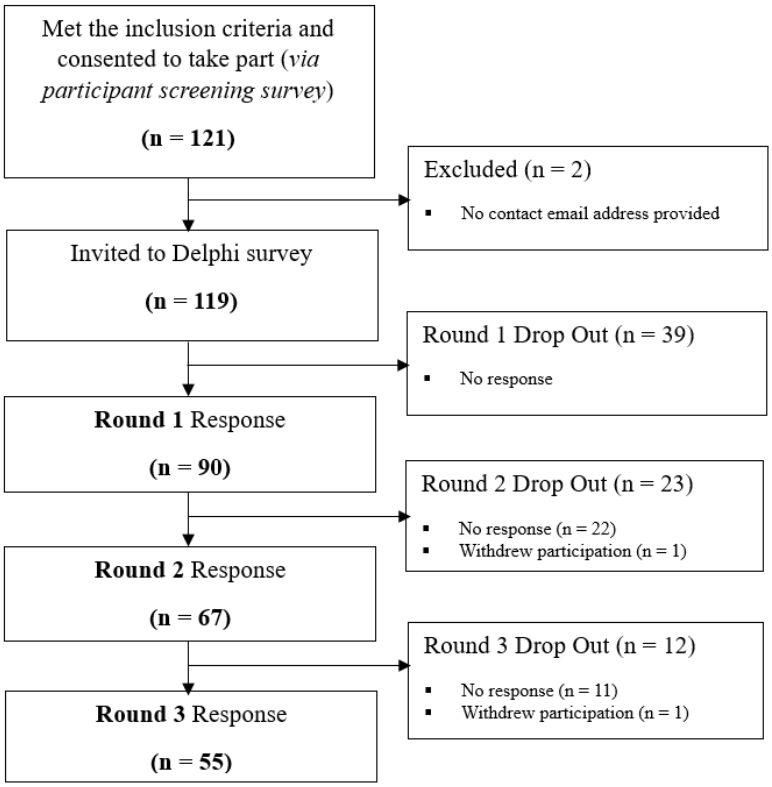
A total of 115 items were developed for inclusion in round one of the Delphi survey (see Appendix Q for each item and its respective source).

Phase Two

Figure 2 summarises participant recruitment and attrition at each round. A total of 90/119 participants took part in round one, 67/90 in round two, and 55/67 in round three. Response rates were 76.27%, 74.44% and 82.09% respectively. Of note, eight participants in round one and two participants in round two only partially completed the survey of the respective round. Responses for completed items were included.

Figure 2

The Delphi Survey: Participant Recruitment and Attrition



Participant characteristics at each round of the Delphi survey are described in Table 5. At least 75% of participants at each round were White though this may be underreported due to limited data available. International participants predominantly resided in Western countries. Healthcare professional roles included Neurologists, Epilepsy Specialist Nurses, Clinical Psychologists / Neuropsychologists, Psychiatrist/Neuropsychiatrists, Psychotherapists, Paediatrician, Neuro Physio, SLT and an Academic / Researcher in healthcare. Figure 3 depicts the Delphi process.

Table 5

Participant Characteristics for each Round of the Delphi Survey (Medians and IQRs Reported)

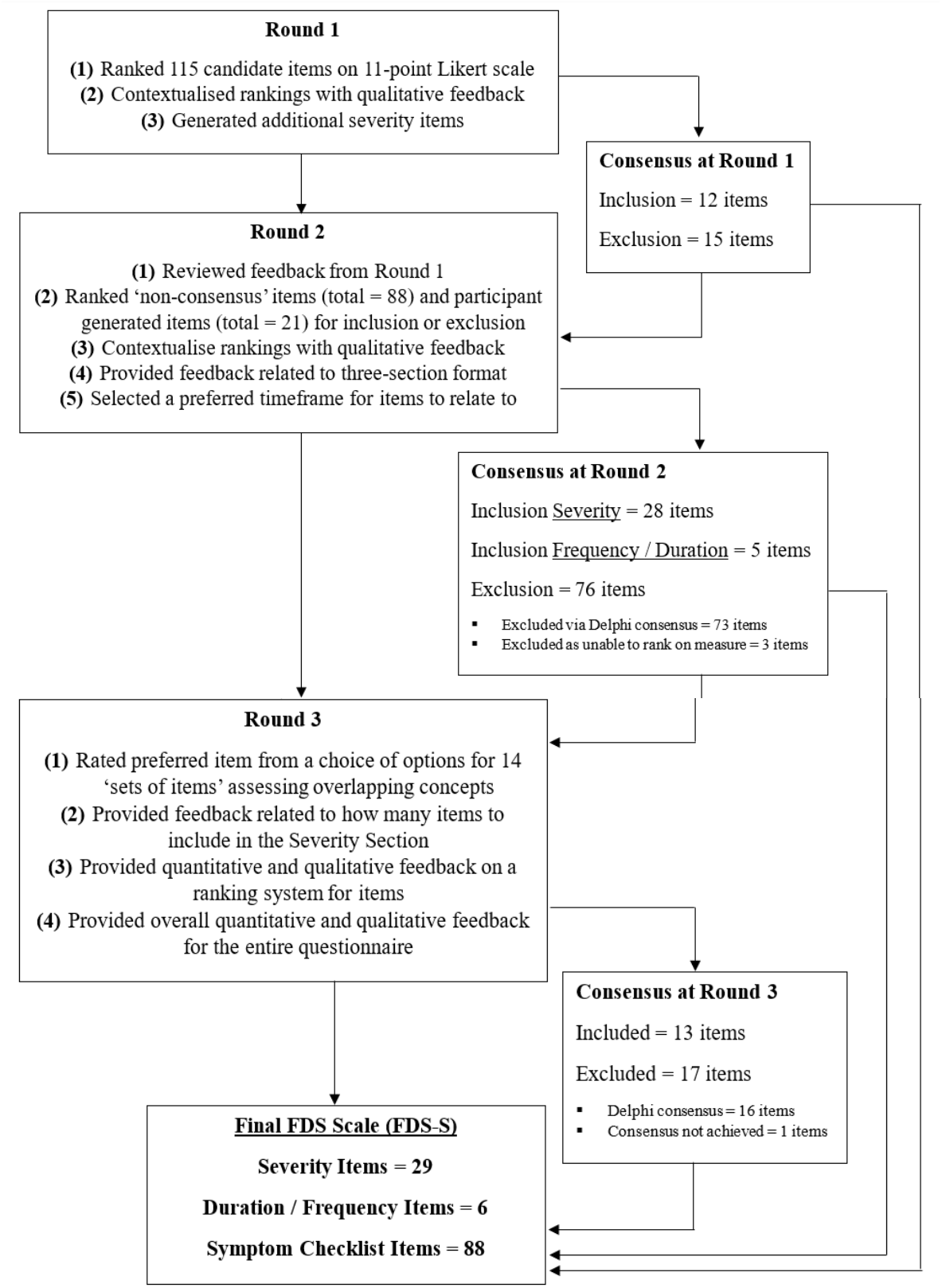
	Individuals with FDS			**Healthcare Professionals**			**Non-Professional Carers**		
	Round One	**Round Two**	**Round Three**	**Round One**	**Round Two**	**Round Three**	**Round One**	**Round Two**	**Round Three**
N (%)	54 (60.00%)	41 (61.19%)	33 (60.00%)	32 (35.56%)	23 (34.33%)	20 (36.36%)	4 (4.44%)	3 (4.48%)	2 (3.64%)
Gender *N* (%)									
Female	46 (51.11%)	33 (49.25%)	25 (45.45%)	18 (20.00%)	11 (16.42%)	10 (18.18%)	4 (4.44%)	3 (4.48%)	2 (3.64%)
Male	5 (5.56%)	5 (7.46%)	5 (9.09%)	14 (15.56%)	12 (17.91%)	10 (18.18%)	-	-	-
Non-binary / Gender Fluid	3 (3.33%)	3 (4.48%)	3 (5.45%)	-	-	-	-	-	-
Median Age (IQR)	43.0 (21.25)	42.0 (22.00)	43.0 (22.00)	47.5 (10.00)	48.0 (8.00)	47.5 (9.75)	54.0 (3.50)	-	-
Age Range	19.0-83.0	19.0-76.0	19.0-76.0	34.0-62.0	35.0-62.0	35.0-62.0	49.0-56.0	54.0-56.0	54.0-56.0
Ethnicity White *N* (%)	38 (42.22%)	29 (43.28%)	23 (41.82%)	29 (32.22%)	20 (29.85%)	19 (34.55%)	4 (4.44%)	3 (4.48%)	2 (3.64%)
Country *N* (%)									
UK	28 (31.11%)	22 (32.84%)	18 (32.73%)	26 (28.89%)	18	16	4 (4.44%)	3 (4.48%)	2 (3.64%)
Republic of Ireland	1 (1.11%)	1 (1.49%)	-	1 (1.11%)	1 (1.49%)	1 (1.82%)	-	-	-
USA	6 (6.67%)	3 (4.48%)	3 (5.45%)	1 (1.11%)	-	-	-	-	-
Canada	6 (6.67%)	4 (5.97%)	3 (5.45%)	-	-	-	-	-	-
Australia	5 (5.56%)	5 (7.46%)	3 (5.45%)	1 (1.11%)	1 (1.49%)	-	-	-	-
New Zealand	3 (3.33%)	2 (2.99%)	2 (3.64%)	-	-	-	-	-	-
Brazil	1 (1.11%)	-	-	-	-	-	-	-	-
South Africa	1 (1.11%)	1 (1.49%)	1 (1.82%)	-	-	-	-	-	-

Sweden	1 (1.11%)	1 (1.49%)	1 (1.82%)	-	-	-	-	-	-
Netherlands	1 (1.11%)	1 (1.49%)	1 (1.82%)	-	-	-	-	-	-
Belgium	1 (1.11%)	1 (1.49%)	1 (1.82%)	-	-	-	-	-	-
Germany	-	-	-	1 (1.11%)	1 (1.49%)	1 (1.82%)	-	-	-
France	-	-	-	1 (1.11%)	1 (1.49%)	1 (1.82%)	-	-	-
Argentina	-	-	-	1 (1.11%)	1 (1.49%)	1 (1.82%)	-	-	-
Frequency of FDS *N* (%)									
At least daily	16 (29.63%)	13 (31.71%)	11 (33.33%)	-	-	-	-	-	-
More than once a week	12 (22.22%)	9 (21.95%)	7 (21.21%)	-	-	-	-	-	-
Weekly	6 (11.11%)	5 (12.20%)	4 (12.12%)	-	-	-	-	-	-
Monthly	8 (14.81%)	5 (12.20%)	4 (12.12%)	-	-	-	-	-	-
1-2 Times Annually	3 (5.56%)	3 (7.32%)	2 (6.06%)	-	-	-	-	-	-
Variable	7 (12.96%)	5 (12.20%)	4 (12.12%)	-	-	-	-	-	-
Controlled (at present)	2 (3.70%)	1 (2.44%)	1 (3.03%)	-	-	-	-	-	-
Duration FDS Median Years (IQR)	3.00 (5.13)	3.00 (6.38)	3.00 (6.38)	-	-	-	-	-	-
Professional Experience of FDS Median Years (IQR)	-	-	-	10.00 (10.25)	10.00 (9.00)	10.00 (10.25)	-	-	-
Years Supporting Individual (Range)	-	-	-	-	-	-	1.00-18.00	1.00-18.00	1.00-6.00

Note, % = percentage of overall sample at each round. 100% at round one (*N* = 90); 100% at round two (*N* = 67); 100% at round three (*N* = 55). For 'Frequency of FDS', overall sample is based on individuals with FDS only therefore 100% at round one (*N* = 54); 100% at round two (*N* = 41); 100% at round three (*N* = 33).

Figure 3

The Delphi Process and Consensus for Item Inclusion and Exclusion



Round One

Item Rankings. Item Likert scale rankings were profoundly favoured toward inclusion. All items obtained a median of at least 6.00 or above (a score of 5.00 indicated neutrality) with 103 items obtaining a median of 8.00 or above. The consensus criteria were defined to accommodate this (see methods). Items reaching consensus are presented in Table 6 (see Appendix K for non-consensus items).

Qualitative Data. As qualitative data was sought to share with participants in the next round; this is presented in the 'Round One Feedback Document' (Appendix K). Twenty-one new items were generated for inclusion in the next round (Appendix R).

Table 6

Items for Inclusion and Exclusion in Round One (with Medians and IQRs)

Items	Median	IQR
Included Items		
I have no control over when my seizures are going to happen.	10.00	2.00
I have had no control of my body during my seizures.	10.00	1.00
I have experienced involuntary physical movements during my seizures.	10.00	2.00
I have experienced contortion or stiffness during my seizures.	10.00	2.00
I have had difficulty speaking during my seizures.	10.00	2.00
I am unable to respond to things happening around me during my seizures.	10.00	1.75
I have not been able to stop my seizures after they had started.	10.00	2.00
I have continued to experience distressing physical symptoms in the hours after my seizures have ended (e.g. shaking, paralysis, involuntary movements, incontinence).	10.00	2.00
I have been exhausted in the hours after my seizures.	10.00	2.00
I have avoided things I enjoy to stop my seizures from happening *(e.g. leaving the house, stopped usual / enjoyable activities, isolated myself).*	10.00	2.00
My seizures have been bothersome.	10.00	2.00
How long does it usually take you to recover after a seizure?	10.00	2.00
Excluded Items		
I have lost control of my breathing in the time before my seizures.	7.00	4.00

Before my seizures, I have negative thoughts about myself related to experiencing a seizure.	6.00	6.25
I have struggled to cope before experiencing a seizure.	7.00	3.25
I have felt to blame for triggering my seizures.	7.00	4.00
During seizures, I have lost bowel control.	6.00	10.00
I have not been able to hear anything during my seizures.	7.00	5.00
I have had thoughts about wanting my life to end or felt suicidal during a seizure.	7.00	5.00
I have had falls in the hours after my seizures.	7.50	5.00
I have felt threatened in the build up to my seizures.	6.00	4.00
I have had hearing difficulties in the hours after my seizures.	7.00	6.00
I have injured myself so badly during a seizure that I have had to seek medical attention.	9.00	6.00
I have forgotten that I have had a seizure.	7.00	8.00
I have not recognised people I know after a seizure.	8.00	8.00
I have not always made the best choices for myself immediately after a seizure.	7.00	5.25
The seizures have negatively impacted on my relationships.	7.50	5.00
How severe would you rate most seizures you have experienced: *Mild, Moderate, Moderate-Severe, Severe.*	8.00	6.25

Note, medians based on an 11-point Likert scale ranging from 0 = 'Extremely Irrelevant'; 5 = 'Neither Irrelevant nor Relevant'; to 10 = 'Extremely Relevant'. Therefore, a median of '10.00' is the highest possible score. Lower IQRs represent the highest levels of agreement.

Round Two

Development of a Three-Section Measure. The idea of a three-section questionnaire was suggested in response to Round One with sections including (1) Severity; (2) Frequency/Duration; and (3) a Symptom Checklist. Rankings were highly inclusive of items, but qualitative feedback suggested several items may be more relevant to characterise seizures (as opposed to measuring severity). Most participants favoured the inclusion of the three sections with frequencies of (N = 62), (N = 57), and (N = 58) respectively. Most participants agreed with this idea (N = 48) or said maybe it could work (N = 15). Two participants did not like this proposal but provided no qualitative data to support this. Most participants agreed a timeframe of four weeks (N = 45) would be sufficient for the items to relate to. Sixteen thought it should be two weeks and four said one week.

Item Rankings (Severity and Frequency/Duration Sections). Like Round One, rankings were favoured towards inclusion. Of the 109 items evaluated, 93 fell above a 50.00% inclusion agreement. To manage this, the consensus threshold for inclusion was set at 75.00% or above (i.e. 75.00% of participants agree with inclusion). This resulted in 33 items for inclusion in the final measure from Round Two, however, four items were later removed as they differed to other items in how they could be rated on a scale. Included items are outlined in Table 7 with respective frequencies and percentages for inclusion or exclusion (see Appendix S for excluded items). As textual data was minimal, qualitative responses from participants were organised into preliminary ideas (see Appendix T). Emerging ideas included a recognition to distinguish between characteristics of a seizure as opposed to severity of a seizure, the complexity of defining seizure severity and of change in FDS overtime, difficulty recalling symptoms for unconscious seizures and, seizure relief. Suggestions were also made to merge items and reduce the questionnaire length.

Table 7

Items for Inclusion at Round Two (with frequencies and percentages of participants in agreement for the items inclusion)

	Inclusion		Exclusion	
Items	**n**	**%**	**n**	**%**
I have taken a long time to recover after my seizures.	62	93.90%	4	6.10%
I have experienced physical symptoms in the build up towards my seizure (e.g. unable to move, visual / hearing difficulties, pain, uncontrollable physical movements).	61	91.00%	6	9.00%
I have experienced seizures in which I suddenly drop to the floor.	61	91.00%	6	9.00%
I have experienced clusters of seizures (i.e. seizures close together over one or several days)	59	90.80%	6	9.20%
My seizures have left me with new neurological symptoms (such as weakness or numbness) that have persisted after the seizure was over.	59	90.80%	6	9.20%
My balance and coordination have been affected in the hours after my seizures.	58	87.90%	8	12.10%
I have had speech difficulties in the hours after my seizures.	58	87.90%	8	12.10%

After a seizure, I have been able to return to what I was doing within **one hour.**	57	87.70%	8	12.30%
The seizures have negatively impacted on my ability to fulfil my role (e.g., parenting, employment).	57	87.70%	8	12.30%
During seizures, a part of my body has become paralysed.	58	86.60%	9	13.40%
During a seizure, I have felt completely "locked in", so I could not communicate with the outside world.	56	86.20%	9	13.80%
I have been completely unconscious during my seizures.	57	85.10%	10	14.90%
I am unable to take care of myself in the hours after a seizure.	55	84.60%	10	15.40%
I have struggled to breathe during my seizures.	56	83.60%	11	16.40%
During seizures, I have wet myself.	56	83.60%	11	16.40%
I have been injured during my seizures.	55	82.10%	12	17.90%
I have not been able to see anything during my seizures.	55	82.10%	12	17.90%
I have lost awareness during my seizures.	55	82.10%	12	17.90%
I had experienced increased sensitivity before a seizure (e.g. to sounds, smells, light, etc.).	54	80.60%	13	19.40%
I have experienced pain during my seizures.	54	80.60%	13	19.40%
I have experienced weakness in my body during my seizures.	54	80.60%	13	19.40%
I have needed to sleep in the hours after my seizures.	53	80.30%	13	19.70%
During seizures, I have become completely paralysed.	53	79.10%	14	20.90%
During my seizures, I have felt like I am outside of my own body.	53	79.10%	14	20.90%
I have experienced pain in the hours after my seizures.	52	78.80%	14	21.20%
On a scale of 0-100% (%Severe? %Moderate? %Mild?)	51	78.50%	14	21.50%
I have experienced distressing emotions in the build up towards my seizures.	52	77.60%	15	22.40%
I become disorientated and confused during the onset of a seizure.	50	76.90%	15	23.10%
I have had difficulties with my eyesight in the hours after my seizures.	50	75.80%	16	24.20%
How long was your longest seizure?	56	86.20%	9	13.80%
How would you best describe the frequency of the seizures you experience?	55	84.60%	10	15.40%
How many seizures have you experienced over the last month?	52	80.00%	13	20.00%
What is the most amount of seizures you have experienced in a single day?	51	78.50%	14	22.50%

Note, 100% of full sample at Round Two (n = 67). Frequencies that do not total 67 (across inclusion and exclusion) is due to partial responses of the respective item.

Draft Questionnaire. A draft questionnaire was developed as a result of Round Two (see Appendix N) to share in the final round (see methods for how this was developed).

Round Three

Items for Inclusion (Severity Section). Table 8 presents items for inclusion and exclusion with consensus percentages and frequencies for each of the proposed options.

Table 8

Items for Inclusion and Exclusion from Round Three (bold items for inclusion in the questionnaire)

Question	Items	%	N
1	**During seizures, a part of my body has become paralysed.**	80.00%	44
	During seizures, I have become completely paralysed.	20.00%	11
2	During seizures, I have felt "locked in", so I could not communicate with the outside world.	21.80%	12
	I am unable to respond to things happening around me during my seizures.	78.20%	43
3	**I have lost awareness during my seizures.**	76.40%	42
	I have been unconscious during my seizures.	23.60%	13
4	I have taken a long time to recover after my seizures.	41.80%	23
	After a seizure I have not been able to return to what I was doing within one hour.	58.20%	32
5	I have had difficulty speaking during my seizures.	30.90%	17
	I have had speech difficulties in the hours after my seizures.	25.50%	14
	I have had speech difficulties because of my seizures.	43.60%	24
6	I have experienced pain during my seizures.	21.80%	12
	I have experienced pain in the hours after my seizures.	18.20%	10
	I have experienced pain because of my seizures.	60.00%	33
7	**I have been exhausted in the hours after my seizures.**	67.30%	37
	I have needed to sleep in the hours after my seizures.	32.70%	18
8	I have lost control of my body during my seizures.	29.10%	16
	I have experienced involuntary movements during my seizures.	70.90%	39
9	I become disorientated and confused during the onset of a seizure.	49.10%	27
	I have become disorientated or confused because of my seizures.	50.90%	28
10	I have experienced distressing emotions in the build up towards my seizures.	36.40%	20
	I have experienced distressing emotions because of my seizures (e.g. fear, anger, sadness).	63.60%	35
11	**I have felt highly sensitive to sounds, smells, light, etc. before a seizure.**	56.40%	31
	I have felt highly sensitive to sounds, smells, light, etc. because of my seizures	43.60%	24
12	I have not been able to see anything during my seizures.	34.50%	19
	I have not been able to see or hear anything during my seizures.	65.50%	36

13	I have continued to experience distressing symptoms in the hours after my seizures have ended (e.g. shaking, paralysis, involuntary movements, incontinence). **AND** I have experienced difficulties with my eyesight in the hours after my seizures. **OR <u>ONLY</u>:** **I have continued to experience distressing symptoms in the hours after my seizures have ended (e.g. shaking, paralysis, involuntary movements, incontinence, <u>difficulties with eyesight</u>).**	30.90% 69.10%	17 38
14	On a scale of 0-100, what percentage of your seizure are severe? (One severity thermometer). On a scale of 0-100%: %Severe? %Moderate? %Mild? (Three thermometers) **No thermometer to measure severity**	40.00% 41.80% 18.20%	22 23 10

Note, % = percentage of participants in favour of the selected option for each of the respective items. 100% at round three (n = 55). Items in **bold font** = included in proposed questionnaire.

Item Count and Ranking. Twenty participants agreed there should be ≤ 15 items on the final severity section of the questionnaire, eighteen said 16-20; ten said 21-30 items; and five suggested 31-40 items. Two said "Other" but provided no qualitative suggestions. It was proposed to participants that items would be ranked on a 5-point Likert scale with (0) = Never; (1) Rarely (2) Sometimes; (3) Often; and (4) Always. Most participants favoured use of this rating system (39 of 55 participants). Supplementary qualitative data was minimal (Appendix U).

Overall Feedback. Participants were asked if they were happy with the proposed questionnaire. Fifty participants (90.91%) said 'Yes'; two (3.64%) said 'No'; and three (5.45%) said 'Don't Know/Unsure'. A small number of participants offered qualitative feedback to support this (see Appendix U for summary).

Symptom Checklist. Nine items were added to the symptom checklist generated from participant suggestions (see Appendix V).

Proposed Questionnaire: Functional Dissociative Seizure Scale (FDS-S). Minor edits were made to the drafted questionnaire according to participant suggestions (Appendix V) and additional editorial changes to ensure the questionnaire was user-friendly (for final questionnaire see Appendix W).

Discussion

This project aimed to develop a PROM for FDS severity. The first part of this study explored the phenomena of FDS severity to generate a list of items relevant for assessment. Focus groups including PwLE and HCPs were conducted to generate items grounded in clinically relevant perspectives. Three main themes emerged, including (1) Seizures take control and "you can't stop it"; (2) Seizures are "physically tough"; and (3) Seizures leave their mark. A fourth theme surrounding the feasibility of developing a measure, reflected both the value and challenges ("…it's a good idea but it's going to be difficult.").

The first theme illustrated distress evoked from loss of control during FDS. Subthemes emphasised a sense of fear, vulnerability and embarrassment associated with an impairment in both physical and emotional control, as well as being unable to respond due to seizures. Often, this was made worse through experiences of stigma during seizures. A recent study exploring illness representations in FDS reported similar accounts from participants who perceived themselves to have no or limited control (Williams et al., 2024). Loss of self-control is widely recognised in the FDS literature. For example, the Integrative Cognitive Model (ICM; Brown & Reuber 2016a), conceptualises FDS as a transient loss of behavioural and cognitive control. In part, psychological interventions aim to support patients to develop seizure control techniques (e.g. Goldstein, 2010; LaFrance, 2009). This supports the idea of seizure control (or lack thereof) as an important experience to assess in a FDS severity measure.

On a similar topic, attempts to regain control was highlighted as a "complex" process in the focus groups. Though delaying or ignoring seizure symptoms could provide short-term management of seizures, this seemed to be associated with worsening seizure severity at a later time. Moreover, attempts to delay seizures usually meant that individuals had to make adjustments in their daily life, such as avoiding situations, which appeared to have a negative impact. This demonstrated the control of FDS over their lives and offers one explanation why studies have shown that lower FDS frequency is not associated with greater HRQoL (Jones et al., 2016). Whilst understanding seizure

triggers and warning signs could be helpful, some seizures were unpredictable. Findings from the analysis inferred that familiarity of FDS reduced perception of their severity and could bring a willingness to allow seizures to pass. This phenomenon has previously been explored (Stone & Carson, 2013).

The second theme emphasised the relevance of "physical symptoms" in understanding seizure severity, reflected by several items in the final measure. Related to this was the lasting and consequential effects of "physical symptoms" described in the third theme, such as pain and injury. A previous systematic review identified that increased somatic symptoms were associated with lower HRQoL in people with FDS (Jones et al., 2016). Moreover, patients with FDS have been shown to reliably report more somatic symptoms relative to controls with epilepsy (Brown & Reuber, 2016b). This suggests the relevance of recognising the significance of physical/somatic symptoms as this may be an important treatment goal for patients. This was again consistent with Williams et al.'s (2024) study that discussed pain and discomfort as consequential effects of seizures. Similarly other measures of seizure severity, albeit initially developed for people with epilepsy, also focus on somatic experiences (e.g. SSQ; Cramer et al., 2002). While high levels of somatic symptoms have been strongly associated with mental health problems like depression, the report of these symptoms by this patient group may also reflect the high levels of medical comorbidities experienced (Tan et al., 2023).

In the second complementary study, a list of candidate items for measuring FDS severity was generated. This was formed both from the focus groups, and a previously conducted systematic review (Whitaker et al., 2024). Items were shared in a series of Delphi rounds with a wider group of experts (both by lived and professional experience) in FDS. Consensus was achieved to a high level. This is a remarkable achievement given the considerable differences between FDS presentations (Adewusi et al., 2021). The Delphi resulted in the development of a self-report FDS severity measure (the *FDS-S*), comprising three sections. An 'FDS Severity' section with 29 items,

a FDS ‘Frequency / Duration’ Section consisting of 6 items, and a FDS symptom checklist of 88 items.

This study is the first step to developing a condition-specific FDS severity PROM. This has not previously been attempted to the researcher’s knowledge. Both study phases achieved the desired sample size suggestive of a high degree of support in the field for the development of a PROM. Interestingly, there was an overlap in discussions during the PwLE and HCPs focus groups. Similar ideas and feedback also emerged in the Delphi rounds related to the practicalities of developing a measure. Reducing items was particularly challenging during this process as participants were highly inclusive in their rankings. This likely represents that FDS are highly subjective and heterogeneous (Reuber & Rawlings, 2016), and treatment needs to be individualised to this. Thus, determining what symptoms are most severe is not a straightforward process.

