From evidence to experience: Centring people in psychological research on Non-Epileptic Attack Disorder.

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Acknowledgements

“Maybe stories are just data with a soul, and maybe I’m just a storyteller.” Brené Brown’s words have stayed with me throughout this journey. As a Fifer, stories have always been close to my heart. I don’t think little me could have imagined just how far that love of stories would carry her, not just personally, but professionally too. Now, at the close of this thesis, I’m more certain than ever that listening to and honouring people’s stories is at the heart of everything I do. Whether in research or clinical work, it’s this belief that continues to guide me. I hope this research tells an important story, one with people at its heart.

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Here’s to research that honours both science and story.

Chapter 1

Attrition Rates and Diversity Reporting in Psychological Interventions for Non-Epileptic Attack Disorder: A Systematic Review

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Epilepsy and Behavior

1.1 Abstract

Background: To systematically review how psychological intervention trials for Non-Epileptic Attack Disorder (NEAD) report participant attrition and diversity using equity-focused frameworks, and to identify patterns and gaps in the inclusion and retention of marginalised groups.

Methods: Randomised controlled trials (RCTs) of psychological interventions for adults with NEAD were included if peer-reviewed, published in English, and reporting quantitative outcomes. MEDLINE, PsycINFO, and Embase were searched via OVID from inception to May 2025. Reference lists were hand-searched. Risk of bias was assessed using the Cochrane RoB 2 tool, with a subset independently rated by a second reviewer.

Results: Thirteen RCTs published between 2003 and 2023 were included. Reporting of attrition varied widely (0%–60.9%). Few studies reported attrition reasons or used retention strategies. While age and sex were universally reported, other equity-relevant domains such as race/ethnicity (31%), disability (23%), and place of residence (8%) were inconsistently reported. No studies disaggregated attrition data by demographics, and most were rated high risk of bias or had concerns due to missing data.

Discussion: Equity-relevant reporting in NEAD trials remains inconsistent, particularly regarding diversity and attrition. Progress is limited, and proactive, tailored retention strategies are rarely used or reported. Improving visibility of diverse characteristics and addressing engagement barriers is needed. Broader use of frameworks like PROGRESS-Plus and CONSORT-Equity, alongside intersectional approaches, may support more inclusive design, enhanced retention, and improved generalisability.

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1.2 Introduction

Non-Epileptic Attack Disorder (NEAD), also referred to as Psychogenic Non-Epileptic Seizures (PNES), is a complex and often misunderstood condition. Although NEAD episodes resemble epileptic seizures, they are not associated with the characteristic electroencephalogram (EEG) abnormalities observed in epilepsy (Doss & LaFrance, 2016) and are classified within the Functional Neurological Disorder (FND) spectrum. The development and maintenance of NEAD are influenced by multiple interacting factors, including cognitive, emotional, and social/interpersonal dynamics (Hallet et al., 2022; Popkirov et al., 2019).

This review adopts the term NEAD to reflect a broader and more inclusive clinical perspective. NEAD conveys a multifaceted, less pathologising understanding that supports holistic, biopsychosocial formulations and promotes inclusive clinical communication. While the landmark COgnitive behavioural therapy versus standardised medical care for adults with Dissociative non-Epileptic Seizures (CODES) trial (Goldstein et al., 2020) used the term *"dissociative seizures"*, based on patient consultation, this terminology implies a single psychological mechanism of dissociation, which may not fully capture the diversity of patient experiences or the complexity of the condition (Loewenberger et al., 2020). In contrast, NEAD aligns with evolving diagnostic frameworks for FND promotes person-centred care, and validates patient experiences without implying blame or exclusively psychological causality. Although the term NEAD is not without limitations, particularly that it defines the condition by what it is not, reflecting a diagnosis of exclusion rather than a positive diagnostic label, this review uses it because of its broad clinical utility, its resonance with biopsychosocial conceptualisations, and its alignment with inclusive communication practices in contemporary psychological research and care.

Estimating the prevalence of NEAD remains challenging due to limited population-based data. However, following a recent systematic review on prevalence rates for FND, it is believed to affect at least 50 per 100,000 people in the United Kingdom (Finkelstein et al., 2025). A relevant, but now dated, population-based prospective study in Scotland examined first-time presentations of NEAD over a three-year period in a cohort of 367,566 individuals. The study identified 68 cases, with 54 diagnoses confirmed via video-EEG, resulting in an estimated annual incidence rate of 4.9 per 100,000 individuals (Duncan & Mulhern, 2011). It has been reported that NEAD disproportionately affects marginalised populations, including women, individuals from lower socioeconomic backgrounds, and those with trauma histories and psychiatric comorbidities (Baslet et al., 2016; Brown & Reuber, 2016; Rawlings & Reuber, 2018).

Cognitive behavioural therapy (CBT) remains the most widely studied psychological intervention in this context (Goldstein et al., 2020). However, despite its potential efficacy, CBT is associated with high attrition rates in both clinical and research contexts (Howlett et al., 2007; Rawlings & Reuber, 2018; Thompson et al., 2009; Underwood et al., 2024; Wyatt, Laraway & Weatherhead, 2014). For example, LaFrance et al. (2014) reported that only 45% of participants completed all treatment sessions in a multicentre RCT. In contrast, broader benchmarks show average attrition rates for CBT across mental health conditions between 15% and 26% (Fernandez et al., 2015). Other trials report similar trends: Hermanny et al. (2023) found 20–25% attrition in a meta-analysis of 10 RCTs comparing CBT formats, while Wu et al. (2022), evaluating a blended CBT programme for anxiety and depression, found rates between 20–30%, influenced by sociodemographic and clinical factors. For example, males had a lower risk of attrition, while individuals on antidepressants or with higher symptom severity were more likely to disengage. Notably, participants who did not disclose their race or ethnicity were also significantly more likely to drop out. While informative, these findings relate to clinical interventions; participation in research trials may involve additional burdens such as consent procedures, data collection appointments, and follow-up measures that contribute uniquely to disengagement. Innovative longitudinal research with marginalised communities (Barnes, 2022) demonstrates that proactive engagement strategies can help support continued participation and reduce inequitable attrition.

Furthermore, Michaelis and colleagues (2020) systematically reviewed 36 RCTs investigating health-related quality of life outcomes in psychological interventions for individuals with epilepsy, including CBT and psychoeducation-based approaches. Attrition rates varied from 1.7% - 51% with an average of 25.2% across the 36 studies. Attrition was higher in studies that required more active participation or longer follow up durations. Demographic reporting often only included age and sex with ethnicity and socioeconomic status more inconsistently reported. More recent and specific to NEAD, Underwood et al. (2024) found similarly high attrition rates in a pragmatic trial of a brief psychological intervention for NEAD, with barriers including logistical challenges, ambivalence about psychological explanations, and participants feeling misunderstood by services. Qualitative research highlights how stigma, prior negative experiences with healthcare, emotional avoidance, and lack of therapeutic alliance may further undermine engagement (Rawlings & Reuber, 2018; Walsh et al., 2024). These findings point to the multifactorial nature of attrition, shaped by a complex interplay of psychological, social, and systemic factors.

High attrition undermines both the clinical effectiveness of psychological interventions and the validity and generalisability of research findings. It raises questions about who benefits from treatment and who is excluded, often reflecting underlying inequities

in access, acceptability, and sustainability of care. Comprehensive and accurate demographic reporting is therefore essential to better understand intervention reach and equity of outcomes (Robson et al., 2018; Finkelstein et al., 2025).

However, demographic underreporting is a widespread issue across psychological research. Reviews consistently identify omissions in key variables such as ethnicity, gender, socioeconomic status, and disability (Guzman et al., 2024; Owusu-Addo et al., 2024; Polo et al., 2019). For instance, a systematic review of over 30 years of psychopathology research found that sociodemographic reporting including race, ethnicity, and socioeconomic status remains inconsistent, limiting the interpretability and generalisability of findings (Wilson, 2024). Similarly, Ong et al. (2024) reviewed three decades of U.S.-based RCTs for anxiety disorders and found persistent overrepresentation of white participants and women, alongside poor reporting of other key demographic variables such as disability and sexual orientation. Notably, there was no evidence of improvement in reporting quality over time.

A closer examination of diversity characteristics in NEAD intervention research is essential for understanding patterns of attrition, recruitment, and engagement. Structural barriers such as financial hardship, limited healthcare access, cultural stigma, and clinician bias may disproportionately affect individuals' ability to participate in and remain engaged with psychological treatment in trials and services (Brown & Reuber, 2016; LaFrance et al., 2009). Gendered experiences, especially those linked to trauma, may also influence engagement and attrition risk (Morsy et al., 2022). Although NEAD is more commonly diagnosed in women, comprehensive demographic data to explore gender-specific differences remain limited (Asadi-Pooya et al., 2013; Brown & Reuber, 2016; Noe et al., 2012). Notably, Stone et al. (2020) found no associations between age, gender, or socioeconomic deprivation and treatment engagement in a sample of 698 NEAD patients from an RCT. However, given the trial's structured referral and attendance supports, these findings may not generalise to routine clinical settings.

Individuals with NEAD face multifaceted challenges at both individual and systemic levels, impacting diagnosis accuracy, treatment adherence, and overall healthcare outcomes. Misdiagnosis is prevalent, often leading to inappropriate treatments and increased healthcare utilisation. Patients with NEAD frequently report poor adherence to treatment regimens and a diminished quality of life (Goldstein et al., 2020; Rawlings & Reuber, 2018; Tilahun & Bautista, 2022). Research has shown that patients often feel misunderstood and marginalised within healthcare systems, which can intensify feelings of isolation and negatively impact engagement with treatment (Walsh et al., 2024). Stigma not only undermines psychological well-being but also reduces patients' willingness to

participate in care and adhere to treatment plans. Qualitative evidence further underscores the importance of patients feeling heard, respected, and understood by healthcare professionals. When healthcare providers are perceived as empathetic and validating, patients report increased trust, greater therapeutic engagement, and improved adherence to recommended interventions (Rawlings & Reuber, 2018; Staton et al., 2024; Walsh et al., 2024). Without adequate reporting, researchers and clinicians risk overlooking cultural, economic, and systemic barriers that contribute to treatment attrition, further exacerbating healthcare inequities.

Ensuring that psychological intervention studies reflect the diversity of the populations they aim to serve is essential for improving engagement, outcomes, and the generalisability of findings, particularly in NEAD research where disparities in care persist (Gedela et al., 2025; Mishra et al., 2024; Rutten-Jacobs et al., 2024). Improving inclusivity has become a growing priority in health services research, exemplified by initiatives like the NIHR-funded INCLUDE project, which provides practical guidance for enhancing representation of underserved groups including ethnic minorities, lower socioeconomic populations, individuals with disabilities, and those with cognitive or communication impairments (Witham et al., 2020). This guidance recommends adapting recruitment pathways, ensuring accessible study materials, and transparently reporting equity-relevant characteristics such as ethnicity, gender identity, and socioeconomic status.

Moreover, demographic factors rarely operate in isolation; intersectionality underscores how overlapping social identities and structural disadvantages compound to shape health experiences and outcomes (Shaw et al., 2022). Applying an intersectional lens is therefore critical when evaluating whether NEAD intervention studies adequately represent and serve those most affected. Without this perspective, research risks perpetuating structural exclusion by overlooking individuals whose lived experiences fall outside dominant clinical narratives or narrowly defined participant categories (Bauer et al., 2021; De Mesa et al., 2023; Tinner et al., 2023).

Several diversity and equity-focused reporting frameworks have been developed to promote more inclusive and transparent research, including CONSORT-Equity (Welch et al., 2017), the APA's JARS-REC (Appelbaum et al., 2018), and the PROGRESS-Plus framework (O'Neill et al., 2014), which supports the synthesis of equity-relevant characteristics such as place of residence, ethnicity, socioeconomic status, disability and other intersecting factors that may influence both access to interventions and outcomes. However, these tools have not, to the best of current knowledge, been systematically applied within RCTs of psychological interventions for NEAD. In parallel, the Cochrane Risk of Bias

2 (RoB 2) tool (Sterne et al., 2019) provides a standardised method for assessing internal validity, which is particularly relevant given the high attrition and variable engagement observed in NEAD studies. This review is the first to apply both PROGRESS-Plus and RoB 2 in this context, taking a dual approach that foregrounds diversity, equity and methodological quality. In doing so, it aims to support a more inclusive and critically informed interpretation of the NEAD intervention evidence base and generate practical recommendations to improve both research and clinical practice.

1.2.1 Aims

This systematic review aims to examine attrition rates and diversity reporting in psychological intervention trials for NEAD. Inadequate demographic reporting limits understanding of intervention reach, differential outcomes, and health inequalities, making it difficult to identify cultural and systemic barriers that may contribute to attrition. It remains unclear whether those most affected by NEAD are adequately represented in the evidence base or whether findings are generalisable across diverse populations. By synthesising existing literature, this review seeks to identify gaps in diversity reporting, assess the impact of demographic factors on treatment engagement, and propose recommendations to foster inclusivity in future clinical trials. Addressing these issues is crucial to ensuring equitable access to effective psychological treatments for all individuals affected by NEAD.

1.2.3 Research questions

1. What are the reported attrition rates in psychological interventions for NEAD?
2. How is diversity (e.g., gender, ethnicity, socioeconomic status, disability) reported in psychological intervention studies for NEAD?
3. What factors contribute to attrition in these interventions, and are there any reported strategies to facilitate engagement?
4. Is attrition higher among individuals from marginalised or from under-represented groups?

1.3 Methods

1.3.1 Protocol registration and review methods

This systematic review protocol was registered on PROSPERO in June 2025 (CRD420251061740; https://www.crd.york.ac.uk/PROSPERO/view/CRD420251061740) and

adhered to PRISMA 2020 guidelines (Page et al., 2021), with reporting following PRISMA statements (Appendix 1.1 & Appendix 1.2).

1.3.2 Systematic search

A comprehensive search strategy was developed in consultation with two specialist librarians. Searches were conducted across three major databases via the OVID platform: MEDLINE(R) 1946 – May 2025, PsycINFO 1806 – May 2025, and Embase 1947 – May 2025. All searches were completed on 15th May 2025.

Searches included titles, abstracts, controlled vocabulary (i.e., MeSH terms), keywords and synonyms relating to NEAD, psychological interventions and randomised controlled trials. For full search strategy see Appendix 1.3. Importantly, terms related to attrition and diversity were intentionally excluded from the search strategy to maximise sensitivity and ensure inclusion of studies that may not explicitly report on these variables. Reference lists of included studies and relevant reviews were hand-searched to identify further eligible publications. Searches were restricted to studies published in English.

1.3.3 Eligibility criteria

To be considered eligible for inclusion, studies had to meet all of the following criteria;

- Participants were adults (aged 18 years and older) diagnosed with Non-Epileptic Attack Disorder (NEAD).
- Evaluation of a psychological intervention explicitly targeting individuals diagnosed with NEAD (e.g., CBT, psychodynamic therapy, psychoeducation, group therapy, third-wave approaches), delivered in any format (e.g., individual, group, online, blended).
- Use of a randomised controlled trial (RCT) design.
- Published in a peer-reviewed journal, in English.

Studies were excluded if any of the following criteria were met;

- Studies focused exclusively on children or adolescents (aged under 18 years).

- Used non-randomised study designs (e.g., observational studies, feasibility studies, pilot studies without randomisation, quasi-experimental designs, case series, case reports, qualitative studies, and literature reviews).
- Studies not involving a psychological treatment (e.g., purely medical/pharmacological management, diagnostic tools, epidemiological studies).
- Interventions not targeted toward NEAD or where NEAD participants are not separately analysed in mixed diagnostic groups.
- Unpublished or published in non-peer-reviewed formats (e.g., theses, dissertations, conference abstracts without full accessible text).
- Studies not available in English.