The ‘Severity’ section demonstrated consistency with Delphi findings and subthemes of focus groups in that the final items for inclusion on the questionnaire generally represented a lack of control and unpredictability of seizures, unresponsiveness, loss of awareness, distressing physical/somatic symptoms, effects of the seizures (e.g. cognitive or communication difficulties, exhaustion, reliance on others, prolonged physical symptoms), distressing emotions and wider seizure impact. Of note, was the exclusion of single items to assess seizure severity (e.g. “How would you best describe the severity of your seizures?” (1) Mild; (2) Moderate; (3) Moderately Severe; (4) Severe). A single-item, Likert scale format to assess seizure severity had been used in some of the studies included in the previously conducted systematic review (Whitaker et al., 2024). Arguably, this may not be the most representative assessment of seizure severity. Exclusions of these items in the current study again emphasises the ideas emerging from the qualitative data in that to understand severity of seizures, a person’s subjective experience of FDS needs to be understood. The format of the questionnaire to include a symptom checklist was developed in response to the over inclusivity of items in the Delphi rounds and conceptually, these items were

more relevant to ‘characterise’ seizures. This is consistent with other measures of heterogenous conditions such as OCD (Y-BOCS; Goodman et al., 1989).

The complexities of measuring seizure frequency have previously been discussed in the literature (Gaskell et al., 2024), many themes of which were reflected in this study. Ultimately, seizure frequency was recognised by people with FDS, and healthcare professionals, as an important part of assessing FDS severity. Moreover, whilst the present study did not set out to include items on the measure representing seizure impact (meaning experiences beyond the immediate seizure period), this was evidently an entwined concept important in the understanding and assessment of FDS severity.

While some items that emerged overlap with measures of epileptic seizure severity, there are noticeable differences. For example, neither the SSQ (Cramer et al., 2002) nor the LSSS-3 (Baker et al., 1998) included items related to unresponsiveness, breathing difficulties, dissociation, paralysis, difficulties with coordination / balance, new physical / neurological symptoms that persist, feeling unable to take care of oneself after seizures or impact on role. ‘Sleepiness’ is represented in the LSSS-3 however this arguably differs to ‘exhaustion after seizures’ included on the FDS-S. Moreover, emotional effects are included on the SSQ (similar to the FDS-S) however not the LSSS-3. Overall, the FDS-S is more inclusive of physical symptoms that are not reflected in either of the measure examples discussed for epilepsy. Of note, the only overlapping physical symptoms with the LSSS-3 are falls, injury and incontinence. The SSQ demonstrated somewhat more overlap in physical symptoms (e.g. incontrollable movements, weakness, loss of speech) but did not include elements of perceived control like the LSSS-3 in its assessment of epilepsy seizure severity. This supports the argument that epilepsy seizure severity measures are unlikely to have accurately represented seizure severity in the FDS population to date, of which the FDS-S can offer novel and comprehensive insights.

Limitations

Focus group data was limited to two groups. Whilst the sample size was consistent with Braun and Clarks (2013) recommendations, it could be argued subthemes were underdeveloped. The concept 'information power' is used to guide adequate sample size in qualitative research; an exploratory study aims to offer new insights that contribute to current understandings opposed to providing a complete description of the phenomenon (Malterud et al., 2015). This methodology was selected instead of qualitative interviews as recommended by alternative guidance for PROM development (COSMIN Checklist; Mokkink et al., 2019). Interviews may have elicited more data and in-depth accounts of experiences (Braun & Clark, 2013). This however was beyond the scope of the current study but may be an area for future research to explore the phenomena of seizure severity. Nevertheless, rich and adequate information was gathered in line with the study aims.

The Delphi method is a flexible approach but generally suffers from a lack of guidance or agreed standards (Iqbal & Pipon-Young, 2009). One limitation was failure to use a predetermined consensus threshold during the Delphi. This was adjusted at each round as the panellist responses were inclined toward inclusion of items as a main aim was to refine and reduce items through consensus (ensuring the measure developed was practical for use including the most relevant items). The COSMIN guidance recommends qualitative methods as best practice to assess content validity (Mokkink et al., 2019) and pose quantitative methods (e.g. surveys) are 'adequate'. Consensus could have more easily been achieved through qualitative discussions of each item's relevance, response options, and recall period. That said, qualitative methods were used in the first instance to generate items and qualitative feedback and results were shared with participants between Delphi rounds to aid consensus. A particular strength of the selected methodology was that it reached a wide sample of experts included both people with lived experience, and HCP experts from a range of disciplines (beneficial given the measure would likely be used by a multidisciplinary team). Of note, a sample of more than or equal to 50 is considered 'very good' for quantitative approaches to

content validity (Mokkink et al., 2019). Moreover, anonymity between participants can encourage a balanced consideration of views (De Meyrick, 2003).

Of note, the majority of participants came from high-income and Western countries. Moreover, the percentage of White participants included is likely underreported. To avoid over generalising ethnic groups, participants were asked to self-report ethnicity. A range of responses were provided making it difficult to group participants more specifically and provide a greater breakdown of ethnicities. Data available is therefore limited and it is difficult to determine if the results are representative of the FDS population. Additionally, the FDS-S and its included items may not be generalisable to people from different cultural backgrounds. Some items may be of less relevance or important items may have been missed.

Similarly, caregivers for people with FDS were largely underrepresented. This may have been influenced by the terminology (i.e. 'caregivers', 'carers') used during recruitment. The terms were used to capture the perspectives of families, partners, friends, etc. likely to have a high-level of expertise and experience of FDS but who did not meet the criteria of HCP. On reflection, this language may have had negative connotations in that may suggest the individual is unable to care for themselves, is reliant on the person for support or, may imply burden posed by the individual. Whilst this was certainly not intended, it may have impacted recruitment and meant useful insights were missed. Of note, patients are commonly invited to bring a close relative to clinical appointments to help gain an alternative perspective on their FDS (Robson et al., 2016). Interestingly, several participants in this study proposed a 'carer' version of the questionnaire. This may be an area for future development.

The FDS-S itself has limitations, some of which highlighted by participants in the Delphi alongside strengths (Appendix U). This included people with FDS accurately recalling and reliably self-reporting seizure symptoms, though, the evidence shows that only a proportion of patients report losing all consciousness during FDS (Rawlings & Reuber, 2016). As noted, it is well known that patients with FDS routinely attend clinical appointments with a companion (Robson et al.,

2013). Whilst this can be advantageous (given the person can support with factual recall to help with diagnosis); it can impact the patient doctor interaction, with patients more likely to resist answering questions about their seizures (Robson et al., 2016).

Future Research and Clinical Implications

There are nine steps to rigorous outcome measure development proposed by Boateng et al. (2018); the first two steps have been achieved in this study. A future quantitative study should endeavour to achieve the subsequent phases of outcome measure development. This should involve statistically reducing items to ensure only those that are useful and internally consistent remain and conducting further psychometric evaluation to ensure the measure is reliable and validated for use in the FDS population (Boateng et al., 2018). This is an essential next step prior to the use of the FDS-S in clinical practice or future research. One issue to this will be assessing convergent validity given that there are no other accepted or validated measures developed assessing seizure severity in the FDS population. It might be expected however that the FDS-S correlates with validated measures that assess constructs such as perceived control, somatisation, dissociation, psychological difficulties (e.g. anxiety, panic, depression) and HRQoL given the content of items.

To the researcher's knowledge, this is first study of its kind to explicitly explore what people with FDS and HCPs say is most severe about FDS. Findings support the notion of psychological interventions focused on management of seizures, to give an individual more autonomy over the condition. Moreover, they emphasise the severity of the physical symptoms for people with FDS. More widely, this study advocates for a multidisciplinary approach to support patients to improve seizure severity alongside the wider impact of the condition.

PROMs have multiple purposes clinically. Subsequent to further development, the FDS-S will provide a comprehensive measure of FDS severity for use in clinical practice. This could provide a baseline assessment of FDS severity to guide interventions. Identification of most severe seizure symptoms would ensure patients are triaged into the most suitable treatment pathways

relevant to their needs and treatment goals. Psychological interventions can be monitored and evaluated across treatment and compared across services.

Conclusions

This study developed a clinically relevant candidate outcome measure to assess FDS severity. This includes aspects of seizure frequency and duration and encompasses the heterogenous experiences of FDS through the inclusion of a symptom checklist for a person-centred understanding. Whilst this study is not without limitations, the measure has been rigorously developed in collaboration with a large sample of experts including individuals with lived experience of FDS, caregivers, and HCPs. Consensus was achieved for items included in the questionnaire. With further psychometric development and evaluation, this measure could be of great clinical value to enhance evidence-based practice and gain insights into patients' subjective evaluation of treatments related to their seizure severity. Moreover, it provides a foundation for future research, assessing the wider impact of psychological interventions with FDS severity as an outcome.

References

Asadi-Pooya, A. A., Brigo, F., Tolchin, B., & Valente, K. D. (2021). Functional seizures are not less important than epilepsy. *Epilepsy & Behavior Reports, 16,* 100495–100495. https://doi.org/10.1016/j.ebr.2021.100495

Baker, G., Smith, D., Jacoby, A., Hayes, J., & Chadwick, D. (1998). Liverpool seizure severity scale revisited. *Seizure, 7,* 201–205. http://dx.doi.org/10.1016/S1059-1311(98)80036- 8.

Baker, G. A., Smith, D. F., Dewey, M., Morrow, J., Crawford, P. M., & Chadwick, D. W. (1991). The development of a seizure severity scale as an outcome measure in epilepsy. *Epilepsy Research*, *8*(3), 245–251. https://doi.org/10.1016/0920-1211(91)90071-M

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *Nursing Plus Open, 2,* 8–14. https://doi.org/10.1016/j.npls.2016.01.001

Boateng, G. O., Neilands, T. B., Frongillo, E. A., Melgar-Quinonez, H. R., & Young, S. L. (2018). Best practices for developing and validating scales for health, social, and behavioural research: A primer. *Frontiers in Public Health, 6*(149). https://doi.org.10.3389/fpubh.2018.00149

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners.* SAGE.

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research, 21*(1), 37-47. https://doi.org/https://doi.org/10.1002/capr.12360

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide.* SAGE.

Brown, R. J., Bouska, J. F., Frow, A., Kirkby, A., Baker, G. A., Kemp, S., Burness, C., & Reuber,

M. (2013). Emotional dysregulation, alexithymia, and attachment in psychogenic nonepileptic seizures. *Epilepsy Behaviour, 29*(1), 178-83. https://doi.org/10.1016/j.yebeh.2013.07.019

Brown, R. J., & Reuber, M. (2016a). Towards an integrative theory of psychogenic nonepileptic seizures. *Clinical Psychology Review*, *47*, 55–70. https://doi.org/10.1016/j.cpr.2016.06.003

Brown, R. J., & Reuber, M. (2016b). Psychological and psychiatric aspects of psychogenic non-epileptic seizures: A systematic review. *Clinical Psychology Review*, *45*, 157– 182. https://doi.org/10.1016/j.cpr.2016.01.003

Cantrill, J. A., Sibbald, B., & Buetow, S. (1996). The Delphi and nominal group techniques in health services research. *The International Journal of Pharmacy Practice, 4*(2)*,* 67-74. https://doi.org/10.1111/j.2042-7174.1996.tb00844.x

Cramer, J. A., Baker, G. A., & Jacoby, A. (2002). Development of a new seizure severity questionnaire: initial reliability and validity testing. *Epilepsy Research*, *48*(3), 187–197. https://doi.org/10.1016/S0920-1211(02)00003-7

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). SAGE.

Creswell, J. W., & Plano Clark, V. L. (2018). *Designing and conducting mixed methods research* (3rd ed.). SAGE.

De Meyrick, J. (2003). The Delphi method and health research. *Health Education, 103*(1), 7–16. https://doi.org/10.1108/09654280310459112

Fetters, M. D., & Tajima, C. (2022). Joint Displays of Integrated Data Collection in Mixed Methods Research. *International Journal of Qualitative Methods, 21*. https://doi.org/10.1177/16094069221104564

Gaskell, C., Power, N., Novakova, B., Simmonds-Buckley, M., Reuber, M., Kellett, S., &

Rawlings, G. H. (2023). A meta-analytic review of the effectiveness of psychological treatment of functional / dissociative seizures on non-seizure outcomes in adults. *Epilepsia, 64*(7), 1722-1738. https://doi.org/10.1111/epi.17626

Gaskell, C., Power, N., Novakova, B., Simmonds-Buckley, M., Kerr, W. T., Reuber, M., Kellett, S., & Rawlings, G. H. (2024). A meta-analytic evaluation of the effectiveness and durability of psychotherapy for adults presenting with functional dissociative seizures. *Seizure, 25*(119), 98-109. https://doi.org/10.1016/j.seizure.2024.05.016.

Goldstein, L. H., Carson, A., McCrone, P., Murray, J., Pilecka, I., Mosweu, I., Perdue, I., Abe, A-M., Allroggen, H., Alvares, D., Angus-Leppan, H., Aram, J., Armstrong, R., Atalaia, A., Bagary, M., Baldellou Lopez, M., Bennett, M., Black, T., Blackburn, D., … Callaghan, H. (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

Goldstein, L. H., Chalder, T., & Chigwedere, C., Khondoker, M. R., Moriarty, J., Toone, B. K., & Mellers, J. D. (2010). Cognitive-behavioural therapy for psychogenic nonepileptic seizures: A pilot RCT. *Neurology, 74*(24)*,* 1986-1994. https://doi.org/10.1212/WNL.0b013e3181e39658

Goldstein, L. H., Stone, J., Reuber, M., Landau, S., Robinson, E. J., Carson, A., Medford, N. & Chalder, T., (2024) Reflections on the CODES trial for adults with dissociative seizures: what we found and considerations for future studies. *BMJ Neurology Open, 6*(1), 000659. https://doi.org/10.1136/bmjno-2024-000659

Goodman, W. K., Price, L. H., Rasmussen, S. A., Mazure, C., Fleischmann, R. L., Hill, C. L., Heninger, G. R., & Charney, D. S. (1989). The Yale-Brown Obsessive Compulsive Scale: I. Development, use, and reliability. *Archives of General Psychiatry, 46*(11), 1006–1011. https://doi.org/10.1001/archpsyc.1989.01810110048007

Harden, C. L., Maroof, D. A., Nikolov, B., Fowler, K., Sperling, M., Liporace, J., Pennell, P.,

Labar, D., & Herzog, A. (2007). The effect of seizure severity on quality of life in epilepsy. *Epilepsy & Behaviour, 11*(2), 208–211. https://doi.org/10.1016/j.yebeh.2007.05.002

Hingray, C., El-Hage, W., Duncan, R., Gigineishvili, D., Kanemoto, K., LaFrance, W. C., Marinis, A., Paul, R., Pretorius, C., Téllez-Zenteno, J. F., Wiseman, H., & Reuber, M. (2018). Access to diagnostic and therapeutic facilities for psychogenic nonepileptic seizures: An international survey by the ILAE PNES Task Force. *Epilepsia*, *59*(1), 203–214. https://doi.org/10.1111/epi.13952

Hingray, C., Ertan, D., Reuber, M., Lother, A-S., Chrusciel, J., Tarrada, A., Michel, N., Meyer, M., Klemina, I., Maillard, L., Sanchez, S., & El-Hage, W. (2022). Heterogeneity of patients with functional/dissociative seizures: Three multidimensional profiles. *Epilepsia, 63*(6), 1500-1515. https//doi.org/10.1111/epi.17230

Hsu, C-C., & Sandford, B. A. (2007). The Delphi technique: making sense of consensus. *Practical Assessment, Research & Evaluation, 12*(10), 1-8. https://openpublishing.library.umass.edu/pare/article/id/1418/

Iqbal, S., & Pipon-Young, L. (2009). The Delphi method. *The Psychologist, British Psychological Society, 22*(7), 598 – 600. https://cms.bps.org.uk/sites/default/files/2023-09/The%20Delphi%20Method%20-%20Iqbal%20and%20Pipon-Young.pdf

Johnston, B., C., Patrick, D. L., Devji, T., Maxwell, L. J., Bingham, I. I. I., Beaton, D., Boers, M., Briel, M., Busse, J. W., Carrasco-Labra, A., Christensen, R., da Costa, B. R., El Dib, R., Lyddiatt, A., Ostelo, R. W., Shea, B., Singh, J., Terwee, C. B., Williamson, P. R., … Guyatt, G. H. (2018). Patient-reported outcomes. In Higgins, J. P. T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M. J., & Welch, V. A. (Eds.). *Cochrane Handbook for Systematic Reviews of Interventions*. Cochrane. https://training.cochrane.org/handbook/current/chapter-18

Jones, B., Reuber, M., & Norman, P. (2016). Correlates of health-related quality of life in adults

with psychogenic nonepileptic seizures: A systematic review. *Epilepsia, 57*(2), 171–181. https://doi.org/10.1111/epi.13268

Kilroy, D., & Driscoll, P. (2006). Determination of required anatomical knowledge for clinical practice in emergency medicine: national curriculum planning using a modified Delphi technique. *Emergency Medicine Journal, 23*(9), 693–696. https://doi.org/10.1136/emj.2006.037309

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*, 606-613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

LaFrance, W. C., Baker, G. A., Duncan, R., Goldstein, L. H., & Reuber, M. (2013). Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: A staged approach: A report from the International League Against Epilepsy Nonepileptic Seizures Task Force. *Epilepsia (Copenhagen)*, *54*(11), 2005–2018. https://doi.org/10.1111/epi.12356

LaFrance, W. C., Miller, I. W., Ryan, C. E., Blum, A. S., Solomon, D. A., Kelley, J. E., & Keitner, G. I. (2009). Cognitive behavioural therapy for psychogenic nonepileptic seizures. *Epilepsy & Behaviour, 14*(4), 591–596. https://doi.org/10.1016/j.yebeh.2009.02.016

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *All Ireland Journal of Higher Education, 8*(3), 3351-3365. https://ojs.aishe.org/index.php/aishe-j/article/view/335/553

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

Marzooqi, S. M., Baker, G. A., Reilly, J., & Salmon, P. (2004). The perceived health status of people with psychologically derived non-epileptic attack disorder and epilepsy: a comparative study. *Seizure, 13*(2), 71–75. https://doi.org/10.1016/S1059-1311(03)00158-4

Mokkink, L. B., Prinsen, C. A. C., Patrick, D. L., Alonso, J., Bouter, L. M., de Vet, H. C. W., &

Terwee, C. B. (2019). COSMIN Study Design checklist for patient-reported outcome measurement instruments. https://www.cosmin.nl/wp-content/uploads/COSMIN-study-designing-checklist_final.pdf

Meadows, K. A. (2011). Patient-reported outcome measures: an overview. *British Journal of Community Nursing*, *16*(3), 146–151. https://doi.org/10.12968/bjcn.2011.16.3.146

National Health Service. (NHS). (2018). The national patient reported outcomes programme. https://www.england.nhs.uk/wp-content/uploads/2018/08/proms-guide-aug-18-v3.pdf

Nicholson, T. R., Carson, A., Edwards, M. J., Goldstein, L. H., Hallett, M., Mildon, B., Nielsen, G., Nicholson, C., Perez, D. L., Pick, S., Stone, J., and the FND-COM (Functional Neurological Disorders Core Outcome Measures) Group, & FND-COM group collaborators. (2020). Outcome Measures for Functional Neurological Disorder: A Review of the Theoretical Complexities. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *32*(1), 33–42. https://doi.org/10.1176/appi.neuropsych.19060128

Onwuegbuzie, A. J., Johnson, R. B., & Collins, K. M. T. (2011). Assessing legitimation in mixed research: a new framework. *Quality & Quantity*, *45*(6), 1253–1271. https://doi.org/10.1007/s11135-009-9289-9

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

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

Rawlings, G. H., & Reuber, M. (2016). What patients say about living with psychogenic

nonepileptic seizures: A systematic synthesis of qualitative studies. *Seizure*, *41*, 100–111. https://doi.org/10.1016/j.seizure.2016.07.014

Reuber, M. (2008). Psychogenic nonepileptic seizures: answers and questions. *Epilepsy & Behaviour, 12*(4), 622-635. https://10.1016/j.yebeh.2007.11.006

Reuber, M. & Rawlings, G. (2016). Nonepileptic seizures – subjective phenomena. *Handbook of Clinical Neurology, 139,* 283-296. https/doi.org.10.1016/B978-0-12-801772-2.00025-4

Robson, C., Drew, P., & Reuber, M. (2013). Duration and structure of unaccompanied (dyadic) and accompanied (triadic) initial outpatient consultations in a specialist seizure clinic. *Epilepsy & Behavior*, *27*(3), 449–454. https://doi.org/10.1016/j.yebeh.2013.03.008

Robson, C., Drew, P., & Reuber, M. (2016). The role of companions in outpatient seizure clinic interactions: A pilot study. *Epilepsy & Behavior*, *60*, 86–93. https://doi.org/10.1016/j.yebeh.2016.04.010

Rosellini, A. J., & Brown, T. A. (2021). Developing and validating clinical questionnaires. *Annual Review of Clinical Psychology, 17*, 55-81. DOI: https/doi.org./doi.org/10.1146/annurev-clinpsy-081219-115343

Stone Fish, L., & Busby, D. M. (2005). The Delphi Method. In D. H. Sprenkle & F. P. Piercy (2nd Ed), *Research Methods in Family Therapy* (pp. 238-253). The Guildford Press.

Stone, J., Binzer, M., & Sharpe, M. (2004). Illness beliefs and locus of control: A comparison of patients with pseudoseizures and epilepsy. *Journal of Psychosomatic Research*, *57*(6), 541–547. https://doi.org/10.1016/j.jpsychores.2004.03.013

Stone, J., & Carson, A. J. (2013). The unbearable lightheadedness of seizing: wilful submission to dissociative (non-epileptic) seizures. *Journal of Neurology, Neurosurgery and Psychiatry*, *84*(7), 822–824. https://doi.org/10.1136/jnnp-2012-304842

Sumsion, T. (1998). The Delphi technique. *British Journal of Occupational Therapy, 61*(4), 153–156. https://doi.org/10.1177/030802269806100403

Tan, M., Pearce, N., Tobias, A., Cook, M. J., & D'Souza, W. J. (2023). Influence of comorbidity on

mortality in patients with epilepsy and psychogenic nonepileptic seizures. *Epilepsia, 64*(4), 1035-1045. https://doi.org.10.1111/epi.17532

Ware, J., Kosinski, M., & Keller, S. D. (1996). A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Medical Care*, *34*(3), 220–233. https://doi.org/10.1097/00005650-199603000-00003

Whitaker, L., Rawlings, G., Gaskell, C., & Reuber, M. (2024). *Psychosocial correlates of seizure severity in adults with functional / dissociative seizures (FDS): A systematic review.* Unpublished manuscript.

Williams, I. A., Morris, P. G., Forristal, K., Stone, J., & Gillespie, D. C. (2024). Illness representations of people with later-onset functional seizures. *Epilepsy & Behavior, 152*, 109666–109666. https://doi.org/10.1016/j.yebeh.2024.109666

Appendix A

Ethical Approval

The University Of Sheffield.

Downloaded: 15/05/2023
Approved: 18/02/2023

Laura Whitaker
Registration number: 210154814
Psychology
Programme: Doctorate of Clinical Psychology (DClin Psy)

Dear Laura

PROJECT TITLE: Developing a Self-Report Seizure Severity Measure for Individuals Experiencing Functional/Dissociative Seizures (FDS)
APPLICATION: Reference Number 050511

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 18/02/2023 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 050511 (form submission date: 17/02/2023); (expected project end date: 01/05/2024).
- Participant information sheet 1116469 version 2 (17/02/2023).
- Participant information sheet 1116470 version 2 (17/02/2023).
- Participant information sheet 1116471 version 2 (17/02/2023).
- Participant consent form 1116473 version 2 (17/02/2023).
- Participant consent form 1116472 version 2 (17/02/2023).
- Participant consent form 1116474 version 2 (17/02/2023).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Department Of Psychology Research Ethics Committee
Ethics Administrator
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/research-services/ethics-integrity/policy
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix B – Study Information

Focus Groups

Delphi Survey

Appendix C

Participant Screening Survey

Focus Groups

Participant Screening Survey – Focus Groups *(to distribute via Qualtrics with research advertisement for focus groups)*

1) Please select an option from the list below:
   a) I have been diagnosed with/have personally experienced functional/dissociative seizures (these sometimes may have also been referred to as nonepileptic attacks)
   b) I am a non-professional caregiver to an individual that is diagnosed with or has experienced functional/dissociative seizures
   c) I am a healthcare professional with experience of working with individuals that have experienced functional/dissociative seizures
   d) None of the above

A – Follow-up Questions

1) Do you also have a diagnosis of epilepsy/epileptic seizures?
   - Yes – ends survey (with brief explanation re; exclusion criteria)
   - No – question 2

2) Are you currently residing in the UK?
   - Yes – question 3
   - No – ends survey (with brief explanation re; exclusion criteria)

3) Are you aged 18 or over?
   - Yes – question 4
   - No – ends survey (with brief explanation re; exclusion criteria)

4) Are you able to communicate in fluent English within a group setting in which you will be required to listen and respond to others?
   - Yes – question 5
   - No – ends survey (with brief explanation re; exclusion criteria)

5) Have you experienced a functional/dissociative seizure within the last two years?
   - Yes – question 6
   - No – ends survey (with brief explanation re; exclusion criteria)

6) Approximately how long have you been living with functional/dissociative seizures?
   _____

7) Approximately, how often do you experience functional/dissociative seizures? (MULTIPLE CHOICE RESPONSES TO BE GENERATED)

8) What is your age? _____

9) What is your gender? _____

10) What is your ethnicity? _____

11) What country do you reside? _____

12) I would like to know more about what this research involves:

Y – PIS Focus Group Lived Experience & Consent Form
N – ends survey

B – Follow-up Questions

1) Does the individual you support also have a diagnosis of epilepsy/epileptic seizures?
   - Yes – ends survey (with brief explanation re; exclusion criteria)
   - No – question 2

2) Are you currently residing in the UK?
   - Yes – question 3
   - No – ends survey (with brief explanation re; exclusion criteria)

3) Are you aged 18 or over?
   - Yes – question 4
   - No – ends survey (with brief explanation re; exclusion criteria)

4) Are you able to communicate in fluent English within a group setting in which you will be required to listen and respond to others?
   - Yes – question 5
   - No – ends survey (with brief explanation re; exclusion criteria)

5) Has the individual you support experienced a functional/dissociative seizure within the last two years?
   - Yes – question 6
   - No – ends survey (with brief explanation re; exclusion criteria)

6) Approximately how long have you supported the individual experiencing dissociative seizures? _____

7) Approximately how long has this individual lived with functional/dissociative seizures? _____

8) Approximately how often does this individual experience functional/dissociative seizures? MULTIPLE CHOICE OPTIONS TO BE GENERATED

9) What is your age? _____

10) What is your gender? _____

11) What is your ethnicity? _____

12) What country do you reside? _____
13) I would like to know more about what this research involves:

Y – PIS Focus Group Lived Experience & Consent Form
N – ends survey

C – Follow-up Questions

1) Are you currently residing in the UK?
   - Yes – question 2
   - No – ends survey (with brief explanation re; exclusion criteria)

2) Are you aged 18 or over?
   - Yes – question 3
   - No – ends survey (with brief explanation re; exclusion criteria)

3) Are you able to communicate in fluent English within a group setting in which you will be required to listen and respond to others?
   - Yes – question 4
   - No – ends survey

4) What is your profession? _____

5) How many years of experience do you have in your profession? _____

6) How many years of experience do you have treating people with functional/dissociative seizures? _____

7) What is your age? _____

8) What is your gender? _____

9) What is your ethnicity? _____

10) What country do you reside? _____

11) I would like to know more about what this research involves:

Y – PIS Focus Group Healthcare Professionals & Consent Form
N – ends survey

D – Ends Survey

Delphi Survey

Participant Screening Survey – Delphi Survey *(to distribute via Qualtrics with research advertisement for Delphi survey)*

1) Please select an option from the list below:
   a) I have been diagnosed with/have personally experienced functional/dissociative seizures (sometimes also referred to as non-epileptic attacks)
   b) I am a non-professional caregiver to an individual that is diagnosed with or has experienced functional/dissociative seizures
   c) I am a healthcare professional with experience of working with individuals that have experienced functional/dissociative seizures
   d) None of the above

A – Follow-up Questions

1) Do you also have a diagnosis of epilepsy/epileptic seizures?
   - Yes – ends survey (with brief explanation re; exclusion criteria)
   - No – question 2

2) Are you aged 18 or over?
   - Yes – question 3
   - No – ends survey (with brief explanation re; exclusion criteria)

3) Have you experienced a functional/dissociative seizure within the last two years?
   - Yes – question 4
   - No – ends survey (with brief explanation re; exclusion criteria)

4) Approximately how long have you been living with functional/dissociative seizures? _____

5) Approximately, how often do you experience functional/dissociative seizures? (MULTIPLE CHOICE RESPONSES TO BE GENERATED)

6) What is your age? _____

7) What is your gender? _____

8) What is your ethnicity? _____

9) What country do you reside? _____

10) I would like to know more about what this research involves:

    Y – PIS Delphi Panel & Consent Form
    N – ends survey

B – Follow-up Questions

1) Does the individual you support also have a diagnosis of epilepsy/epileptic seizures?
    - Yes – ends survey (with brief explanation re; exclusion criteria)
    - No – question 2

2) Are you aged 18 or over?
    - Yes – question 4
    - No – ends survey (with brief explanation re; exclusion criteria)

3) Has the individual you support experienced a functional/dissociative seizure within the last two years?
    - Yes – question 6
    - No – ends survey (with brief explanation re; exclusion criteria)

4) Approximately how long have you supported the individual experiencing dissociative seizures? _____

5) Approximately how long has this individual lived with functional/dissociative seizures? _____

6) Approximately how often does this individual experience functional/dissociative seizures? MULTIPLE CHOICE OPTIONS TO BE GENERATED

7) What is your age? _____

8) What is your gender? _____

9) What is your ethnicity? _____

10) What country do you reside? _____

11) I would like to know more about what this research involves:

Y – PIS Delphi Panel & Consent Form
N – ends survey

C – Follow-up Questions

1) Are you aged 18 or over?
    - Yes – question 2
    - No – ends survey (with brief explanation re; exclusion criteria)

2) What is your profession? _____

3) How many years of experience do you have in your profession? _____

4) How many years of experience do you have treating people with functional/dissociative seizures? _____

5) What is your age? _____

6) What is your gender? _____

7) What is your ethnicity? _____

8) What country do you reside? _____

9) I would like to know more about what this research involves:

Y – PIS Delphi Panel & Consent Form
N – ends survey

D – Ends Survey

Appendix D

Participant Information Sheets

Focus Groups (Lived Experience)

Participant Information Sheet

Preliminary development of a self-report questionnaire to assess functional / dissociative seizure severity.

You are being invited to take part in a research study which aims to develop a self-report questionnaire to assess functional/dissociative seizure severity (also known as non-epileptic attacks). The research is being conducted as part of a Doctorate in Clinical Psychology at The University of Sheffield being undertaken by Laura Whitaker (Trainee Clinical Psychologist).

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

ABOUT THE RESEARCH

What is the purpose of this research?
Functional/dissociative seizures are a common symptom of Functional Neurological Disorder and have a significant impact for individuals living with them. Individuals experiencing functional/dissociative seizures have extremely varied and subjective experiences. There is currently no measure to assess the severity of functional/dissociative seizures. The current research aims to develop a self-report questionnaire that can be used with individuals experiencing functional/dissociative seizures to better understand their experience. We are inviting individuals with lived experience of functional/dissociative seizures and/or non-professional carers supporting individuals that have experienced functional/dissociative seizures to take part in a focus group discussion. The aim of this is to identify factors associated with functional/dissociative seizure severity to be included in a self-report questionnaire.

What would I be asked to do if I took part?
You will be asked to take part in a 1.5-2-hour focus group with other individuals experiencing functional/dissociative seizures and non-professional carers to explore items to be considered for a self-report questionnaire assessing functional/dissociative seizure severity. This will be facilitated online via video call on Google Meet at an arranged time (a working day within the hours of 9am to 5pm). There will be a maximum of 8 participants taking part in the focus group alongside the researchers.

Should I take part in this study?
Signing up to this study is voluntary and it is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time without giving a reason and without a detriment to yourself. Prior to the focus group you can withdraw by contacting Laura Whitaker. You will then not be contacted with further details. If you choose to withdraw during the focus group you can exit the video call at any time. However, any comments you have already contributed to the focus group discussion will be included in the analysis and write-up. If you do not wish for your comments to be included in the final analysis and write-up, you will need to request this from the lead researcher by an agreed date. This does not affect your data protection rights. If you decide not to take part then you do not need to do anything further.

Will the outcomes of the research be published?
The research will be written up as an empirical paper and submitted to a chosen appropriate journal. It will be included in Laura Whitaker's thesis and may be presented at conferences.

Are there any risks to taking part?
There is a low risk of becoming distressed in the focus group due to the nature of the topic discussed (functional/dissociative seizure severity) however it is not anticipated this will be likely.

Will I be compensated for taking part?
There is no financial reward for participating in this study. However, it is an opportunity to express your views about how to understand and help people with functional/dissociative seizures, which may contribute to the future care of people with the condition.

Who has reviewed the research project?
The project has been reviewed by The University of Sheffield Research Ethics Committee and a Research Sub-Committee within the Clinical Psychology Doctorate programme department.

	Yes	No
I have read the above information and agree to continue.	○	○

→

DATA PROTECTION AND CONFIDENTIALITY

What information will you collect about me?
In order to participate in this research project we will need to collect information that could identify you, called "personal identifiable information". Specifically, we will need to collect: name, age, gender, ethnicity, and country of residence. If you are an individual with lived experience of functional/dissociative seizures, we will request information about how long you have experienced your seizures and the frequency of your seizures. If you are a non-professional carer for individuals experiencing functional/dissociative seizures, we will request information about how long you have supported the individuals and years since the individuals functional/dissociative seizure diagnosis/experience. Your name will only be used to contact you and it will not be published or disclosed to anyone else.

Under what legal basis are you collecting this information?
We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

What are my rights in relation to the information you will collect about me?
You have several rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research.

Will my participation in the study be confidential and my personal identifiable information be protected?
In accordance with data protection law, The University of Sheffield is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way: all data will be collected electronically and stored securely on University servers in accordance with the University of Sheffield policies on data protection, the Data Protection Act (2018) and General Data Protection Regulations (GDPR, 2018). No hard copies of data will be collected. The researchers will have access to the University servers through the VPN global connect facility. All data will be encrypted before being stored. Following the completion of consent forms, participants will be provided with a unique identifier, which will be placed on all data instead of their name; this will ensure their details are kept secure. A separate file containing participants corresponding details (e.g., email address) will be stored in an encrypted file on the University RDMS and only accessible to the research team. Consent forms will be stored securely on the RDMS separately from the research data.

If you have a query about the research or wish to raise a complaint, please contact the researcher **(lwhitaker1@sheffield.ac.uk)** or their supervisor **Professor Markus Reuber (m.reuber@sheffield.ac.uk).** If you feel your complaint has not been handled satisfactorily, you can also contact the Head of the Psychology Department Professor Elizabeth Milne (psy-hod@sheffield.ac.uk).

If you would like to take part please read and complete the online consent form on the next page.

	Yes	No
I have read the above information and agree to continue.	○	○

→

Focus Groups (Healthcare Professionals)

The University Of Sheffield.

Department of Psychology

Participant Information Sheet

Preliminary development of a self-report questionnaire to assess functional / dissociative seizure severity.

You are being invited to take part in a research study which aims to develop a self-report questionnaire to assess functional/dissociative seizure severity (also known as non-epileptic attacks). The research is being conducted as part of a Doctorate in Clinical Psychology at The University of Sheffield being undertaken by Laura Whitaker.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

ABOUT THE RESEARCH

What is the purpose of this research?
Functional/dissociative seizures (also known as non-epileptic attacks) are a common symptom of Functional Neurological Disorder and have a significant impact for individuals living with them. Individuals experiencing functional/dissociative seizures have extremely varied and subjective experiences. There is currently no measure to assess the severity of functional/dissociative seizures or to understand the needs of each individual. The current research aims to develop a self-report questionnaire that can be used with individuals experiencing functional/dissociative seizures to better understand their experience.

We are inviting healthcare professionals working with individuals living with functional/dissociative seizures to take part in a focus group discussion to identify factors associated with functional/dissociative seizure severity to be included in a self-report questionnaire.

What would I be asked to do if I took part?
You will be asked to take part in a 1.5-2 hour focus group with other healthcare professionals to explore items to be considered for a self-report questionnaire assessing functional/dissociative seizure severity. This will be facilitated via video call on Google Meet and arranged at a convenient time for all participants (a working day within the hours of 9am to 5pm). There will be a maximum of 8 participants taking part in the focus group alongside the researchers.

Should I take part in this study?
Signing up to this study is voluntary and it is up to you to decide whether or not to take part in this study. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. Prior to the focus group you can withdraw by contacting Laura Whitaker. You will then not be contacted with further details. If you choose to withdraw during the focus group you can exit the video call at any time. However, any comments you have already contributed to the focus group discussion will be included in the analysis and write-up. If you do not wish for your comments to be included in the final analysis and write-up, you will need to request this from the lead researcher by an agreed date. This does not affect your data protection rights. If you decide not to take part then you do not need to do anything further.

Will the outcomes of the research be published?
The research will be written up as an empirical paper and submitted to a chosen appropriate journal. It will be included in Laura Whitaker's thesis and may be presented at conferences.

Are there any risks to taking part?
No, we do not think there are any risks to you in taking part.

Will I be compensated for taking part?
There is no financial reward for participating in this study. However, it is an opportunity to express your views about how to understand and help people with functional/dissociative seizures, which may contribute to the future care of people with the condition.

Who has reviewed the research project?
The project has been reviewed by The University of Sheffield Research Ethics Committee and a Research Sub-Committee within the Clinical Psychology Doctorate programme department.

	Yes	No
I have read the above information and agree to continue.	○	○

DATA PROTECTION AND CONFIDENTIALITY

What information will you collect about me?
In order to participate in this research project we will need to collect information that could identify you, called "personal identifiable information". Specifically, we will need to collect: name, age, gender, ethnicity, country of residence, professions, area of specialism, and years of experiences supporting individuals experiencing functional/dissociative seizures. Your name will only be used to contact you and it will not be published or disclosed to anyone else.

Under what legal basis are you collecting this information?
We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

What are my rights in relation to the information you will collect about me?
You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research.

Will my participation in the study be confidential and my personal identifiable information be protected?
In accordance with data protection law, The University of Sheffield is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way: All data will be collected electronically and stored securely on University servers in accordance with the University of Sheffield policies on data protection, the Data Protection Act (2018) and General Data Protection Regulations (GDPR, 2018). No hard copies of data will be collected. The researchers will have access to the University servers through the VPN global connect facility. All data will be encrypted before being stored. Following the completion of consent forms, participants will be provided with a unique identifier, which will be placed on all data instead of their name; this will ensure their details are kept secure. A separate file containing participants corresponding details (e.g., email address) will be stored in an encrypted file on the University RDMS and only accessible to the research team. Consent forms will be stored securely on the RDMS separately from the research data.

If you have a query about the research or wish to raise a complaint, please contact the researcher **(lwhitaker1@sheffield.ac.uk)** or their supervisor **Professor Markus Reuber (m.reuber@sheffield.ac.uk).** If you feel your complaint has not been handled satisfactorily, you can also contact the Head of the Psychology Department Professor Elizabeth Milne (psy-hod@sheffield.ac.uk).

If you would like to take part please read and complete the online consent form on the next page.

	Yes	No
I have read the above information and agree to continue.	○	○

→

Delphi Survey

The University Of Sheffield.

Department of Psychology

Participant Information Sheet

Preliminary development of a self-report questionnaire to assess functional / dissociative seizure severity.

You are being invited to take part in a research study which aims to develop a self-report questionnaire to assess FDS severity (also known as non-epileptic attacks).

The research is being conducted as part of a Doctorate in Clinical Psychology at The University of Sheffield being undertaken by Laura Whitaker. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

ABOUT THE RESEARCH - DELPHI SURVEY

What is the purpose of this research?
FDS are a common symptom of Functional Neurological Disorder and have a significant impact for individuals living with them. Individuals experiencing FDS have extremely varied and subjective experiences. There is currently no measure to assess the severity of FDS. The current research aims to develop a self-report questionnaire that can be used with individuals experiencing FDS to better understand their seizure experiences. We hope to gain feedback from individuals experiencing FDS and professionals working with FDS regarding what items should be included in the measure from a preliminary list we have developed from previous research.

What would I be asked to do if I took part?
We are asking participants to take part in a "Delphi" survey. This involves gaining expert perspectives and so will include professionals working in the field of FDS and individuals with lived experience coming to an agreement on what items should be included on a self-report scale measuring FDS severity. We will ask participants to take part in three rounds of a survey conducted via Qualtrics. Qualtrics is a web-based software that allows for surveys to be generated and responded to online via a weblink. During each round, a questionnaire will be sent out for anonymous feedback to be provided. You will have up to two weeks to complete this and we will send you a reminder during this time. We will ask you to rank items associated with FDS severity considering the relevance/importance of each item. You will also be invited to provide open feedback about your ranking and if you feel there are any items missing. Between each round, your responses and feedback will be reviewed, and the questionnaire amended based on this. The group will be made aware of the feedback from the previous round at each new round and asked to re-evaluate their original feedback. There will be three rounds in total, with gaps of 5-10 days between each two-week round.

Should I take part in this study?
Signing up to this study is voluntary and it is up to you to decide whether or not to take part in this study. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. Prior to the Delphi Rounds you can withdraw by contacting Laura Whitaker. You will then not be contacted with further details. If you choose to withdraw during the Delphi Rounds you can exit the e-survey at any time. However, it will not be possible to remove responses you have already submitted from the project. This does not affect your data protection rights. If you decide not to take part then you do not need to do anything further.

Will the outcomes of the research be published?
The research will be written up as an empirical paper and submitted to a chosen appropriate journal. It will be included in Laura Whitaker's thesis and may be presented at conferences.

Are there any risks to taking part?
No, we do not think there are any risks to you in taking part.

Will I be compensated for taking part?
There is no financial reward for participating in this study. However, it is an opportunity to express your views about how to understand and help people with FDS, which may contribute to the future care of people with the condition.

Who has reviewed the research project?
The project has been reviewed by The University of Sheffield Research Ethics Committee and a Research Sub-Committee within the Clinical Psychology Doctorate programme department.

	Yes	No
I have read the above information and agree to continue.	○	○

DATA PROTECTION AND CONFIDENTIALITY

What information will you collect about me?
In order to participate in this research project, we will need to collect information that could identify you, called "personal identifiable information". Specifically, we will need to collect: name, age, gender, ethnicity, and country of residence. If you are a healthcare professional, we will request your professional title, area of specialism and years of experience in FDS. If you are an individual with lived experience of FDS, we will request how long you have experienced FDS and the frequency of your FDS. If you are a non-professional carer for individuals experiencing FDS, we will request information about how long you have supported the individual, how long they have experienced FDS, and how frequently they experience FDS. Your name will only be used to contact you and it will not be published or disclosed to anyone else.

Under what legal basis are you collecting this information?
We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

What are my rights in relation to the information you will collect about me?
You have a number of rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research.

Will my participation in the study be confidential and my personal identifiable information be protected?
In accordance with data protection law, The University of Sheffield is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way: All data will be collected electronically and stored securely on University servers in accordance with the University of Sheffield policies on data protection, the Data Protection Act (2018) and General Data Protection Regulations (GDPR, 2018). No hard copies of data will be collected. The researchers will have access to the University servers through the VPN global connect facility. All data will be encrypted before being stored. Following the completion of consent forms, participants will be provided with a unique identifier, which will be placed on all data instead of their name; this will ensure their details are kept secure. A separate file containing participants corresponding details (e.g., email address) will be stored in an encrypted file on the University RDMS and only accessible to the research team. Consent forms will be stored securely on the RDMS separately from the research data.

If you have a query about the research or wish to raise a complaint, please contact the researcher (lwhitaker1@sheffield.ac.ukl) or their supervisor Professor Markus Reuber (m.reuber@sheffield.ac.uk). If you feel your complaint has not been handled satisfactorily, you can also contact the Head of the Psychology Department Professor Elizabeth Milne (psy-hod@sheffield.ac.uk).

If you would like to take part please read and complete the online consent form on the next page.

	Yes	No
I have read the above information and agree to continue.	○	○

Appendix E

Consent Forms

Focus Groups (Lived Experience)

Consent Form

Online Focus Group for Individuals with Lived Experience of Functional/Dissociative Seizures (FDS) and Non-Professional Carers

Preliminary development of a self-report questionnaire to assess FDS severity

Project Contact Details (for further information):

Lead Researcher: Laura Whitaker **(lwhitaker1@sheffield.ac.uk)**
Research Supervisor: Professor Markus Reuber **(m.reuber@sheffield.ac.uk)**

In the event of a complaint, please contact the Head of Department: **Professor Elizabeth Milne (psy-hod@sheffield.ac.uk)**

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

In the event that you want to contact any of the above named people by email, **please telephone**:
Research Support Officer Amrit Sinha on: 0114 222 6650
A message will be passed onto the staff member, who will return your call. You may also **email** Amrit Sinha if required on: **a.sinha@sheffield.ac.uk**

Please select the appropriate boxes.

Taking part in the study:

	Yes	No
I have read and understood the participant information displayed on the previous page or the project has been fully explained to me. (If you will answer 'No' to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean).	○	○
I have been given the opportunity to ask questions about the project.	○	○
I give permission to be contacted by Laura Whitaker to arrange convenient dates for the focus group to take place. I agree for Laura Whitaker to contact me using the contact details I have provided below.	○	○
I understand and agree to take part in the project. I understand that taking part in the project will include a 1.5-2 hour focus group that will be conducted online via Google Meet.	○	○
I agree to the online focus group being video recorded.	○	○
I understand there is a small possibility I may be recognised by others in the online focus group and that I may recognise other individuals taking part.	○	○
I confirm that I will not disclose any information discussed during the focus group outside of the focus group. I will also not disclose information about the people I have met in the focus group.	○	○
I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself.	○	○
If I withdraw my participation, I understand that any contributions to the focus groups I have already made will be included in the analysis and that this will be anonymised as described below. If I do not wish for the comments I have submitted to be included in the write-up, I will contact Laura Whitaker via email (lwhitaker1@sheffield.ac.uk) by February 2024.	○	○
I agree to take part on this basis.	○	○

How my information will be used during and after the project:

	Yes	No
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	○	○
I understand and agree that any data collected may be included in anonymous form in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs.	○	○
I understand that data will be anonymised such that no names or uniquely identifying personal details will be given in the write-up but, to contextualise quotes, some non-identifying personal information will be written up. For example, the publication will phrase quotes such as, "an individual who has lived with functional/dissociative seizures for 2 years stated...".	○	○
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	○	○
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	○	○
So that the information you provide can be used legally by the researchers: I agree to assign the copyright I hold in any materials generated as part of this project to the University of Sheffield.	○	○

The following activities are optional, you may participate in the research without agreeing to the following:

	Yes	No
I agree that the researchers may contact me in future about other research projects.	○	○
I would like to be contacted about future research specifically related to this project. This would include taking part in a "Delphi" survey. This involves gaining expert perspectives and so will include individuals with lived experience of FDS and healthcare professionals working in the field coming to an agreement on what items should be included on a self-report scale measuring functional/dissociative seizure severity. We will ask participants to take part in three rounds of a survey conducted via Qualtrics. Qualtrics is a web-based software that allows for surveys to be generated and responded to online via a weblink. During each round, a questionnaire will be sent out for anonymous feedback to be provided. You will have up to two weeks to complete this and we will send you a reminder during this time. We will ask you to rank items associated with functional/dissociative seizure severity considering the relevance/importance of each item. You will also be invited to provide open feedback about your ranking and if you feel there are any items missing. Based on the information above, I would like to be contacted with more information about participating in the Delphi survey.	○	○
I agree that the researchers may retain my contact details in order to provide me with a summary of the findings for this study.	○	○

Consent

	Yes	No
I agree to take part in this study according to the information provided.	○	○

→

Thank you for your response.

Please note, this survey will have automatically discontinued if you do not meet the inclusion criteria for the study or you have not consented to take part. If you think this was an error, you can restart the survey or contact the lead researcher using the information provided below.

If you have consented to take part in this study, the lead researcher will be in contact with you via email with more information.

If you have any further questions about this research, please see the project contact details:
Lead Researcher: Laura Whitaker **(lwhitaker1@sheffield.ac.uk)**
Research Supervisor: Professor Markus Reuber **(m.reuber@sheffield.ac.uk)**

In the event of a complaint, please contact the Head of Department: **Professor Elizabeth Milne (psy-hod@sheffield.ac.uk)**
Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

In the event that you want to contact any of the above named people by email, **please telephone**:
Research Support Officer Amrit Sinha on: 0114 222 6650
A message will be passed onto the staff member, who will return your call. You may also **email** Amrit Sinha if required on: **a.sinha@sheffield.ac.uk**

Focus Groups (Healthcare Professionals)

Consent Form

Healthcare Professionals Online Focus Group

Preliminary development of a self-report questionnaire to assess functional / dissociative seizure (FDS) severity

Project Contact Details (for further information):

Lead Researcher: Laura Whitaker **(lwhitaker1@sheffield.ac.uk)**
Research Supervisor: Professor Markus Reuber **(m.reuber@sheffield.ac.uk)**

In the event of a complaint, please contact the Head of Department: **Professor Elizabeth Milne (psy-hod@sheffield.ac.uk)**

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

In the event that you want to contact any of the above named people by email, **please telephone**:
Research Support Officer Amrit Sinha on: 0114 222 6650
A message will be passed onto the staff member, who will return your call. You may also **email** Amrit Sinha if required on: **a.sinha@sheffield.ac.uk**

Please select the appropriate boxes.

Taking part in the study:

	Yes	No
I have read and understood the participant information displayed on the previous page or the project has been fully explained to me. (If you will answer 'No' to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean).	○	○
I have been given the opportunity to ask questions about the project.	○	○
I give permission to be contacted by Laura Whitaker to arrange convenient dates for the focus group to take place. I agree for Laura Whitaker to contact me using the contact details I have provided below.	○	○
I understand and agree to take part in the project. I understand that taking part in the project will include a 1.5-2 hour focus group that will be conducted online via Google Meet.	○	○
I understand that I may know other healthcare professionals taking part in the study and they may know me.	○	○
I confirm that I will not disclose any information discussed during the focus group outside of the focus group. I will also not disclose information about the people I have met in the focus group.	○	○
I agree to the online focus group being video recorded.	○	○
I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself.	○	○
If I withdraw my participation, I understand that any contributions to the focus groups I have already made will be included in the analysis and that this will be anonymised as described below. If I do not wish for the comments I have submitted to be included in the write-up, I will contact Laura Whitaker via email (lwhitaker1@sheffield.ac.uk) by February 2024.	○	○
I agree to take part on this basis.	○	○

How my information will be used during and after the project:

	Yes	No
I understand my personal details such as name, phone number, address and email address, location etc. will not be revealed to people outside the project.	○	○
I understand and agree that any data collected may be included in anonymous form in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs.	○	○
I understand that data will be anonymised such that no names or uniquely identifying personal details will be given in the write-up but, to contextualise quotes, some non-identifying personal information will be written up. For example, the publication will phrase quotes such as, "a clinical psychologist with 8 years of experience working with individuals experiencing FDS stated…".	○	○
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	○	○
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	○	○
So that the information you provide can be used legally by the researchers: I agree to assign the copyright I hold in any materials generated as part of this project to the University of Sheffield.	○	○

The following activities are optional, you may participate in the research without agreeing to the following:

	Yes	No
I agree that the researchers may contact me in future about other research projects.	○	○
I would like to be contacted about future research specifically related to this project. This would include taking part in a "Delphi" survey. This involves gaining expert perspectives and so will include individuals with lived experience of FDS and healthcare professionals working in the field coming to an agreement on what items should be included on a self-report scale measuring functional/dissociative seizure severity. We will ask participants to take part in three rounds of a survey conducted via Qualtrics. Qualtrics is a web-based software that allows for surveys to be generated and responded to online via a weblink. During each round, a questionnaire will be sent out for anonymous feedback to be provided. You will have up to two weeks to complete this and we will send you a reminder during this time. We will ask you to rank items associated with functional/dissociative seizure severity considering the relevance/importance of each item. You will also be invited to provide open feedback about your ranking and if you feel there are any items missing. Based on the information above, I would like to be contacted with more information about participating in the Delphi survey.	○	○
I agree that the researchers may retain my contact details in order to provide me with a summary of the findings for this study.	○	○

→

Consent

	Yes	No
I agree to take part in this study according to the information provided.	○	○

→

Thank you for your response.

Please note, this survey will have automatically discontinued if you do not meet the inclusion criteria for the study or you have not consented to take part. If you think this was an error, you can restart the survey or contact the lead researcher using the information provided below.

If you have consented to take part in this study, the lead researcher will be in contact with you via email with more information.

If you have any further questions about this research, please see the project contact details:
Lead Researcher: Laura Whitaker **(lwhitaker1@sheffield.ac.uk)**
Research Supervisor: Professor Markus Reuber **(m.reuber@sheffield.ac.uk)**

In the event of a complaint, please contact the Head of Department: **Professor Elizabeth Milne (psy-hod@sheffield.ac.uk)**
Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

In the event that you want to contact any of the above named people by email, **please telephone**:
Research Support Officer Amrit Sinha on: 0114 222 6650
A message will be passed onto the staff member, who will return your call. You may also **email** Amrit Sinha if required on: **a.sinha@sheffield.ac.uk**

Delphi Survey

Consent Form

Delphi Survey

Preliminary development of a self-report questionnaire to assess FDS severity

Project Contact Details (for further information):

Lead Researcher: Laura Whitaker **(lwhitaker1@sheffield.ac.uk)**
Research Supervisor: Professor Markus Reuber **(m.reuber@sheffield.ac.uk)**

In the event of a complaint, please contact the Head of Department: **Professor Elizabeth Milne (psy-hod@sheffield.ac.uk)**

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

In the event that you want to contact any of the above named people by email, **please telephone**:
Research Support Officer Amrit Sinha on: 0114 222 6650
A message will be passed onto the staff member, who will return your call. You may also **email** Amrit Sinha if required on: **a.sinha@sheffield.ac.uk**

Please select the appropriate boxes.

Taking part in the study:

	Yes	No
I have read and understood the participant information displayed on the previous page or the project has been fully explained to me. (If you will answer 'No' to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean).	○	○
I have been given the opportunity to ask questions about the project.	○	○
I give permission to be contacted by Laura Whitaker for the information (prior to survey distribution) and links to each of the Delphi Rounds (three separate surveys throughout an 8 to 10-week period). I agree for Laura Whitaker to contact me using the contact details I have provided below.	○	○
I agree to take part in the project. I understand taking part in the project will include ranking items on a Likert scale and providing some brief feedback for my response. This process will be repeated a total of three times.	○	○
I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself.	○	○
If I withdraw my participation, I understand that any responses I have already submitted in the survey (i.e. rankings on the Likert scale or written feedback) will be included in the analysis and that this will be anonymised.	○	○
I agree to take part on this basis.	○	○

How my information will be used during and after the project:

	Yes	No
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	○	○
I understand and agree that any data collected may be included in anonymous form in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs.	○	○
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	○	○
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	○	○
So that the information you provide can be used legally by the researchers: I agree to assign the copyright I hold in any materials generated as part of this project to the University of Sheffield.	○	○

→

The following activities are optional, you may participate in the research without agreeing to the following:

	Yes	No
I agree that the researchers may contact me in future about other research projects.	○	○
I agree that the researchers may retain my contact details in order to provide me with a summary of the findings for this study.	○	○

Consent

	Yes	No
I agree to take part in this study according to the information provided.	○	○

→

Thank you for your response.

Please note, this survey will have automatically discontinued if you do not meet the inclusion criteria for the study or you have not consented to take part. If you think this was an error, you can restart the survey or contact the lead researcher using the information provided below.

If you have consented to take part in this study, the lead researcher will be in contact with you via email with more information.