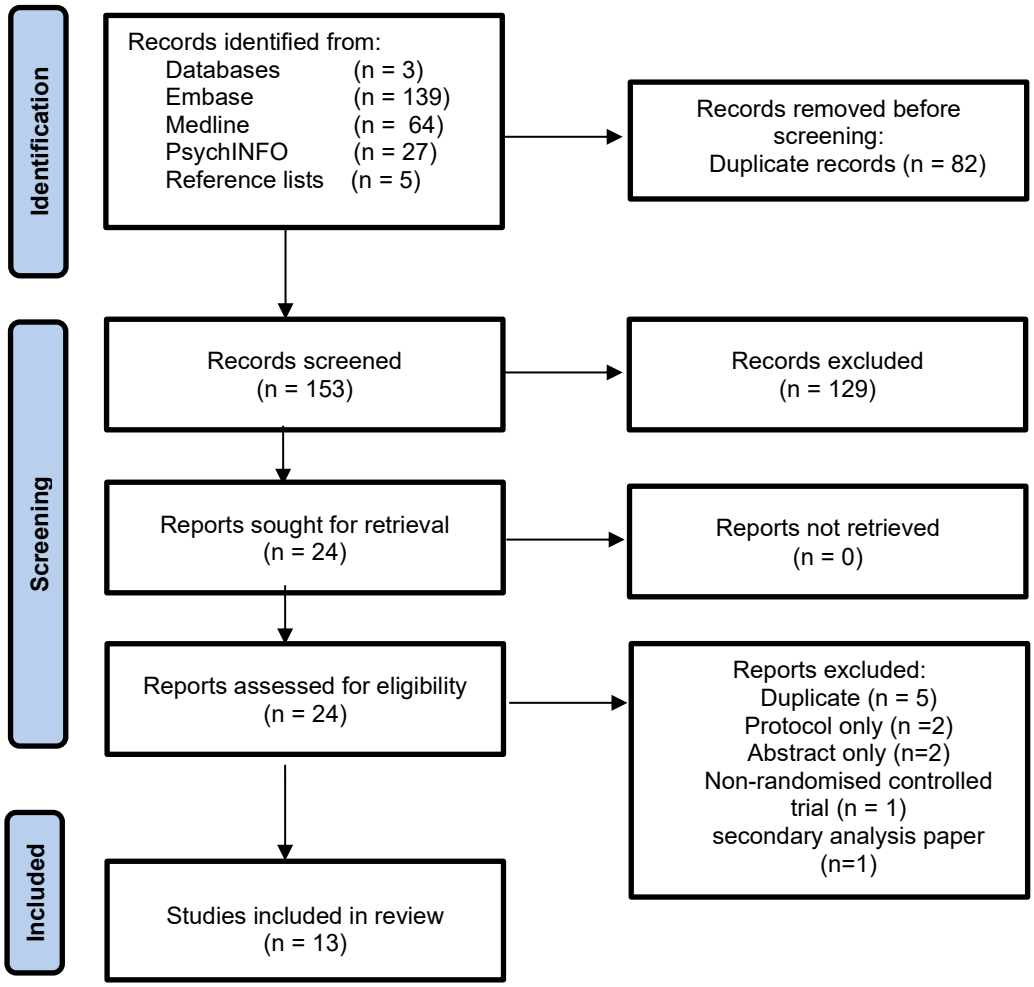
1.3.4 Study screening

235 records were initially identified and exported to Rayyan systematic review software, where 82 duplicate records were removed before screening. The primary reviewer (SD) conducted the initial title and abstract screening to assess studies against the eligibility criteria. Records marked as “maybe,” which were unclear, were retained for further evaluation. A subset of 24 studies underwent joint title and abstract screening by both SD and a second reviewer (JF) to enhance transparency and support independent verification. Of these, 13 studies were agreed for full text screening, and 11 were excluded following consensus discussion.

Reasons for exclusion included duplicate records (n = 5), abstracts only (n = 2), study protocols only without associated outcome data (n = 2), a non-randomised controlled trial (n = 1), and a secondary analysis from an existing RCT (n = 1) (see Figure 1.1 below for inclusion breakdown).

Figure 1.1

PRISMA flow diagram of included studies



Full-text screening was completed by the primary reviewer (SD), who assessed all potentially relevant studies against the pre-specified inclusion and exclusion criteria. Thirteen studies met all eligibility criteria at the full-text stage and were subsequently included in the final review.

1.3.5 Quality appraisal/Risk of bias

Risk of bias was assessed using the Cochrane Risk of Bias 2 (RoB 2) tool (Sterne et al., 2019). Assessments were conducted using the official RoB 2 Microsoft Word template for completion, covering five domains: bias arising from the randomisation process, deviations from intended interventions, missing outcome data, measurement of the outcome, and selection of the reported result. The primary reviewer (SD) completed RoB 2 assessments for all included studies. To enhance reliability, the second reviewer (JF) independently assessed a random subset comprising 54% of the included studies (n = 7), selected using a computerised random generator.

Both reviewers reached full agreement on the overall risk of bias ratings for all seven studies. Minor domain-level discrepancies were identified in four studies and were resolved through discussion, facilitating a shared understanding of the RoB 2 criteria and decision rules, in line with guidance from the RoB 2 manual. No third-party adjudication was required. To enhance consistency and ensure fidelity, the primary reviewer (SD) reappraised the remaining eight studies originally assessed independently. This re-review process aimed to verify alignment with the consensus criteria and strengthen the reliability of the final risk of bias ratings across the full sample.

1.3.6 Data extraction

Data extraction was completed by SD using a structured extraction template developed for this review. Key variables extracted included study characteristics, participant demographics, intervention details, attrition rates, reporting of diversity-related variables, and, where available, documented reasons for participant attrition.

1.3.7 Equity and diversity considerations

To support the review's aims of examining how diversity and inclusion are addressed in psychological intervention trials for NEAD, the PROGRESS-Plus framework was used to guide data extraction and synthesis of diversity and equity-related information. This framework, developed by the Cochrane and Campbell Equity Methods Group and recommended within the PRISMA-Equity extension (O'Neill et al., 2014), provides a structured yet flexible tool for identifying and analysing factors that may contribute to health disparities. The acronym covers: Place of residence, Race/ethnicity/culture/language, Occupation, Gender/sex, Religion, Education, Socioeconomic status, Social capital, with "Plus" capturing additional characteristics such as age, disability, and sexual orientation. PROGRESS-Plus was judged to be a more appropriate and pragmatic framework at the data extraction stage, enabling a broader mapping of inclusion and attrition across diverse social groups. Although all included studies were RCTs, additional reporting standards, namely, the CONSORT-Equity extension (Welch et al., 2017), were considered to support analysis of participant flow, recruitment, and engagement strategies. While not adopted as the primary analytic lens, these guidelines informed specific data extraction fields related to attrition and representation.

Customised extraction fields were developed based on PROGRESS-Plus domains and selected CONSORT-Equity extension domains, capturing:

- Clarity in reporting recruitment procedures and participant flow.
- Inclusivity of design, e.g., considerations of language, disability, or comorbidities.
- Demographic reporting completeness and granularity of data on gender, ethnicity, socioeconomic status, education, and disability.
- Use of subgroup analyses or considerations of generalisability to underserved populations.
- Recruitment and retention: description of strategies to reduce participation barriers.
- Attrition: whether group-specific attrition was reported or explained.
- Equity considerations in outcomes: whether analyses addressed disparities or potential inequities.

This approach supported not only the synthesis of existing practices but also informed the review's discussion of how researchers might better attend to equity considerations in future NEAD psychological intervention clinical trials. Utilising these frameworks ensured that data extraction captured who was represented in trials, patterns of attrition, and how equity-relevant characteristics were reported or omitted in participant flow and outcomes.

1.3.8 Method of synthesis

A narrative synthesis was used to analyse and present findings across the included studies. This method enabled a structured and descriptive summary of heterogeneous data, particularly suited to capturing patterns related to attrition rates, diversity reporting, and equity-relevant features and engagement strategies. The synthesis approach was informed by principles outlined in the ESRC Guidance on Narrative Synthesis (Popay et al., 2006).

Studies are first summarised in tabular form, including study design, sample demographics, intervention characteristics, and risk of bias. Thematic synthesis was then organised around the review's core questions. Themes were developed deductively from the data extraction framework and refined iteratively as synthesis progressed. The unit of analysis was the individual study, with comparisons made across intervention types, study settings, and country contexts where appropriate.

Convergence and divergence in findings were noted, and contextual factors such as service setting, sample characteristics, and intervention modality were explored to identify

potential influences on participant representation and reporting quality. While some outcomes, such as attrition rates and reporting of PROGRESS-Plus criteria, are quantitative, the wide variability in interventions and reporting methods across studies precludes meta-analysis. Therefore, a narrative synthesis of the quantitative and qualitative data was planned to provide a more informative and nuanced overview. Interpretations were reviewed collaboratively to enhance consistency and transparency in reporting.

1.4 Results

Thirteen studies met the inclusion criteria and were included in this systematic review. The results are presented following the four review questions, beginning with an overview of study characteristics. Subsequent sections address: (1) reported attrition rates across NEAD psychological intervention trials, (2) the extent and quality of diversity reporting, including demographic variables such as gender, ethnicity, socioeconomic status, and disability, (3) factors associated with participant attrition and retention, and (4) whether attrition patterns differ across marginalised or under-represented groups. Where relevant, narrative synthesis is supported by summary tables to highlight key patterns and limitations in the evidence base.

1.4.1 Study characteristics

The 13 included studies were conducted across eight countries, with the United Kingdom (n = 4) and the United States (n = 4) being the most represented. Other contributing countries were Pakistan, Turkey, Mexico, Switzerland, and Germany.

Sample sizes ranged from 18 to 386 participants. Most studies were small to medium in scale, with only one large-scale trial (Goldstein et al., 2020) including over 300 participants. The remaining studies had sample sizes between 18 and 82.

A variety of psychological interventions were evaluated across the included studies. CBT or CBT-informed interventions were the most commonly studied, featured in five trials. Other intervention types included behaviour therapy, paradoxical intention, brief group psychoeducation, brief psychodynamic therapy, body-focused group therapy (CORDIS), motivational interviewing combined with psychotherapy, and brief interdisciplinary psychotherapy. Three studies evaluated self-help or home-based approaches, such as stress management workbooks and expressive writing interventions.

Comparator conditions varied, with standard medical care (SMC) or treatment-as-usual (TAU) being the most frequent, appearing in six studies. Other comparators included

pharmacotherapy, delayed intervention controls, guided self-help groups, and active psychotherapy controls.

Seizure frequency was the most common primary outcome, reported in seven studies. Other primary outcomes included appointment or psychotherapy adherence, psychosocial functioning, stress, quality of life, seizure severity, and physical symptom reduction. Secondary outcomes across studies included anxiety, depression, psychosocial functioning, quality of life, health service use, emergency department visits, and clinical impression of improvement.

Interventions were delivered through a range of formats. Seven studies delivered individual therapy, three delivered group-based interventions, and three evaluated self-administered or home-based formats. Three interventions were delivered as single sessions, while the remainder involved multiple sessions ranging from four to 36.

Settings included outpatient neuropsychiatry, neurology or epilepsy clinics (n = 6), hospital-based or specialist units (n = 5), and community/home settings (n = 2).

Treatment duration varied considerably, ranging from a single 40-minute session to nine months of weekly therapy. Most interventions were delivered over 4 to 16 weeks. Eleven of the 13 studies included follow-up assessments, with time points ranging from 1 month to 12 months post-intervention. The most frequently reported follow-up durations were at 2–3 months and 6 months post-treatment. See Table 1.1 below for a summary.

Table 1.1
Study Characteristics Summary

Study	Country	Sample size	Psychological intervention type	Comparator	Primary outcome	Secondary outcomes	Delivery format	Setting	Treatment duration	Follow up
Aamir et al. (2011)	Pakistan	n = 18	Behaviour therapy	TAU - pharmacotherapy	Seizure frequency	Anxiety and depression	15 individual therapy sessions	Psychiatry Unit	11 weeks	2 months post-treatment
Ataoglu et al. (2003)	Turkey	n = 30	Paradoxical Intention (PI)	Diazepam treatment	Cessation of 'conversion symptoms'	Anxiety	PI: inpatient, 2 sessions/day. Diazepam: outpatient visits	Emergency unit	6 weeks	At the end of week 6, no further follow-up
Chen et al. (2014)	United States	n = 64	Brief group psychoeducation	TAU - routine seizure-clinic follow-up	Psychosocial functioning	ER/hospital visits, new unexplained symptoms, patient knowledge/perception	Group sessions, 3 sessions a month	Epilepsy Monitoring Unit	3 months	3 and 6 months post-treatment
De Santiago-Trevino et al. (2017)	Mexico	n = 23	Brief Psychodynamic Therapy (BPT); Cognitive Behavioural Therapy (CBT)	Monthly interview-only control	Seizure frequency	QoL	36 individual therapy sessions	Sleep Disorders Clinic	9 months	3 and 6 months post-treatment
Goldstein et al. (2010)	United Kingdom	n = 66	CBT	SMC	Seizure frequency	Seizure freedom, health service use, employment status, psychosocial functioning	12 face-to-face individual sessions	Outpatient neuropsychiatric clinics	4 months	6-month post-baseline assessments
Goldstein et al. (2020)	United Kingdom	n = 386	CBT	SMC	Seizure frequency	Seizure intensity, seizure bothersomeness, seizure-free periods, psychosocial functioning, health-related QoL, psychological distress, somatic symptom burden, clinical impression of improvement and satisfaction	12 face-to-face individual sessions	Outpatient neuropsychiatry/neurology clinics	4 months	Outcomes captured at 6 and 12 months post-assessment
Hubschmid et al. (2015)	Switzerland	n = 23	Brief interdisciplinary psychotherapy	SMC	Physical symptom reduction	Disability level, health service use, depression, QoL	4-6 individual therapy sessions	Hospital-based consultation-liaison psychiatry	2 months	2, 6, and 12 months post-intervention
LaFrance et al. (2014)	United States	n = 38	CBT-informed psychotherapy (CBT-ip)	CBT-ip + sertraline; sertraline only; TAU	Seizure frequency	Depression, anxiety, QoL, global functioning	16 weekly individual sessions + standardised medication	Outpatient epilepsy/psychiatry clinics	16 weeks	Outcome assessment at week 16 - no further follow-up

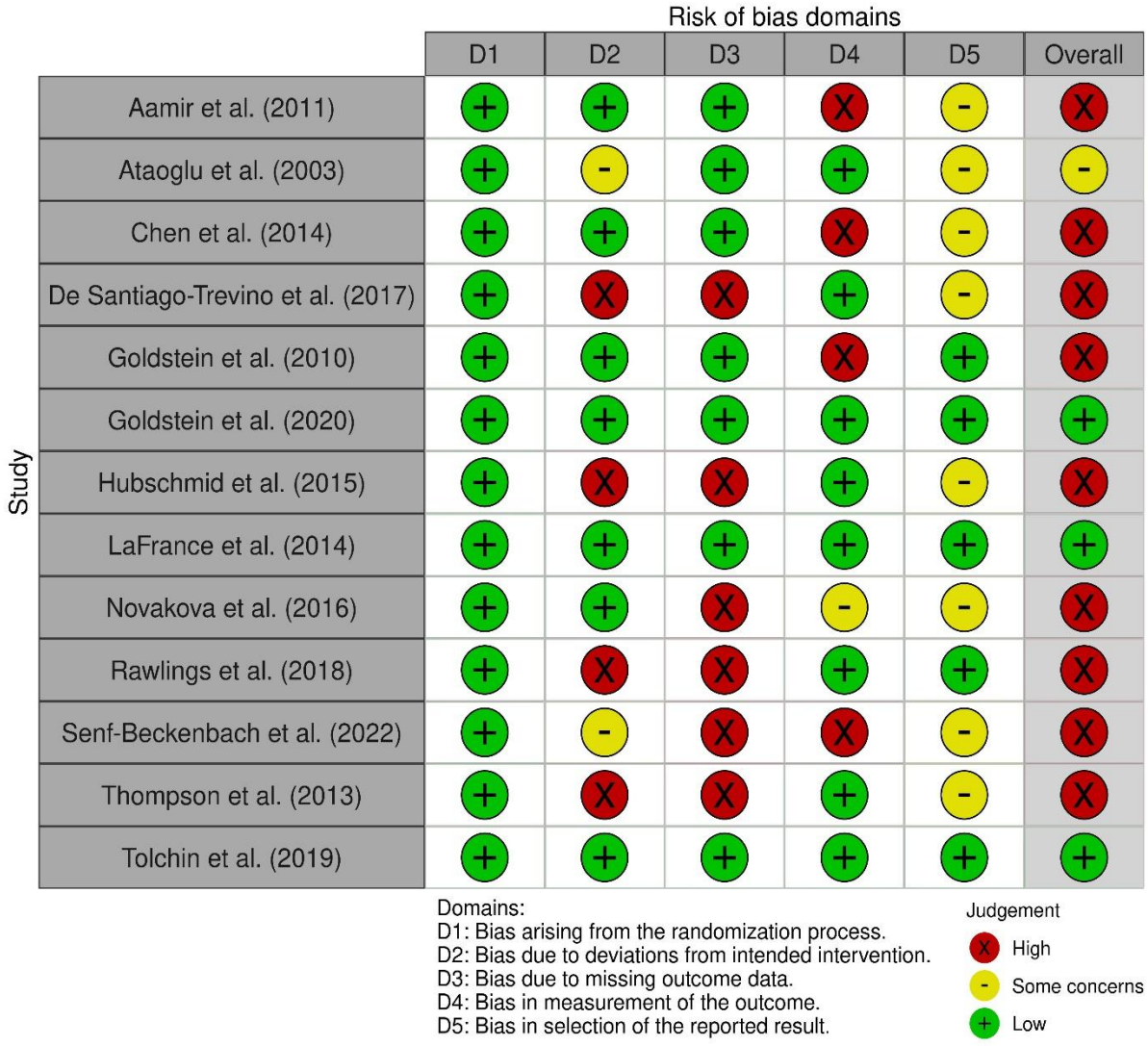
Novakova et al. (2016)	United Kingdom	n = 82	Self-help stress management workbook	Delayed-intervention control	Stress	Anxiety, depression, QoL, seizure severity and frequency	Self-administered with optional phone support	Outpatient neurology clinics	4 weeks	1 and 2 months post-baseline
Rawlings et al. (2018)	United Kingdom	n = 68	Focused expressive writing intervention	Control writing condition	Health-related QoL	Anxiety, depression, and illness perception	4 home-based self-directed learning sessions	Community/home settings	4 weeks	1 month and 3 months
Senf-Beckenbach et al. (2022)	Germany	n = 53	CORDIS (body-focused group therapy)	SHG (guided self-help group)	Seizure severity	Dissociation, psychiatric symptoms, QoL, functional impairment	6 group therapy sessions	Specialised outpatient clinic	6 weeks	2 weeks and 6 months post-treatment
Thompson et al. (2013)	United States	n= 19	Brief educational session	SMC	Appointment adherence	Seizure frequency and intensity	In-person, one-time session	Epilepsy Monitoring Unit	40-90 minutes	6–8 weeks post-intervention
Tolchin et al. (2019)	United States	n = 60	Motivational Interviewing session + psychotherapy	Standard psychotherapy sessions	Psychotherapy adherence	Seizure frequency, QoL, emergency department utilisation	In-person, one-time MI session + 12 psychotherapy sessions	Comprehensive epilepsy care outpatient clinic	16 weeks	16 weeks post-referral - no further follow-up

1.4.2 Quality appraisal

Across the 13 studies included, three studies were overall rated as low risk of bias (Goldstein et al., 2020; LaFrance et al., 2014 & Tolchin et al., 2019). One study was rated as having some concerns (Ataoglu et al., 2003), and nine were judged to be at high risk of bias (Aamir et al., 2011; Chen et al., 2014; De Santiago-Treviño et al., 2017; Goldstein et al., 2010; Hubschmid et al., 2015; Novakova et al., 2016; Rawlings et al., 2018; Senf-Beckenbach et al., 2022 & Thompson et al., 2013). For individual risk of bias domain ratings, see Figure 1.2 below, which was created using the Risk-of-bias VISualization (robvis) tool (McGuinness & Higgins, 2020).