If you have any further questions about this research, please see the project contact details:
Lead Researcher: Laura Whitaker **(lwhitaker1@sheffield.ac.uk)**
Research Supervisor: Professor Markus Reuber **(m.reuber@sheffield.ac.uk)**

In the event of a complaint, please contact the Head of Department: **Professor Elizabeth Milne (psy-hod@sheffield.ac.uk)**
Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

In the event that you want to contact any of the above named people by email, **please telephone**:
Research Support Officer Amrit Sinha on: 0114 222 6650
A message will be passed onto the staff member, who will return your call. You may also **email** Amrit Sinha if required on: **a.sinha@sheffield.ac.uk**

Appendix F

Focus Group Topic Guides

Lived Experience

Interview Schedule – Functional / Dissociative Seizure Focus Groups (Lived Experience)

1) Introduction:

- Researcher to introduce self / thank group for attendance.
- Remind group the meeting is being video recorded for purpose of transcribing.
- Reminder of confidentiality and right to withdraw. If anyone does leave unexpectedly, the researcher will send a follow-up email as outlined in previous emails.
  Please help us protect the privacy of other members of the group. Do not share any information about anyone else taking part or any details about the information discussed. Please remember, you can leave at any time if you no longer wish to take part. I will send a follow-up email to anyone that does leave unexpectedly just to check-in but there is no pressure to reply to this. If you do withdraw, we will exclude anything you contributed to the group discussion prior unless you tell us you are happy for this to be included.
- Introductions – to go round each participant and invite them to introduce themselves.
- Set group ground rules – invite participants to contribute. Include agreement regarding break times.

2) Brief outline related to plan and aims of the focus group:

The meeting will last 1.5-2hrs to make sure we have time to hear everyone's views.

To clarify, we will be using the term FDS here however we aware that the condition is also known as psychogenic nonepileptic seizures, nonepileptic attack disorder and dissociative seizures. We are also aware the term seizure in this context can be known by another name such as event or episode. Please use the term you feel most comfortable with.

Functional/dissociative seizures have a significant impact for individuals living with them and are extremely varied and subjective experiences (meaning an individual person may not experience a typical FDS event, and how two people experience FDS events can be different). There is currently no patient reported outcome measure specifically designed to assess the severity of functional/dissociative seizures or to understand the different needs of each individual.

Patient reported outcome measures typically consist of a series of questions that respondents answer using a structured response e.g., strongly agree – strongly disagree. While there are general measures such as those measuring health-related quality of life (add link to SF12 v2), there are also specific measures such as those investigating depression (add link for PHQ-9) or anxiety (GAD-7). You may have completed one of these measures at some point in your life.

Outcome measures have their limitations. For example, they ask very specific questions some of which may not be relevant to everyone and do not give respondents the opportunity to expand on their answer. This may be more likely if the measure was not developed specifically for that clinical group in mind or if people with lived experience were not included in the development of the measure.

Measures can help to assess and screen people on a specific difficulty, monitor or track change over time and help to inform people's care and treatment. For example, the person's responses on the measure can be looked at such as by adding participant's responses together, you may be able to say whether their FDS events are more or less severe overtime.

The current research aims to develop a self-report questionnaire that can be used with people experiencing functional/dissociative seizures to better understand their seizure experiences. We want to understand the different factors people experiencing FDS associate with severity so we can include this in the questionnaire.

There are already measures of general functioning and HRQoL. We would like to develop a measure of FDS severity because the seizures themselves typically are the key symptom for people. Many researchers have previously used measures for epileptic seizures to measure FDS severity. However, given that epileptic seizures and FDS do not affect people in the same way, this may not be the best way of capturing seizure severity.

We want to hear your thoughts and ideas on this topic which we will use to help develop the measure. We hope this will help make sure it is representative of the experiences of people it is designed to help. We also hope that your involvement will help make the measure more acceptable and useful. For example, the measure can only include a certain number of questions and be answered in a specific way.

We will use your ideas to create a measure which we will then share with a larger number of people with FDS and healthcare professionals who support people with FDS to further develop it.

3) Can we start off by asking whether people think a FDS specific measure is a good idea and if so why? **Prompt –** ***what is it about the measure that would make it a better idea/more helpful/more acceptable?***

4) Factors associated with FDS Severity:

A. ***What factors would you consider important for measuring how severe a functional / dissociative seizure event is?*** **Prompt -** ***what is it about FDS events that make them more or less severe? It might be helpful to think about the period immediately before, during and immediately after a seizure or event.***

B. *I have a brief list of some different factors discussed identified from a review of previous research.* ***It may be helpful to hear people's thoughts about.*** Present a slide with the below factors.

Possible Themes for Discussion:

Anxiety	Emotional	Dissociation / Awareness
Distress	Physical Symptoms	Acceptance
Stress	Warning signs / experiences before a FDS event	Symptom Attribution (i.e. psychological vs physical)
Low Mood	Pain	Avoidance
Suicidal Ideation	Injury	Coping
Paranoia	Self-control	Social Functioning
Self-esteem	Stigma	Amnesia
Difficulty regulating / recognising / expressing emotions	Trauma symptoms	Negative Thinking / Cognitions
Beliefs about emotions	Sleep and Fatigue	Independence

C. ***What do people think about including frequency in a measure of seizure severity? How should this be measured?***

D. ***Would it be helpful for us to ask a more general question on the measure, such as "how bad are your seizures?"?***

5) Measuring FDS Severity:

We would also like to think about how we could best rate or rank the different factors associated with FDS Severity. ***What do you think would be a helpful way to rate or rank the different items on a questionnaire?*** *(i.e. Likert Scale, Numerical, Statements?)*

Present example on slide:

"I have felt confident in being able to control / manage my seizures." Circle the appropriate response.

1 = Strongly Agree	2 = Somewhat Agree	3 = Neither Agree / Disagree	4 = Somewhat Disagree	5 = Strongly Disagree

6) How would you want the measure to be used in practice?

- *When, where, how is it completed (alone, with a healthcare provider)?*
- *How often would it make sense to complete the measure? (i.e. how changeable are FDS seizures? How far back do you think people can think back to report seizure severity?)*
- *What timeframe would it be helpful to answer the questions about? (Last two weeks? 6 months?)*

7) Ending:

- Brief summary of discussion / next steps (i.e. future research) and thank for participation.
- Reminder that a lay summary of research will be sent out via email.
- Space for final thoughts / questions.

Healthcare Professional

Interview Schedule – Functional / Dissociative Seizure Focus Groups (Healthcare Professionals)

8) Introduction:

- Researcher to introduce self / thank group for attendance.
- Remind group the meeting is being video recorded for purpose of transcribing.
- Reminder of confidentiality and right to withdraw. If anyone does leave unexpectedly, the researcher will send a follow-up email as outlined in previous emails.
- Introductions – to go round each participant and invite them to introduce themselves.
- Set group ground rules – invite participants to contribute. Include agreement regarding break times.

9) Brief outline related to plan and aims of the focus group:

The meeting will last 1.5-2hrs to make sure we have time to hear everyone's views.

To clarify, we will be using the term FDS here however we aware that the condition is also known as psychogenic nonepileptic seizures, nonepileptic attack disorder and dissociative seizures. We are also aware the term seizure in this context can be known by another name such as event or episode. Please use the term you feel most comfortable with.

As you may be aware, functional/dissociative seizures have a significant impact for individuals living with them and are extremely varied and subjective experiences. Recent treatment studies have used generic Health Related Quality of Life, Psychopathology, distress and social functioning to assess outcomes. However, there is currently no patient reported outcome measure specifically designed to assess the severity of functional/dissociative seizures. Given that the seizures themselves are an important source of distress for many patients with FDS, an FDS severity measure would be desirable. The fact that clinicians and researchers would like such a measure is reflected in the fact that recent research has often used seizure severity measures validated in patients with epilepsy to assess FDS severity or studies have relied on measures of FDS frequency. It is not clear that these methods are reliable or relevant for individuals with FDS.

The current research aims to develop a self-report questionnaire that can be used with people experiencing functional/dissociative seizures to capture the severity of their seizures. We hope to develop a measure that can assess FDS and monitor / track change overtime considering whether their FDS are more or less distressing or disabling. We want to understand which factors people experiencing FDS and healthcare professionals, associate with FDS severity, so we can consider them for inclusion in this questionnaire. We also hope to discuss how we can make the measure more acceptable and useful in routine practice from your perspective and also that of patients.

We will use the ideas discussed today, alongside the ideas shared in a focus group with individuals with lived experience of FDS to create a measure. The next stage of our study is to share this in a Delphi survey with a larger group of participants – again, including healthcare professionals and individuals with lived experience, to further develop the measure.

10) *We understand that the condition FDS can affect people in everyday life, and this can be more than the seizure events themselves.* ***Can we start off by asking whether people think a measure focussing specifically on FDS severity is a good idea and if so, why?*** (i.e. is there a better focus such as intensity or burden).

11) Factors associated with FDS Severity:

E. ***What items would you consider important for measuring how severe a functional / dissociative seizure event is?*** **Prompt** ***- what is it about FDS events that make them more or less severe? It might be helpful to think about the period before, during and after a seizure or event.***

F. *I have a brief list of some different factors discussed identified from a review of the current research.* ***It may be helpful to hear people's thoughts about.*** Present a slide with the below factors.

Possible Themes for Discussion:

Anxiety	Emotional	Dissociation / Awareness
Distress	Physical Symptoms	Acceptance
Stress	Warning signs / experiences before a FDS event	Symptom Attribution (i.e. psychological vs physical)
Low Mood	Pain	Avoidance
Suicidal Ideation	Injury	Coping
Paranoia	Self-control	Social Functioning
Self-esteem	Stigma	Amnesia
Difficulty regulating / recognising / expressing emotions	Trauma symptoms	Negative Thinking / Cognitions

Beliefs about emotions	Sleep and Fatigue	Independence

G. ***What do people think about including frequency? –*** *there is evidence to suggest asking people to count the number of FDS events over a period of time can be challenging and not very reliable.* ***What might the most relevant measure of frequency look like?***

H. ***Given how seizures may affect people in different ways – would it be better to try and capture different domains of potential distress, or to ask fewer, broader questions such as, "how bad are your seizures?"?***

12) Measuring FDS Severity:

We would also like to think about how we could best rate or rank the different factors associated with FDS Severity. ***What do you think would be a helpful way to rate or rank the different items on a questionnaire?*** *(i.e. Likert Scale, Numerical, Statements?)*

Present example on slide:

"I have felt confident in being able to control / manage my seizures." Circle the appropriate response.

1 = Strongly Agree	2 = Somewhat Agree	3 = Neither Agree / Disagree	4 = Somewhat Disagree	5 = Strongly Disagree

13) How would it be helpful to use the measure in practice?

- *When, where and how would it be used in clinical practice or research? Completed alone, with a healthcare provider?*
- *How often would it be helpful to complete the measure? (Weekly? pre / post?)*
- *What timeframe would it be best to answer the questions about? (Last two weeks? 6 months?)*

14) What is it about the measure that would make it a better idea/more helpful/more acceptable?

15) How many items do you think would be a reasonable amount for an individual to answer?

16) Ending:

- Brief summary of discussion / next steps (i.e. future research) and thank for participation.
- Reminder that a lay summary of research will be sent out via email.
- Space for final thoughts / questions.

Appendix G

Reflexive Statement

The researcher identifies as a White British woman from a working-class background in the North West of England. The region where the researcher grew up is largely underfunded and under resourced in relation to healthcare services with several barriers to accessing support, particularly for individuals with more complex neurological and mental health presentations. The researcher has worked in a primary healthcare service in which such barriers, related to neurological conditions and comorbid presentations, were apparent. The researcher has a strong desire to ensure people receive appropriate and efficient psychological support. This aligns with the current research in that it recognises the complexity of FDS and aims to develop a standardised measure to ensure patients receive the most effective treatments, to demonstrate the effectiveness of therapeutic interventions, and, to aid with development of the evidence-base for different psychological approaches within this population.

At the time of this statement, the researcher is working as a Trainee Clinical Psychologist in an outpatient epilepsy service and an inpatient neurorehabilitation service. Clinically, the researcher therefore has more experience working with individuals experiencing epileptic seizures and acquired brain injury than with individuals with functional presentations. However, the severity, impact and complexity of functional neurological conditions has been apparent to the researcher throughout her clinical work. This is likely to have influenced the researcher's alignment with this population group. It is probable that this has been made stronger through witnessing stigma towards patients experiencing functional conditions, likely another motivational factor to complete this research. Therapeutically, the researcher favours a person-centred approach to support patients accessing healthcare service for support, to ensure they receive the "best fit" treatment for their needs.

Appendix H

Reflexive Log

Stage	Reflexive Comments
Lived experience focus group	Drop out during recruitment was high and I worried if enough participants would attend the initial focus group. I contemplated whether I should try to reschedule which was perhaps fuelled by my own anxiety. More than anything I did not want to have to cancel on those that were able to attend. I was reassured through research supervision and the group fortunately went ahead. I wondered if my anxieties were due to not having had any clinical experience with FDS and not wanting to come across as "lacking in knowledge" by the group. The group dynamic felt relaxed and supportive; it was joyful to hear participants share similar perspective at the end of the focus group and seemingly validating each other's experiences. I don't know why but I was mesmerised by how insightful and knowledgeable the group were when talking about FDS. I do wonder how they perceived me. I definitely did not feel like the 'expert' in the room and hope I did not come across like this. I'm not sure why I feel averse to that. On reflection, I wonder if I had a different expectation of the group due to the literature related to patient difficulties talking about FDS. Interestingly it could be difficult to interrupt the group at times and I do wonder how much it went off track. I feel apprehensive that this may impact the data collection. It was difficult to witness people experience a FDS during the focus group and a naively hadn't expected this. It felt one lady had less opportunity to contribute to the discussions due to the frequency of her seizures. I notice I was avoidant of trying to bring her into the discussion more as I did not want to

	potentially trigger further seizures. I think this may be influenced by my role as a therapist and feeling pulled to take a protective role for service users.
Healthcare professional focus group	I had been more anxious to facilitate this focus group which was definitely due to amount of expertise "in the room". I think facilitating this group second probably eased my anxiety. This group felt much less free flowing than the first group or 'professional' so to say. I felt more uneasy facilitating this. I notice I was pulled to ensure there were no gaps of silence and at times I found myself contributing to the discussions, almost as though I was advocating for what the individuals with FDS had said. I realise this probably reflects my clinical role and I find it difficult to switch to the 'researcher hat'. I do wonder if interviews would have been a better option with healthcare professionals – or maybe this is just because I feel awkward about how the group went? There was a very dominant voice in the group and I found myself frustrated waiting for them to finish what they were saying. I wonder if this frustration was fuelled by the fact I need this data in such a short time scale and don't want it to be irrelevant. I will need to be mindful of this when coding to make sure I pay as much attention to these comments. Having had both group discussions, I'm even more disappointed we do not have any caregiver representation and wonder if this would have impacted how this analysis pans out.
Transcription / Familiarisation	This has been a more time-consuming process than I anticipated and at times, it has been frustrating transcribing content when it has not been directly relevant to the research aims. Though, I do feel some of the context of this will be important to understand seizure severity and I therefore do not want to overlook this. This is my first-time transcribing, and I am surprised by how helpful it has been in getting to know the data. I'm noticing more dominant voices now that I'm relistening to the audio

	files and I'm surprised I didn't notice this in the group. I wonder if I felt more aligned with these participants than others. I notice one of the quieter voices was the only male participant with lived experience. He shared being newly diagnosed and I wonder if this influence group dynamics (as was the lady who was experiencing seizures). *Initial notes – emphasis on physical symptoms, so much overlap between the groups, this really is going to be more difficult than I anticipated (and the participants agree!), FDS is even more complex than I realised, LE are very insightful about the condition (knowledge of subjectivity, heterogeneity), advocation for a caregiver measure (discuss with supervisors?), management of seizures doesn't reduce severity (acceptance? Getting used to it? Normalising?), rating/ranking system – I don't know where to start (I want to include suggestions from the lived experience participants but it does not feel feasible for use clinically), self-report of symptom severity, awareness impact? So much stigma, I'm not sure how this will come out in the analysis, it feels away from the research aims but I feel obliged to talk about this, these experiences seem to impact "in-the-moment" thoughts and feelings during seizures. I really failed at trying to avoid the QoL discussions which I guess is interesting.*
Coding	This is a much more time-consuming process than I anticipated. I never feel done with the codes. Like previous stages, I wonder if I feel pressured by the timescales of the project. I need to take breaks from this and go back to it or I find I am pulled to rush through. It has been difficult generating codes that feel succinct enough but reflect the importance of what someone is saying. I

	worry about doing the people with LE a misjustice by missing what they say. I wonder if my alignment to this group is making me find more of what they're saying is relevant. I also feel a pull to pay extra attention to those that spoke less. I've mapped out some of my initial codes and how they link and I am feeling overwhelmed. I do not know how I am going to make sense of all the data. I've shared this with my supervisors and I know I'm going to need to go back to refine the codes which is frustrating. It has made me realise however how much I overlooked the emotional / psychological aspects initially. Especially in the LE group. Though they emphasised the physical symptoms they definitely talk about the rest too. I wonder if this was perhaps influence by my knowledge of the literature. I feel the need to recheck more of the codes in case I have missed something. I've gone back to refine codes again and I'm noticing I'm starting to find this easier. It really helps to start to notice succinct phrases that manage to capture what people are saying (almost like a win). It's a weird feeling noticing something new even though I've read it several times. This is definitely driving me forward to keep going. I wonder if this relief is more from a perspective of wanting to get this work completed. I've started mapping out some codes and I'm noticing a lack of control is an obvious theme coming through. I'm surprised it's taken me to this point to see this. It's made me reflect on what control means to me and I realise this feels like something that is easy to forget about until you experience something that makes you feel like you lose your sense of control and independence. I feel strongly about advocating for this theme. I'm noticing when I'm making reflections so much of it is about the participants with LE. I feel worried that I have not

	appreciated the contributions of the healthcare professionals as much. Perhaps this is because I'm a healthcare professional myself? I wonder if it would have been different if I'd facilitated this group first.
Generating themes	Its definitely helping to have thematic maps for this process, even if I have started with far too much information. Each time I've refined the codes I'm noticing I'm starting to make more links with the data. There's definitely something about the worst types of seizures being the worst physical symptoms, emotional reactions, etc. But I'm not sure this is a theme. This feels more broadly about what all the data is about. I need to somehow represent the physical symptoms somehow but without neglecting the rest. I'm starting to notice the consequences of seizures is constantly appearing in so many different forms. Every time a new theme or subtheme starts to emerge I almost feel surprised like it's a 'lightbulb moment' although it is somewhat not surprising. I do feel I've neglected to report a lot about the stigma experienced by the group but wonder if that is influenced more by my own need to "shout about" it than relevant to the research aims. I find it frustrating rereading these quotes and knowing colleagues have been part of that stigma at times. I notice I'm coming back to one of my initial ideas about familiarity of the seizures. For some reason it has stuck with me since the LE focus group. Perhaps something about how the group spoke about their seizures is influencing this. It was so blasé and that's what's stuck with me more than the words. I wonder if I'm comparing this to some of the patients I've seen recently with epilepsy. It does make me reflect on my own privilege to not be suffering with any physical health comorbidities.

	I can imagine it is hard to truly understand such a chronic diagnosis until you experience one. I feel slightly guilty about this and wonder if it is another aspect that has held me with such a strong alliance to the LE group. I feel relieved to have gotten to where I am with the themes and even more relieved that the research team are in agreement.

Appendix I

Reiterations of Thematic Maps

Version 1

Figure I1

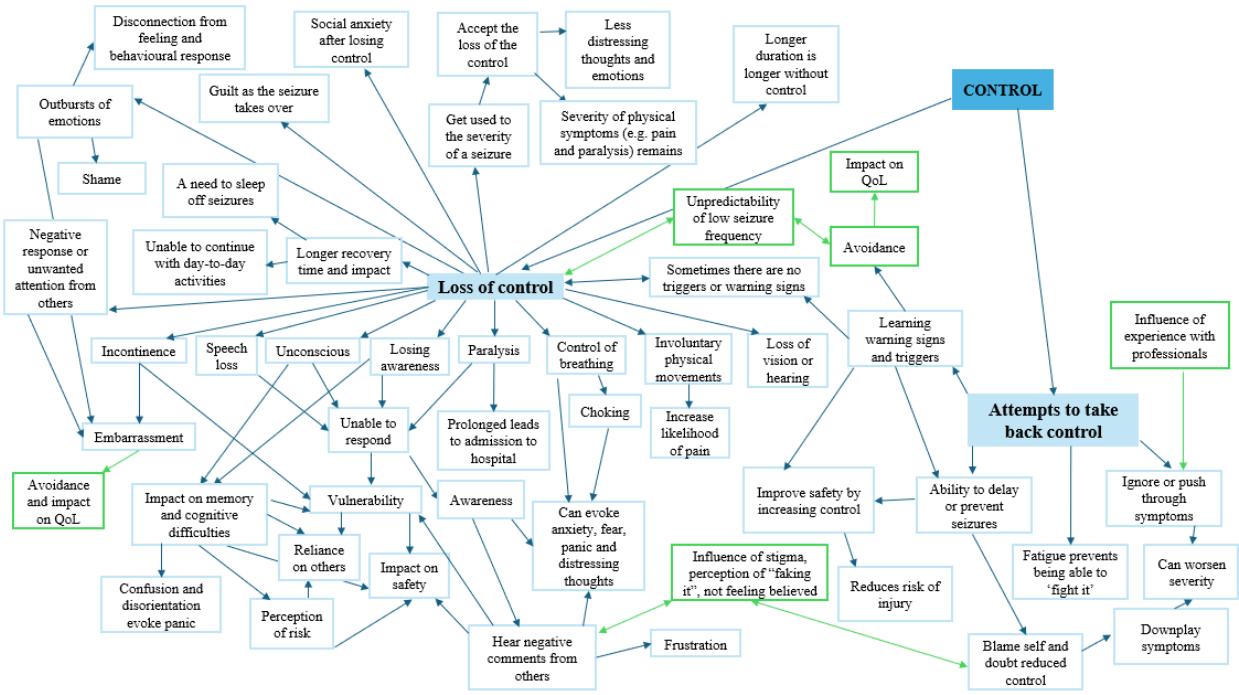
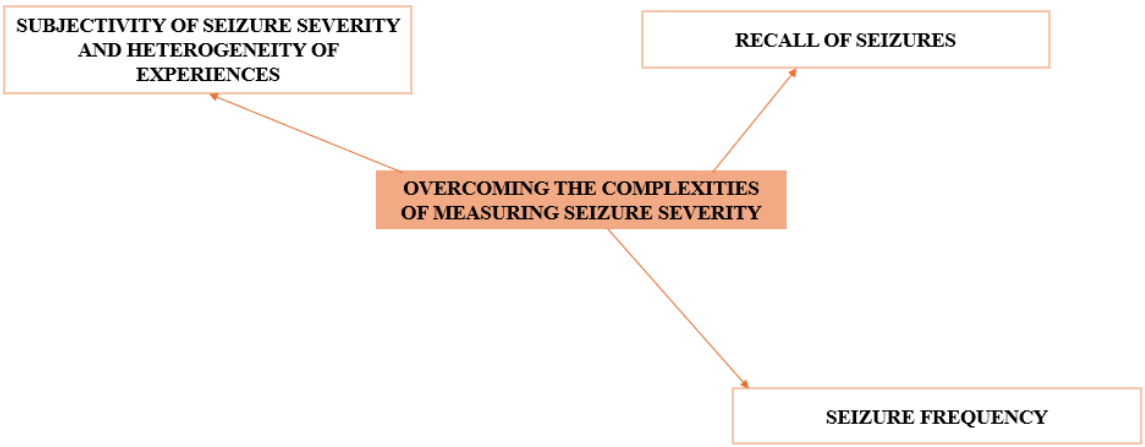


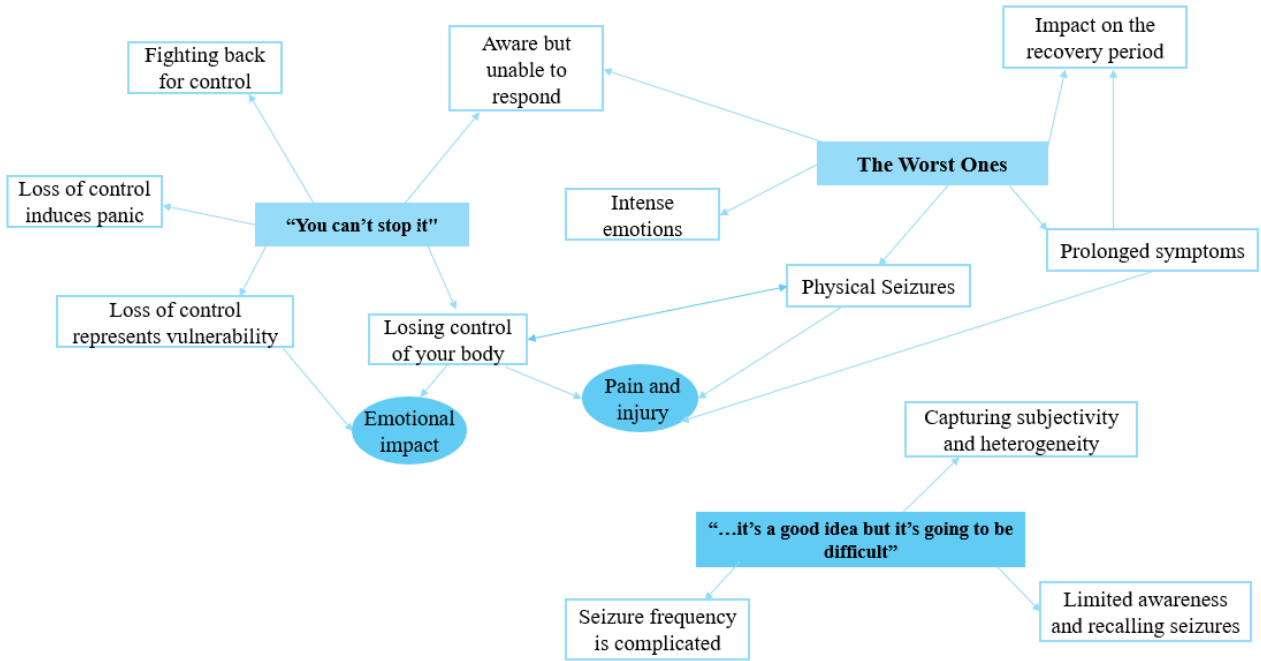
Figure I2

Figure I3



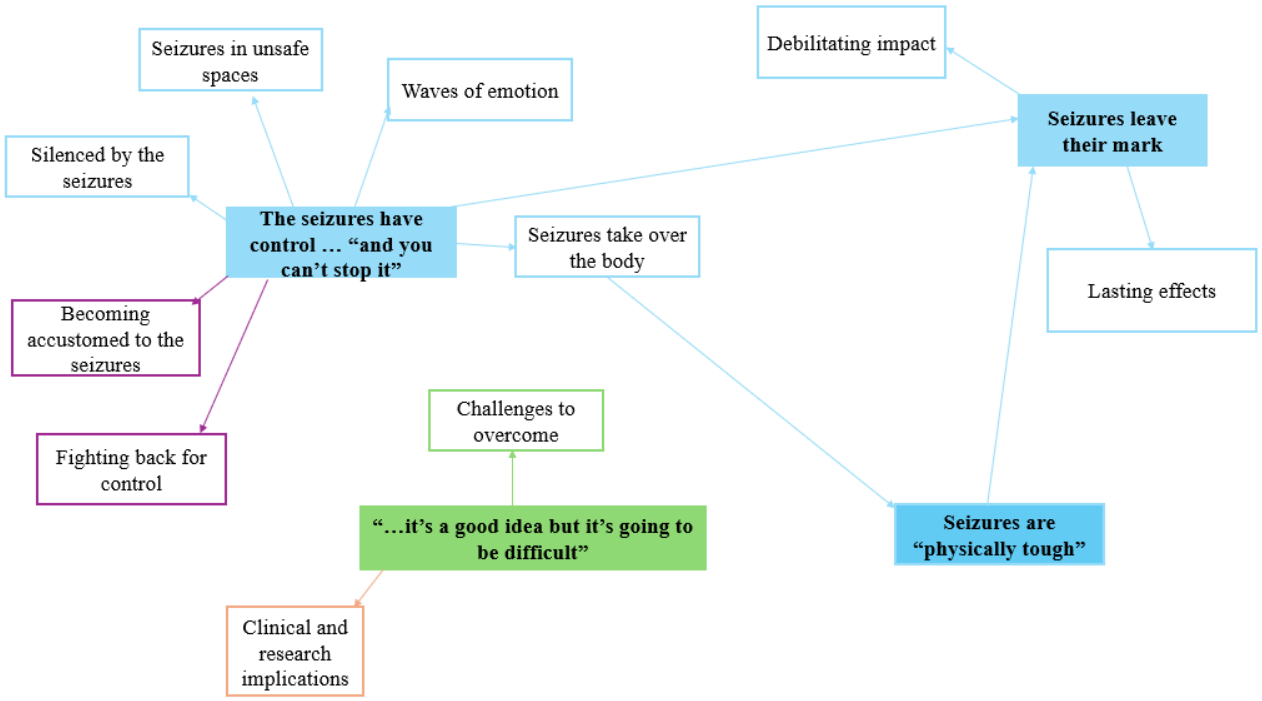
Version 2

Figure I4



Version 3

Figure I5



Appendix J

Round One Delphi Survey

* Developing a Self-Report Questionnaire of Functional / Dissociative Seizure Severity

Functional / Dissociative Seizures are a common symptom of Functional Neurological Disorder (FND) and have a significant impact for individuals living with them. We are developing a self-report questionnaire that will be used to understand and assess the severity of Functional / Dissociative Seizures.

There is currently no measure that assesses the severity of the seizures themselves which are typically a key and distressing symptom for the individuals that experience them. We will therefore be asking you about factors related to **immediately before, during, and immediately after a Functional / Dissociative Seizure**. Please be aware of this when providing your responses.

We understand that these seizures can have a significant impact on the wider quality of life for individuals living with them and general functioning however there are already general measures that aim to assess this.

*

BEFORE A SEIZURE

Thinking about the period immediately before a seizure...

For each item, **please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.**

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I have felt anxious or scared waiting for a seizure to happen.	○	○	○	○	○	○	○	○	○	○	○
2. I have struggled to cope before experiencing a seizure.	○	○	○	○	○	○	○	○	○	○	○
3. I have no control over when my seizures are going to happen.	○	○	○	○	○	○	○	○	○	○	○
4. My seizures have been unpredictable.	○	○	○	○	○	○	○	○	○	○	○
5. My seizures seem to come on from nowhere.	○	○	○	○	○	○	○	○	○	○	○
6. I have been unable to relax in the build up towards my seizures.	○	○	○	○	○	○	○	○	○	○	○

7. I have felt tired or fatigued in the build up towards my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
8. I have experienced physical symptoms in the build up towards my seizure (e.g. unable to move, visual / hearing difficulties, pain, uncontrollable physical movements)	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
9. I have experienced distressing emotions in the build up towards my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
10. I have felt overwhelmed in the build up to my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
11. I have felt threatened in the build up to my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
12. I have struggled to get my words out in the build up towards my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
13. I have lost control of my breathing in the time before my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
14. I have felt oversensitive before a seizure (e.g. to sounds, smells, light, etc.)	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
15. Before my seizures, I have negative thoughts about myself related to experiencing a seizure.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

*

BEFORE A SEIZURE

Thinking about the period immediately before a seizure...

For each item, **please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.**

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I know what triggers my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
2. My awareness of seizure triggers has allowed me to cope better with my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
3. I have felt to blame for triggering my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
4. I have had warning signs before my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
5. I've had enough warning to make myself safe before my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
6. Being aware of my seizure warning signs has helped me to cope better with my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

Optional **space for you to tell us why you think these items should or should not be included in the questionnaire** (this will be shared with other participants anonymously before ranking items in the next round).

BEFORE A SEIZURE

Are there any other questions related to the period immediately before a seizure you feel should be considered to assess seizure severity? (Skip to the next page if No).

DURING A SEIZURE

Thinking about the period **during a seizure**...

For each item, **please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.**

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I have had no control of my body during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
2. I have experienced pain during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
3. I have been injured during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
4. I have struggled to breathe during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
5. I have experienced involuntary physical movements during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
6. I have experienced contortion or stiffness during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
7. I have experienced weakness in my body during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
8. During my seizures, I have become completely paralysed.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
9. During my seizures, a part of my body has become paralysed.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
10. During my seizures, I have wet myself.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
11. During my seizures, I have lost bowel control.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

12. I have not been able to see anything during my seizures.	○	○	○	○	○	○	○	○	○	○	○
13. I have not been able to hear anything during my seizures.	○	○	○	○	○	○	○	○	○	○	○
14. I have had difficulty speaking during my seizures.	○	○	○	○	○	○	○	○	○	○	○
15. I have experienced seizures in which I suddenly drop to the floor.	○	○	○	○	○	○	○	○	○	○	○
16. I have experienced hypersensitivity during a seizure (e.g. to sounds, smells, light, etc.)	○	○	○	○	○	○	○	○	○	○	○
17. I have experienced hypo-sensitivity during a seizure (e.g. to sounds, smells, light, etc.)	○	○	○	○	○	○	○	○	○	○	○

Optional space for you to tell us why you think these items should or should not be included in the questionnaire (this will be shared with other participants anonymously before ranking items in the next round).

*

DURING A SEIZURE

Thinking about the period **during a seizure**...

For each item, **please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.**

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I have had distressing emotions during my seizures (such as fear, anger, or sadness).	○	○	○	○	○	○	○	○	○	○	○
2. I have felt embarrassed during my seizures.	○	○	○	○	○	○	○	○	○	○	○
3. I have felt helpless during my seizures.	○	○	○	○	○	○	○	○	○	○	○
4. I have felt like I am losing my mind during my seizures.	○	○	○	○	○	○	○	○	○	○	○
5. During my seizures, I have panicked they were never going to end.	○	○	○	○	○	○	○	○	○	○	○
6. During my seizures, I have panicked that my seizure would get worse.	○	○	○	○	○	○	○	○	○	○	○
7. I have had distressing thoughts during my seizures.	○	○	○	○	○	○	○	○	○	○	○
8. I have had thoughts about wanting my life to end or felt suicidal during a seizure.	○	○	○	○	○	○	○	○	○	○	○

*

DURING A SEIZURE

Thinking about the period **during a seizure**...

For each item, **please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.**

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I have lost awareness during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
2. I have been completely unconscious during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
3. During my seizures, I have felt like I am on the outside of my own body.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
4. During my seizures, I have felt like the world around me is not real or like I am in a dream.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
5. I have been aware of what is going on around me during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
6. I am unable to respond to things happening around me during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

Optional space for you to tell us why you think these items should or should not be included in the questionnaire (this will be summarised and shared with other participants anonymously before ranking items in the next round).

*

DURING A SEIZURE

Thinking about the period **during a seizure**...

For each item, **please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.**

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. My seizures have happened in places where I do not feel safe.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
2. I have not been able to stop my seizures after they had started.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
3. I have made my seizures worse when I have tried to fight against them or stop them.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

Optional space for you to tell us why you think these items should or should not be included in the questionnaire (this will be summarised and shared with other participants anonymously before ranking items in the next round).

DURING A SEIZURE

Are there any other questions related to the period during a seizure you feel should be considered to assess seizure severity? (Skip to the next page if No).

*

AFTER A SEIZURE

Thinking about the period **immediately after** **a seizure**...

For each item, please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I have continued to experience distressing physical symptoms in the hours after my seizures have ended (e.g. shaking, paralysis, involuntary movements, incontinence).	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
2. I have experienced pain in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
3. I have taken a long time to recover after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
4. I have been exhausted in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
5. I have needed sleep in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
6. My balance and coordination have been affected in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
7. I have had falls in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
8. I have had difficulties with my eyesight in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
9. I have had hearing difficulties in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

AFTER A SEIZURE

Thinking about the period **immediately after a seizure**...

For each item, **please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.**

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I have felt confused in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
2. I have had difficulties thinking straight in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
3. I have been disorientated in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
4. I have felt 'spaced out' in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
5. I have forgotten what has happened during my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
6. I have forgotten that I have had a seizure.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
7. I have not recognised people I know after a seizure.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
8. I have not always made the best choices for myself immediately after a seizure.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

Optional **space for you to tell us why you think these items should or should not be included in the questionnaire** (this will be summarised and shared with other participants anonymously before ranking items in the next round).

*

AFTER A SEIZURE

Thinking about the period **immediately after** **a seizure**...

For each item, please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I have experienced overwhelming emotions after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
2. I have felt extremely low, sad, or tearful after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
3. I have felt like the seizures have 'won' in the hours after I have had them.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
4. I have felt stressed in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
5. I have felt anxious or scared in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
6. I have felt ashamed or embarrassed in the hours after my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
7. I have had negative thoughts about myself soon after having a seizure.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
8. My seizures have made me feel hopeless.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
9. I have worried I would have another seizure in the hours after a seizure.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
10. I have not felt in control of my body's emotional reaction in the hours immediately after a seizure (e.g. I may be crying but I do not feel sad).	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
11. My seizures have caused me to panic immediately after I have had one.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
12. I have struggled to cope in the time after a seizure.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

Optional space for you to tell us why you think these items should or should not be included in the questionnaire (this will be summarised and shared with other participants anonymously before ranking items in the next round).

*

AFTER A SEIZURE

Thinking about the period **immediately after** **a seizure**...

Please indicate on the scale how relevant you think the item is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.

1a. "After a seizure, I have been able to return to what I was doing within 'X'"
(with 'X' being replaced by "a reasonable amount of time")

0	1	2	3	4	5	6	7	8	9	10
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

* **1b. If we included the question above, what would you think of as a "reasonable amount of time" to ask?** *(i.e. to replace 'X' in the question above)*

- ◯ Ten minutes
- ◯ One hour
- ◯ One day

Optional space for you to tell us why you think this item should or should not be included in the questionnaire (this will be summarised and shared with other participants anonymously before ranking items in the next round).

AFTER A SEIZURE

Are there any other questions related to the period immediately after a seizure you feel should be considered to assess seizure severity? (Skip to the next page if No).

*

GENERAL SEIZURE BURDEN

Thinking about functional / dissociative seizures more **generally...**

For each item, please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.

	Extremely Irrelevant 0	1	2	3	4	Neither Relevant nor Irrelevant 5	6	7	8	9	Extremely Relevant 10
1. I have avoided things I enjoy to stop my seizures from happening (e.g. leaving the house, stopped usual / enjoyable activities, isolated myself).	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
2. I have experienced clusters of seizures (i.e. seizures close together over one or several days).	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
3. I have been in and out of a seizure with full recovery in between.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
4. I have been admitted to hospital because of my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
5. My seizures have been distressing for me.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
6. My seizures have been getting worse.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
7. I have been experiencing seizures that have been unusual or changed.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
8. I have struggled to cope in between seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯
9. I have felt able to manage my seizures.	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

10. I have felt as though I cannot keep living with these seizures.	○	○	○	○	○	○	○	○	○	○	○
11. The frequency of my seizures is increasing.	○	○	○	○	○	○	○	○	○	○	○
12. The duration of my seizures is increasing.	○	○	○	○	○	○	○	○	○	○	○
13. The time in between my seizures is increasing.	○	○	○	○	○	○	○	○	○	○	○
14. The time it takes me to recover from a seizure is increasing.	○	○	○	○	○	○	○	○	○	○	○
15. My seizures have been bothersome.	○	○	○	○	○	○	○	○	○	○	○
16. The seizures have negatively impacted on my sleep.	○	○	○	○	○	○	○	○	○	○	○
17. The seizures have negatively impacted on my diet.	○	○	○	○	○	○	○	○	○	○	○
18. The seizures have negatively impacted on my relationships.	○	○	○	○	○	○	○	○	○	○	○
19. The seizures have negatively impacted on my ability to fulfil my role (e.g. parenting, employment)	○	○	○	○	○	○	○	○	○	○	○

20. "How severe would you rate most seizures you have experienced?"

1) Mild

2) Moderate

3) Moderate-Severe

4) Severe

○	○	○	○	○	○	○	○	○	○	○
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

<u>Optional</u> space for you to tell us why you think this item should or should not be included in the questionnaire (this will be summarised and shared with other participants anonymously before ranking items in the next round).

GENERAL SEIZURE BURDEN

Are there any other questions related to general seizure burden you feel should be considered to assess seizure severity? (Skip to the next page if No).

*

ADDITIONAL SEIZURE MEASURES

Thinking about some additional questions to ask about functional / dissociative seizures severity...

For each item, please indicate on the scale how relevant you think it is to include on a questionnaire that will assess the severity of a Functional / Dissociative Seizure.

1. "How would you best describe the frequency of the seizures you experience?"

My seizures have been more common than one per day

Less common than one per day but more than one per week

Less common than one per week but more common than one per month

Less common than one per month but more common than one per year

No seizures for the last year

0	1	2	3	4	5	6	7	8	9	10
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

***2. "How many seizures have you experienced over the last month?"**

0	1	2	3	4	5	6	7	8	9	10
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

*3. "What is the most amount of seizures you have experienced in a single day?"

0	1	2	3	4	5	6	7	8	9	10
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

*4. "How long was your longest seizure?"

..... second(s) / minute(s) / hour(s)

0	1	2	3	4	5	6	7	8	9	10
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

*5. "When was the last time you had a seizure?"

..... hour(s) / day(s) / week(s) / month(s) / year(s) ago

0	1	2	3	4	5	6	7	8	9	10
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

*6. "How long does it usually take you to recover after a seizure?"

..... second(s) / minute(s) / hour(s) / day(s)

0	1	2	3	4	5	6	7	8	9	10
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

*7. "What has been the longest gap between your seizures?"

0	1	2	3	4	5	6	7	8	9	10
Extremely Irrelevant					Neither Irrelelevant nor Relevant					Extremely Relevant

Optional **space for you to tell us why you think this item should or should not be included in the questionnaire** (this will be summarised and shared with other participants anonymously before ranking items in the next round).

ADDITIONAL SEIZURE MEASURES

Are there any other questions you feel should be considered to assess seizure severity? (Skip to the next page if No).

*

Thinking about all of the items you have seen today, in what timeframe would it be helpful to ask these questions about?

- ◯ A certain time frame such as 'over the last two weeks' or 'over the last month'
- ◯ A more general time frame such as "these days"
- ◯ A more general time frame such as "recently"

Appendix K

Round One Delphi Feedback Document

Delphi Survey Round 1 Feedback

As you are aware, we aim to develop a self-report questionnaire (also known as a patient reported outcome measure) that describes the current severity of an individual's Functional / Dissociative Seizures (FDS) from their perspective. This will be a measure related to the seizures themselves (i.e. the period immediately before, during and after a seizure) as opposed to measuring the impact of seizures on the patient's wider quality of life or wellbeing (as there are already measures for this).

In **Round 1**, we asked you to rate **a total of 116 items** in terms of relevance. A total of **90 participants** completed this process. The participants included individuals with lived experience of FDS, caregivers and professionals. This is a fantastic response and we want to thank everyone who took part!

We now aim further to reduce the number of items which will be included in the final questionnaire so that we are ultimately left with a questionnaire that is short enough to be used in clinical practice. The final questionnaire should only include the items which are most relevant to the assessment of FDS severity as determined by a consensus by those taking part in this project.

As a result of your responses to **Round 1** of the survey we have:

- **Set aside 12 items** because overall, people agreed that these were the **most relevant items.**
- **Removed 16 items** because overall, people agreed that these were the **least relevant items.**

In **Round 2** we have a **total of 88 items which continue to be candidates for inclusion.** In order to **reduce this further,** we want you to decide whether each item:

1) Should be **included** in the final questionnaire measuring FDS severity.
   OR
2) Can be **excluded** from the final questionnaire measuring FDS severity.

Before you make your decision, we would like you to **read the qualitative feedback on the candidate items provided by participants in Round 1** of the Delphi survey. **This is available on the Qualtrics survey as you complete it but can also be seen in this document.** This should help you to consider other participants' perspectives. While not everyone's written feedback is shown below, please be assured that we have read all comments and sought to reflect all points raised in our summaries. If we included all of the comments we received, this document would be four times longer.

In addition to the qualitative feedback, we will share the participants' ratings from Round 1 of the Delphi process with you. We will show you the **median rating** and **interquartile range** for each of the items. These are provided on the next page.

The **median** rating is the middle score of all participants for that particular item. You may recall that items were rated from 0-10 on a Likert scale with 0 being the least and 10 the most relevant rating. For example, the 12 items we have set aside achieved a medium of 10, with 10 representing most relevant.

The **interquartile range (IQR)** tells us how spread-out participants' scores were around the median. A lower IQR indicates a high level of agreement between raters. A high IQR a broader range of different views.

To summarise, a median as high as possible (10.00) and an IQR as low as possible (0.00) indicated a high level of relevance and complete agreement between participants. As the median decreases this suggests the item may be less relevant. As the IQR increases, this suggests there is less agreement amongst participants about whether this item is relevant or irrelevant.

Scores and Feedback from Round 1

Please note, some of these items may have been slightly reworded based on feedback from the previous round.

Before a Seizure

Items	Median	IQR
1. I have felt anxious or scared waiting for a seizure to happen.	8.00	3.00
2. My seizures have been unpredictable.	9.00	3.00
3. My seizures seem to come on from nowhere.	8.00	4.00
4. I have been unable to find ways to relax when I feel that I might have a seizure.	8.00	4.00
5. I have felt tired or fatigued in the build up towards my seizures.	8.00	3.00
6. I have experienced physical symptoms in the build up towards my seizure (e.g. unable to move, visual / hearing difficulties, pain, uncontrollable physical movements).	9.00	2.00
7. I have experienced distressing emotions in the build up towards my seizures.	8.00	4.00
8. I have felt overwhelmed in the build up to my seizures.	8.00	3.25
9. I have struggled to get my words out in the build up towards my seizure.	8.00	4.00
10. I experience increased sensitivity before a seizure (e.g. to sounds, smells, light, etc.).	8.00	3.00

In the box below is some of the written feedback summarised from participants.

'Why are items relevant'	'Why are items not relevant'
The items are related to treatment. Two participants mentioned how the items help to understand the condition and support insight. One participant said this could help improve control of seizures. One participant felt the items were extremely relevant and they had noticed a pattern to their FDS involving sounds, light, overload in pain, and the unpredictability of the events.	Five participants felt some of the items may be important and relevant to characterise a seizure but may not be relevant to assess seizure severity. Two participants suggested some of the items were similar. When this is the case, it was suggested items could be combined, or preferred items selected. One participant said they do not generally feel pre-seizure questions should be part of the

One participant talked about how for some people, seizures can be linked to emotional distress but in her daughter's case, they were directly linked to pain levels. One person thought Item 2 is relevant to guide treatment decisions. One participant felt Item 6 included a lot of different aspects that would affect severity very differently. Another person thought Item 9 was extremely relevant and often missed. One participant stated they particularly liked items on fear of having a seizure, lack of control, and unpredictability. Symptoms of hypersensitivity, panic, and other physical symptoms were described as important/relevant as well.	questionnaire unless the symptoms themselves are disabling. One participant felt some of the items were not relevant to this period as they would occur within a longer time scale. One person explained Item 1 may suggest an individual has control of when their seizure is coming and could sound blaming. Two participants felt Item 3 was similar to another item ('I have no control of when my seizures are going to happen' - this item is among those previously rated as highly relevant with low levels of disagreement, so it has already been set aside for inclusion in the final questionnaire).

Triggers / Warning Signs

Items	Median	IQR
1. I know what triggers my seizures.	8.00	4.00
2. My awareness of seizure triggers has allowed me to cope better with my seizures.	8.00	4.00
3. I have had warning signs before my seizures.	8.00	4.00
4. I've had enough warning to make myself safe before my seizures.	8.00	5.00
5. Being aware of my seizure warning signs has helped me to cope better with my seizures.	8.50	4.00

In the box below is some of the written feedback summarised from participants.

'Why are items relevant'	'Why are items not relevant'
One participant felt these are important questions as the answers may support ways a person's safety could be improved. Similarly, another participant felt understanding triggers / warning signs allowed them to take themselves out of a situation.	Two participants talked about how for some people, seizures feel unpredictable and random so these questions do not feel relevant. Two participants felt that many people do not recognise warning signs or a build-up of

Four participants mentioned it can be helpful to identify potential triggers as this can help individuals to understand their seizures better and potentially help to manage them. Two participants felt these may help people to feel more in control of their seizures. One participant described how the main difference between their epileptic seizures and FDS is she knows when a seizure is imminent.	physical or emotional symptoms before a seizure. One person explained seizure triggers and warning signs can change which makes it difficult to understand them. Four participants said these questions may be useful but their relevance to severity of seizures is indirect. It may be likely that more warning signs suggest someone is better able to manage them. Similarly, another participant talked about how warning signs can affect individuals positively or negatively. Warning signs before a seizure might add to the overall discomfort of having a seizure but can also be experienced as a seizure not being as bad as one that comes from nowhere and leaves no time for preparations. One participant felt these questions were different ways of asking the same thing and one question about awareness of triggers and warning signs may be more useful. One participant felt questions should be excluded if they ask about how often the triggers are the same and if different triggers mean different styles of seizure.

During a Seizure

During a Seizure – Section 1

Items	Median	IQR
1. I have experienced physical pain during my seizures.	9.00	4.00
2. I have been injured during my seizures.	9.00	3.00
3. I have struggled to breathe during my seizures.	9.00	2.00
4. I have experienced weakness in my body during my seizures.	10.00	3.00
5. During seizures, I have become completely paralysed.	9.00	3.00
6. During seizures, a part of my body has become paralysed.	9.00	4.00
7. During seizures, I have lost control of my bladder.	8.00	5.00
8. I have not been able to see anything during my seizures.	8.00	5.00
9. I have experienced seizures in which I suddenly drop to the floor.	9.00	4.00
10. I have felt highly sensitive during a seizure (e.g. to sounds, smells, light, etc.)	9.00	3.00

11. I have felt under sensitive during a seizure (e.g. to sounds, smells, light, etc.)	8.00	5.00

In the box below is some of the written feedback summarised from participants.

'Why are items relevant'	'Why are items not relevant'
One person said items 5 and 6 could be grouped. One participant thought this gives a clear picture of what a person does during a seizure. Another said these symptoms are extremely relevant to how severe seizures are.	One participant felt a number of these items may be relevant to the intensity of seizures but was uncertain they explicitly addressed seizure severity. Similarly, another participant felt they were characteristics of a seizure but did not relate to severity.

During a Seizure – Section 2

Items	Median	IQR
1. I have had distressing emotions during my seizures (such as fear, anger, or sadness).	8.00	4.00
2. I have felt embarrassed during my seizures.	8.00	4.00
3. I have felt helpless during my seizures.	10.00	3.00
4. I have felt like I am losing my mind during my seizures.	8.00	4.00
5. During my seizures, I have panicked that they were never going to end.	8.00	5.00
6. During my seizures, I have panicked that my seizure would get worse.	8.00	5.00
7. I have had distressing thoughts during my seizures.	8.00	3.75

In the box below is some of the written feedback summarised from participants.

'Why are items relevant'	'Irrelevant'
One participant described how these feelings and thoughts can impact the severity and duration of a seizure. It was suggested these items may indicate how to support a person as part of their care plan. One participant said these questions are not commonly asked and felt containing.	Four participants suggested some of these items may not be specifically relevant to the severity of a seizure. One thought Item 7 may be too broad for people to identify with and could be reworded. Another said Item 5 and 6 could be combined.

During a Seizure – Section 3

Items	Median	IQR
1. I have lost awareness during my seizures.	9.50	3.00
2. I have been completely unconscious during my seizures.	9.00	4.00
3. During my seizures, I have felt like I am disconnected from or on the outside of my own body.	9.00	3.00
4. During my seizures, I have felt like the world around me is not real or like I am in a dream.	8.00	4.00
5. I have been aware of what is going on around me during my seizures.	10.00	2.75

In the box below is some of the written feedback summarised from participants.

'Why are items relevant'	'Why are items not relevant'
Several participants wrote about how they agreed these items were directly relevant to seizure severity. It was also talked about how seizures can be severe both when a person is aware versus not aware for different reasons.	

During a Seizure – Section 4

Items	Median	IQR
1. My seizures have happened in places where I do not feel safe.	9.00	4.00
2. I have made my seizures worse when I have tried to fight against them or stop them.	8.50	4.00

In the box below is some of the written feedback summarised from participants.

'Why are items relevant'	'Why are items not relevant'
One participant described how having a seizure in an unsafe place can make you feel worse which in turn can heighten or lengthen a seizure. One participant described how they have stopped a seizure on one occasion with distraction techniques but this came back worse later on.	Four participants suggested these are important but not necessarily related to seizure severity. Another person explained that these items may suggest an individual can control their seizures. One person said Item 2 may be blaming towards individuals. Finally, one said item 2 could be reworded to take the blame off the individual.

After a Seizure

After a Seizure – Section 1

Items	Median	IQR
1. I have experienced pain in the hours after my seizures.	9.00	3.00
2. I have taken a long time to recover after my seizures.	9.00	2.00
3. I have needed to sleep in the hours after my seizures.	9.00	2.00
4. My balance and coordination have been affected in the hours after my seizures.	9.50	2.00
5. I have had difficulties with my eyesight in the hours after my seizures.	8.00	5.00
6. I have had speech difficulties in the hours after my seizures.	9.00	3.00
7. I have been injured during a seizure but have not needed medical attention.	8.00	5.00

In the box below is some of the written feedback summarised from participants.

'Why are items relevant'	'Why are items not relevant'
	Item 3 may be a duplication of another item 'I have been exhausted in the hours after my seizure' (the latter item was included in the previous round as the majority of participants agreed it was highly relevant).

After a Seizure – Section 2

Items	Median	IQR
1. I have felt confused in the hours after my seizures.	9.00	3.00
2. I have had difficulties thinking straight in the hours after my seizures.	9.00	3.00
3. I have been disorientated or not known where I was in the hours after my seizures.	9.00	3.00
4. I have felt 'spaced out' in the hours after my seizures.	9.00	3.00
5. I have forgotten what has happened during my seizures.	8.00	4.00
6. I have not always made the best choices for myself immediately after a seizure.	7.00	5.25

In the box below is some of the written feedback summarised from participants.

'Why are items relevant'	'Why are items not relevant'
One participant thought Item 1 and 2 could be combined. Another explained that Items 1, 2 and 3 could be combined.	One person said item 6 may be too vague. One participant felt these items may not be relevant to assess subjective seizure severity.

After a Seizure – Section 3

Items	Median	IQR
1. I have experienced overwhelming emotions after my seizures.	9.00	3.00
2. I have felt extremely low, sad or tearful after my seizures.	9.00	3.00

3. I have felt like the seizures have “won” in the hours after I have had them.	8.00	5.00
4. I have felt stressed in the hours after my seizures.	8.00	3.00
5. I have felt anxious or scared in the hours after my seizures.	9.00	3.00
6. I have felt ashamed or embarrassed in the hours after my seizures.	8.50	4.00
7. I have had negative thoughts about myself soon after having a seizure.	8.00	4.00
8. My seizures have made me feel hopeless.	8.00	3.25
9. I have worried I would have another seizure in the hours after a seizure.	8.00	4.00
10. I have not felt in control of my body’s emotional reaction in the hours immediately after a seizure (for example, I may be crying but I do not feel sad).	9.00	3.25
11. My seizures have caused me to panic or have a panic attack immediately after I have had one.	8.00	4.00
12. I have struggled to cope in the time after a seizure.	8.00	4.00

In the box below is some of the written feedback summarised from participants.

‘Why are items relevant’	‘Why are items not relevant’
One person said these items may help to assess and manage risk. One person explained some of these items could be combined to avoid repetition of similar items. Item 1 may cover several other items.	One participant felt these items related more to outcome than severity of a seizure. One participant felt these items related more to impact on quality of life as opposed to seizure severity.