Figure 1.2

RoB 2 Quality Appraisal



These findings suggest that while randomisation procedures were generally robust across studies according to RoB 2 rating measurements, concerns remain regarding missing outcome data (D3) and selective reporting (D5). Concerns related to D3 (missing outcome data) often stemmed from high attrition rates and incomplete follow-up, while issues in D5 (selection of the reported result) reflected unclear reporting on pre-specified outcomes or outcome switching. These were the most frequent sources of concern, with several studies rated as high risk or having some concerns in these domains.

It should be acknowledged that RoB 2 criteria can sometimes be met with relatively minimal information to assign a low risk rating, which may mask subtler issues in trial conduct or reporting. Consequently, although randomisation appears generally robust, the observed attrition and selective reporting concerns underscore the necessity for more rigorous trial designs and transparent reporting practices such as pre-registration of analysis plans and outcomes, alongside systematic approaches to handling missing data to enhance the internal validity and replicability of NEAD psychological intervention research.

1.4.3 Reporting, patterns, and strategies related to attrition

This subsection examines how attrition was reported across the 13 included studies, covering terminology, rates, reasons for attrition, and strategies to enhance participant retention and engagement.

1.4.3.1 Terminology Used

The terminology used to describe participant attrition varied across the 13 included studies. The most commonly used term was “dropout,” which appeared in six studies: Aamir et al. (2011), Hubschmid et al. (2015), LaFrance et al. (2014), Novakova et al. (2016), Rawlings et al. (2018), and Senf-Beckenbach et al. (2022). Two studies, Ataoglu et al. (2003) and De Santiago-Trevino et al. (2017), did not report any attrition-related terminology; the former due to full retention, and the latter due to missing data on follow-up completion. Other terms identified included “lost to follow-up,” “withdrawal,” “refused to participate,” “attrition,” and “non-adherent.” The frequent use of “dropout” suggests some consistency, but the presence of alternative or undefined terms may hinder comparison and synthesis across trials. The CONSORT statement (Item 13) recommends that authors provide a detailed participant flow diagram reporting the number of participants at each trial stage, including enrolment, allocation, follow-up, and analysis, and explicitly document numbers lost to follow-up or who discontinued intervention, with reasons given where possible. To enhance clarity and facilitate cross-study comparisons, future NEAD intervention trials would benefit from using

standardised attrition terminology and adhering to CONSORT guidelines for transparent reporting.

1.4.3.2 Attrition reporting and rates

Attrition rates varied widely across the included studies, perhaps reflecting heterogeneity in study design, sample characteristics, and intervention delivery. Nine studies used CONSORT-style flow diagrams and reported group-specific attrition data. Reported attrition rates across studies ranged from 0% to 60.9%. The highest attrition rate was observed in Novakova et al. (2016), where 60.9% of participants withdrew from the study. This was followed by Senf-Beckenbach et al. (2022) with 54.7% attrition, and Rawlings et al. (2018) at 48%. By contrast, studies such as Ataoglu et al. (2003), Tolchin et al. (2019), and Goldstein et al. (2020) reported comparatively low attrition (16.1%).

Attrition often differed markedly between study arms. For example, LaFrance et al. (2014) reported 80% attrition in the TAU group versus 11.1% in the intervention arm, while Aamir et al. (2011) also showed higher control group attrition (33.3% vs. 11.1%). Self-management or protocol-driven interventions showed similarly high attrition, including 60.9% in a stress management workbook trial (Novakova et al., 2016) and 48% in an expressive writing study (Rawlings et al., 2018), suggesting that burden or limited therapeutic contact may impact retention. In contrast, more interactive or personalised interventions such as CBT (Goldstein et al., 2020; 16.1%) or motivational interviewing plus psychotherapy (Tolchin et al., 2019; 13.3%) tended to achieve lower attrition rates. These findings suggest that retention is influenced not only by trial design and setting, but also by how engaging or meaningful participants find the intervention, underscoring the importance of thoughtfully selecting and reporting comparator conditions in NEAD trials.

1.4.3.3 Timing of attrition

The timing of participant attrition was reported with varying specificity across the included studies. Three studies (Aamir et al., 2011; De Santiago-Trevino et al., 2017; Thompson et al., 2013) did not provide any timing information. Among those that did, attrition most commonly occurred during treatment or at follow-up.

Several studies reported detailed timing breakdowns. For example, Hubschmid et al. (2015) and LaFrance et al. (2014) identified participant losses at multiple stages: pre-treatment, during intervention, and at follow-up. Chen et al. (2014) and Tolchin et al. (2019) similarly noted attritions primarily during intervention and follow-up. Follow-up attrition was

particularly high in Novakova et al. (2016), where substantial losses occurred across baseline and both post-treatment time points.

Goldstein et al. (2020) reported substantial early attrition, with 30 participants withdrawing from the intervention group and 25 from the control group shortly after randomisation. Rawlings et al. (2018) reported 63 attritions following allocation, although further timing details were not provided.

Overall, while the majority of studies captured attrition timing in some form, the inconsistency in time-point definitions and terminology limits cross-study comparability. However, the lack of standardised reporting across trials and reporting errors regarding the number of participants at different stages of the trial limit the ability to make direct comparisons or draw firm conclusions about when participants are most likely to disengage. Improved clarity and consistency in reporting attrition timing, particularly using standardised time points aligned with trial phases, can enhance the interpretability of retention data in future NEAD intervention studies. Early withdrawal may indicate challenges in participant engagement or initial acceptability, whereas follow-up attrition may reflect retention burden, reduced perceived benefit, or systemic follow-up issues

1.4.3.4 Reasons for attrition

Reasons for participant attrition were reported inconsistently across the included studies. Of the 13 studies, six (Aamir et al., 2011; Atoglu et al., 2003; Chen et al., 2014; De Santiago-Trevino et al., 2017; Novakova et al., 2016; Thompson et al., 2013) either did not report reasons or provided only limited or speculative explanations. For example, Novakova et al. (2016) hypothesised in their discussion that attrition may have been linked to the burden of baseline assessments and feedback demands, although this was not formally investigated.

Among studies that did report reasons, explanations encompassed both participant-level and systemic factors. Individual reasons included physical illness, competing commitments such as full-time education, travel difficulties, and reduced motivation or engagement. Goldstein et al. (2010) provided the most detailed breakdown, reporting post-randomisation withdrawals due to a range of issues including refusal to participate, non-response, physical illness, social barriers, travel distance, full-time education, difficulty engaging with the intervention, and becoming seizure-free. Several studies also cited loss to follow-up, initiation of alternative treatments (LaFrance et al., 2014), or non-adherence to intervention protocols (Rawlings et al., 2018). Disappointment in group allocation and transition to other forms of care, such as individual therapy, were also noted (Senf-

Beckenbach et al., 2022), highlighting how trial design and delivery can influence participant retention.

Overall, these findings reflect a wide range of attrition drivers, including practical barriers (e.g., travel, illness), dissatisfaction with or difficulty engaging in treatment, competing life demands, and limited capacity for engagement or follow-up. This further suggests that attrition in NEAD intervention trials is driven by a complex interplay of practical, clinical, and psychosocial factors. However, the limited and inconsistent reporting of attrition reasons across studies constrains understanding of these patterns and their implications. Encouraging greater standardisation in documenting and reporting reasons for attrition, particularly aligned with CONSORT guidance, may enhance the interpretability of attrition data and inform strategies to improve retention in future trials.

1.4.3.5 Strategies to enhance engagement and retention

Retention strategies were inconsistently reported across the included studies. Five studies made no mention of any strategies to enhance participant engagement or retention. Among the remaining studies, a range of approaches were used. These included:

- Regular contact with researchers to encourage continued participation and adherence to study requirements (e.g., seizure diary completion).
- Multi-disciplinary follow-up, where participants met with both psychiatrists and neurologists at regular intervals (e.g., 2, 6, and 12-month follow-ups).
- Reducing participant burden, such as therapist-rated outcomes instead of self-report questionnaires.
- Flexible delivery methods, such as offering video appointments to participants with travel or motor difficulties.
- Proactive and sustained efforts to encourage follow-up, including multiple phone calls or mailed reminders.

Notably, several studies reflected on lessons for reducing attrition and strengthening participant–researcher rapport. Suggestions included providing dedicated contact time, particularly for self-help interventions, to build confidence and adherence, using neutral group labelling to reduce early attrition, and offering eHealth options to ease travel and cost burdens. While some creative, participant-centred strategies were implemented, systematic retention plans were often absent. Although such strategies may be detailed in accompanying protocol papers, with the exception of CODES (Goldstein et al., 2020), these were rarely cited in the main trial reports. Future reviews would benefit from examining all

related publications to fully capture retention practices and support more inclusive, engagement-focused trial design.

1.4.3.6 Handling of missing data

Approaches to handling missing data varied across the 13 studies, with inconsistent use of established strategies. Intention-to-treat (ITT) analysis, generally considered a rigorous approach for maintaining the benefits of randomisation, was used in six studies (Goldstein et al., 2010, 2020; Hubschmid et al., 2015; LaFrance et al., 2014; Senf-Beckenbach et al., 2022; Tolchin et al., 2019). Per-protocol analysis, which includes only participants who completed treatment as intended, was used in three studies (Chen et al., 2014; Novakova et al., 2016; Rawlings et al., 2018), potentially introducing bias through the exclusion of non-completers.

Notably, four studies (Aamir et al., 2011; De Santiago-Trevino et al., 2017; Thompson et al., 2013; Ataoglu et al., 2003) did not report how missing data were handled. All four of these studies were rated as high risk of bias (or some concerns), with missing outcome data (RoB 2 Domain 3) commonly flagged, indicating that a lack of transparency around data handling may have contributed to reduced methodological quality.

Overall, the inconsistent use and reporting of missing data strategies and attrition across NEAD intervention trials pose challenges for interpretation and cross-study comparison. These findings underscore the importance of clear, consistent, and equity-sensitive reporting, particularly in trials involving populations at high risk of attrition. Adherence to CONSORT guidelines and pre-specification of missing data handling procedures can support transparency and enhance the interpretability of findings.

The following section builds on this by examining how diversity-related variables are reported across studies, including which groups are represented in, or underrepresented within, the existing evidence base.

1.4.4 Reporting of participant diversity

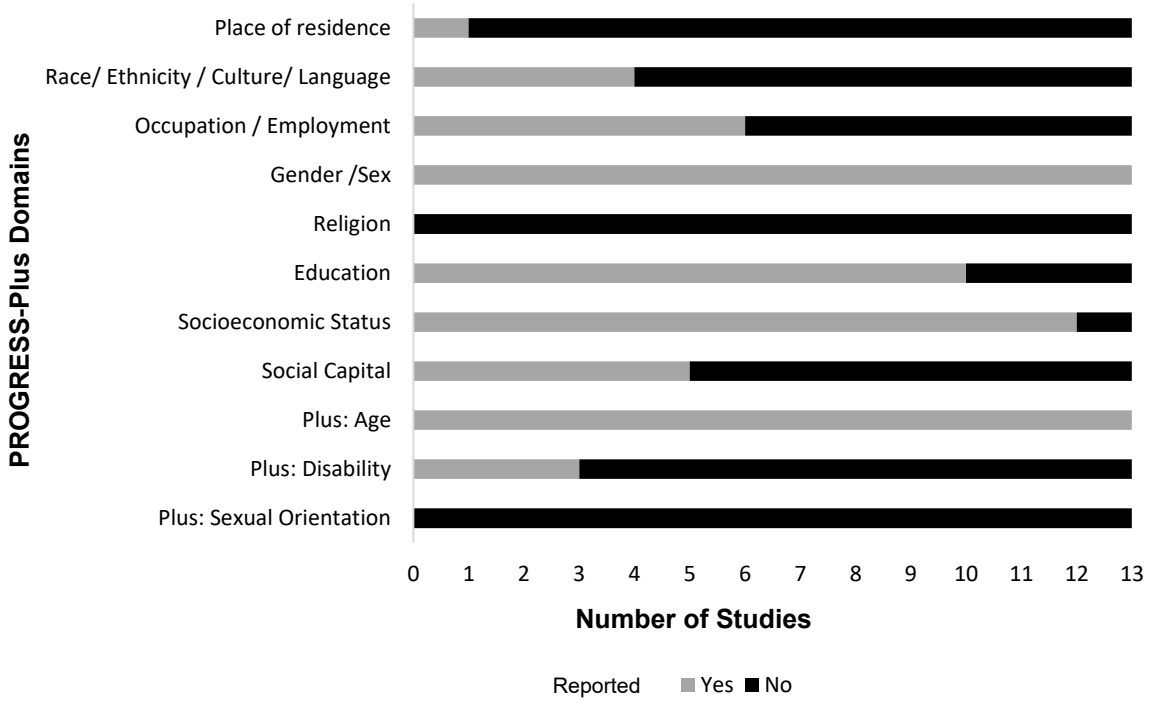
Figure 1.3 below illustrates the frequency with which PROGRESS-Plus domains were reported across the 13 included studies. Gender/sex and age were the only characteristics reported in all studies, although reporting was only on sex assigned at birth (typically coded as male/female), and not on gender identity, which reflects an individual's personal and social experience of gender and may differ from their assigned sex.

Socioeconomic status (n = 12 / 92%) and education (n = 10 / 77%) were also commonly reported, followed by occupation/employment (n = 10 / 46%) and social capital (n

= 5 / 38%). In contrast, equity-relevant domains such as race/ethnicity/culture/language (n = 4 / 31%), disability (n = 3 / 23%), and place of residence (n = 1 / 8%) were infrequently reported. Religion and sexual orientation reporting were absent from all studies. This pattern reflects an emphasis on select demographic variables, while characteristics associated with health inequities receive comparatively less attention across clinical trials.

Figure 1.3

Overall Reporting of PROGRESS-Plus Domains Across Included Studies.



1.4.4.1 Place of residence

Only one of the 13 included studies (Aamir et al., 2011) reported on participants' place of residence, distinguishing between rural and urban settings. The majority of participants in this study were from rural areas (n = 16 / 88.8%), with only two participants (11.1%) residing in urban locations. However, no further analysis or interpretation was offered regarding how the place of residence may have influenced treatment engagement, accessibility, or attrition. The absence of this variable in the remaining studies represents a significant gap, particularly given that geographic location can impact access to care, service delivery models, and participant retention.

1.4.4.2 Race/Ethnicity/Culture/Language

Only four of the 13 included studies (Goldstein et al., 2010; Goldstein et al., 2020; Thompson et al., 2013; Tolchin et al., 2019) reported participant race or ethnicity, with only one study

(Aamir et al., 2011) providing information on cultural background reflecting on the influence of stigma and self-prejudice related to mental health in Pakistan, as well as socio-cultural self-consciousness, factors which can shape both research design and participants' willingness to disclose sensitive demographic information. Consequently, missing, incomplete, or ambiguous data regarding these characteristics may result from reluctance to reveal stigmatised details, underscoring the challenges inherent in capturing equity-relevant diversity data in NEAD intervention research.

White/Caucasian participants predominated in these samples, constituting between 69% and 90% of participants. For instance, in Goldstein et al. (2020), 90% identified as White, while fewer than 10% represented Asian, Black, Mixed, or other ethnic groups.

These findings would benefit from being contextualised within the geographic distribution of the included studies, which spanned diverse regions including Pakistan, Turkey, Mexico, Germany, Switzerland, the United Kingdom, and the United States. The majority were conducted in Western countries, specifically the UK, US, Germany, and Switzerland, where demographic compositions and systemic inequities shape the underrepresentation of minoritised groups in clinical research. The paucity of ethnocultural diversity reporting and representation likely reflects broader recruitment challenges, access barriers, and systemic biases embedded within Western healthcare systems.