After a Seizure – Section 4

Items	Median	IQR
1. After a seizure, I have been able to return to what I was doing within X time. (with X being replaced by “a reasonable amount of time”).	8.00	4.00

We asked you to replace “a reasonable amount of time” with a timeframe you felt was appropriate. The majority of participants (60) voted for **one hour.**

General Seizure Burden

Items	Median	IQR
1. I have experienced clusters of seizures (i.e. seizures close together over one or several days)	10.00	2.25
2. I have been in and out of seizures with full recovery in between.	8.00	5.00
3. I have been admitted to hospital as an emergency because of seizures.	10.00	3.00
4. My seizures have been distressing for me.	9.00	2.00
5. My seizures have been getting worse.	8.00	5.00
6. I have been experiencing seizures that have been unusual or changed.	8.00	4.00
7. I have struggled to cope in between seizures.	8.00	3.00
8. I have felt able to manage my seizures.	8.00	4.00
9. I have felt as though I cannot keep living with these seizures.	8.50	4.00

10. My seizures are becoming more frequent.	8.00	5.00
11. My seizures are lasting longer than they used to.	8.00	4.00
12. The time in-between my seizures is increasing.	8.00	4.25
13. The time it takes me to recover from a seizure is increasing.	8.00	4.00
14. The seizures have had a negative impact on my sleep.	8.00	5.00
15. The seizures have had a negative impact on my diet.	8.00	3.00
16. The seizures have had a negative impact on my ability to fulfil my role (e.g., parenting, employment).	9.00	3.00

'What are items relevant'	'Why are items not relevant'
	Two participants felt it is unclear what is meant by Item 2. One person explained item 3 is more related to the response of others around you and may not relate to seizure severity. One said these questions give someone's perception of their seizures but may not measure severity.

Additional Measures

Items	Median	IQR
1. How would you best describe the frequency of the seizures you experience? My seizures have been more common than one per day Less common than one per day but more common than one per week Less common than one per week but more common than one per month Less common than one per month but more common than one per year No seizures for the last year	9.00	3.00
2. How many seizures have you experienced over the last month?	9.00	3.00
3. What is the most amount of seizures you have experienced in a single day?	9.50	2.25
4. How long was your longest seizure?	9.50	2.00
5. When was the last time you had a seizure?	9.00	4.25
6. What has been the longest gap between your seizures?	9.00	4.00

'Why are items relevant'	'Why are items not relevant'
One person said Item 1 is excellent and providing these categories will make the data more reliable but I would also ask for more detail.	One said Item 1 should be removed. It is hard to read and make sense of. If I'd already answered several other questions, I would leave this out rather than try to work out what you are asking.

One participant felt the questions are relevant but very difficult to answer for someone who has a lot of seizures. One said item 5 and Item 6 seem most reliable. All should be included as they indicate a cluster or pattern of occurrence that can be established over time.	One person said one measure of frequency and one measure of duration would be more sufficient. One person felt the questions were challenging to answer and perhaps not relevant to this study.

General Comments

Generally, one participant felt there was not much difference between the phases before, during and after a seizure because they are either building towards a seizure or having one.

Timeframe

We asked you to tell us what timeframe it would be helpful to ask all the above questions about. The majority of participants (56) voted for a **specific** timeframe (e.g. in the past two weeks…).

Appendix L

Round Two Delphi Survey

* Developing a Self-Report Questionnaire of Functional / Dissociative Seizure Severity

Delphi Survey Round 2

As you are aware, we aim to develop a self-report questionnaire that describes the current severity of an individual's Functional / Dissociative Seizures (FDS) from their perspective. This will be a measure related to the seizures themselves (i.e. the period immediately before, during and after a seizure) as opposed to measuring the impact of seizures on the patient's wider quality of life or wellbeing (as there are already measures for this).

We now aim further to **reduce the number of items** which will be included in the final questionnaire so that we are ultimately left with a questionnaire that is short enough to be used in clinical practice. **The final questionnaire should only include the items which are most relevant to the assessment of FDS severity as determined by a consensus by those taking part in this project.**

Before completing this survey, please use the box below to type in your unique ID code that was emailed to you:

*

BEFORE A SEIZURE

For **each item below**, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe).
(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe).

Please consider the comments of other participants before making your selection.

'Why are items relevant'	'Why are items not relevant'
The items are related to treatment. Two participants mentioned how the items help to understand the condition and support insight. One participant said this could help improve control of seizures. One participant felt the items were extremely relevant and they had noticed a pattern to their FDS involving sounds, light, overload in pain, and the unpredictability of the events. One participant talked about how for some people, seizures can be linked to emotional distress but in her daughter's case, they were directly linked to pain levels. One person thought Item 2 is relevant to guide treatment decisions. One participant felt Item 6 included a lot of different aspects that would affect severity very differently. Another person thought Item 9 was extremely relevant and often missed. One participant stated they particularly liked items on fear of having a seizure, lack of control, and unpredictability. Symptoms of hypersensitivity, panic, and other physical symptoms were described as important/relevant as well.	Five participants felt some of the items may be important and relevant to characterise a seizure but may not be relevant to assess seizure severity. Two participants suggested some of the items were similar. When this is the case, it was suggested items could be combined, or preferred items selected. One participant said they do not generally feel pre-seizure questions should be part of the questionnaire unless the symptoms themselves are disabling. One participant felt some of the items were not relevant to this period as they would occur within a longer time scale. One person explained Item 1 may suggest an individual has control of when their seizure is coming and could sound blaming. Two participants felt Item 3 was similar to another item ('I have no control of when my seizures are going to happen' - this item is among those previously rated as highly relevant with low levels of disagreement, so it has already been set aside for inclusion in the final questionnaire).

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have felt anxious or scared waiting for a seizure to happen.	○	○
2. My seizures have been unpredictable.	○	○
3. My seizures seem to come on from nowhere.	○	○
4. I have been unable to find ways to relax in the build up towards my seizures.	○	○
5. I have felt tired or fatigued in the build up towards my seizures.	○	○
6. I have experienced physical symptoms in the build up towards my seizure (e.g. unable to move, visual / hearing difficulties, pain, uncontrollable physical movements)	○	○
7. I have experienced distressing emotions in the build up towards my seizures.	○	○
8. I have felt overwhelmed in the build up to my seizures.	○	○
9. I have struggled to get my words out in the build up towards my seizures.	○	○
10. I have experienced increased sensitivity before a seizure (e.g. to sounds, smells, light, etc.)	○	○

Next page ›

*

TRIGGERS & WARNING SIGNS

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments of other participants before making your selection.

'Why are items relevant'	'Why are items not relevant'
One participant felt these are important questions as the answers may support ways a person's safety could be improved. Similarly, another participant felt understanding triggers / warning signs allowed them to take themselves out of a situation. Four participants mentioned it can be helpful to identify potential triggers as this can help individuals to understand their seizures better and potentially help to manage them. Two participants felt these may help people to feel more in control of their seizures. One participant described how the main difference between their epileptic seizures and FDS is she knows when a seizure is imminent.	Two participants talked about how for some people, seizures feel unpredictable and random so these questions do not feel relevant. Two participants felt that many people do not recognise warning signs or a build-up of physical or emotional symptoms before a seizure. One person explained seizure triggers and warning signs can change which makes it difficult to understand them. Four participants said these questions may be useful but their relevance to severity of seizures is indirect. It may be likely that more warning signs suggest someone is better able to manage them. Similarly, another participant talked about how warning signs can affect individuals positively or negatively. Warning signs before a seizure might add to the overall discomfort of having a seizure but can also be experienced as a seizure not being as bad as one that comes from nowhere and leaves no time for preparations. One participant felt these questions were different ways of asking the same thing and one question about awareness of triggers and warning signs may be more useful. One participant felt questions should be excluded if they ask about how often the triggers are the same and if different triggers mean different styles of seizure.

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I know what triggers my seizures.	○	○
2. My awareness of seizure triggers has allowed me to cope better with my seizures.	○	○
3. I have had warning signs before my seizures.	○	○
4. I've had enough warning to make myself safe before seizures.	○	○
5. Being aware of my seizure warning signs has helped me to cope better with my seizures.	○	○

Next page ›

*

DURING A SEIZURE

SECTION 1

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments from other participants before making your selection.

'Why are items relevant'	'Why are items not relevant'
One person said items 5 and 6 could be grouped. One participant thought this gives a clear picture of what a person does during a seizure. Another said these symptoms are extremely relevant to how severe seizures are.	One participant felt a number of these items may be relevant to the intensity of seizures but was uncertain they explicitly addressed seizure severity. Similarly, another participant felt they were characteristics of a seizure but did not relate to severity.

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have experienced physical pain during my seizures.	○	○
2. I have been injured during my seizures.	○	○
3. I have struggled to breathe during my seizures.	○	○
4. I have experienced weakness in my body during my seizures.	○	○
5. During seizures, I have become completely paralysed.	○	○
6. During seizures, a part of my body has become paralysed.	○	○
7. During seizures, I have lost control of my bladder.	○	○
8. I have not been able to see anything during my seizures.	○	○
9. I have experienced seizures in which I suddenly drop to the floor.	○	○
10. I have felt highly sensitive during a seizure (e.g. to sounds, smells, light, etc.)	○	○
11. I have felt under sensitive during a seizure (e.g. to sounds, smells, light, etc.)	○	○

Next page ›

*

DURING A SEIZURE

SECTION 2

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments from other participants before making your selection.

'Why are items relevant'	'Why are items not relevant'
One participant described how these feelings and thoughts can impact the severity and duration of a seizure. It was suggested these items may indicate how to support a person as part of their care plan. One participant said these questions are not commonly asked and felt containing.	Four participants suggested some of these items may not be specifically relevant to the severity of a seizure. One thought Item 7 may be too broad for people to identify with and could be reworded. Another said Item 5 and 6 could be combined.

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have had distressing emotions during my seizures (such as fear, anger, or sadness).	○	○
2. I have felt embarrassed during my seizures.	○	○
3. I have felt helpless during my seizures.	○	○
4. I have felt like I am losing my mind during my seizures.	○	○
5. During my seizures, I have panicked that they were never going to end.	○	○
6. During my seizures, I have panicked that my seizure would get worse.	○	○
7. I have had distressing thoughts during my seizures.	○	○

Next page >

*

DURING A SEIZURE

SECTION 3

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments from other participants before making your selection.

'Why are items relevant'	'Why are items not relevant'
Several participants wrote about how they agreed these items were directly relevant to seizure severity. It was also talked about how seizures can be severe both when a person is aware versus not aware for different reasons.	

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have lost awareness during my seizures.	○	○
2. I have been completely unconscious during my seizures.	○	○
3. During my seizures, I have felt like I am disconnected from my own body or on the outside of my own body.	○	○
4. During my seizures, I have felt like the world around me is not real or like I am in a dream.	○	○
5. I have been aware of what is going on around me during my seizures.	○	○

Next page >

*

DURING A SEIZURE

SECTION 4

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments from other participants before making your selection.

'Why are items relevant'	'Why are items not relevant'
One participant described how having a seizure in an unsafe place can make you feel worse which in turn can heighten or lengthen a seizure. One participant described how they have stopped a seizure on one occasion with distraction techniques but this came back worse later on.	Four participants suggested these are important but not necessarily related to seizure severity. Another person explained that these items may suggest an individual can control their seizures. One person said Item 2 may be blaming towards individuals. Finally, one said item 2 could be reworded to take the blame off the individual.

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. My seizures have happened in places where I do not feel safe.	○	○
2. I have made my seizures worse when I have tried to fight against them or stop them.	○	○

Next page ›

*

AFTER A SEIZURE

SECTION 1

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

'Why are items relevant'	'Why are items not relevant'
	Item 3 may be a duplication of another item 'I have been exhausted in the hours after my seizure' (the latter item was included in the previous round as the majority of participants agreed it was highly relevant).

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have experienced pain in the hours after my seizures.	○	○
2. I have taken a long time to recover after my seizures.	○	○
3. I have needed to sleep in the hours after my seizures.	○	○
4. My balance and coordination have been affected in the hours after my seizures.	○	○
5. I have had difficulties with my eyesight in the hours after my seizures.	○	○
6. I have had speech difficulties in the hours after my seizures.	○	○
7. I have been injured during a seizure but have not had to seek medical attention.	○	○

Next page ›

*

AFTER A SEIZURE

SECTION 2

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments from other participants before making your selection.

'Why are items relevant'	'Why are items not relevant'
One participant thought Item 1 and 2 could be combined. Another explained that Items 1, 2 and 3 could be combined.	One person said item 6 may be too vague. One participant felt these items may not be relevant to assess subjective seizure severity.

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have felt confused in the hours after my seizures.	○	○
2. I have had difficulties thinking straight in the hours after my seizures.	○	○
3. I have been disorientated in the hours after my seizures.	○	○
4. I have felt 'spaced out' in the hours after my seizures.	○	○
5. I have forgotten what has happened during my seizures.	○	○
6. I have not always made the best choices for myself immediately after a seizure.	○	○

Next page ›

*

AFTER A SEIZURE

SECTION 3

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments from other participants before to making your selection.

'Why are items relevant'	'Why are items not relevant'
One person said these items may help to assess and manage risk. One person explained some of these items could be combined to avoid repetition of similar items. Item 1 may cover several other items.	One participant felt these items related more to outcome than severity of a seizure. One participant felt these items related more to impact on quality of life as opposed to seizure severity.

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have experienced overwhelming emotions after my seizures.	○	○
2. I have felt extremely low, sad or tearful after my seizures.	○	○
3. I have felt like the seizures have "won" in the hours after I have had them.	○	○
4. I have felt stressed in the hours after my seizures.	○	○
5. I have felt anxious or scared in the hours after my seizures.	○	○
6. I have felt ashamed or embarrassed in the hours after my seizures.	○	○
7. I have had negative thoughts about myself soon after having a seizure.	○	○
8. My seizures have made me feel hopeless.	○	○
9. I have worried I would have another seizure in the hours after a seizure.	○	○
10. I have not felt in control of my body's emotional reaction in the hours immediately after a seizure (for example, I may be crying but I do not feel sad).	○	○
11. My seizures have caused me to panic or have a panic attack immediately after I have had one.	○	○
12. I have struggled to cope in the time after a seizure.	○	○

Next page ›

*

AFTER A SEIZURE

SECTION 4

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. After a seizure, I have been able to return to what I was doing within one hour.	○	○

Next page ›

*

GENERAL SEIZURE BURDEN

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments from other participants before making your selection.

'What are items relevant'	'Why are items not relevant'
	Two participants felt it is unclear what is meant by Item 2. One person explained item 3 is more related to the response of others around you and may not relate to seizure severity. One said these questions give someone's perception of their seizures but may not measure severity.

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have experienced clusters of seizures (i.e. seizures close together over one or several days).	○	○
2. I have been in and out of seizures with full recovery in between.	○	○
3. I have been admitted to hospital as an emergency because of seizures.	○	○
4. My seizures have been distressing for me.	○	○
5. My seizures have been getting worse.	○	○
6. I have been experiencing seizures that have been unusual or changed.	○	○
7. I have struggled to cope in between seizures.	○	○
8. I have felt able to manage my seizures.	○	○
9. I have felt as though I cannot keep living with these seizures.	○	○
10. My seizures are becoming more frequent.	○	○
11. My seizures are lasting longer than they used to.	○	○
12. The time in-between my seizures is increasing.	○	○
13. The time it takes me to recover from a seizure is increasing.	○	○
14. The seizures have had a negative impact on my sleep.	○	○
15. The seizures have had a negative impact on my diet.	○	○
16. The seizures have had a negative impact on my ability to fulfil my role (e.g., parenting, employment).	○	○

Next page ›

ADDITIONAL MEASURES

For each item, please **select one** of the following options:

(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)

(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe)

Please consider the comments from other participants before making your selection.

'Why are items relevant'	'Why are items not relevant'
One person said Item 1 is excellent and providing these categories will make the data more reliable but I would also ask for more detail. One participant felt the questions are relevant but very difficult to answer for someone who has a lot of seizures. One said item 5 and Item 6 seem most reliable. All should be included as they indicate a cluster or pattern of occurrence that can be established over time.	One said Item 1 should be removed. It is hard to read and make sense of. If I'd already answered several other questions, I would leave this out rather than try to work out what you are asking. One person said one measure of frequency and one measure of duration would be more sufficient. One person felt the questions were challenging to answer and perhaps not relevant to this study.

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

*1. **"How would you best describe the frequency of the seizures you experience?"**

My seizures have been more common than one per day

Less common than one per day but more common than one per week

Less common than one per week but more common than one per month

Less common than one per month but more common than one per year

No seizures for the last year

◯ (1) Should be included in my view

◯ (2) Can be excluded in my view.

*2. **"How many seizures have you experienced over the last month?"**

◯ (1) Should be included in my view

◯ (2) Can be excluded in my view.

*3. **"What is the most amount of seizures you have experienced in a single day?"**

- ◯ (1) Should be included in my view
- ◯ (2) Can be excluded in my view.

*4. **"How long was your longest seizure?"**

..... second(s) / minute(s) / hour(s)

- ◯ (1) Should be included in my view
- ◯ (2) Can be excluded in my view.

*5. **"When was the last time you had a seizure?"**

..... hour(s) / day(s) / week(s) / month(s) / year(s) ago

- ◯ (1) Should be included in my view
- ◯ (2) Can be excluded in my view.

*6. **"What has been the longest gap between your seizures?"**

- ◯ (1) Should be included in my view
- ◯ (2) Can be excluded in my view.

Next page ›

Optional space for you to provide any further feedback about the items you have ranked (please skip if you do not have anything else to add):

Next page ›

*

NEW ITEMS

Below is a list of new items proposed by participants in 'Round 1' of the Delphi survey.

For each item, please **select one** of the following options:
(1) Should be included in my view (i.e. the item is relevant in indicating whether seizures are severe)
(2) Can be excluded in my view (i.e. the item is not relevant in indicating whether seizures are severe).

Please note, we want you to consider whether you feel the item explicitly measures severity of seizures. Some of the items may be important in describing FDS but may not necessarily be relevant to assess how severe seizures are. If you feel the item is important to describe a seizure but does not make it more or less severe, please select option 2 'can be excluded'.

	(1) Should be included in my view	(2) Can be excluded in my view
1. I have difficulties with my speech in the build up to a seizure.	○	○
2. I become light-headed and dizzy in the period immediately before a seizure.	○	○
3. I experience headaches in the period immediately before a seizure.	○	○
4. I become disorientated and confused during the onset of a seizure.	○	○
5. My seizures have had a negative impact on my senses, such as making my eyesight or hearing worse.	○	○
6. I have lost my appetite because of my seizures.	○	○
7. I was able to take measures to delay or prevent a seizure.	○	○
8. I have felt nauseous during a seizure.	○	○
9. I have needed support from others to get the seizures to stop or make them less severe.	○	○

10. I am unable to take care of myself in the hours after a seizure.	○	○
11. I have experienced 'brain fog' after seizures.	○	○
12. I have experienced feelings of relief after my seizures.	○	○
13. I have experienced migraines or headaches after my seizures.	○	○
14. I have needed support with intimate care from someone else during and after a seizure.	○	○
15. My seizures have left me with new neurological symptoms (such as weakness or numbness) that have persisted after the seizure was over.	○	○
16. I have thought that I might die during my seizures.	○	○
17. During a seizure, I have felt completely "locked in", so I could not communicate with the outside world.	○	○
18. I do not have any recollection of what has happened during my seizures.	○	○
19. After a seizure, I have been able to return to what I was doing within a reasonable time.	○	○

*20. "What has been the average duration of your seizures?"

..... second(s) / minute(s) / hour(s)

◯ (1) Should be included in my view

◯ (2) Can be excluded in my view.

*21. On a scale of 0-100%:

- What percentage of your seizures have been severe? ____%
- What percentage of your seizures have been moderate? ____%
- What percentage of your seizures have been mild? ____%

◯ (1) Should be included in my view

◯ (2) Can be excluded in my view.

Optional space for you to provide any feedback about the new items you have ranked (please skip if you do not have anything else to add):

Next page >

*After listening to people's comments, we wonder whether the final questionnaire could take the form of three sections:

1. **Section 1**: A checklist of common symptoms people experience associated with their seizures.
2. **Section 2**: A list of items that aim to assess the severity of seizures before, during and after.
3. **Section 3**: Some items asking about the frequency and duration of seizures.

Please select your preference:

- ◯ Yes I like this idea
- ◯ This idea could work
- ◯ No, I do not like this idea
- ◯ I am not sure

*Based on the question above, please tick all that apply.

I think the questionnaire should include:

- ☐ **Section 1:** A checklist of common symptoms people experience associated with their seizures.
- ☐ **Section 2:** A list of items that aim to assess the severity of seizures before, during and after.
- ☐ **Section 3:** Some items asking about the frequency and duration of seizures.
- ☐ I am not sure.

*What specific time frame do you think it would be helpful to ask individuals to answer these questions about?

- ◯ In the past 7 days.
- ◯ In the past two weeks
- ◯ In the past month

Next page ›

Appendix M

Round Two Delphi Feedback Document

Delphi Survey Round 2 Feedback

As you are aware, we aim to develop a self-report questionnaire (also known as a patient reported outcome measure) that describes the current severity of an individual's Functional / Dissociative Seizures (FDS) from their perspective.

During Round 2, we showed you **a total of 88 items** and asked you to decide whether you thought each item should be **included or excluded** for the final questionnaire. A total of **67 participants** completed this process including individuals with lived experience of FDS, caregivers, and professionals. We again cannot thank you enough for this incredible response!

In Round 2, we asked you whether the questionnaire should take the form of three sections:

1) **Section 1: FDS Symptom Checklist**
2) **Section 2: Items Measuring FDS Severity**
3) **Section 3: Duration and Frequency of FDS**

A total of 65 participants agreed with this idea. With this in mind, we have developed a proposed measure to hear your thoughts in Round 3, which will be the final round of collecting feedback.

Section 1 of the questionnaire includes a range of different FDS symptoms which may have an impact on how distressing or disabling the seizures are for the individual. We have included all the different symptoms which people have told us about throughout the Delphi process.

Section 2 of the questionnaire includes the items that relate specifically to measuring FDS severity and which were ranked highly in Rounds 1 and 2 of this survey.

> **From Round 1, we included 12 items that had the highest medians and lowest interquartile ranges (i.e. items which most participants agreed were highly relevant to assess FDS severity).**
>
> **From Round 2, we included 27 items that at least 75% of participants had agreed should be included.** We removed four items because it was not possible to rank them on the severity scale, however, these are reflected in the symptom checklist.

Section 3 of the questionnaire includes open-ended items related to the frequency and duration of FDS. We have included 6 items based on the same criteria as above (high levels of agreement in Round 1 or Round 2).

We note that the majority of participants (45) said the time period we should ask the questions about should be **one month**.

If you would like to review the inclusion and exclusion agreement percentages for the different items, you can see them by following this link:

https://drive.google.com/file/d/1ofuqU5331yEq-2HvMfG0bRUrkp9NAN3w/view?usp=sharing

Round 3

In this final **Round 3 of the Delphi process,** we are aiming to produce a final raw version of a self-report measure combining an FDS symptom checklist with two following questionnaires that allow users to describe the severity and frequency of their FDS. The resulting measure will then be subjected to further refinement and validation in a future study. Your tasks for Round 3 are:

- **In Section 1** – **to tell us any additional symptoms** likely to have an impact on the level of distress or disability associated with FDS which you think we have missed and that you think should be included on the checklist.

- **In Section 2 – to decide which of the similar items is your preferred option**. We are also going to ask you **how we should rate these items** on the questionnaire. Following feedback from Round 2, we have noticed that there are a small number of questions that may overlap in what they are asking about. We are keen to **reduce the number of questions in section two** of the questionnaire, which specifically aims to measure FDS severity. We think that this will be important if we want the measure to be used in clinical and research settings in the future. This is why we are therefore asking you to rate which of the questions you prefer.

Finally, we want you to **tell us if you are happy with the emerging measure** which has been attached to this document on the next page.

END OF FEEDBACK DOCUMENT

Appendix N

Draft Questionnaire (shared in Round 3 of Delphi)

FUNCTIONAL / DISSOCIATIVE SEIZURE SEVERITY QUESTIONNAIRE

SECTION ONE: Functional / Dissociative Seizure Symptom Checklist

Listed below are a range of symptoms that might be related to the period immediately before, during, and immediately after functional / dissociative seizures. Thinking about your own functional / dissociative seizures, **tick if your seizures have had the following features** in the past month.

☐ Seizure Warning Signs ☐ Seizure Triggers

Symptoms:

☐ Weakness	☐ Loss of balance	☐ Dizziness	☐ Uncontrollable movements
☐ Shakes	☐ Pain	☐ Tiredness	☐ Lost control of my body
☐ Tics	☐ Aches	☐ Fatigue	☐ Drop attacks
☐ Stiffness	☐ Injury	☐ Incontinence	☐ Cold and/or shivery
☐ Contortion	☐ Falls	☐ Nausea	☐ Hot and /or sweating
☐ Tremors	☐ Paralysis	☐ Changes to appetite	☐ Visual difficulties
☐ Tensing	☐ Migraines	☐ Speech difficulties	☐ Hearing difficulties
☐ Unable to move	☐ Headaches	☐ Unable to speak	☐ Struggled to breath

☐ Over sensitivity (to sounds, smells, light, etc.)

☐ Under sensitivity (e.g. to sounds, smells, light, etc.)

Things I have done because of the seizures…

☐ Avoided or stopped enjoyable activities	☐ Needed an emergency admission to hospital
☐ Struggled with day-to-day activities	☐ Struggled to make decisions
☐ Pretended I am okay	☐ Taken a long time to recover
☐ Downplayed symptoms	☐ Tried to fight against the seizures
☐ Done or said things without thinking	☐ Tried to stop the seizures

During my seizures (or just before / just after my seizures), I have experienced…

☐ Negative thoughts about myself	☐ Memory loss or memory difficulties
☐ Difficult or challenging thoughts	☐ Loss of awareness

☐ Worries about more seizures ☐ Brain fog

☐ Worries the seizures will never stop

During my seizures (or just before / just after my seizures), I have felt…

☐ Anxious	☐ Embarrassed	☐ Suicidal	☐ Happy
☐ Scared	☐ Vulnerable	☐ Hopeless	☐ Excited
☐ Threatened	☐ Unsafe	☐ Ashamed	☐ Relieved
☐ Stressed	☐ Frustrated	☐ Defeated	☐ Disconnected from my body
☐ Guilty	☐ Helpless	☐ Overwhelmed	☐ Like the world is not real
☐ Paranoid	☐ Panicky	☐ Confused	☐ Like I am in a dream
☐ Restless	☐ Tearful	☐ Disorientated	☐ Unable to respond
☐ Worried	☐ Blamed		

Any Features Not Listed:

SECTION TWO: Seizure Severity

Thinking about your functional / dissociative seizures in the **past month**…

Please **rate on the scale** how often you have experienced the symptom:

	Item	Never	Rarely	Sometimes	Often	Always
1.	I have no control over when my seizures are going to happen.	**0**	**1**	**2**	**3**	**4**
2.	I have experienced distressing symptoms in the build up towards my seizure (e.g. unable to move, visual / hearing difficulties, pain, uncontrollable movements).	**0**	**1**	**2**	**3**	**4**
3.	I have experienced increased sensitivity before a seizure (e.g. to sounds, smells, light, etc.).	**0**	**1**	**2**	**3**	**4**
4.	I have experienced distressing emotions in the build up towards my seizures.	**0**	**1**	**2**	**3**	**4**
5.	I have struggled to breathe during my seizures.	**0**	**1**	**2**	**3**	**4**
6.	I have lost control of my body during my seizures.	**0**	**1**	**2**	**3**	**4**

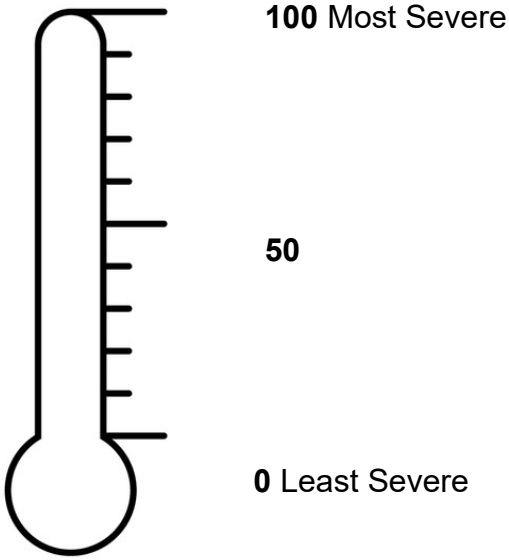
7.	I have experienced involuntary movements during my seizures.	**0**	**1**	**2**	**3**	**4**
8.	I have experienced contortion or stiffness during my seizures.	**0**	**1**	**2**	**3**	**4**
9.	I have experienced weakness in my body during my seizures.	**0**	**1**	**2**	**3**	**4**
10.	I have had difficulty speaking during my seizures.	**0**	**1**	**2**	**3**	**4**
11.	During seizures, I have wet myself.	**0**	**1**	**2**	**3**	**4**
12.	During seizures, a part of my body has become paralysed.	**0**	**1**	**2**	**3**	**4**
13.	During seizures, I have become completely paralysed.	**0**	**1**	**2**	**3**	**4**
14.	During a seizure, I have felt “locked in”, so I could not communicate with the outside world.	**0**	**1**	**2**	**3**	**4**
15.	I am unable to respond to things happening around me during my seizures.	**0**	**1**	**2**	**3**	**4**
16.	I have been unconscious during my seizures.	**0**	**1**	**2**	**3**	**4**
17.	I have lost awareness during my seizures.	**0**	**1**	**2**	**3**	**4**
18.	I have been injured during my seizures.	**0**	**1**	**2**	**3**	**4**
19.	I have experienced pain during my seizures.	**0**	**1**	**2**	**3**	**4**
20.	I have not been able to see anything during my seizures.	**0**	**1**	**2**	**3**	**4**
21.	I become disorientated and confused during the onset of a seizure.	**0**	**1**	**2**	**3**	**4**
22.	During my seizures, I have felt like I am outside of my own body.	**0**	**1**	**2**	**3**	**4**
23.	I have needed to sleep in the hours after my seizures.	**0**	**1**	**2**	**3**	**4**
24.	I have been exhausted in the hours after my seizures.	**0**	**1**	**2**	**3**	**4**
25.	I am unable to take care of myself in the hours after a seizure.	**0**	**1**	**2**	**3**	**4**
26.	I have taken a long time to recover after my seizures.	**0**	**1**	**2**	**3**	**4**
27.	After a seizure, I have been able to return to what I was doing within one hour.	**0**	**1**	**2**	**3**	**4**
28.	My balance and coordination have been affected in the hours after my seizures.	**0**	**1**	**2**	**3**	**4**
29.	I have not been able to stop my seizures after they had started.	**0**	**1**	**2**	**3**	**4**
30.	I have continued to experience distressing physical symptoms in the hours after my seizures have ended (e.g. shaking, paralysis, involuntary movements, incontinence).	**0**	**1**	**2**	**3**	**4**

31.	I have experienced pain in the hours after my seizures.	**0**	**1**	**2**	**3**	**4**
32.	I have experienced difficulties with my eyesight in the hours after my seizures.	**0**	**1**	**2**	**3**	**4**
33.	I have had speech difficulties in the hours after my seizures.	**0**	**1**	**2**	**3**	**4**
34.	My seizures have left me with new neurological symptoms (such as weakness or numbness) that have persisted for more than one day after the seizure was over.	**0**	**1**	**2**	**3**	**4**
35.	I have experienced seizures in which I suddenly drop to the floor.	**0**	**1**	**2**	**3**	**4**
36.	The seizures have negatively impacted on my ability to fulfil my role.	**0**	**1**	**2**	**3**	**4**
37.	I have avoided things I enjoy to stop my seizures from happening *(e.g. leaving the house, stopped usual / enjoyable activities, isolated myself).*	**0**	**1**	**2**	**3**	**4**
38.	My seizures have been bothersome.	**0**	**1**	**2**	**3**	**4**

On a scale of 0-100, please indicate the severity of your seizures in the last one month:

100 means the most severe or the worst the seizures could have been.