Moreover, the lack of reported cultural or language-related data limits the ability to assess the accessibility and cultural relevance of interventions, particularly for individuals who may experience linguistic or cultural barriers to care. This omission limits efforts to evaluate equity in treatment delivery and understand how intersecting social identities shape health outcomes within NEAD populations. Future research would benefit from more comprehensive and culturally sensitive demographic reporting, alongside thoughtful efforts to include and meaningfully analyse diverse participant groups, particularly in multicultural contexts.

1.4.4.3 Occupation/Employment

Occupation/Employment status was reported in seven out of 13 studies, though the level of detail and consistency varied. Where reported, a substantial proportion of participants were either unemployed, medically retired, or economically inactive, suggesting that functional impairment related to NEAD may significantly impact occupational engagement. For instance, in Aamir et al. (2011), only 11.1% of participants were in paid work, while 88.8% were described as not working or as housewives. Similarly, Goldstein et al. (2010) and Goldstein et al. (2020) reported low rates of full or part-time employment across both

intervention and control groups, with many participants categorised as unemployed, students, homemakers, or medically retired.

Some studies, such as Hubschmid et al. (2015), documented a marked drop in employment from pre-symptom onset to trial inclusion, indicating potential illness-related occupational disruption. However, few studies provided a breakdown of employment by intervention group or used this variable to explore differential attrition or engagement. Furthermore, no studies reported on participants' type of employment, job stability, or whether flexible work arrangements impacted treatment adherence.

The limited and inconsistent reporting of employment status constrains the ability to assess its role in treatment access and attrition. Nonetheless, available data suggest that NEAD participants often experience employment disadvantage, highlighting the relevance of this variable for understanding treatment feasibility and the broader psychosocial impact of the condition.

1.4.4.4 Gender/Sex

All 13 studies reported on participants' sex assigned at birth, making this the only PROGRESS-Plus domain with complete coverage alongside age. Across studies, female participants were substantially overrepresented, typically comprising 60% to 100% of study samples. For example, in Goldstein et al. (2020), women made up 75% of the intervention group and 69% of the control group, while LaFrance et al. (2014) reported 100% female participation in two of the trial arms. Only Chen et al. (2014) featured a predominantly male sample, though this was not commented on further by the authors.

While this trend has often been cited as aligning with NEAD prevalence data, it is important to critically consider that such findings may reflect recruitment patterns, clinical referral pathways, and gendered biases in diagnosis, rather than true population-level prevalence. In particular, men and gender-diverse individuals may be under-recognised or less likely to be referred for psychological intervention studies. Despite universal reporting of binary sex, no studies collected or reported data on gender identity, nor explored how gender-related social roles or stigma may influence treatment engagement or attrition.

Despite consistent reporting of binary sex (male/female), no studies captured data on gender identity, such as transsexual, non-binary, or other gender-diverse identities, nor did they examine how gender-related factors (e.g., caregiving roles, gender-based stigma) might influence engagement, attrition, or treatment outcomes. Moreover, sex was largely presented descriptively without being used to explore group-specific attrition rates or intervention responses.

1.4.4.5 Religion

None of the 13 included studies reported on participants' religious affiliation, spiritual beliefs, or engagement with faith-based communities. The lack of reporting on this variable represents an important gap, particularly given that religious identity and spiritual practices can influence help-seeking behaviour, treatment preferences, perceptions of illness, and engagement with psychological interventions. Additionally, religion can intersect with other equity-relevant characteristics such as ethnicity, gender, and migration status to influence individuals' engagement with healthcare.

The omission of religion as a demographic or contextual variable limits the ability to explore how spiritual or faith-based factors might relate to intervention acceptability, cultural relevance, or attrition, especially in populations where religious values may significantly influence mental health narratives or stigma. Future NEAD intervention trials may benefit from considering whether and how religion or spirituality plays a role in participant experiences and treatment engagement, particularly in cross-cultural or global research contexts.

1.4.4.6 Education

Education was reported in ten of the 13 studies, making it one of the more frequently addressed PROGRESS-Plus domains. However, reporting varied substantially; some studies used categorical levels (e.g., primary, secondary school), while others reported mean years of education, limiting cross-study comparability.

Overall, many participants had low to moderate educational attainment. In Aamir et al. (2011), two-thirds had only primary or secondary education, while Atoglu et al. (2003) highlighted limited literacy in both study arms. A few studies included more highly educated samples, such as Rawlings et al. (2018) and Goldstein et al. (2020), where vocational and higher education were more common.

Despite relatively frequent reporting, few studies considered how education, or related factors such as literacy or health literacy, may have influenced trial feasibility, engagement, or attrition. Only Goldstein et al. (2020) provided a detailed breakdown of educational levels, but this was not integrated into any subgroup analyses. As such, the potential impact of educational disadvantage on treatment access and outcomes remains underexplored in the current literature.

1.4.4.7 Socioeconomic Status

Socioeconomic status was indirectly reported in 12 of the 13 studies, mostly via proxies such as education, employment, disability benefits, and, in one case, household income. No study explicitly defined or measured SES as a distinct variable. Only Tolchin et al. (2019) directly reported household income, with median incomes between $30,000 and $42,000 (USD). By comparison, the 2021 U.S. median household income was approximately $70,784 (Oka, 2023), suggesting that participants may have been disproportionately from lower-income brackets.

Employment and education were the most common SES indicators. Several studies (e.g., Goldstein et al., 2020; LaFrance et al., 2014) noted high unemployment rates and receipt of state benefits, suggesting socioeconomic disadvantage in samples. Thompson et al. (2013) uniquely reported health insurance coverage, an important SES factor in the U.S.

Despite these indicators, few studies analysed SES as a factor influencing engagement, attrition, or outcomes. The inconsistent use and lack of direct SES measures limit understanding of economic barriers to access and retention. Furthermore, no studies assessed material deprivation, housing instability, or financial strain, which may be particularly relevant for the NEAD population.

1.4.4.8 Social Capital

Reporting on social capital was limited and inconsistently defined, with only six of the 13 studies including related indicators. Most studies reported marital or relationship status, while a few additionally noted cohabitation, caregiving support, or living arrangements. However, these variables were rarely analysed in relation to treatment engagement or attrition. Goldstein et al. (2020) provided the most detailed account, capturing multiple aspects of social context, including caregiving roles and household composition, suggesting potential relevance to participant support needs. In contrast, most studies reported marital status only, with partnered individuals comprising 44% to 67% of samples (e.g., LaFrance et al., 2014; Chen et al., 2014).

Notably, none of the included studies explicitly defined or operationalised social capital, nor examined the role of social support, isolation, or community engagement in intervention uptake or retention. This narrow and proxy-based reporting constrains understanding of how social relationships and support structures may influence participation, particularly in a population often affected by psychosocial complexity.

1.4.4.9 Plus: Age

Age was consistently reported across all 13 included studies, typically as a mean with standard deviation or as an age range. Participant ages spanned from 16 to 66 years, reflecting a broad adult population.

Most studies included participants with mean ages in their thirties to early forties. For instance, Goldstein et al. (2020) reported mean ages of 37.3 (intervention) and 37.7 (control), while Rawlings et al. (2018) and Tolchin et al. (2019) reported similar means around 40. A few studies focused on older participants (e.g., Chen et al., 2014; mean age ≈ 50), whereas others sampled notably younger groups (e.g., Aamir et al., 2011; Atoglu et al., 2003; mean ages in the low to mid-twenties).

While this review found no subgroup analyses examining age in relation to attrition or engagement within the main trial reports, such analyses or investigations of treatment moderators may exist in supplementary publications or secondary papers associated with these trials. Similar to the observation regarding retention strategies and protocol papers, future reviews might benefit from systematically including all related publications to provide a more comprehensive understanding of demographic influences on treatment outcomes. However, this review focuses primarily on data reported in the main outcome papers to maintain consistency and comparability across studies.

1.4.4.10 Plus: Disability

Disability was explicitly reported in only one of the 13 included studies. Chen et al. (2014) identified physical disability in 52.9% of the intervention group and 63.3% of the control group. However, no further detail was provided regarding the nature or severity of these disabilities, nor whether disability status influenced intervention engagement, feasibility, or attrition.

Importantly, while most studies did not explicitly report disability status in baseline characteristics, disability-relevant constructs such as physical symptom burden, quality of life, and functional impairment were frequently included as outcome measures. This suggests that disability considerations were integrated into the study design, but often in relation to outcomes rather than as independently or equity, diversity, and inclusion (EDI) focused baseline variables. Additionally, disability may be indirectly reflected in exclusion criteria (e.g., excluding individuals with learning disabilities), further complicating assessment of its prevalence and impact. Consequently, it remains challenging to determine the baseline presence and influence of disability on engagement, accessibility, or attrition in these interventions.

This gap in explicit and consistent baseline disability reporting represents a notable limitation within the current NEAD intervention literature. Although disability, encompassing physical, cognitive, and mental health aspects, is reportedly prevalent and clinically relevant in this population, its inconsistent characterisation in these studies limits understanding of potential structural or clinical barriers faced by disabled participants. Future research would benefit from systematically capturing disability status at baseline, ideally with detail on type and severity, to facilitate more inclusive intervention design and enable subgroup analyses.

1.4.4.11 Plus: Sexual Orientation

None of the 13 included studies reported participants' sexual orientation. This notable absence of data represents a significant gap in equity-relevant reporting, particularly in light of known health disparities and barriers to care experienced by LGBTQ+ populations.

Given that sexual orientation can intersect with stigma, mental health, and access to psychological services, its omission precludes any meaningful analysis of representation or differential attrition within this group. It also reflects a broader pattern of exclusion where sexual orientation, and often gender identity, is treated as peripheral rather than integral to understanding participant diversity. The gap in reporting may partly reflect historic limitations in research norms or discomfort in collecting these data, but it also underscores the need for greater inclusivity in clinical trials.

1.4.4.12 Cross-Domain synthesis

Taken together, the diversity data reported across studies suggest a selective emphasis on readily accessible demographic variables, particularly age and binary sex, while equity-relevant domains such as race, disability, sexual orientation, and religion were largely overlooked. Although socioeconomic factors like education and employment were more frequently reported, inconsistencies in definitions and measurement approaches limited interpretability. Notably, no study provided a comprehensive or intersectional account of participant characteristics, despite the known impact of intersecting structural inequities on access to and engagement with psychological interventions.

The limited reporting of variables linked to social disadvantage is particularly challenging given that NEAD is known to disproportionately affect marginalised populations, including those facing socioeconomic hardship, trauma histories, and structural barriers to care. When trials do not consistently report on characteristics such as ethnicity, socioeconomic status, or disability, it becomes difficult to determine whether the populations most affected by NEAD, often those experiencing multiple and intersecting forms of disadvantage, are adequately represented. This limited scope of demographic reporting may

hinder efforts to assess equity, generalisability, and cultural relevance, and could inadvertently constrain the development of more inclusive, person-centred interventions. Encouraging greater standardisation, transparency, and alignment with equity-oriented frameworks is therefore needed to ensure that NEAD intervention research meaningfully reflects the diversity of those it seeks to serve.

Table 1.2 provides a study-level overview of PROGRESS-Plus domain reporting, illustrating the patterns of selective and inconsistent demographic documentation outlined above. It offers a concise summary of which equity-relevant characteristics were reported in each of the 13 included trials, highlighting areas of strength as well as notable gaps.

Table 1.2
Reporting of PROGRESS-Plus Domains Across Included Studies

Study	Place of Residence	Race/ Ethnicity / Culture/ Language	Occupation / Employment	Gender /Sex	Religion	Education	Socioeconomic Status	Social Capital	Age	Disability	Sexual Orientation
Aamir et al. (2011)	Y	N	Y	Y	N	Y	Y	Y	Y	N	N
Atoglu et al. (2003)	N	N	N	Y	N	Y	Y	N	Y	N	N
Chen et al. (2014)	N	N	Y	Y	N	Y	Y	Y	Y	Y	N
De Santiago-Trevino et al. (2017)	N	N	N	Y	N	N	N	N	Y	N	N
Goldstein et al. (2010)	N	Y	Y	Y	N	N	Y	Y	Y	N	N
Goldstein et al. (2020)	N	Y	Y	Y	N	Y	Y	Y	Y	Y	N
Hubschmid et al. (2015)	N	N	Y	Y	N	N	Y	N	Y	N	N
LaFrance et al. (2014)	N	N	Y	Y	N	Y	Y	Y	Y	Y	N
Novakova et al. (2016)	N	N	Y	Y	N	Y	Y	N	Y	N	N
Rawlings et al. (2018)	N	N	N	Y	N	Y	Y	N	Y	N	N
Senf-Beckenbach et al. (2022)	N	N	N	Y	N	Y	Y	N	Y	N	N
Thompson et al. (2013)	N	Y	N	Y	N	Y	Y	N	Y	N	N
Tolchin et al. (2019)	N	Y	N	Y	N	Y	Y	N	Y	N	N

1.4.5 Attrition and representation of marginalised or under-represented groups

This subsection examines whether attrition patterns differed among marginalised or under-represented groups, with a particular focus on how demographic and socioeconomic factors may intersect with participant retention. While detailed subgroup analyses were not typically conducted within the included studies, some observations can be drawn from the data available.

Gender and sex were consistently reported across all studies, with women comprising the majority of participants in most trials. This predominance aligns with broader epidemiological trends suggesting higher NEAD prevalence among women. However, the apparent absence of gender-diverse participants and the underrepresentation of men limit the ability to explore gendered experiences of treatment and engagement. It also precludes examination of whether individuals of different gender identities may encounter distinct barriers to participation or retention. In some cases, this may reflect the way demographic data were collected, for instance, if studies only recorded biological sex rather than self-identified gender, highlighting the need for more inclusive and nuanced demographic measures in future research.

Race, ethnicity, and culture were reported in only four studies and often in aggregate or inconsistent formats. Where data were available, participants were predominantly White. In Goldstein et al. (2020) and Tolchin et al. (2019), small numbers of Black, Asian, Mixed and Hispanic participants were included. However, none of the studies disaggregated attrition data by race or explored whether these participants disengaged at higher rates or faced specific barriers to retention. The limited use of intersectional analysis represents a missed opportunity to investigate racial inequities in access, acceptability, or engagement.

Socioeconomic status was variably reported, primarily through employment, education, or benefit receipt. Several studies, including Goldstein et al. (2010, 2020) and Hubschmid et al. (2015), highlighted high unemployment or benefit receipt, suggesting that economic marginalisation was common in these samples. However, there was limited discussion of how SES influenced attrition, despite plausible links between economic disadvantage and challenges in attending appointments, affording travel, or sustaining engagement in longer interventions. Without attrition data separated by SES, it is difficult to draw firm conclusions.

Disability, which could also influence representation and retention, was poorly characterised. Only one study (Chen et al., 2014) reported baseline disability rates,

despite the frequent inclusion of physical and psychosocial functioning as outcome measures. This suggests that while impairment may have affected engagement, it was not explicitly tracked or discussed in relation to attrition.

Other equity-relevant domains, including sexual orientation, religion, and place of residence, were rarely or never reported, further impeding any assessment of attrition among marginalised subgroups. Only one study (Aamir et al., 2011) provided rural/urban residence data with some cultural context, and none captured data on LGBTQ+ identity or faith background.

Overall, the available data provided limited support for a robust analysis of whether marginalised groups were more likely to drop out of psychological intervention trials for NEAD. The inconsistent and often limited demographic reporting across PROGRESS-Plus domains, together with the scarcity of subgroup analyses on attrition patterns, suggests that equity considerations may not yet be fully integrated within this body of literature. Addressing these gaps could enhance future research's ability to meaningfully evaluate who engages with and benefits from NEAD interventions.

1.5 Discussion

1.5.1 Summary of Findings

This review reveals substantial variability and inconsistency in reporting attrition, participant diversity, and the representation of marginalised groups within psychological intervention trials for NEAD. While attrition rates varied widely, higher attrition observed in control groups and less engaging interventions suggests that perceived treatment value and acceptability play important roles in retention. However, limited subgroup analyses restrict understanding of whether attrition disproportionately impacts marginalised populations.

Although basic demographics such as age and sex were consistently reported, key equity-relevant domains, including race/ethnicity, disability, sexual orientation, and place of residence, were frequently underreported. This emphasis on more accessible or routinely collected demographic variables highlights ongoing challenges in capturing and analysing complex, intersecting social determinants of health within clinical research.

The predominance of cisgender female participants aligns with NEAD prevalence but may also reflect recruitment or referral biases that risk

underrepresenting men and gender-diverse individuals, whose treatment experiences might differ.

Socioeconomic status, disability, and social capital were similarly inconsistently and indirectly reported, with few studies examining their influence on engagement or attrition. These gaps limit the capacity to identify and address barriers faced by participants experiencing economic hardship, functional impairment, or social isolation, factors that likely compound vulnerability and affect trial feasibility.

Findings from related populations can help contextualise these results. For example, Michaelis et al. (2020) reported attrition rates between 1.7~% and 51% in psychological interventions for people with epilepsy. In comparison, NEAD trials in this review showed slightly greater variability between 0% and 60.9%, with several studies exceeding the upper range reported in epilepsy interventions. For example, interventions requiring high levels of self-direction (Novakova et al., 2016) or where participants reported lower acceptability (Rawlings et al.,2018) reported attrition approaching or surpassing 50%. This pattern suggests that while attrition is recognised as a challenge across psychological intervention trials in both epilepsy and NEAD, this review highlights, especially through its use of the PROGRES-Plus framework, specific reasons why individuals with NEAD can face additional and distinct barriers to sustained engagement in clinical trials relative to epilepsy populations. Both systematic reviews highlight the need for increased adherence in reporting standards such as using CONSORT guidelines and extensions, to ensure more consistent reporting of equity-related participant characteristics in clinical trials.

1.5.2 Methodological and reporting limitations in NEAD research

NEAD intervention trials represent an emerging evidence base with important clinical contributions. However, current studies often lack comprehensive representation of diverse, real-world populations. While basic demographic information is commonly reported, there is limited emphasis on the inclusion, detailed characterisation, and analysis of marginalised or underrepresented groups. This highlights an opportunity to enhance ecological validity and cultural sensitivity in future interventions.

A significant gap remains in considering intersectionality, how overlapping identities such as race, gender, socioeconomic status, and disability jointly influence treatment access, engagement, and outcomes. Addressing these complexities is

essential for tailoring interventions to diverse needs and enhancing retention among underserved populations.

Attrition remains a methodological and clinical challenge. Beyond attrition rates, attrition may signal systemic barriers, treatment acceptability issues, or social determinants that warrant deeper exploration. Inconsistent attrition reporting and scarce subgroup analyses indicate the need for more rigorous, equity-informed monitoring and transparency in future trials.

Methodological variability such as differing attrition definitions, approaches to missing data, and incomplete demographic reporting, limits robust synthesis. Adoption of standardised frameworks like CONSORT-Equity could promote clearer, more inclusive reporting. The predominance of studies in Western healthcare contexts also calls for broader cultural and contextual diversity, including better representation of sexual orientation, gender identity, and language factors. Together, these findings reflect promising advances while underscoring critical areas where equity-focused improvements could enhance the relevance, generalisability**,** and impact of NEAD intervention research going forward.

1.5.3 Study limitations

This review applied robust systematic methods but has several limitations. Restricting to published, English-language studies may have excluded relevant grey literature or non-English research with different equity reporting practices, potentially limiting comprehensiveness. Reliance on published reports also meant demographic details and subgroup analyses could not be explored beyond what was documented, possibly underestimating inclusivity in trial conduct.

Additionally, second rater involvement was limited, with no independent double screening of full texts or data extraction, which may affect reliability.

While the PROGRESS-Plus framework helped structure demographic reporting, it cannot fully capture intersectionality or the complex interplay of social determinants influencing engagement and retention. Some domains (e.g., social capital, religion) were inconsistently defined, and heterogeneity across study designs and outcomes complicated synthesis.

The RoB 2 tool, while widely used, also posed challenges; its structure sometimes allowed studies to be rated as low risk despite limited reporting, potentially underrepresenting methodological concerns.

The review's temporal cut-off excludes more recent trials in this rapidly evolving field. Notably, the CODES trial exemplifies emerging improvements in equity reporting that future research may build upon. Lastly, the focus on quantitative studies excluded qualitative insights that could further illuminate attrition and diversity issues.

1.5.4 Recommendations for practice

To enhance inclusivity, transparency, and relevance in future NEAD intervention research, the following recommendations are proposed:

- **Standardise reporting:** Employ frameworks such as PROGRESS-Plus and CONSORT-Equity to comprehensively capture and transparently report diverse participant characteristics, detailed attrition data, reasons for attrition, and methods for handling missing data.
- **Embed equity and intersectionality:** Integrate equity considerations throughout trial design, implementation, and analysis, including intersectional subgroup analyses, to understand how overlapping identities influence engagement and attrition.
- **Develop and evaluate retention strategies:** Proactively design retention approaches tailored to participant needs such as flexible delivery, financial support, and culturally adapted content, and rigorously evaluate their effectiveness. Incorporating qualitative methods can yield valuable insights into participant experiences and systemic barriers.
- **Expand demographic measures:** Collect detailed data on gender identity, sexual orientation, religion, language, and disability using validated, inclusive tools to enable nuanced analyses of intervention reach and outcomes.
- **Apply intersectional frameworks:** Move beyond single-axis demographic reporting to examine how intersecting disadvantages (e.g., low income, minority ethnicity, chronic illness) jointly affect participation and retention.
- **Align policy and funding:** Encourage funders and ethics committees to require equity-focused trial designs and transparent diversity reporting as conditions for support, in line with initiatives such as NIHR INCLUDE and APA JARS-Equity, and broader efforts to address health inequalities.

1.6 Conclusion

This systematic review examined how psychological intervention trials for NEAD report participant diversity and attrition, identifying persistent gaps in equity-focused practices and transparency. While the underrepresentation and inconsistent reporting of marginalised groups remain a concern, the review also underscores the emerging recognition of these issues within this evolving field. Importantly, this review offers a foundation to support more inclusive, rigorous, and culturally sensitive research practices that can enhance the relevance and effectiveness of interventions for all individuals living with NEAD. By embracing standardised frameworks, intersectional analyses, participant-centred retention strategies, and incorporating qualitative methods to enrich understandings, future research has the potential to dismantle barriers and foster equitable access to care. Ultimately, this review serves not only as a critical reflection on current limitations but also as a call to action, encouraging the field to embrace more equitable, nuanced, and patient-centred research practices that will foster the development of psychological interventions truly responsive to the diverse needs of all individuals living with NEAD.

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Chapter 2

A Qualitative Exploration of Patient Experiences of an Online Group Intervention Focused on Living Well with Non-Epileptic Attack Disorder (NEAD).

Prepared in accordance with the author requirements for Epilepsy & Behaviour

Epilepsy and Behavior

Plain Language Summary

Title:

Understanding People's Experiences of an Online Group for Non-Epileptic Attack Disorder (NEAD)

Background:

Non-Epileptic Attack Disorder (NEAD) is a condition where people have seizure-like episodes that are not caused by epilepsy. These episodes are often linked to stress or emotional difficulties. Many people with NEAD feel misunderstood by health professionals and find it hard to get the support they need. There is growing interest in offering psychological help, such as group programmes, but little is known about what it's like for patients to take part, especially when the groups are run online. More research is needed that makes sure patients' voices and experiences are at the heart of how services are designed and delivered.

Aims & Questions:

This study aimed to understand how people experienced an online NHS group programme for NEAD. The key questions were:

- What did people find helpful or unhelpful about the group?
- What were the challenges of attending online?
- What would improve the experience in future?

Methods:

Ten people who had attended at least one session of a four-week online NEAD group intervention, within an NHS Greater Glasgow & Clyde Neuropsychology service, took part in either a group discussion or a one-to-one interview. They talked about their experiences, and the researcher looked for common themes using a type of analysis called reflective thematic analysis, which helps identify patterns in what people say.

Main findings:

Five main themes were identified:

1. Feeling Seen and Understood – Meeting others with NEAD helped people feel validated and less alone.
2. One Size Doesn't Fit All – The group didn't work for everyone; people wanted more flexibility based on their individual needs.

3. Subtle Shifts – Many noticed changes in how they thought or felt about their condition.
4. Online Format Has Pros and Cons – Being online made it easier to attend, but sometimes harder to connect or feel supported.
5. What Happens Next? – People wanted more follow-up support and clearer next steps after the group ended.

Conclusions:

This research shows that online group support for NEAD can be helpful, especially when it helps people feel more understood and connected. Building on what already works well, services may benefit from offering different options to suit people's needs, providing follow-up support, and making sure groups are designed with a range of experiences in mind.

2.1 Abstract

Introduction: Non-Epileptic Attack Disorder (NEAD) is a complex, often misunderstood condition linked to diagnostic delay, distress, and fragmented care. Despite growing interest in psychological interventions, patient experiences of online group support in NHS contexts remain underexplored.

Research questions: This study explored how patients experienced an online NEAD group intervention delivered by the NHS Greater Glasgow and Clyde Neuropsychology service, including perceived benefits, challenges, and factors influencing engagement or disengagement.

Design: A qualitative design was used to centre patient voice and explore lived experiences in depth.

Methods: Three semi-structured focus groups and one individual interview were conducted with ten participants who had attended at least one session of a four-week online NEAD intervention. Transcript data was analysed using Reflexive Thematic Analysis (RTA).

Results: Five themes were developed: (1) Finally felt seen, (2) One size doesn't fit all, (3) Subtle shifts, (4) Convenience vs connection, and (5) Beyond the group. Findings highlighted the therapeutic value of peer validation, the need for flexible design, and limitations of brief interventions without follow-up support.

Conclusions: This study offers novel, patient-centred insights into the acceptability and impact of online group interventions for NEAD. Findings support the need for psychologically safe, neurodiversity-informed, and flexible care aligned with national policy for person-centred, joined-up neurological services. Building on these existing strengths, future development may benefit from incorporating follow-up support and tailoring groups to the diverse and evolving needs of those they serve.

Keywords: dissociative seizures, online group therapy, patient experience, psychological intervention, qualitative research.

2.2 Introduction

Non-Epileptic Attack Disorder (NEAD), often referred to as Psychogenic Non-Epileptic Seizures (PNES), or Dissociative Seizures, is a condition characterised by episodes that resemble epileptic seizures but lack the corresponding electrical discharges in the brain (LaFrance, Reuber, & Goldstein, 2013; Rawlings & Reuber, 2018). NEAD is increasingly understood as a complex biopsychosocial condition arising from the interplay of multiple interacting risk factors including trauma, chronic stress, emotion dysregulation, and relational adversity (Brown & Reuber, 2016; Green et al., 2017; Myers et al., 2019; Williams et al., 2018). The development and maintenance of NEAD is complex and multifaceted, involving various cognitive, emotional and social/interpersonal factors (Hallet et al., 2022; Popkirov et al., 2019).

These complex aetiological processes often contribute to prolonged and challenging diagnostic pathways. Individuals are frequently misdiagnosed, most commonly with epilepsy or stroke, and may receive unnecessary anti-epileptic medication or other pharmacotherapy before NEAD is correctly diagnosed (Lehn et al., 2021; Walzl, Carson & Stone, 2019; Xu et al., 2016). Diagnostic ambiguity may be further exacerbated by lengthy periods of investigation aimed at excluding other neurological conditions (Cuoco et al., 2023; Kerr et al., 2016). However, recent literature emphasises the importance of approaching diagnosis as a process of inclusion rather than exclusion, encouraging clinicians to actively identify positive features of NEAD rather than relying solely on ruling out other conditions (Bennett et al., 2021; Stone et al., 2024).

Misdiagnosis or changes in diagnosis can lead to significant unintended psychological and social consequences, including distress, identity confusion, and mistrust in healthcare services (Carton et al., 2003; Green et al., 2004; McLoughlin, Lee, Carson, & Stone, 2025). Qualitative research further echoes these themes (Rawlings & Reuber, 2016; Walsh et al., 2024) and highlights these challenges are frequently compounded by limited access to integrated, multidisciplinary care, contributing to diagnostic delays, functional impairment, and a reduced quality of life (Rawlings & Reuber, 2018; Williams et al., 2018).

There is growing evidence for psychological treatment approaches in the management of NEAD. A Cochrane review concluded that despite several randomised controlled trials (RCTs), there remains insufficient high-quality evidence to recommend any specific treatment for NEAD, including cognitive behavioural therapy (CBT) (Martlew et al., 2014). The review also noted that while many trials have focused on

biomedical outcomes such as seizure frequency and intensity as important indicators of symptom change, fewer have assessed outcomes that reflect broader patient priorities, such as psychological wellbeing and quality of life (QoL).

More recently, the Cognitive Behavioural Therapy for adults with Dissociative Seizures (CODES) trial delivered a 12-week, individual CBT intervention to patients with NEAD, in addition to standardised medical care (SMC), and compared outcomes against SMC alone. While the intervention did not significantly reduce seizure frequency, the trial's primary outcome, it led to improvements in secondary outcomes such as QoL, psychosocial functioning, and psychological distress (Goldstein et al., 2020). This pivotal study highlighted the complexity of treating NEAD and suggested that interventions may be more effective in addressing broader psychosocial goals rather than symptom reduction alone.

Across the research, a notable limitation is the underrepresentation of qualitative accounts capturing patient voice and choice, particularly concerning which outcomes are feasible, acceptable, and meaningful to individuals with NEAD. For example, Goldstein et al. (2024) reflect that seizure frequency is often chosen as a primary outcome, partly due to this being the primary symptom patients often initially present with, partly due to funder priorities and partly due to its clinical salience. However, it can be challenging for patients to reliably record seizure diaries over extended periods, leading to missing data and measurement variability. This highlights the importance of carefully selecting additional outcome measures that align with patient experiences and capacities. A companion qualitative study conducted alongside the CODES trial further illuminated participants' experiences, highlighting that many valued the opportunity to develop a better understanding of their seizures, felt emotionally supported during therapy, and perceived positive changes in their ability to manage symptoms and navigate daily life (Read et al., 2020). A recent meta-analysis reinforced this perspective, recommending that future interventions prioritise mechanisms that support living well with the condition (Gaskell et al., 2023). These insights emphasise the importance of integrating patient-centred outcomes, such as meaning-making, empowerment, and therapeutic alliance, into future intervention design and evaluation.

Most intervention research to date has focused on individual therapy, though there is growing interest in group-based formats, particularly those grounded in psychoeducation and acceptance-based approaches. For example, Cope et al. (2017) evaluated a three-session CBT-informed psychoeducation group and found

improvements in illness understanding and reduced psychological distress, despite no statistically significant changes in mood or functioning. However, group interventions, especially those delivered online, remain under-researched, and little is known about how people with NEAD experience these formats. Furthermore, qualitative studies exploring patient perspectives and choice in these interventions are notably scarce (Walsh et al., 2024). Cognitive difficulties commonly reported by people with NEAD, such as poor concentration, poor memory and slowed processing speed, may pose additional challenges to engagement and retention in online groups (Steele et al., 2023). Understanding these barriers and research limitations is essential to developing accessible, acceptable group treatments that truly reflect the lived experiences of patients and promote collaborative progress in this field.

This gap is particularly important given the rapid expansion of digital health delivery following the COVID-19 pandemic. Research exploring online interventions for NEAD remains in its early stages, with existing evidence limited to small-scale service evaluations that have not yet been published in peer-reviewed journals (Coman et al., 2023; Steele et al., 2023). Steele and colleagues (2023) additionally note the absence of studies that specifically examine attrition, completion rates, outcomes, or the usability and acceptability of online interventions from the patient perspective. Furthermore, a recent scoping review of psychoeducation interventions for NEAD did not identify any studies involving online or remote delivery formats (Underwood et al., 2024). This underscores the urgent need for further research to explore the experiences, outcomes, and accessibility of online group interventions for people living with NEAD, to inform the development of effective, patient-centred digital services.

Policy directives increasingly emphasise co-producing services and research with those affected by neurological conditions. The Scottish Government's five-year framework for improving neurological care advocates person-centred approaches that support people to live well with their conditions (Scottish Government, 2020). These goals are echoed in Scotland's 2024 Functional Neurological Disorder National Pathway (NHS Scotland, 2024) and the principles of Realistic Medicine (Scottish Government, 2023), which promote shared decision-making, equity, and collaborative partnerships through co-production. Together, these frameworks underscore the importance of ensuring that individuals with neurological conditions have meaningful choice and agency in accessing care that truly supports their well-being.

Building on these broader policy priorities, an NHS Greater Glasgow and Clyde (NHSGGC) Neuropsychology service identified a local challenge: high referral rates for

patients with NEAD, accompanied by high rates of non-attendance. This observation reflects broader concerns documented in the NEAD literature around treatment engagement and attrition. While studies frequently report or suggest high attrition rates and difficulties with psychological intervention uptake, often linked to stigma, complex psychosocial needs, and service accessibility (Goldstein et al., 2020; Myers et al., 2019; Rawlings & Reuber, 2018; Reuber & Rawlings, 2016), systematic data on attrition rates, particularly in online group interventions, remains limited and inconsistent.

In response to operational change following the pandemic and to continue offering an accessible service, the NHSGGC service piloted a four-week online group intervention as a quality improvement initiative and waiting list support. The intervention was designed to promote living well with NEAD through psychoeducation and self-management, shifting from traditional CBT to Acceptance and Commitment Therapy (ACT) informed principles, with a focus on values, acceptance, and psychological flexibility to empower participants.

The pathway into the group was carefully structured to support patient choice and individual needs. All referrals were initially screened by a Clinical Psychologist through a one-to-one phone call or online session, during which eligibility was assessed, and patients received a brief formulation and introduction to ACT principles. Prior to the first formal session, a technology support meeting was provided to help participants navigate the online format to try reducing barriers to attendance.

Flexibility was further embedded into the intervention to accommodate individual preferences: some participants were offered one-to-one support when preferred or clinically indicated, and those unable to attend some or all group sessions were invited to join subsequent groups. This person-centred and inclusive approach aligns with the service ethos, aiming to enhance accessibility, engagement, and acceptability for a diverse patient population. Initially developed during the COVID-19 pandemic, the group continues to be delivered online to meet ongoing patient needs and promote digital inclusion in post-pandemic care.

2.2.1 Aims and research questions

This research project is closely aligned with the policy priorities of NHSGGC and national frameworks, including the Scottish Government's Neurological Care Action Plan (Scottish Government, 2020) and the Functional Neurological Disorder National Pathway (NHS Scotland, 2024), which highlight the importance of centring patient voice and choice in the development of care and services. In line with these priorities,

the study explored patient experiences of an online group intervention to support individuals in living well with NEAD. It aimed to capture a range of perspectives, including those who attended the full programme and those who disengaged early, and to understand factors influencing engagement, as well as the perceived benefits and challenges of group participation, such as shared understanding and peer support. It was hoped that the findings would help identify unmet needs and inform future service development, contributing to the wider policy agenda of delivering responsive, meaningful, and patient-centred care for people with long-term neurological conditions.

The primary research question was:

1. What is the experience of patients who have attended and who have disengaged from the online NEAD group intervention?

The secondary research questions were:

2. Do patients report any perceived therapeutic benefit from attending the online NEAD group intervention?

3. Do patients report a value in having a shared experience with others in the context of attending the online NEAD group intervention?

2.3 Methods

2.3.1 Design

This study employed a qualitative research design to explore patient experiences of attending an online group intervention for individuals with NEAD within a specialist neuropsychology service. Semi-structured focus group interviews were selected as the primary method of data collection, to complement the group context of the intervention, however the decision was made to allow individual interviews if that format were preferred.

To ensure the quality and relevance of the study, Patient and Public Involvement and Engagement (PPIE) activity was undertaken during the study development period. Two members of the clinical care team, who also served as field supervisors for this research, identified and provided the primary researcher with the preferred contact details of three patients who had consented to be approached for consultation purposes. All three patients were approached and accepted the invitation to be involved in this phase and provided feedback on the participant information sheet (PIS) and the focus group topic guide. Consultations were conducted via email and

video call, and their feedback informed the development and refinement of study materials to improve design and accessibility.

Ethical approval for this study was obtained through the Integrated Research Application System (IRAS; Project ID: 350685), which was reviewed and granted by an NHS Research Ethics Committee on the 27th February 2025 (Appendix 2.3). Approval was also granted by the NHS Research and Development (R&D) department of NHS Greater Glasgow and Clyde (NHSGGC), the host health board, on the 13th March 2025 (Appendix 2.4).

2.3.2 Participants and recruitment procedure

Participants were recruited from the Neuropsychology service within the Institute of Neurological Sciences (INS), based at the Queen Elizabeth University Hospital, NHSGGC. The service maintains a record of individuals who previously attended the online NEAD group intervention and had consented to be contacted regarding future research.

Participants were eligible for inclusion in the study if they had a diagnosis of NEAD, were aged 18 years or older, and had attended at least one session of the online intervention. This minimum attendance requirement was set to provide valuable insights across different levels of engagement in the NEAD group. Only individuals who had previously provided consent to be contacted for future research were approached. Participants were also required to have the capacity to provide informed consent (either verbally or in writing, which was assessed by the clinical care team) and to have sufficient fluency in spoken and written English. This language criterion reflects the inclusion criteria of the intervention itself, which was conducted in English.

The clinical care team shared a list of names and preferred contact methods of eligible individuals. Eligible participants were then contacted by the primary researcher via their preferred method (telephone or email). During this initial contact, the researcher introduced the study, provided an overview of its aims and procedures, and shared the participant information sheet (Appendix 2.5). The information sheet included details about the purpose of the research, the voluntary nature of participation, the assurance that clinical care would not be affected by any decision to participate or decline, as well as information on potential risks and signposting to support services.

Patients were encouraged to ask questions and consider their participation. Those who expressed interest were offered the option of a follow-up call at least 24

hours later to support informed decision-making. This additional time was particularly important in recognition of potential cognitive symptoms associated with NEAD, such as difficulties with memory or information processing. Reminder prompts via email were also offered to facilitate participation and minimise barriers to engagement.

Participants were given the option to receive study materials via email or by post. For those who agreed to participate, a consent form was sent by email (Appendix 2.6), and participants were asked to sign and return the completed form electronically to the primary researcher. In cases where participants experienced difficulties accessing or completing the electronic consent form, such as issues related to digital access, IT literacy, or device limitations, verbal consent was obtained instead. Verbal consent was documented by the primary researcher, who then signed the consent form on the participant's behalf. All participants, regardless of the method used, received a copy of their completed consent form for their records. A record of consent was also noted in the participant's clinical care file by a member of their clinical team. This flexible approach was adopted to accommodate the specific needs of the participant population and promote equitable participation.

Participants were then offered a choice between taking part in an online focus group or an individual interview, depending on their preference and accessibility needs. A total of 24 patients were approached to take part in the study, and 13 agreed to participate. Four patients declined participation: two no longer wished to be contacted regarding research, one declined due to emotional distress related to the period when they had previously attended the group, and one cited competing commitments with higher education. Of the 13 who agreed and provided consent forms to participate, 10 went on to participate in interviews. Three participants did not attend their scheduled sessions: one later reported their absence was due to forgetting, while the remaining two did not provide a reason for non-attendance. One PPIE contributor expressed interest in participating. Ethical considerations were explored in supervision and consultation, and as they met eligibility criteria and ethical approval did not preclude PPIE contributors from participating, they were included.

All 10 participants were recorded as female in their clinical case records documentation; gender identity data was not collected. Participants' ages ranged between 25 to 66 years old (M = 40.7, SD = 13.7). Among the 10 participants, attendance at the online NEAD group intervention sessions varied. Half of the participants (50%) attended all four sessions offered. Three participants (30%) attended three out of the four sessions, while two participants (20%) attended only one

session. This variation in attendance levels provided a diverse range of participant engagement, enriching the breadth of experiences captured in the study.

2.3.3 Materials

Materials included the PIS, the consent form, and the focus group topic guide (Appendix 2.7). Participants received a £25 online shopping voucher in thanks and honorarium for their time commitment. The researcher used a Windows laptop and Microsoft Teams to audio record and auto-transcribe focus group sessions. Audio files were downloaded and further manually reviewed, transcribed and corrected for accuracy using Microsoft Word (Office 365). The same software was used throughout data familiarisation, coding, and theme development stages of the reflective thematic analysis (RTA). This study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong, Sainsbury & Craig, 2007), a 32-item tool to ensure comprehensive and transparent reporting of qualitative interviews and focus groups (Appendix 2.8).

2.3.4 Procedure

Focus groups were conducted via Microsoft Teams, a platform familiar to participants through NEAD online group intervention sessions. Each session was planned to last approximately 90 minutes, including breaks, with each group having no more than five participants. All focus groups were facilitated by the primary researcher. Interviews were led by a co-designed topic guide through PPIE consultation to sensitively and flexibly guide discussions, allowing space for organic dialogue to emerge. At the start of each session, the primary researcher welcomed all participants, introduced themselves and their role, and provided an overview of the study, emphasising the importance of patient contributions to the NEAD research literature. All participants reviewed the PIS, reiterated their consent verbally and were reminded of their right to withdraw at any time. Participants were provided with an overview of the NEAD online group intervention to support memory.

A collaborative “comfort agreement” was co-created by each group at the start of the session to establish a sense of psychological safety, support confidentiality, and define group etiquette. This agreement empowered participants to shape how the space would be used, often including principles such as maintaining privacy and allowing everyone a chance to speak. In each focus group, participants agreed it was acceptable for a loved one to be nearby, either in the same room or in a neighbouring space, for supportive purposes only, particularly in case of a seizure. These individuals

did not participate in the discussions and were bound by the same confidentiality agreement as group members.

At each session's end, the primary researcher summarised key themes, thanked participants, and outlined how to receive the £25 shopping voucher as well as the next steps in the research. Participants were also reminded of contact details from the PIS for any questions or concerns.

The one individual interview followed the same process as the focus groups, grounded in its use of the topic guide, comfort agreement and procedural framework. While the content and structure remained consistent, the 1:1 format allowed for more in-depth exploration of the participant's personal experiences in a private setting in line with their needs and preferences, without the influence of group dynamics.

A total of three focus groups were conducted across three separate dates between March and April 2025. Nine participants took part in these focus groups, with each session comprising between two and four participants. The first focus group lasted 57 minutes, the second focus group lasted 63 minutes, and the final focus group lasted 27 minutes. The one-to-one interview was conducted by the primary researcher via Microsoft Teams and lasted approximately 60 minutes.

2.3.5 Data handling and management

All audio recordings from focus groups and interviews were securely uploaded to the primary researcher's NHS Trust-approved encrypted account immediately following data collection. Transcriptions were manually reviewed and corrected using Microsoft Word on a secure device. Participant identifiers were removed during transcription to ensure anonymisation, where pseudonyms were used throughout analysis and reporting to protect confidentiality. All digital files, including audio recordings, transcripts, reflective notes, and coding documents, were stored on encrypted drives accessible only to the research team. Data management procedures adhered strictly to NHS Research Ethics Committee guidelines, the Data Protection Act (2018), and GDPR regulations to maintain participant privacy and data security throughout the study. In line with the University of Glasgow's Research Data Management Policy, data will be retained for a period of ten years following study completion.

2.3.6 Theoretical framework, research team and reflexivity

Reflexivity was a central component of the research process and is a key expectation within reflective thematic analysis (RTA), which conceptualises knowledge production as an interpretative, situated, and inherently subjective process (Braun & Clarke,

2023). In RTA, the researcher's positionality, e.g. their values, identities, experiences, and assumptions, is recognised as shaping every stage of the analytic process. Rather than viewing subjectivity as a bias to be minimised, RTA positions it as a resource that enriches analysis when acknowledged transparently (Braun & Clarke, 2021). This perspective allowed the research to attend to participants' subjective experiences while also recognising the influence of broader social and structural contexts.

The primary researcher was a female Trainee Clinical Psychologist completing a Doctorate in Clinical Psychology. They had prior training and experience in qualitative research methods and were solely responsible for conducting all interviews and focus groups, as well as leading the analysis. The researcher was not involved in participants' clinical care and had no prior relationship with participants, with the exception of one individual who had contributed to early PPIE consultation during the study's design phase. This prior contact was limited to a non-clinical, advisory capacity and was transparently acknowledged in the research process.

Following each focus group and interview, the primary researcher recorded reflective field notes to document immediate impressions, contextual observations, and emerging ideas. These notes were written post-session to avoid disrupting the flow of dialogue and were used to enhance reflexivity throughout the research process. In addition to supporting theme development and aiding interpretation during analysis, reflective notes were brought to regular research supervision meetings. These discussions helped the researcher critically examine their assumptions, explore potential biases, and refine their analytic lens in line with the principles of RTA. All notes were stored securely and did not include identifiable participant information.

In line with this approach, the researcher engaged in sustained reflexive practice throughout the study. A reflective journal was maintained to document assumptions, emotional reactions, and evolving interpretations, enabling ongoing critical self-awareness (Appendix 2.9). This process facilitated transparency and supported the researcher in examining how their positionality may have influenced coding and theme development. Additionally, the researcher participated in regular research supervision and as-required consultation with an experienced qualitative researcher within the University, independent of the research team. These offered structured spaces to explore the researcher's motivations, personal investment in the topic, and the interpretative choices made throughout the research process. These discussions supported reflexivity by challenging assumptions and encouraging a

deeper exploration of how the researcher's worldview informed the construction of meaning from the data.

Overall, the researcher did not aim for objectivity or neutrality but instead embraced the subjectivity of the co-constructed nature of qualitative knowledge, in line with the epistemological assumptions of RTA (Braun & Clarke, 2019; Luttrell, 2019). This stance acknowledges that meaning is not simply discovered in data but actively generated through the interaction between participant accounts and researcher interpretation. RTA produced rich, insightful, and theoretically coherent interpretations of patterned meaning throughout the dataset. This approach aligns with the interpretative nature of the theoretical framework and reflexive methodology underpinning the study.

2.3.7 Data analysis

The six-phase process of RTA was utilised for data analysis conducted recursively and flexibly (Braun & Clarke, 2021). This involves familiarisation, coding, generating initial themes, reviewing and developing themes, refining, defining and naming themes, and writing up findings. The analysis process was inductive and semantic–latent. Initial coding was grounded in the content and context of participants' subjective accounts (semantic level), while the subsequent analysis also attended to the underlying meanings, assumptions, and broader social contexts that shaped those narratives (latent level). Rather than being linear, the process was iterative, with movement back and forth between phases as understanding deepened and themes were refined.

The six phases included:

1. **Familiarisation**: Audio recordings were transcribed verbatim. The researcher immersed themselves in the data through repeated reading of the transcripts and active notetaking to begin identifying potential patterns of meaning.
2. **Generating codes**: Initial codes were developed manually using Microsoft Word. Coding was open and interpretative, applied across the full dataset, and aimed to capture both explicit content and underlying ideas relevant to the research questions.
3. **Constructing initial themes**: Codes were then grouped into initial candidate themes based on shared patterns of meaning. This phase involved interpretative work in identifying how different codes clustered together conceptually relevant to the research questions.

4. **Developing and reviewing themes**: Themes were reviewed iteratively against the coded data and the dataset as a whole. This phase involved refining the scope, coherence, and distinctiveness of each theme.
5. **Refining, defining and naming themes**: Themes were clearly defined in terms of their central organising concept and named to capture their analytic essence. The final themes represent constructed patterns of meaning, developed through the dynamic interplay between the data, the research context, and the researcher's interpretative lens.
6. **Writing up**: The final analytic narrative was written up by integrating illustrative data extracts with interpretative commentary. Themes were situated within the study's broader theoretical framework and relevant literature. Reflexive insights were embedded throughout to acknowledge the researcher's active role in the construction of meaning.

2.4 Results

This section presents five themes constructed through reflective thematic analysis of data gathered from three focus groups and one individual interview. An overview of the five themes can be found in Table 2.1 below.

Table 2.1
Overview of Major Themes

Theme	Central Meaning	Key Insights
Finally felt seen	Experiencing validation through shared diagnosis and peer connection	Group identity reduces isolation and provides emotional safety
One size doesn't fit all	The group did not entirely align with participants' cognitive needs or expectations	Mismatch leads to disengagement; flexibility is crucial
Subtle shifts	Subtle internal changes toward acceptance and coping	Small-scale benefit matters, even without symptom reduction
Convenience vs connection	Online delivery increased access but limited emotional connection for some	Remote access must be balanced with psychological connection and cognitive accessibility
Beyond the group	Persistent gaps in support beyond the intervention	Group may be a helpful starting point, but sustainable change requires ongoing, joined-up care

The analysis was conducted within a contextualist epistemology and guided by a commitment to amplifying patient voice. Themes were developed through an iterative and interpretative process to explore how participants made sense of their experiences with the online NEAD group intervention. The findings are situated within the broader context of patient-centred psychological care for long-term conditions, with particular attention to the dynamics of online, group-based delivery. Each theme is presented with interpretative commentary and illustrative quotes. Pseudonyms are used to preserve participant anonymity.

2.4.1 Theme 1: Finally felt seen – finding validation in shared experiences

Across all interviews, participants described the group as a powerful source of emotional validation. After reported years of feeling misunderstood, dismissed, or stigmatised by healthcare professionals, being among others who shared their diagnosis provided a rare and meaningful sense of recognition. Participants consistently described the emotional relief of being with others who understood their experiences. Many expressed that, for the first time, they felt recognised, believed, and part of a shared reality:

> *"It's just good to see other people who have been diagnosed, it good to see other people with it so you are not alone."* (Fran)

These accounts suggest that peer recognition acted as a powerful counter to previous invalidating experiences within healthcare settings. The therapeutic value of shared identity emerged as central to participants' engagement and sense of emotional safety through peer empathy. Furthermore, these shared experiences provided comfort, safety, coherence, and legitimacy in a context where diagnostic uncertainty and disbelief had previously undermined self-trust:

> *"You feel like a bit of validation when you're around other people who are in the same boat […] it sort of validates to yourself that this is real, it's not just all in your head. … being around other people who are going through the same thing […] it calms my mental health a little, because […] you're safe here with these other people."* (Emma)

> *"I felt as if it was a really safe space and aye, I enjoyed the group, it was stressful at times, right enough. But I did enjoy it."* (Kelly)

Being in a group with others who "get it" offered powerful validation, normalised their condition, and alleviated isolation. This connection was described as deeply meaningful, even when other aspects of the group didn't meet expectations. For many,

this experience of feeling understood for the first time was more impactful than the psychoeducational content. It speaks to the therapeutic potential of peer connection and shared identity:

> *“It's that confirmation to know that you're not going crazy, that you're not the only one. You know, you're not like, it's not all in your head. You're like, this is the actual thing [...] just that confirmation to know that you're not so isolated.”* (Christiana)

2.4.2 Theme 2: One size doesn’t fit all – misalignment between needs and intervention

This theme reflects a tension between accessibility and personal relevance within the group intervention. While several participants found the group as a valuable and supportive space, others described a sense of misalignment between their individual needs and the structure of delivery. This theme offers thoughtful insights into how timing, pacing, content and delivery style impact engagement even among participants who were motivated and open to support.

These accounts point to the importance of aligning group-based interventions with individual expectations, emotional readiness, and cognitive capacity. For example, some participants felt that the group was not what they had anticipated and that the format did not match how the group had been described during referral:

> *“Yeah, it wasn't a barrier as in like technology or whatever. It was more a case of it wasn't what was discussed with myself before actually attending.”* (Dawn)

> *“I found the same thing. It was more like, here's the facts of how the condition works…you've had your work, you've got the information on you go. There's no kind of follow-up. It's just that you we've given you. We've done our part. We've given you all the information, but we're not going to see you again sort of situation which I think would have been better if it was more of a support group rather than just information.”* (Christiana)

While some participants engaged meaningfully, others described a misfit between their needs and what the group intervention offered. Some found the pace too fast or the material too generic, which limited its impact:

> *“Avoid stress and I'm like, oh I'm neurodivergent life is stress, how do I avoid life, so yeah, I didn't. Not helpful […] It felt like a standardised anxiety class I’ve been to since I was really young.”* (Beth)

> *"I think the group assumes that you've got no knowledge of anything like mindfulness, all that sorts of sort of stuff […] and a lot of disabled people are really good at doing research and like I read research papers all the time[…] but rather than imagine a lemon like, I would have much rather have had your scientific paper that proves what we're talking about."* (Clair)

For others, the timing of the intervention felt out of sync with where they were in their NEAD diagnosis and treatment pathways. Participants described feeling emotionally or cognitively unready to engage in group work soon after diagnosis or during periods of overwhelm:

> *"I think because I've lived with it I already had most of the strategies as well. To me, it didn't seem like I was going to learn anything new or helpful, to be honest…I don't need it told to me again because at that point you're made to feel like you're stupid. Like at that point… I know what it is, I live with it, I don't need you to tell me."* (Dawn)

> *"I think cognitively, I wasn't maybe in a good place, and because my memory and things weren't great at the time and working, working on an iPad wasn't great at that time. So I find it quite difficult to sort of maybe take some of it in."* (Nicola)

Crucially, participants' critiques were not solely of psychological therapy in principle, but a call for increased flexibility and responsiveness in how interventions are designed and delivered. Participants highlighted that when interventions do not align with individual readiness, needs, or capacity, they can inadvertently feel exclusionary or tokenistic, particularly given participants' broader systemic experiences of other group-based psychological treatments and prolonged waiting times. These lengthy waits may raise expectations for treatment, making mismatches between intervention delivery and personal needs especially impactful:

> *"But I've found that especially at the moment, the NHS has a tendency to almost gatekeep care with groups. Every service now you have to go and do a group before you then progress to any other sort of care. I've had this experience with neurology, with mental health services, within a group for the pain clinic, physio have done a group for them as well, so it does feel a bit like you have to do the patronising PowerPoint presentation before you get any actual care."* (Clair)

> *“And it's like, oh, no, there's the way to stop your seizures and to cure you for life of this problem that you didn't know you had is to think of lemons and I'm like what? Visualise this lemon and you shall be cured. OK, how do you visualise when you're dissociating? How do you visualise when you're already unconscious?” (Beth)*

These reflections speak to the strengths of current service efforts to provide accessible, group-based care for people with NEAD, and the value that many participants found in connecting with others and receiving structured support. At the same time, they highlight opportunities for services to consider a more personalised approach, offering flexible options in terms of timing, format, and content to better accommodate the diverse needs, preferences, and cognitive capacities of those they aim to support.

2.4.3 Theme 3: Subtle shifts – small steps toward acceptance and coping

Participants described how attending the group helped shift their perspective on living with NEAD, even in subtle or gradually meaningful ways. While most did not frame the experience as transformative, they described the changes as not being about eliminating symptoms, but rather reflecting their emerging self-compassion, emotional insight, and a growing sense of acceptance. The group helped participants recognise their condition as legitimate and moved them toward integrating NEAD into their self-understanding and their daily lives.

For some, hearing from others with the same diagnosis helped reduce internalised stigma and foster a more compassionate self-view:

> *“I think it was more coming to a bit more acceptance and being a bit easier on myself because I had saw other people in the same boat. I think you tend to be very hard on yourself and say, you know I need to snap out of this, I need to get control on my body. Whereas it was a bit more acceptance of this is a real condition and this is something that I can't help you know … I came away feeling like to be a bit less hard on myself.*” (Emma)

Others described how the group supported a reframing of their diagnosis, helping them move from confusion or denial toward greater clarity:

> *“It took me a long time to accept my diagnosis, I couldn’t wrap my head around that this is like a mind body thing […] it was just good in a sense hearing other people going through it […] just kind of accepting it for what it is, it’s real, it’s not in my head.”* (Kelly)

> *"Definitely. I would just say that I just accept it from day-to-day and deal with it as it comes along, you know."* (Jenny)

Participants described gaining helpful tools such as mindfulness practices, grounding strategies, seizure diaries, and the "stress bucket" metaphor, which supported their ability to understand and manage their symptoms in daily life. These strategies were viewed as valuable starting points, particularly when participants were able to adapt them in ways that felt personally meaningful. For many, the opportunity to draw on their own insight, learning styles, and coping strengths played a key role in making the material more relevant. While participants reported that the group did not always offer explicit support with individual tailoring, these reflections highlight the group's aims of empowering patients to have autonomy and ownership in self-management strategies. These insights offer a thoughtful foundation for the continued development of the programme, building on its existing strengths.

> *"The mindfulness I find quite good. I have a local group that I do online with still […] I still do that diary of taking note of the seizures that I do have and taking a note of what's leading up to them and saying what helps."* (Nicola)

> *"Yeah I think it was a positive experience and I do go back to the pack yes and I use the tools so it's useful […] I went back every week cause I wanted to see if there's anything I can do to help the situation […] I want to live with this […] so it's getting better using the techniques, its helped." (*Fran)

> *"I like the idea of the stress bucket but using it as like a sensory bucket so I kind of adjusted it to that."* (Emma)

These reflections, though modest in scale, represent meaningful psychological movement toward living well alongside NEAD. They align with broader therapeutic goals in self-management and acceptance-based approaches, where increased awareness, self-kindness, and emotional regulation are seen as valuable outcomes in their own right. This theme highlights the importance of measuring change beyond traditional clinical outcomes. For these participants shifts in perspective, such as feeling more capable, less alone, or more accepting of their condition, were key indicators of therapeutic benefit.

2.4.4 Theme 4: Convenience vs connection – the complex role of online delivery

Participants expressed mixed views about the online delivery of the NEAD group. For some, it offered crucial accessibility, removing barriers related to geography, hospital anxiety, or physical health-related adjustments. Attending from home provided a sense

of safety, convenience and comfort that allowed participants to engage when they may otherwise have been unable to do so:

> *"So online versus in person, I have done both online groups and in person groups. Personally, for me, I find online way more accessible. I found in person groups very painful […] so doing it online really did make it more accessible for me."* (Clair)

> *"Obviously talking about seizures could trigger a seizure, so it's nice to be like in my own space and know that I feel safe."* (Naina)

> *"Well not having to get to a place, that can be tricky you know, so that was good, and finding the department and it was good and being in your own home I suppose you know you're safe."* (Jenny)

However, others described the online format as emotionally and cognitively challenging at times, which impacted their ability to engage. Several participants highlighted difficulties with screen fatigue, sensory overload, and reduced interpersonal connection compared to in-person interactions:

> *"I think cognitively, I wasn't maybe in a good place, and because my memory and things weren't great at the time and working, working on an iPad wasn't great at that time. So I find it quite difficult to sort of maybe take some of it in."* (Nicola)

> *"I had tried again and it was just so many video screens on and there was no way for me to turn them all off and just see the ones with the slides […] it was just too much visually for me at that point […] that would have helped me come back in."* (Emma)

> *"I can't process all that information in a week and expect to make a change. You know what I mean? And then by next week, show improvements like it, it takes me a little bit longer to try…But I feel like it is very much like you need to be showing kind of like showing that you're trying to do the things but because it's like every week it's something new that you need to compile keeping up with the last week's thing and then you're adding a new thing in it is sometimes you can get a bit, you know, tripped over like you're running, but you're not your feet are not going fast enough, that's the kind of feeling I got from it."* (Christiana)

This theme reflects the complex and evolving nature of online delivery. While virtual formats were experienced as enabling, reducing physical demands, hospital-related anxiety, and meeting key accessibility needs, they also presented new challenges for some participants. These included screen fatigue, a reduced sense of emotional presence, and occasional feelings of relational distance. Importantly, some participants noted that it was harder to express their needs or preferences in this format, which could make it more difficult for facilitators to respond to subtle cues of distress or dis-engagement to make real time adaptations. These reflections do not diminish the strengths of remote delivery but instead offer thoughtful guidance on how virtual spaces might be further shaped to support emotional safety, connection, and clear communication for all group members.

2.4.5 Theme 5: Beyond the group – persistent gaps and unmet needs

While the group intervention provided important validation and coping tools for some participants, many highlighted a lack of continuity and follow-up once the intervention concluded. Several participants expressed a strong sense of feeling left behind or unsupported after the group intervention ended. In the reported absence of structured follow-up or clear pathways for continued support, participants described feeling let down and forgotten, with limited to no access to ongoing psychological care despite their engagement with the group:

> *“There is no help, there is no support, there is nothing out there […] it kind of leaves you feeling like, OK, hey, I’m surviving on friends.”* (Beth)

> *“No, there wasn't anything else and it's coming to sort of the end with the neurologist as well. So I think the worry is now what happens now because it's, you know, the understanding GP that I had is retired now and you know I sort of deal with the seizures and everything on my own and I'm not kind of notifying the GP every time I have one […] And you know what? What are we doing if we're not notifying anybody? Are we just surviving with these things and not telling anybody so? You know what do we do when we don't have any services involved? You know, it's where do we go from here, which is sort of you know, taking part in like today, we're trying to sort of hopefully raise some awareness and see if there is gonna be anything else for us is the hope you know so where do we go from here when there's when there's nothing out there for us?”* (Nicola)

This sense of being left behind was compounded by uncertainty in the reported absence of referral pathways, peer support, or services offering long-term input for those with NEAD. Whilst many valued aspects of the group, this theme highlights the emotional impact of navigating a complex and chronic condition without clearly defined next steps. Participants expressed a desire for more joined-up care, where psychological support, neurology input, and community resources are better connected to strengthen continuity and integration within NEAD care pathways:

> *"And it, you know, the first week she did phone me and we went through it sort of quickly but then after that, they never, they never replied, they never got back in touch and just that was it."* (Emma)

> *"There are no resources. I went asking for some… the only note I took the whole course was 'find an anchor."* (Clair)

This theme reinforces the importance of embedding group interventions within a broader, sustainable care pathway. Participants emphasised that while group spaces can be helpful entry points, they are not sufficient in isolation.

2.5 Discussion

2.5.1 Summary of findings

This study aimed to explore the experiences of individuals who attended an online group intervention for NEAD within a regional Neuropsychology service. By centring patient voice and examining the subjective impact of group participation, the research sought to contribute to the development of more responsive, patient-informed approaches to group-based psychological support for people living with NEAD.

Using Reflexive Thematic Analysis (RTA), five themes were constructed: (1) *Finally felt seen*, (2) *One size doesn't fit all*, (3) *Subtle shifts*, (4) *Convenience vs connection*, and (5) *Beyond the group*. These findings offered nuanced insights into how the group intervention was received, where it proved beneficial, and where it highlighted development opportunities. Participants reported deeply meaningful experiences of peer validation, often for the first time, which helped counter previous experiences of stigma and dismissal in healthcare. Others described how the intervention supported subtle but important shifts in acceptance and emotional regulation. However, not all participants found the group suitable. Variability in cognitive capacity, expectations, and digital accessibility impacted engagement and

satisfaction. While the online format offered flexibility and comfort, it also limited opportunities for emotional connection and containment. Finally, many participants emphasised a lack of follow-up or continuity, which contributed to feelings of being left behind and highlighted the need for integrated pathways beyond the group itself.

2.5.2 Interpretation of findings

This research affirms the critical importance of centring patient experience in the design of psychological interventions for conditions like NEAD. Acknowledging the complexity of the diagnostic journey, often marked by confusion, stigma and invalidation, reinforces the need for holistic, person-centred approaches that attend to the whole individual and their lived experiences.

The theme *"Finally felt seen"* highlights the therapeutic value of peer connection and diagnosis-specific support, with participants consistently describing the group as a space of emotional validation and relational safety. For many, the most impactful aspect of the intervention was not the psychoeducational content, but the opportunity to connect with others who shared their diagnosis, which for some counteracted years of feeling dismissed, stigmatised, or misunderstood in healthcare contexts. This mirrors findings from previous qualitative studies, which show how the absence of diagnostic legitimacy and peer recognition can erode self-trust and deepen psychological distress (Rawlings & Reuber, 2018; Read et al., 2020; Walsh et al., 2024). Within the group, this shared understanding functioned as a reparative, relational experience, where being believed and seen by others with similar lived experiences fostered emotional connection, coherence, and psychological safety. These findings emphasise the importance of embedding opportunities for peer validation into NEAD interventions, recognising the therapeutic significance of feeling understood as a foundation for engagement and change.

The theme *"One size doesn't fit all"* captured the experiences of participants who felt the intervention did not meet their individual needs. Some found the pace overwhelming or the content too generic, while others described cognitive barriers such as memory issues and fatigue. This aligns with broader critiques in the NEAD and FND literature, which call for more responsive, modular intervention models tailored to fluctuating capacities and varying stages of readiness (Cope et al., 2017; Gaskell et al., 2023; Goldstein et al., 2020; Steele et al., 2023). Importantly, several participants identified as neurodivergent and emphasised how rigid or standardised delivery formats can inadvertently alienate rather than support. These findings underscore the necessity of adaptive, inclusive design in group interventions, one that

can accommodate and invite people to share differences, honour lived experience and promote meaningful engagement on each individual's terms.

The theme *"It shifted something"* captured the small but meaningful psychological changes participants described through group participation, such as increased self-compassion, emotional insight, and a growing sense of acceptance. These shifts reflect a growing consensus in the NEAD literature that therapeutic progress should be evaluated in collaboration with person-centred outcomes that go beyond symptom reduction, including insight, confidence, and emotional wellbeing (Goldstein et al., 2020; Goldstein et al., 2024). These reflections align closely with acceptance-based approaches like ACT, which prioritise psychological flexibility and values-led coping/living. For many participants, feeling more equipped to understand and navigate their condition was itself experienced as therapeutic. These findings reinforce the need to reframe success in NEAD care as supporting individuals to live well with their condition, particularly given the complexity and variability of symptom trajectories.

The theme *"Convenience vs connection"* captured the double-edged nature of online group delivery. For many participants, remote access removed significant practical barriers including travel fatigue, hospital-related anxiety, and scheduling constraints, while offering the comfort and safety of participating from home. However, these benefits were counterbalanced by new challenges. Participants described experiences of screen fatigue, sensory overload, and a diminished sense of emotional connection. Some found it difficult to communicate their needs in a virtual setting, which limited facilitators' ability to offer responsive, real-time support/adjustments. These accounts illustrate how online delivery, while enhancing logistical access, can inadvertently create new forms of exclusion. They reflect broader concerns raised in post-pandemic telehealth literature, which caution that digital interventions may compromise emotional attunement and psychological safety if not carefully adapted (Le Cunff, Giampietro & Dommett, 2024; Knox, McDermott & Hobson, 2022; Steele et al., 2023). This highlights the imperative to design virtual interventions that are not only practically accessible but also relationally responsive, proactively facilitated, and grounded in inclusive, trauma-informed and neurodiversity-aware principles.

Finally, "*Beyond the group"* reveals the fragility of current care pathways. While participants welcomed the support received, they described a lack of continuity and follow-up, reinforcing long-standing concerns in the NEAD literature about fragmented and episodic care (Myers et al., 2019; Rawlings & Reuber, 2018). These accounts sit

in contrast with national policy aspirations that emphasise person-centred, integrated care (NHS Scotland, 2024; Scottish Government, 2020), revealing a troubling disconnect between policy vision and the practical realities of service delivery within the current NHS landscape. Participants reflected that enhancements, such as planned follow-up check-ins, clearer signposting to psychological, neurological, or community-based supports, or the opportunity for peer-led continuation groups, could have improved their sense of support and care continuity.

Importantly, this theme also raises a broader structural issue of the gap in equitable resourcing for NEAD across policy and commissioning levels. Whilst service design plays a crucial role in shaping patient experiences, it cannot operate in isolation. Targeted investment to support policy aspirations will ensure that individuals with NEAD, and the systems surrounding them, including family and carers, are adequately supported. Community-based psychosocial resources and family-oriented support would benefit from being integrated into future funding and service models to reflect the complex relational impacts of NEAD and provide more robust scaffolding around care pathways.

Overall, these findings reinforce the fluctuating and multifaceted realities of living with NEAD and the challenges of addressing this within the scope of a four-session psychoeducation group intervention. Despite its brevity, the service undertook a holistic approach capable of holding this complexity, valuing both structure and personalisation, and appreciating that engagement is not only shaped by individual readiness, but by the relational and systemic context in which care is delivered.

2.5.3 Limitations

While the study provides valuable insights, several limitations must be acknowledged. All participants reported sex was female, limiting the gender diversity of the sample and potentially excluding perspectives shaped by gendered experiences of diagnosis or healthcare access. Additionally, participants were recruited from a single NHS health board, which may limit generalisability across regions or service models. Although variation in engagement levels was captured, those who never attended any group sessions were not included, meaning their views on barriers to initial uptake remain unknown.

Including one PPIE contributor as a participant may have influenced their engagement with the research. Although prior involvement could have influenced their perspective, their motivation to participate in this dual role meant that offering the

opportunity was deemed appropriate from ethical, methodological and moral standpoints, particularly given the reported engagement challenges observed in this population. Additionally, the sample size, though appropriate for the depth and design of this qualitative study, does not support population-level generalisation; rather, it offers transferable insights to inform service development and policy.