0 means the least severe the seizures could have possibly been.



SECTION THREE: Frequency and Duration

Thinking about your functional / dissociative seizures in the **past month**, please **answer the following questions** to the best of your knowledge.

1. **How would you best describe the frequency of the seizures you experience?** *(Circle the most appropriate option)*

1	2	3	4
My seizures have been more common than one per day	Less common than one per day but more than one per week	Less common than one per week but more common than one per month	No seizures for the last month.

2. **Approximately how many seizures have you experienced over the last month?**

   ……

3. **What is the most amount of seizures you have experienced in a single day?**

   ……..

4. **How long was your longest seizure?**

…….. second(s) / minute(s) / hour(s)

5. **How long does it usually take you to recover after a seizure?**

…….. second(s) / minute(s) / hour(s) / day(s)

6. **Have you experienced seizure clusters (i.e. seizures close together over one or several days)?** Yes / No

   If 'Yes', **approximately how many clusters of seizures have you experienced?**

   ……...

END OF QUESTIONNAIRE

Appendix O

Round Three Delphi Survey

* Developing a Self-Report Questionnaire of Functional / Dissociative Seizure Severity

Delphi Survey Round 3

As you are aware, we aim to develop a self-report questionnaire that describes the current severity of an individual's Functional / Dissociative Seizures (FDS) from their perspective. This will be a measure related to the seizures themselves (i.e. the period immediately before, during and after a seizure) as opposed to measuring the impact of seizures on the patient's wider quality of life or wellbeing (as there are already measures for this).

In this final round, we are aiming to produce a final raw version of a self-report questionnaire in three sections:

1) Section One: FDS Symptom Checklist
2) Section Two: Items Measuring FDS Severity
3) Section Three: Duration and Frequency of FDS

You will need to see the proposed questionnaire before completing Round 3. You can access this via the email we sent to you or by following this link:
https://drive.google.com/file/d/1IpaknrrTCmOj3NK1jyYdwRD5dYUqzqzf/view?usp=drive_link

Before completing this survey, please use the box below to type in your unique ID code that was emailed to you:

Next page >

Section One: Seizure Symptom Checklist

Before answering this section, **please ensure you have reviewed the symptom checklist proposed in the questionnaire**. If you have not already seen this, you can access the proposed measure in the email we sent to you or by following this link:
https://drive.google.com/file/d/1IpaknrrTCmOj3NK1jyYdwRD5dYUqzqzf/view?usp=drive_link

Use the box below to tell us any additional features of functional / dissociative seizures you think we have missed and should be included on the checklist (or if you have no additional suggestions please skip to the next page):

Next page >

Section Two: Seizure Severity

We are keen to **reduce the number of items in section two** of the questionnaire, which specifically aims to measure FDS severity. We think that this will be important if we want the measure to be used in clinical and research settings in the future.

In this section, we have identified items which respondents in Rounds 1 and 2 agreed were highly relevant to the measurement of seizure severity but, these items show so much overlap, that one of the presented options should be enough to capture the particular theme.

Please decide which option you prefer for each of the items.

Please **choose which option you prefer to be included in the questionnaire**:

- ◯ **A.** During seizures, a part of my body has become paralysed.
- ◯ **B.** During seizures, I have become completely paralysed.

Please **choose which option you prefer to be included in the questionnaire**:

- ◯ **A.** During a seizure I have felt "locked in", so I could not communicate with the outside world.
- ◯ **B.** I am unable to respond to things happening around me during my seizures.

Please **choose which option you prefer to be included in the questionnaire**:

- ◯ **A.** I have lost awareness during my seizures.
- ◯ **B.** I have been unconscious during my seizures.

Please **choose which option you prefer to be included in the questionnaire**:

- ◯ **A.** I have taken a long time to recover after my seizures.
- ◯ **B.** After a seizure I have not been able to return to what I was doing within one hour.

Please **choose which option you prefer to be included in the questionnaire**:

- ◯ **A.** I have had difficulty speaking during my seizures.
- ◯ **B.** I have had speech difficulties in the hours after my seizures.
- ◯ **C.** I have had speech difficulties because of my seizures.

*Please **choose which option you prefer to be included in the questionnaire**:

- ◯ **A.** I have experienced pain during my seizures.
- ◯ **B.** I have experienced pain in the hours after my seizures.
- ◯ **C.** I have experienced pain because of my seizures.

*Please **choose which option you prefer to be included in the questionnaire**:

- ◯ **A.** I have been exhausted in the hours after my seizures.
- ◯ **B.** I have needed to sleep in the hours after my seizures.

*Please **choose which option you prefer to be included in the questionnaire**:

- ◯ **A.** I have lost control of my body during my seizures.
- ◯ **B.** I have experienced involuntary movements during my seizures.

*Please **choose which option you prefer to be included in the questionnaire.**

A. I have continued to experience distressing symptoms in the hours after my seizures have ended (e.g. shaking, paralysis, involuntary movements, incontinence).

B. I have experienced difficulties with my eyesight in the hours after my seizures.

C. I have continued to experience distressing symptoms in the hours after my seizures have ended (e.g. shaking, paralysis, involuntary movements, incontinence, **difficulties with eyesight).**

- ◯ Include both '**A**' and '**B**' as separate items.
- ◯ Include option '**C**' only.

Section Two: Seizure Severity

We are keen to **reduce the number of items in section two** of the questionnaire, which specifically aims to measure FDS severity. We think that this will be important if we want the measure to be used in clinical and research settings in the future.

In this section, we want you to decide which of the similar items can be combined.

Please choose which option you prefer to be included in the questionnaire:

- ◯ **A.** I become disorientated and confused during the onset of a seizure.
- ◯ **B.** I have become disorientated or confused because of my seizures.

*Please choose which option you prefer to be included in the questionnaire:

- ◯ **A.** I have experienced distressing emotions in the build up towards my seizures.
- ◯ **B.** I have experienced distressing emotions because of my seizures (such as fear, anger, or sadness).

*Please choose which option you prefer to be included in the questionnaire:

- ◯ **A.** I have felt highly sensitivity to sounds, smells, light, etc. before a seizure.
- ◯ **B.** I have felt highly sensitive to sounds, smells, light, etc. because of my seizures.

*Please choose which option you prefer to be included in the questionnaire:

- ◯ **A.** I have not been able to see anything during my seizures.
- ◯ **B.** I have not been able to see or hear anything during my seizures.

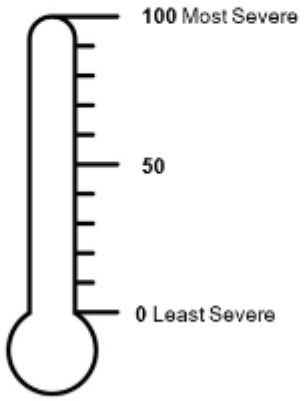
Please tell us which option you prefer:

A)

On a scale of 0-100, please indicate the severity of your seizures in the last one month:

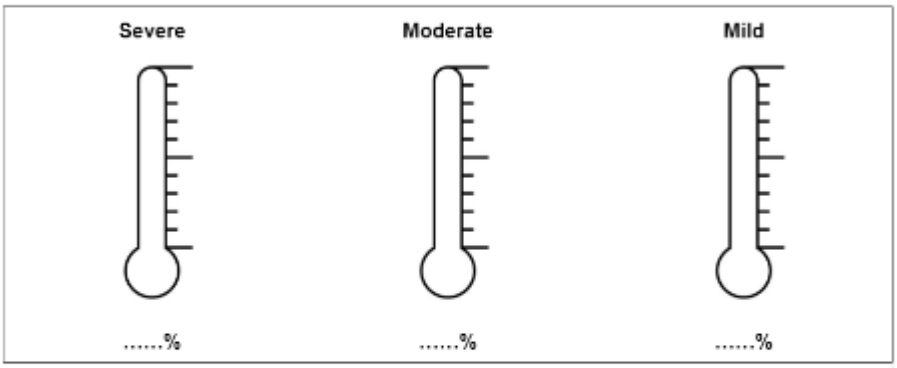
100 means the most severe or the worst the seizures could have been.

0 means the least severe the seizures could have possibly been.



B)

On a scale of 0-100%, please indicate what percentage of your seizures have been:



(For example… 10% of my seizures over the last month have been severe, 50% moderate and 40% mild)

- ◯ **A)** One Thermometer
- ◯ **B)** Three Thermometers
- ◯ **C)** Do not include neither **A** nor **B**

Section Two: Seizure Severity

We want this questionnaire to be used in clinical and research settings in the future and so we want to make sure there are not too many questions.

Please tell us approximately **how many questions you think is appropriate for 'Section Two: Seizure Severity'** of the questionnaire:

- ◯ Up to a maximum of 15 questions / items
- ◯ 16 - 20 questions / items
- ◯ 21 - 30 questions / items
- ◯ 31 - 40 questions / items
- ◯ Other: [ ]

*As you will see on the questionnaire, **we have proposed to rate each item on a scale**, were:

0 = Never
1 = Rarely
2 = Sometimes
3 = Often
4 = Always

Please tell us what you think about ranking the items in this way:

- ◯ Yes, I like this idea
- ◯ This idea could work
- ◯ No I do not like this idea
- ◯ Not sure

If you have **any comments about how we are proposing to rank the items**, please tell us in the box below (if not, skip to the next page):

[ ]

Next page ›

*

General Feedback

Finally, thinking about the questionnaire* as a whole:

Section One: Symptom Checklist

Section Two: Seizure Severity

Section Three: Duration and Frequency of FDS

**Can be accessed via the email we sent.*

Are you happy with the questionnaire we have proposed at this stage?

- ◯ Yes I like the questionnaire
- ◯ No I do not like the questionnaire
- ◯ Don't Know / Unsure

Use the box below to **provide any further and final feedback about the questionnaire** (if you have nothing further to add, skip to the next page):

Next page >

Appendix P

Fourth Theme '…it's a good idea but it's going to be difficult'

Illustrative quotes are presented in Table P1. Two subthemes emerged: challenges to overcome and clinical and research implications.

Challenges to overcome. Discussions emphasised the "subjectivity" and heterogeneity of seizures with one participant stating "It's subjective. What one person is having is not the same as all". Subjectivity also related to what is meant by severity (Q1) and differences in the seizures of one person emphasised (Q2). One participant with FDS wondered how opposing concepts such as "conscious" or "unconscious" would be represented when both can be severe. Similarly, one HCP wondered how to "weight individual items" measuring severity. PwLE worried that quantifying severity could be used as a barrier against them accessing healthcare services for support (Q3). Both groups emphasised the need to make sure that "clinical relevance" of a measure does not get "lost" at the expense of quantifying seizure severity, and people are not "diluted or converged into boxes".

Participants discussed the complexities of seizure frequency. It was felt for some, frequency of seizures is an important part of severity (Q4). However, HCPs discussed that low seizure frequency could be "misleading" as it may be due to "restricting their lives in lots of different ways" having a "negative impact" more broadly (Q5). Difficulties were highlighted with "defining what the episode is that we are talking about" in order to "count" seizures. Similarly to frequency, seizure severity was discussed in relation to its contrasts with quality of life (Q6) and the need for a measure to cover seizure impact more broadly (Q7).

HCPs agreed the measure needs to be concise for meaningful use with patients (Q8) and considered the influence of completing this with a clinician (Q9). Somewhat similarly, participants talked about the influence of a person's ability to accurately recall their seizures (Q10). Related to this, both groups proposed a "carer version" of the measure may be of value.

Clinical and research implications. One HCP identified the value of understanding what makes seizures "more or less severe". Both groups suggested a questionnaire would provide a "shared language" for patients to articulate, and for professionals to understand, an individual's subjective experience of FDS (of which participants with FDS felt a "tick chart" of symptoms would be beneficial to provide a "map of the seizure"). Healthcare professionals discussed how a measure would provide a tangible means to show patients they believe their seizures are "real" and would help to validate their experiences (Q11). Moreover, that this would help to "share consistent information" amongst professionals. Both groups referred to "monitoring change" in seizures overtime. Specifically, healthcare professionals identified "triaging" patients into treatment and monitoring change to seizures in response, "service evaluation", and "clinical trials

Table P1

Quotes Representing the Fourth Subtheme

Theme	Subtheme	Quote No.	Illustrative Quotes	Participant
"…it's a good idea but it's going to be difficult" **(Development of a PROM)**	Challenges to overcome	**Q1**	"…severity for one person might not be severity for another … [referred to another participant rating their seizure] …you only rated it a six. For somebody else, that might be the worst kind of seizure they've ever had, so again, it goes back to the subjectivity".	LE3
		Q2	"I mean I'm one person but I could say, one seizure could be different from the other. [Gives examples of different types of seizure] … it's such a wide thing even just for me as one person, it'd be very difficult to put that on a scale for everyone".	LE2
		Q3	"… it's so stigmatised anyway and we get so much push back about … 'this could just be in your head' and 'there's nothing measurable about it'. To then put something measurable in place opens up the possibility for a doctor to say 'actually we've done this test, this measurable test and you've only come out at a two' … it could be another way another thing to use against us …It could just be my anxiety talking…".	LE3
		Q4	"…like my personal sort of measure of severity is how many do I have. If I just have one and then I'm fine, then that's like a low-level seizure episode. If I have like four or five in a row over a couple of hours, that's worse…but that's not the severity of a seizure that's the frequency."	LE4
		Q5	"…the measurement of seizure frequency can sometimes be misleading. There are a whole load of things that some people end up doing to prevent a seizure happening but, they're then restricting their lives in lots of different ways. So, the seizure frequency might be relatively low, but there having to do lots of things which have a negative impact. Then there's also the sort of anticipatory avoidance, anxious avoidance of doing things for fear that a seizure might happen, which again, has an impact well beyond the actual frequency of seizures...."	HCP8
		Q6	"…for some people their symptoms can be relatively mild but it affects their life very, very seriously, and for other people, you know for whatever circumstances… they can carry on for some reason.	LE1
		Q7	"…I agree that the measure would be really useful, but I think in terms of looking at outcomes, it's important to look at a much wider range of outcomes because people's quality of life and other factors can change massively even if the seizure level doesn't change that much. So, I think this is really useful but in terms of outcomes, it's important to look at other things as well."	HCP2
		Q8	"… the length of it … in terms of how you want it to be used. Is it going to be something that's quite short that someone will fill in a clinic space before they come and see you and you can then go through it within the clinic space? So… there aren't that many questions on it cause obviously you're quite time constrained. Or is it going to be a very long in-depth thing? Because, if they've spent a lot of time trying to fill it out and then in a clinic environment you're like 'okay, lovely' and	HCP3

		you're skimming through it, that's going to be frustrating and demoralizing and reinforce that we're not really listening because we haven't got the time…"	
	Q9	"… it does make a difference whether or not something that's going to be done by the clinician in session or whether or it's something they do separately. There are probably different benefits from each … in terms of consistency, does the clinician sort of guide people in how they answer questions by explaining what's going on there? Or, is it something everyone's doing on their own so their understanding of the questions is just based on what they're reading? When clinicians get involved in that process it can affect, what comes back as well…"	HCP2
	Q10	"…it surprised me when I started going to appointments with my husband just how different our accounts of my seizures and things that I experienced were erm because yeah you don't see unless somebody films you for medical purposes… I had no idea. I was going to appointments saying 'oh I probably have a couple of seizures a day' my husband was like 'Ten. Ten. You have at least ten.' (*laughs*)."	LE3
Clinical and research implications	**Q11**	"… taking time out to sit, and allow that person to talk through it, is, I suppose part of saying actually you know "I believe you. You're not faking it" that "you're not making it up" and that "it is important to you".	HCP3

Appendix Q

Round One Delphi Items and Sources

Table Q1

Item Development Sources

Delphi Survey Section	No.	Item	Source
Immediately before a seizure	**1.**	I have felt anxious or scared waiting for a seizure to happen.	Subtheme: Debilitating impact Subtheme: Waves of emotion
	2.	I have struggled to cope before experiencing a seizure.	Subtheme: Debilitating impact Subtheme: Waves of emotion
	3.	I have had no control of when my seizures are about to happen.	Theme: The seizures have control
	4.	My seizures have been unpredictable.	Theme: The seizures have control
	5.	My seizures seem to come on from nowhere.	Theme: The seizures have control
	6.	I have been unable to relax in the build up towards my seizures.	Subtheme: Debilitating impact
	7.	I felt tired or fatigued in the build up towards my seizures.	Subtheme: Debilitating impact
	8.	I experienced physical symptoms in the build up towards my seizures (e.g. unable to move, visual / hearing difficulties, pain, uncontrollable physical movements).	Theme: Seizures are physically tough Subtheme: Seizures take over the body
	9.	I have experienced distressing emotions in the build up towards my seizures (such as feeling anxious, stressed, guilty, or paranoia)	Subtheme: Waves of emotion
	10.	I have felt overwhelmed in the build up towards my seizures.	Subtheme: Waves of emotion
	11.	I have felt threatened in the build up towards my seizures.	Subtheme: Waves of emotion
	12.	I have struggled to get my words out in the build up towards my seizures.	Subtheme: Silenced by the seizures
	13.	I have lost control of my breathing in the time before my seizures.	Subtheme: Seizures take over the body
	14.	I have felt oversensitive before a seizure (e.g. to sounds, smells, light, etc.).	Subtheme: Seizures take over the body
	15.	Before my seizures, I have had negative thoughts about myself related to experiencing a seizure.	Subtheme: Fighting back for control Subtheme: Lasting effects
	16.	I know what triggers my seizures.	Subtheme: Fighting back for control

Warning signs and triggers	**17.**	My awareness of seizure triggers has allowed me to cope better with my seizures.	Subtheme: Fighting back for control
	18.	I have felt to blame for triggering my seizures.	Subtheme: Fighting back for control LE Transcript
	19.	I have had warning signs before my seizures.	Subtheme: Fighting back for control
	20.	I have had enough warning to make myself safe before my seizures happen.	Subtheme: Seizures in unsafe spaces Subtheme: Taking back control
	21.	Being aware of my seizure warning signs has helped me to cope better with my seizures.	Subtheme: Taking back control
During a seizure	**22.**	I have had no control of my body during my seizures.	Subtheme: Seizures take over the body
	23.	I have experienced pain during my seizures	Theme: Seizures are physically tough
	24.	I have been injured during my seizures	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	25.	I have struggled to breathe during my seizures.	Subtheme: Seizures take over the body Subtheme: Waves of emotion
	26.	I have experienced involuntary physical movements during my seizures.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	27.	I have experienced contortion or stiffness during my seizures.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	28.	I have experienced weakness in my body during my seizures.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	29.	During my seizures, I have become completely paralysed.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	30.	During my seizures, a part of my body has become paralysed.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	31.	During my seizures, I have wet myself.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	32.	During my seizures, I have lost bowel control.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	33.	I have not been able to see anything during my seizures.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	34.	I have not been able to hear anything during my seizures.	Subtheme: Seizures take over the body Theme: Seizures are physically tough
	35.	I have had difficulty speaking during my seizures.	Subtheme: Seizures take over the body

		Theme: Seizures are physically tough
36.	I have experienced seizures in which I suddenly drop to the floor.	Subtheme: Seizures take over the body
37.	I have experienced hypersensitivity during a seizure (e.g. to sounds, smells, light, etc.)	Subtheme: Seizures take over the body
38.	I have experienced hyposensitivity during a seizure (e.g. to sounds, smells, light, etc.)	Subtheme: Seizures take over the body
39.	I have had distressing emotions during my seizures (such as fear, anger or sadness).	Subtheme: Wave of emotions
40.	I have felt embarrassed during my seizures.	Subtheme: Wave of emotions
41.	I have felt helpless during my seizures.	Theme: Seizures have control Subtheme: Silenced by the seizures Subtheme: Seizures take over the body Subtheme: Waves of emotion Subtheme: Seizures in unsafe spaces
42.	I have felt like I am losing my mind during my seizures.	Systematic review
43.	During my seizures, I have panicked they were never going to end.	Subtheme: Seizures take over the body Subtheme: Waves of emotion Subtheme: Unpredictability
44.	During my seizures, I have panicked that my seizure would get worse.	Theme: Seizure has control Subtheme: Wave of emotions Subtheme: Lasting effects Subtheme: Unpredictability
45.	I have had distressing thoughts during my seizures.	Theme: Seizure has control Subtheme: Silenced by the seizures Subtheme: Seizures leave the mark Reference to specific examples of thoughts in LE focus group.
46.	I have had thoughts about wanting my life to end or felt suicidal during a seizure.	Subtheme 6: Intense emotions Reference to specific thoughts in LE focus group
47.	I have lost awareness during my seizures.	Subtheme: Silenced by the seizures Theme: Seizure takes control
48.	I have been completely unconscious during my seizures.	Subtheme: Silenced by the seizures

	49.	During my seizures, I have felt like I am on the outside of my own body.	Systematic Review LE and HCP Transcripts
	50.	During my seizures, I have felt like the world around me is not real or I am in a dream.	Systematic Review LE and HCP Transcripts
	51.	I have been aware of what is going on around me during my seizures.	Subtheme: Silenced by the seizures
	52.	I have been unable to respond to things happening around me during my seizures.	Subtheme: Silenced by the seizures
	53.	My seizures have occurred in places where I do not feel safe.	Subtheme: Unpredictability Subtheme: Debilitating Impact
	54.	I have not been able to stop my seizures after they had started.	Theme: Seizure has control Subtheme: Unpredictability
	55.	I have made my seizures worse when I have tried to fight against them or stop them.	Subtheme: Fighting back for control
Immediately after a seizure	**56.**	I have continued to experience distressing physical symptoms in the hours after my seizures have ended (e.g. shaking, paralysis, involuntary movements, incontinence).	Subtheme: Lasting effects
	57.	I have experienced pain in the hours after my seizures.	Theme: Seizures leave their mark Theme: Physically tough
	58.	I have taken a long time to recover after my seizures.	Theme: Seizures leave their mark Theme: Physically tough
	59.	I have been exhausted in the hours after my seizures.	Theme: Seizures leave their mark Theme: Physically tough
	60.	I have needed sleep in the hours after my seizures.	Theme: Seizures leave their mark Theme: Physically tough
	61.	My balance and coordination have been affected in the hours after my seizures.	Theme: Seizures leave their mark
	62.	I have had falls in the hours after my seizures.	Theme: Seizures leave their mark Theme: Physically tough
	63.	I have had difficulty with my eyesight in the hours after my seizures.	Theme: Seizures leave their mark Theme: Physically tough
	64.	I have had hearing difficulties in the hours after my seizures.	Theme: Seizures leave their mark Theme: Physically tough
	65.	I have had speech difficulties in the hours after my seizures.	Theme: Seizures leave their mark Theme: Physically tough

66.	I have injured myself so badly during a seizure that I have had to seek medical attention.	Theme: Seizures leave their mark Theme: Physically tough
67.	I have injured myself during a seizure but not had to seek medical attention.	Theme: Seizures leave their mark Theme: Physically tough
68.	I have felt confused in the hours after my seizures.	Subtheme: Lasting effects
69.	I have had difficulties thinking straight in the hours after my seizures.	Subtheme: Lasting effects
70.	I have been disorientated in the hours after my seizures.	Subtheme: Lasting effects
71.	I have felt 'spaced out' in the hours after my seizures.	LE Transcript
72.	I have forgotten what has happened during my seizures.	LE and HCP Transcripts
73.	I have forgotten that I have had a seizure.	LE Transcripts
74.	I have not recognised people I know after a seizure.	Co-authors
75.	I have not always made the best choices for myself immediately after a seizure.	Subtheme: Lasting effects Subtheme: Waves of emotions
76.	I have experienced overwhelming emotions after my seizures.	Subtheme: Lasting effects Subtheme: Waves of emotions
77.	I have felt extremely low, sad or tearful after my seizures.	Subtheme: Lasting effects Subtheme: Waves of emotions
78.	I have felt like the seizures have 'won' in the hours after I have had them.	Theme: Seizures have control
79.	I have felt stressed in the hours after my seizures.	Subtheme: Lasting effects Subtheme: Waves of emotions
80.	I have felt anxious or scared in the hours after my seizures.	Subtheme: Lasting effects Subtheme: Waves of emotions
81.	I have felt ashamed or embarrassed in the hours after my seizures.	Subtheme: Lasting effects Subtheme: Waves of emotions
82.	I have had negative thoughts about myself soon after having a seizure.	Subtheme: Lasting effects
83.	My seizures have made me feel hopeless.	Subtheme: Lasting effects Subtheme: Waves of emotions
84.	I have worried I would have another seizure in the hours after a seizure.	Theme: Seizures leave their mark Subtheme: Waves of emotions
85.	I have not felt in control of my body's emotional reaction in the hours immediately after a seizure (e.g. I may be crying but I do not feel sad).	Subtheme: Waves of emotions
86.	My seizures have caused me to panic immediately after I have had one.	Subtheme: Waves of emotions
87.	I have struggled to cope in the time after a seizure.	Subtheme: Waves of emotions

	88.	After a seizure, I have been able to return to what I was doing within X amount of time. (*Follow-up question to define 'X'*).	Theme: Seizures leave their mark
General burden	**89.**	I have avoided things I enjoy to stop my seizures from happening (e.g. leaving the house, stopped usual / enjoyable activities, isolated myself).	Subtheme: Debilitating Impact
	90.	I have experienced clusters of seizures (i.e. seizures close together over one or several days).	Theme: Physically tough Subtheme: Debilitating Impact
	91.	I have been in and out of a seizure with full recovery in between.	Subtheme: Debilitating Impact
	92.	I have been admitted to hospital because of my seizures.	Subtheme: Debilitating Impact
	93.	My seizures have been distressing for me.	Co-authors
	94.	My seizures have been getting worse.	Co-authors
	95.	I have been experiencing seizures that have been unusual or changed.	Co-authors
	96.	I have struggled to cope in between seizures.	Subtheme: Unpredictable
	97.	I have felt able to manage my seizures.	Subtheme: Fighting back for control
	98.	I have felt as though I cannot keep living with these seizures.	Subtheme: Waves of emotion Theme: Seizures leave their mark
	99.	The frequency of my seizures is increasing.	Co-authors / Transcripts
	100.	The duration of my seizures is increasing.	Co-authors / Transcripts
	101.	The time in between my seizures is increasing.	Co-authors / Transcripts
	102.	The time it takes me to recover from a seizure is increasing.	Co-authors / Transcripts
	103.	My seizures have been bothersome.	Co-authors / Systematic Review
	104.	The seizures have negatively impacted on my sleep.	Subtheme: Debilitating Impact
	105.	The seizures have negatively impacted on my diet.	Subtheme: Debilitating Impact
	106.	The seizures have negatively impacted on my relationships.	Subtheme: Debilitating Impact
	107.	The seizures have negatively impacted on my ability to fulfil my role (e.g. parenting, employment).	Subtheme: Debilitating Impact
	108.	How severe would you rate most seizures you have experienced? (1) Mild (2) Moderate (3) Moderate – Severe (4) Severe	Coauthors / Systematic Review
Frequency and duration	**109.**	How would you best describe the frequency of the seizure you experience? (1) More common than one per day (2) Less common than one per day but more common than one per week (3) Less common than one per week but more common than one per month (4) Less common than one per month but more common than one per year (5) No seizures for the last year	Co-authors
	110.	How many seizures have you experienced over the last month?	Co-authors / Transcripts

111.	What is the most amount of seizures you have experienced in a single day?	Co-authors / Transcripts
112.	How long was your longest seizure? …. second(s) / minute(s) / hour(s)	Co-authors / Transcripts
113.	When was the last time you had a seizure? …. hour(s) / day(s) / week(s) / month(s) / year(s) ago	Co-authors / Transcripts
114.	How long does it usually take you to recover from a seizure? …. second(s) / minute(s) / hour(s) / day(s)	Co-authors / Transcripts
115.	What has been the longest gap between your seizures?	Co-authors / Transcripts

Appendix R

Participant Generated Items at Round One

1. I have difficulties with my speech in the build up to a seizure.
2. I become light-headed and dizzy in the period immediately before a seizure.
3. I experience headaches in the period immediately before a seizure.
4. I become disorientated and confused during the onset of a seizure.
5. My seizures have had a negative impact on my senses, such as making my eyesight or hearing worse.
6. I have lost my appetite because of my seizures.
7. I was able to take measures to delay or prevent a seizure.
8. I have felt nauseous during a seizure.
9. I have needed support from others to get the seizures to stop or make them less severe.
10. I am unable to take care of myself in the hours after a seizure.
11. I have experienced 'brain fog' after seizures.
12. I have experienced feelings of relief after my seizures.
13. I have experienced migraines or headaches after my seizures.
14. I have needed support with intimate care from someone else during and after a seizure.
15. My seizures have left me with new neurological symptoms (such as weakness or numbness) that have persisted after the seizure was over.
16. I have thought that I might die during my seizures.
17. During a seizure, I have felt completely "locked in", so I could not communicate with the outside world.
18. I do not have any recollection of what has happened during my seizures.
19. After a seizure, I have been able to return to what I was doing within a reasonable time.
20. On a scale of 0-100%:

    - What percentage of your seizures have been severe?
    - What percentage of your seizures have been moderate?
    - What percentage of your seizures have been mild?