The study collected limited data on participants' personal characteristics, a decision initially made to minimise participant burden and appropriate given the scope of an exploratory doctoral project. It is important to note that the research proposal and ethical approval were developed prior to the systematic review, and therefore learnings regarding the value of reporting the full characteristics emerged later. While these insights could not be incorporated due to ethical and practical constraints of the research timeline, this experience highlights the importance and value of balancing participant burden with comprehensive demographic reporting in future research to learn more about the people at the heart of the research.

Future research may benefit from exploring NEAD interventions across more diverse populations and people with limited access to technology. Longitudinal research following participants post-intervention would help assess whether subtle shifts in perspective translate into lasting gains in wellbeing, functioning, and service engagement. Furthermore, co-produced research is particularly warranted in this field to ensure intervention design remains grounded in the realities of those most affected. Finally, research on comparative evaluations between different therapeutic models (e.g., ACT vs. CBT) may further illuminate which mechanisms of change are most meaningful from a patient perspective.

2.5.4 Considerations for practice and policy

The findings align strongly with key priorities in current health policy, including the Neurological Care and Support Framework (Scottish Government, 2020), Realistic Medicine (Scottish Government, 2023), and the FND National Pathway (NHS Scotland, 2024), all of which advocate for care that is person-centred, joined-up, and informed by lived experience. This study extends these priorities by illuminating how individuals with NEAD experience current service provision and by identifying practical ways to enhance the design and delivery of psychological support.

To respond meaningfully to patient voice and advance policy into practice, the following priorities are suggested for consideration:

- **Prioritise peer connection and validation** by protecting space for peer dialogue and mutual support, particularly in the first session, to foster trust, safety, and early engagement.
- **Implement hybrid delivery models** that combine online accessibility with opportunities for in-person connection, supporting broader inclusion and personal preference.
- **Offer flexible access formats** by providing the NEAD group workbook to all patients, offering both one-to-one and group options, and tailoring delivery to an individual's place in their diagnostic or treatment journey.
- **Design modular, adaptable content** that accommodates a range of cognitive, emotional, sensory, and learning needs. This is especially crucial for neurodivergent participants or those managing fatigue and cognitive difficulties.
- **Broaden outcome measurement** to include person-centred indicators of change such as self-efficacy, insight, emotional regulation, and quality of life, moving beyond purely symptom-focused metrics.
- **Create feedback mechanisms for accessibility and emotional safety** through brief in-session check-ins (e.g. polls or discussions) that invite participants to reflect on pace, content relevance, and delivery style. Responsive feedback loops support inclusive practice and iterative improvement.
- **Integrate pre- and post-group support** by embedding clear scaffolding before the intervention and structured follow-up or signposting after, positioning groups as part of a coherent care pathway rather than stand-alone events.
- **Ensure psychological safety in online formats** by drawing on trauma-informed and neurodiversity-aware principles. This includes intentional facilitation, accessible communication, and opportunities for post-session reflection or support.
- **Embed patient voice through co-production** by actively partnering with expert patients in intervention design, co-facilitation, and ongoing evaluation via PPIE frameworks.

By embracing these priorities, services can build on their existing strengths to provide care that is equitable, sustainable, and deeply attuned to the psychological needs of individuals living with NEAD. This approach fosters support that is not only available but also accessible, validating, and enduring, creating a foundation for continual growth and responsive refinement to better meet diverse needs over time.

2.6 Conclusion

This study adds an important, patient-centred perspective to the growing evidence base on group-based psychological interventions for NEAD, particularly in the context of online delivery. The findings demonstrate that even within a brief, structured intervention, it can provide powerful emotional validation, promote acceptance, and equip individuals with accessible coping strategies for self-management. These benefits reflect the commitment, innovation, and responsiveness already embedded within the NHSGGC Neuropsychology service.

Importantly, the research highlights that meaningful engagement is most effective when interventions are flexibly designed, psychological safe and situated within a broader care pathway. Participants' insights emphasise the need for support that can responsively attune and adapt to individual readiness, diverse neurocognitive needs, and the realities of living alongside a complex and often misunderstood condition.

In the evolving digital health landscape, the service's early adoption of online psychological support, grounded in psychoeducation and ACT principles, and delivered with care and sensitivity, represents a commendable step toward more inclusive and scalable care. To fully realise the potential of such innovations, service-level efforts must be matched by policy and commissioning frameworks that prioritise continuity, equity, and systems-oriented support. By centring lived experience and investing in responsive design and co-production, this work contributes to the broader goal of advancing holistic, sustainable, and values-based care for individuals living with complex neurological conditions.

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Appendices

Appendix 1:1 PRISMA Checklist for Abstracts

Section and Topic	Item #	Checklist item	Reported (Yes/No)
TITLE			
Title	1	Identify the report as a systematic review.	Yes
BACKGROUND			
Objectives	2	Provide an explicit statement of the main objective(s) or question(s) the review addresses.	Yes
METHODS			
Eligibility criteria	3	Specify the inclusion and exclusion criteria for the review.	Yes
Information sources	4	Specify the information sources (e.g. databases, registers) used to identify studies and the date when each was last searched.	Yes
Risk of bias	5	Specify the methods used to assess risk of bias in the included studies.	Yes
Synthesis of results	6	Specify the methods used to present and synthesise results.	Yes
RESULTS			
Included studies	7	Give the total number of included studies and participants and summarise relevant characteristics of studies.	Yes
Synthesis of results	8	Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e. which group is favoured).	Yes
DISCUSSION			
Limitations of evidence	9	Provide a brief summary of the limitations of the evidence included in the review (e.g. study risk of bias, inconsistency and imprecision).	Yes
Interpretation	10	Provide a general interpretation of the results and important implications.	Yes
OTHER			
Funding	11	Specify the primary source of funding for the review.	Yes
Registration	12	Provide the register name and registration number.	Yes

Appendix 1.2: PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 8
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 87
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 14
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 14
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 15
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.	Page 14 & 15
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 91 & 92
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.	Page 16 & 17
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.	Page 16, 17, 18 & 19
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.	Page 17, 18 & 19
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 17,18, 19, 23, 24 & 28
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.	Page 17, 23 & 24
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.	N/A
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)).	Page 17, 18 & 19
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 17, 18 & 19

Section and Topic	Item #	Checklist item	Location where item is reported
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 117, 18 & 19
	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.	Page 17, 18 & 19
	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).	Page 17, 23 & 24
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.	Page 16
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 16
Study characteristics	17	Cite each included study and present its characteristics.	Page 21 & 22 (Table 1.1)
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 23& 24 (figure 1.2)
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.	Page 19 - 39
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Page 19 - 39
	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.	Page 19 - 39
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Page 25
	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.	Page 23, 24 & 28
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 19-35
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 39 & 40
	23b	Discuss any limitations of the evidence included in the	Page 40 &

Section and Topic	Item #	Checklist item	Location where item is reported
		review.	41
	23c	Discuss any limitations of the review processes used.	Page 41
	23d	Discuss implications of the results for practice, policy, and future research.	Page 41-42
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.	Page14
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 14
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Page 14
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 9
Competing interests	26	Declare any competing interests of review authors.	Page 9
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.	Page 87

Appendix 1.3: Search Strategy

Search Strategy – 15th May 2025

Database: Embase (Embase 1947-Present, updated daily)

1. exp Non?epileptic attack disorder/

2. (non?epileptic attack disorder* or Functional seizure* or hysterical seizure* or psychogenic non?epileptic seizure* or dissociative seizure* or pseudoseizure* or non?epileptic attack disorder or non?epileptic seizure* or psychogenic seizure* or conversion seizure* or nonepileptic* or PNES* or NEAD).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]

3. (Psychotherap* or psychological therap* or psychological treatment* or psychological intervention* or therap*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]

4. (Randomised controlled trial* or randomized controlled trial* or randomised control trial* or randomized control trial* or RCT).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]

5. 1 or 2

6. 3 and 4 and 5

Database: MEDLINE(R) ALL <1946 to May 14, 2025>

1. non-epileptic attack disorder.mp.

2. (non-epileptic attack disorder* or Functional seizure* or hysterical seizure* or psychogenic non-epileptic seizure* or dissociative seizure* or pseudoseizure* or non-epileptic attack disorder or non-epileptic seizure* or psychogenic seizure* or conversion seizure* or nonepileptic* or PNES* or NEAD).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

3. (Psychotherap* or psychological therap* or psychological treatment* or psychological intervention* or therap*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

4. (Randomised controlled trial* or randomized controlled trial* or randomised control trial* or randomized control trial* or RCT).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]

5. 1 or 2

6. 3 and 4 and 5

Database: PsychINFO <1806 to May 2025 Week 1>

1. Non?epileptic attack disorder.mp.

2. (non?epileptic attack disorder* or Functional seizure* or hysterical seizure* or psychogenic non?epileptic seizure* or dissociative seizure* or pseudoseizure* or non?epileptic attack disorder or non?epileptic seizure* or psychogenic seizure* or conversion seizure* or nonepileptic* or PNES* or NEAD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

3. (Psychotherap* or psychological therap* or psychological treatment* or psychological intervention* or therap*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

4. (Randomised controlled trial* or randomized controlled trial* or randomised control trial* or randomized control trial* or RCT).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

5. 1 or 2

6. 3 and 4 and 5

Appendix 2.1: MRP Proposal

https://osf.io/cbukj

Appendix 2.2: Proceed to Ethics

University of Glasgow

School of Health & Wellbeing

KD/PR

10 October 2024

Shauna Donaldson
@student.gla.ac.uk

Dear Shauna,

Major Research Project Proposal

A qualitative exploration of patient experiences of an online group intervention focused on living well with Non-Epileptic Attack Disorder (NEAD)

The above project has been reviewed by your University Research Supervisor and by a member of staff not involved in your project and has now been deemed fit to proceed to ethics.

Congratulations and good luck with the study.

Yours sincerely

[redacted]

Prof Hamish McLeod
Professor of Clinical Psychology
DClinPsy Acting Research Director

School of Health & Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow
Mental Health and Wellbeing, Clarice Pears Building
90 Byres Road, Glasgow G12 8TB
Email: dclinpsy@glasgow.ac.uk

Appendix 2.3: Ethical Approval - IRAS

Health Research Authority

South West - Cornwall & Plymouth Research Ethics Committee
2 Redman Place
Stratford
London
E20 1JQ

Telephone:

27 February 2025

Dr Jessica Fish
Senior Lecturer in Clinical Psychology and Academic Director for DClinPsy & Research Director for Applied/Clinical Neuropsychology
University of Glasgow
Mental Health and Wellbeing
University of Glasgow, Clarice Pears Building
G12 8TB

Dear Dr Fish

Study title:	**A qualitative exploration of patient experiences of an online group intervention focused on living well with Non-Epileptic Attack Disorder (NEAD).**
REC reference:	**25/SW/0013**
Protocol number:	350685
IRAS project ID:	350685

Thank you for your letter responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Good practice principles and responsibilities

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

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

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

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

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

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

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

Registration of Clinical Trials

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

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

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

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

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

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

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

Publication of Your Research Summary

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

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

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

After ethical review: Reporting requirements

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

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

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Consent to contact]	V1	15 January 2025
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter]		17 January 2025
Interview schedules or topic guides for participants [Topic Guide]	V1	15 January 2025
IRAS Application Form [IRAS_Form_27022025]		27 February 2025
Other [Privacy Notice]	V1	15 January 2025
Other [Proceed to Ethics]		10 October 2024
Other [study proposal]	v3	26 February 2025
Participant consent form [consent form]	version 2	26 February 2025
Participant information sheet (PIS) [PIS V5 26.02.25]	V5	26 February 2025
Summary CV for Chief Investigator (CI) [CI CV]		16 January 2025
Summary CV for student [Student CV]		16 January 2025
Summary CV for supervisor (student research) [Supervisor SV]		16 January 2025

Statement of compliance

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 350685	**Please quote this number on all correspondence**

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

Yours sincerely

Sharon Northey
Approvals Manager

Appendix 2.3: Ethical Approval - NHS GGC R&D

Coordinator/administrator: Euan Rennie
Telephone Number:

Website: https://www.nhsggc.org.uk/about-us/professional-support-sites/research-innovation

Research & Innovation
Gartnavel Royal Hospital
Admin Building, Level 2
1055 Great Western Road
Glasgow, G12 0XH
Scotland, UK

13/03/2025

Shauna Donaldson
University of Glasgow, Clarice Pears Building
90 Byres Road
G12 8TB

NHS GG&C Board Approval

Dear Shauna,

Study Title:	A qualitative exploration of patient experiences of an online group intervention focused on living well with Non-Epileptic Attack Disorder (NEAD).
Principal Investigator:	Shauna Donaldson
GG&C HB site	Queen Elizabeth University Hospital
Sponsor	University of Glasgow
R&I reference:	UGN25NE011
REC reference:	25/SW/0013
Protocol no: (including version and date)	V3 26/02/2025

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
   a. During the life span of the study GGHB requires the following information relating to this site
      i. Notification of any potential serious breaches.
      ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file. Researchers must follow NHS GG&C local policies, including incident reporting.

2. **For all studies** the following information is required during their lifespan.
   a. First study participant should be recruited within 30 days of approval date.
   b. Recruitment Numbers on a monthly basis
   c. Any change to local research team staff should be notified to R&I team
   d. Any amendments – Substantial or Non Substantial
   e. Notification of Trial/study end including final recruitment figures

f. Final Report & Copies of Publications/Abstracts

g. You must work in accordance with the current NHS GG&C COVID19 guidelines and principles.

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

[redacted]

Euan Rennie
Senior Research Administrator

CC: Sinead Traynor

Appendix 2.5: Participant Information Sheet

https://osf.io/cvab7

Appendix 2.6: Consent Form

https://osf.io/hu4sm

Appendix 2.7: Focus Group Topic Guide

https://osf.io/2nb8s

Appendix 2.8: COREQ Checklist

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	63
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	65
3. Occupation	What was their occupation at the time of the study?	65
4. Gender	Was the researcher male or female?	65
5. Experience and training	What experience or training did the researcher have?	65
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	65
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	63
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	65

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	65
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	61
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	61
12. Sample size	How many participants were in the study?	62
13. Non-participation	How many people refused to participate or dropped out? Reasons?	62
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	63
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	63
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	62
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	60 & 63
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	None
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	63
20. Field notes	Were field notes made during and/or after the interview or focus group?	64
21. Duration	What was the duration of the interviews or focus group?	63
22. Data saturation	Was data saturation discussed?	
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	One
25. Description of the coding tree	Did authors provide a description of the coding tree?	No
26. Derivation of themes	Were themes identified in advance or derived from the data?	66 & 67
27. Software	What software, if applicable, was used to manage the data?	63

27. Software	What software, if applicable, was used to manage the data?	63
28. Participant checking	Did participants provide feedback on the findings?	No
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	68-75
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	67-75
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	No

Appendix 2.9: Reflective Log Extract

Reflective Log – Post Focus Group Facilitation 02/04/2025

Engaging in this research completing a Doctorate in Clinical Psychology offered an immensely valuable learning experience, personally and professionally. As I reflect on my role within the data collection phase, particularly facilitating the focus groups, I am struck by the duality of the space: both a research encounter and, unexpectedly for some participants, a therapeutic one.

I entered the focus groups prepared to hold space for open, honest accounts of participants experiences. What unfolded went beyond what I anticipated. Participants expressed that the group itself felt "therapeutic," offering validation, peer recognition, and a reported rare opportunity to be heard. A number of participants shared that, in taking part, they felt that "the NHS does care" and that "someone is listening." These moments left a deep impression on me as both a researcher and clinician.

A participant experienced a non-epileptic attack during the focus group. Despite having planned for this within the comfort agreement, it was the first time I had observed an attack. I recognised the importance of balancing immediate participant safety in a calm and clear way to support not just the individual, but the group as a whole. This highlighted the value of safety planning, supervision and flexibility, and reinforced how attending to wellbeing within the research spaces mirrors the care and attunement required in clinical work. It also affirmed the dual role I hold as a clinical psychologist and the importance of integrating both research and clinical skills and identities.

In the current context of NHS services, marked by reduced resources, long waits, and staff under pressure, I was mindful of how these systemic challenges shape expectations. Some participants explicitly referenced low expectations of follow-up or continuity, reflecting broader disillusionment. Yet, despite this, there was real openness and generosity in what people shared. I became acutely aware of the emotional responsibility I held in navigating stories of frustration, gratitude, and unmet need, while also feeling a deepened respect for the resilience and insights of those living with NEAD.

From an RTA perspective, I recognise how my positioning inevitably shaped the data. As a trainee psychologist with lived investment in mental health care, I brought values of compassion, curiosity, and person-centred care into the room. These values informed the tone I set as facilitator, the questions I asked, and the attunement I offered. I also noted how the space created a feedback loop, where participant trust deepened as they felt listened to, reminding me of the importance of psychological safety not only in clinical settings but also within research.

This experience has reaffirmed my belief in the necessity of embedding lived experience voices in service development. It also deepened my understanding of the therapeutic potential of being heard, even outside formal therapy spaces. While the focus groups were not intended as interventions, they clearly carried relational and reparative value for some. As I move forward in my clinical career, I carry with me this learning: that making space for people's voices is a priority and a fundamental part of ethical, effective care.