21. What has been the average duration of a seizure?

Appendix S

Excluded Items at Round 2

Table P1

Item	N	Inclusion %	N	Exclusion %
I have been admitted to hospital as an emergency because of seizures. *(Excluded as would not fit with ranking system. Included on symptom checklist.)*	56	86.20%	9	13.80%
I have been aware of what is going on around me during my seizures. *(Excluded as not possible to rank in terms of its severity. Ability to respond reflected by other items.)*	56	83.60%	11	16.40%
My seizures are lasting longer than they used to. *(Excluded as would not fit with ranking system. Duration reflected by other items.)*	52	80.00%	13	20.00%
My seizures are becoming more frequent. *(Excluded as would not fit with ranking system. Frequency reflected by other items.)*	49	75.40%	16	24.60%
My seizures have been unpredictable.	50	74.60%	17	25.40%
I have struggled to get my words out in the build up towards my seizure.	50	74.60%	17	25.40%
I have felt highly sensitive during a seizure (e.g. to sounds, smells, light, etc.)	50	74.60%	17	25.40%
I have had distressing emotions during my seizures (such as fear, anger, or sadness).	50	74.60%	17	25.40%
I have forgotten what has happened during my seizures.	49	74.20%	17	25.80%
I have injured myself during a seizure but have not had to seek medical attention	48	72.70%	18	27.30%
I have been disorientated in the hours after my seizures.	48	72.70%	18	27.30%
The time it takes me to recover from a seizure is increasing.	47	72.30%	18	27.70%
I have difficulties with my speech in the build up to a seizure.	47	72.30%	18	27.70%
I have felt confused in the hours after my seizures.	47	71.20%	19	28.80%
I have needed support with intimate care from someone else during and after a seizure.	46	70.80%	19	29.20%
After a seizure, I have been able to return to what I was doing within a reasonable time.	45	69.20%	20	30.80%
My awareness of seizure triggers has allowed me to cope better with my seizures.	46	68.70%	21	31.30%
I have had warning signs before my seizures.	46	68.70%	21	31.30%
I have been experiencing seizures that have been unusual or changed.	44	67.70%	21	32.30%
I have felt able to manage my seizures.	44	67.70%	21	32.30%
I have needed support from others to get the seizures to stop or make them less severe.	44	67.70%	21	32.30%
I have experienced ‘brain fog’ after seizures.	44	67.70%	21	32.30%
I was able to take measures to delay or prevent a seizure.	44	67.60%	21	32.30%

I've had enough warning to make myself safe before my seizures.	45	67.20%	22	32.80%
My seizures have happened in places where I do not feel safe.	45	67.20%	22	32.80%
I have not felt in control of my body's emotional reaction in the hours immediately after a seizure (for example, I may be crying but I do not feel sad).	43	66.20%	22	33.80%
The time in-between my seizures is increasing.	43	66.20%	22	33.80%
I become light-headed and dizzy in the period immediately before a seizure.	43	66.20%	22	33.80%
I have experienced migraines or headaches after my seizures.	43	66.20%	22	33.80%
I have experienced overwhelming emotions after my seizures.	42	64.60%	23	35.40%
My seizures have been getting worse.	42	64.60%	23	35.40%
The seizures have had a negative impact on my sleep.	42	64.60%	23	35.40%
I do not have any recollection of what has happened during my seizures.	42	64.60%	23	35.40%
I have felt tired or fatigued in the build up towards my seizures.	43	64.20%	24	35.80%
I know what triggers my seizures.	43	64.20%	24	35.80%
My seizures have had a negative impact on my senses, such as making my eyesight or hearing worse.	41	63.10%	24	36.90%
I have had distressing thoughts during my seizures.	42	62.70%	25	37.30%
Being aware of my seizure warning signs has helped me to cope better with my seizures.	41	61.20%	26	38.80%
I have felt helpless during my seizures.	41	61.20%	26	38.80%
My seizures have caused me to panic immediately after I have had one.	39	60.00%	26	40.00%
I have been in and out of seizures with full recovery in between.	39	60.00%	26	40.00%
I have felt as though I cannot keep living with these seizures.	39	60.00%	26	40.00%
I have felt overwhelmed in the build up to my seizures.	40	59.70%	27	40.30%
I experience headaches in the period immediately before a seizure.	38	58.50%	27	41.50%
I have struggled to cope in the time after a seizure.	37	56.90%	28	43.10%
My seizures seem to come on from nowhere.	38	56.70%	29	43.30%
During my seizures, I have felt like the world around me is not real or like I am in a dream.	38	56.70%	29	43.30%
I have had negative thoughts about myself soon after having a seizure.	36	55.40%	29	44.60%
I have worried I would have another seizure in the hours after a seizure.	36	55.40%	29	44.60%
The seizures have had a negative impact on my diet.	36	55.40%	29	44.60%

During my seizures, I have panicked that they were never going to end.	37	55.20%	30	44.80%
I have made my seizures worse when I have tried to fight against them or stop them.	37	55.20%	30	44.80%
I have had difficulties thinking straight in the hours after my seizures.	36	54.50%	30	45.50%
I have felt anxious or scared in the hours after my seizures.	35	53.80%	30	46.20%
My seizures have made me feel hopeless.	34	52.30%	31	47.70%
I have felt anxious or scared waiting for a seizure to happen.	34	50.70%	33	49.30%
I have felt under sensitive during a seizure (e.g. to sounds, smells, light, etc.)	34	50.70%	33	49.30%
I have felt extremely low, sad or tearful after my seizures.	32	49.20%	33	50.80%
I have felt 'spaced out' in the hours after my seizures.	32	48.50%	34	54.50%
I have been unable to find ways to relax when I feel I might have a seizure.	32	47.80%	35	52.20%
I have felt like I am losing my mind during my seizures.	32	47.80%	35	52.20%
I have felt nauseous during a seizure.	31	47.70%	34	52.30%
I have thought that I might die during my seizures.	31	47.70%	34	52.30%
During my seizures, I have panicked that my seizure would get worse.	31	46.30%	36	53.70%
I have lost my appetite because of my seizures.	30	46.20%	35	53.80%
I have not always made the best choices for myself immediately after a seizure.	30	45.50%	36	54.50%
My seizures have been distressing for me.	29	44.60%	36	55.40%
I have felt ashamed or embarrassed in the hours after my seizures.	28	43.10%	37	56.90%
I have felt stressed in the hours after my seizures.	27	41.50%	38	58.50%
I have felt embarrassed during my seizures.	27	40.30%	40	59.70%
I have struggled to cope in between seizures.	25	38.50%	40	61.50%
I have experienced feelings of relief after my seizures.	21	32.30%	44	67.70%
I have felt like the seizures have "won" in the hours after I have had them.	17	26.20%	48	73.80%
When was the last time you had a seizure?	48	73.80%	17	26.20%
What has been the longest gap between your seizures?	44	67.70%	21	32.30%
What has been the average duration of a seizure?	33	50.80%	32	49.20%

Appendix T

Round 2 Qualitative Data (arranged into emerging ideas)

Table T1

Participant Quotes Round 2 Arranged into Emerging Ideas

Emerging Ideas	Participant Textual Data (arranged into similar ideas)
Complexity due to change in FDS overtime	"Several of the questions... are dismissive of individuals who may have experienced frequent intense & complex daily seizures and are now having longer intervals between seizures. If the overarching purpose of the survey is assessing the severity for seizures while they're currently happening at their peak... assessment for diagnostic purposes which is the important key; this differs from those who are responding to the survey and experiencing reduced symptoms, are in a period of remission from seizures, or a relapse. FND isn't curable and prioritizing ones health and wellbeing is key for continued wellbeing. It feels dismissive to ask someone who's experienced literally hundreds of complex daily seizures, and many in a single day some of which lasted for over half an hour or intermittently for hours... that if they haven't had one within a period of time (days, weeks, months, years) that this helps assess the severity of seizures… I wouldn't want to be dismissed by a diagnostic survey that asks about intervals of remission rather than the severity of the most recent..." "Some questions are difficult to answer as they are sometimes so different and changeable but in all the questions have experienced at some stage in the last segment so feel it is pertinent." "The seizures I had which they took 8 years to diagnose are very different to those that, effectively took over my life and to those more recent."
Characteristics of seizures opposed to severity	**"**All of the items are important but a few of them describe characteristics other than specifically severity." "I think that there are lots of really useful questions that would be helpful for patients to be able to get more of a sense of their triggers and management of seizures in here. they may be useful to collate for additional clinical use, but are less relevant for seizure severity… not knowing when a seizure is likely to happen is probably going to mean it's more severe as there is no chance to prepare/mitigate for it. However, the majority of people I see at the start of therapy say they have no awareness of when it will happen and therapy helps them to be more able to notice and recognise their triggers. So, a questionnaire asking about these can be helpful in starting that process but won't relate directly to the severity of seizures." "Many of the questions I marked irrelevant were definitely still important for describing the seizure but may not indicate severity... I feel some of those questions may be dependent on the person more so than the severity." "I have tried to be subjectional when ranking the statements/questions. I know that everyone is different with their FND symptoms, that said, the statements/questions that I have omitted are few, as I feel the majority of the questions are relevant." "…has given me a better understanding in the overall variations of peoples seizures."
Merging items to make the measure briefer	"…there are a few that are quite similar so could be combined."

	"I've tried to exclude some items which seem to duplicate, to make the measure briefer - but other respondents may have done the same but selected the other (very similar) item." "I think a lot of them can be grouped together, like how you feel before/after a seizure. So where I've put can be left out I think it's because it has already been covered." "I found some of the questions I had to mark not relevant because they could definitely be combined with other questions." "Questions regarding post-event confusion could be combined into something like "back to normal within one hour"."
Complexity of what is meant by severity	"It was a bit confusing because "severity" is such a difficult concept to nail down." "I found it hard to separate the idea of severity (as in medical emergency) as opposed to severity of psychological distress."
Difficulty recalling symptoms of unconscious seizures	"One question regarding how long was your longest is an incredibly difficult question as sometimes I'm conscious and other times completely out of it. The one I had the other day, was while I was asleep and the only knowledge I had of it was the symptoms of exhaustion, confusion and a very soggy bed!"
Relief	**"**There doesn't seem much recognition that many people experience a sense of relief and feel better after a seizure. Seizures in many people appear to be a form of emotional regulation. My patients will often feel that once they've had one then they feel safer that it will be some time before they have another one. All the questions about symptoms after a seizure are about bad things not this issue. One reason why seizure frequency isn't helpful – as some people prefer to have seizures from time to time in a safe place to regulate – rather than none at all – or fewer (when they tend to be more severe). If you aren't asking whether people feel any relief /benefit of a seizure then you are missing out on that dimension which counteracts bad feelings that other people get after a seizure. No one wants to have a seizure but many patients learn that having intermittent seizures keeps them regulated."
SPECIFIC ITEM SUGGESTIONS	**Seizure duration** **"**Seizure duration data is notoriously unreliable." **Item: 'The seizures have negatively impacted on my ability to fulfil my role (e.g., parenting, employment).'** "This is really important but gives the example of parenting or employment – this unfortunately biases it against people who don't have children or are not employed (which is the case with a lot of young people)." **Coping after a seizure** "The questions describing how you felt/cope after a seizure would definitely be useful in a treatment plan." "How a person copes with seizures is important but should be at the end of the severity questions as a separate section…" **Seizure bothersomeness** "We have a lot of data on seizure bothersomeness from CODES – it would be scientifically valuable if any scale you come up with replicates that question exactly within your scale so that data can be compared. Ultimately, I cant help feeling that the patients own general assessment of how much their seizures bother them is the most useful measure of severity rather than trying to break down the severity of individual parts of the event or asking them to guess at frequency."

Appendix U

Round 3 Qualitative Data

Table U1

Qualitative Data Item Rankings

	Participant Textual Data
Favourable Feedback	"The proposed ranking is already widely used therefore it would be better to use it."
	"The ranking is already used in other questionnaires therefore it is likely to be more easily understood and comparable."
Alternative Suggestions	"This feels more like a measure of frequency than severity - that the clinician then makes the decision as to whether experiencing x that often makes it severe. Although that's obviously how mood questionnaires work. The alternative would be to get the patient directly to rate the severity in terms of how distressing/debilitating that particular item is."
	"Not sure if psychometrically viable but would prefer simplified Likert: Have you experienced the following problems during your seizures: 0 = No; 1 = Yes, on some occasions; 2 = Yes, with every seizure. (Or simply "No", "Yes, sometimes" and "Yes, always")."
	"The rankings of 'rarely', 'sometimes' and 'often' are quite subjective. For example, what I might view as being 'sometimes' may be viewed as 'often' by others."
	"Remove 'Rarely' and 'Often'."

Overall Feedback

Six participants referred to the questionnaire providing a clear and comprehensive overview of FDS with one commenting the questionnaire encompassed the variety of FDS experiences and another stating this could aid with understanding. Two participants referred to the questionnaire being useful to ascertain severity. Three commented on the measures use in future clinical or research practice (e.g. as a diagnostic tool, a standardised measure used internationally). Eight participants offered critiques. Three commented on the lengthiness of the questionnaire though one acknowledged statistical analysis could reduce items. Three participants felt people with FDS may have difficulties completing it due to challenges recalling seizures or because the content could be upsetting. Three participants felt a caregiver version of the questionnaire would be useful. One participant commented on adjusting the timeframe to two weeks. A different participant felt FDS severity could be established with a one-item measure, suggested one item may not be accurately answered by people who are unresponsive during seizures and felt specific items (excluded from previous rounds) should be included in the severity section.

Appendix V

Participant Suggestions and Changes / Edits to Questionnaire

Round 3 Symptom Checklist Participant Suggestions (added to checklist):

- Difficulty coordinating movement
- Changes to breathing
- Heart racing
- Unable to open eyes and changes to vision (replaced visual difficulties)
- "Slowed down" thinking or unable to think straight
- Felt disbelieved
- Felt out of control
- Emotionally sensitive
- Intense emotions

Table V1

Specific Textual Data Extracts and Edits

Textual Data	Edits
"I take objection to the term "hearing Difficulties" It should be termed "Hearing loss". … the word "difficulties" for both hearing loss and loss of sight should be removed. Loss of sight is how to word it..." (Round 3)	Visual difficulties and hearing difficulties adapted to 'changes'.
I think 'lost control of my body' is a bit vague and could refer to a number of the symptoms listed." (Round 3)	Lost control of my body' removed.
"I think 'contortion' on the symptom checklist is hard to understand (in the items you have put contortion/stiffness, so maybe change to that?)." (Round 3)	Contortion removed (symptom checklist and severity section).
"It's not obvious why "warning signs" and "triggers" are written above the symptoms." "The inclusion of the two initial items (seizure warning signs/seizure triggers) without prior clarification is confusing." "I'm not sure people will know the difference between warning signs and seizure triggers." (Round 3)	Subheading added before triggers / warning signs and definitions outlined.
"What are the 'symptoms' meant to be - is that general symptoms they have as well as seizures" (Round 3)	Subheadings refined.
"…the symptoms are all jumbled up which will make it hard to do research or interpret the answers." (Round 3)	Symptom checklist further categorised.

Table V2

Additional Edits and Rationale

Edits	Rationale
Structure of questionnaire changed with symptom checklist placed at the end of the questionnaire.	Qual data related to questionnaire length. Severity and frequency/duration sections prioritised.
Overall instructions made clearer in addition to instructions for each section, subheadings added to severity section, severity items reordered, and wording refined for severity items and frequency / duration items.	Questionnaire more user-friendly.
Numbers on ranking scale removed from severity section	Until further quantitative analysis supports use of ordinal rankings.
Tick box system adapted for symptom checklist to include the before, during and after period.	Clinical value of distinguishing between these periods where possible to support and guide treatment (e.g. recognising warning signs or triggers).
Drop attacks amended to sudden falls on symptom checklist	Terminology too specific.
Symptom checklist items related to avoidance of activities and stopping activities adapted into separate items	Differing concepts.

Appendix W

Final Drafted Questionnaire

FUNCTIONAL / DISSOCIATIVE SEIZURE SCALE

This scale about Functional / Dissociative Seizures (FDS) consists of three parts:

1) Questions about the severity of your seizures
2) Questions about the frequency and duration of your seizures
3) Questions about recent symptoms caused by your seizures

This is a **self-report** measure of your seizures. Please answer the questions, to the best of your knowledge, based on your own experience of your seizures. The questions refer to the period before, during and a short time after your seizures. If you have different types of FDS, please report the symptoms of all types of FDS events you have experienced.

Please answer these questions thinking about the symptoms of your FDS in the **last month.**

SECTION ONE: Functional / Dissociative Seizure Severity

Please **rate on the scale** how often you have experienced the symptom in the **last month**:

	Item	Never	Rarely	Sometimes	Often	Always
1.	Had no control over when my seizures are going to happen.					
2.	Experienced increased sensitivity (e.g., to sounds, smells, light, etc.).					
3.	Experienced distressing symptoms (e.g., unable to move, changes to vision / hearing, pain, uncontrollable movements).					
During a seizure I have:						
4.	Been unable to stop my seizures after they have started.					
5.	Not been able to see or hear anything.					
6.	Felt like I am outside of my own body.					
7.	Been unable to respond to things happening around me.					
8.	Lost awareness.					
9.	Struggled to breathe.					
10.	Experienced involuntary movements.					

11.	Experienced stiffness.					
12.	Experienced weakness in my body.					
13.	Experienced a part of my body becoming paralysed.					
14.	Suddenly dropped to the floor.					
15.	Been injured.					
16.	Wet myself.					
My seizure have:						
17.	Caused me to become disorientated and/or confused.					
18.	Caused me to have speech difficulties.					
19.	Caused me pain.					
20.	Caused me distressing emotions such as fear, anger, sadness.					
21.	Negatively impacted on my ability to fulfil my role.					
22.	Caused me to avoid things I enjoy to stop seizures from happening *(e.g. leaving the house, stopped usual / enjoyable activities, isolated myself).*					
23.	Been bothersome.					
After a seizure I have:						
24.	Had difficulty with my balance and coordination.					
25.	Been exhausted.					
26.	Been unable to take care of myself.					
27.	Not been able to return to what I was doing within one hour.					
28.	Experienced distressing physical or neurological symptoms (e.g., shaking, paralysis, involuntary movements, incontinence, difficulties with eyesight).					
29.	Been left with new physical or neurological symptoms (such as weakness or numbness) that have persisted for more than one day.					

SECTION TWO: Functional / Dissociative Seizure Frequency and Duration

Please **answer the following questions** to the best of your knowledge.

1. How would you best describe the frequency of the seizures you have experienced over the last month? *(Circle the most appropriate option)*

1	2	3	4
No seizures for the last month.	My seizures have been more common than one per day	Less common than one per day but more than one per week	Less common than one per week but more common than one per month

2. Approximately how many seizures have you experienced over the last month? ……

3. What is the highest number of seizures you have experienced in a single day in the last month? ……

4. How long was your longest seizure in the last month?

…….. second(s) / minute(s) / hour(s)

(Please add a number and circle the time which describes your longest seizure best)

5. How long has it usually taken you to recover after a seizure in the last month?

…….. second(s) / minute(s) / hour(s) / day(s)

(Please add a number and circle the time which describes your longest seizure best)

6. Have you experienced seizure clusters (i.e. seizures close together over one or several days)? Yes / No

If 'Yes', **approximately how many clusters of seizures have you experienced in the last month? ……...**

SECTION THREE: FDS Symptom Checklist

Listed below are a range of symptoms that might be related to the period immediately before, during, and immediately after a FDS. Thinking about your own seizures, **tick** if they have had the following features in the **past month** and use the before, during after boxes to identify when you have noticed this.

Before seizures I have experienced:

☐ Seizure Warning Signs
(i.e. signs or symptoms that happen before a seizure which mean I can tell when a seizure is about to happen)

☐ Seizure Triggers
(i.e. any factor(s) that makes it more likely a seizure will happen such as a certain time, place, activity, emotion, etc.)

At the time of my seizures, I have experienced…

Physical sensations	↘	Before	During	After
Weakness	☐	☐	☐	☐
Migraines	☐	☐	☐	☐
Headaches	☐	☐	☐	☐
Dizziness	☐	☐	☐	☐
Pain	☐	☐	☐	☐
Aches	☐	☐	☐	☐
Injury	☐	☐	☐	☐
Tiredness	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐
Nausea	☐	☐	☐	☐
Appetite change	☐	☐	☐	☐
Incontinence	☐	☐	☐	☐

Movement changes	↘	Before	During	After
Shakes	☐	☐	☐	☐
Tics	☐	☐	☐	☐
Stiffness	☐	☐	☐	☐
Tremors	☐	☐	☐	☐
Tensing	☐	☐	☐	☐
Paralysis	☐	☐	☐	☐
Sudden falls	☐	☐	☐	☐
Uncontrollable movements	☐	☐	☐	☐
Unable to move	☐	☐	☐	☐
Loss of balance	☐	☐	☐	☐
Difficulty coordinating movement	☐	☐	☐	☐

Sensory changes	↘	Before	During	After
Changes to vision	☐	☐	☐	☐
Unable to open eyes	☐	☐	☐	☐
Changes to hearing	☐	☐	☐	☐
Hot and / or sweating	☐	☐	☐	☐
Cold and / or shivery	☐	☐	☐	☐
Over sensitivity (to sounds, smells, light, etc.)	☐	☐	☐	☐

Cardiovascular changes	↘	Before	During	After
Struggled to breath	☐	☐	☐	☐
Changes to breathing	☐	☐	☐	☐
Heart racing	☐	☐	☐	☐

Communication changes	↘	Before	During	After
Speech difficulties	☐	☐	☐	☐

Under sensitivity (to sounds, smells, light, etc.) ☐ ☐ ☐ ☐

Unable to speak ☐ ☐ ☐ ☐

Thoughts and Worries	✓	Before	During	After
Negative thoughts about myself	☐	☐	☐	☐
Difficult or challenging thoughts	☐	☐	☐	☐
Worries about more seizures	☐	☐	☐	☐
Worries the seizures will never stop	☐	☐	☐	☐

Cognitive Difficulties	✓	Before	During	After
Memory loss or memory difficulties	☐	☐	☐	☐
Loss of awareness	☐	☐	☐	☐
Brain fog	☐	☐	☐	☐
"Slowed down" thinking or unable to think straight	☐	☐	☐	☐

At the time of my seizures I have felt…

	✓	Before	During	After
Anxious	☐	☐	☐	☐
Scared	☐	☐	☐	☐
Threatened	☐	☐	☐	☐
Stressed	☐	☐	☐	☐
Guilty	☐	☐	☐	☐
Paranoid	☐	☐	☐	☐
Restless	☐	☐	☐	☐
Worried	☐	☐	☐	☐
Unsafe	☐	☐	☐	☐
Vulnerable	☐	☐	☐	☐
Embarrassed	☐	☐	☐	☐
Ashamed	☐	☐	☐	☐

	✓	Before	During	After
Frustrated	☐	☐	☐	☐
Helpless	☐	☐	☐	☐
Panicky	☐	☐	☐	☐
Tearful	☐	☐	☐	☐
Blamed	☐	☐	☐	☐
Disbelieved	☐	☐	☐	☐
Overwhelmed	☐	☐	☐	☐
Suicidal	☐	☐	☐	☐
Hopeless	☐	☐	☐	☐
Defeated	☐	☐	☐	☐
Confused	☐	☐	☐	☐
Disorientated	☐	☐	☐	☐

	✓	Before	During	After
Happy	☐	☐	☐	☐
Excited	☐	☐	☐	☐
Relieved	☐	☐	☐	☐
Out of control	☐	☐	☐	☐
Unable to respond	☐	☐	☐	☐
Disconnected from my body	☐	☐	☐	☐
Like the world is not real	☐	☐	☐	☐
Like I am in a dream	☐	☐	☐	☐
Emotionally sensitive	☐	☐	☐	☐
Intense emotions	☐	☐	☐	☐

Because of the seizures I have…. (tick all that apply):

- ☐ Purposefully avoided activities
- ☐ Stopped doing enjoyable activities
- ☐ Struggled with day-to-day activities
- ☐ Pretended I am okay
- ☐ Downplayed symptoms
- ☐ Done or said things without thinking
- ☐ Needed an emergency admission to hospital
- ☐ Struggled to make decisions
- ☐ Taken a long time to recover
- ☐ Tried to fight against the seizures
- ☐ Tried to stop the seizures

Any symptoms or experiences not listed: