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Psychological support for post-viral fatigue: evidence from a systematic review and lived experiences of Long Covid using interpretative phenomenological analysis, a portfolio thesis

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Table of Contents

Portfolio Lay Summary

Post-viral fatigue syndromes (PVFS), including conditions such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and Long Covid, are associated with long-term fatigue, distress, and reduced quality of life. At present, there are no cures for these conditions, and so treatment usually focuses on helping people manage their symptoms. Psychological support has been one area of interest, but there has been disagreement over what type of support should be offered and whether it is helpful.

A number of studies have explored 'third-wave' psychological therapies, such as Acceptance and Commitment Therapy and mindfulness-based approaches. These therapies focus on acceptance, mindfulness, and living in line with personal values, rather than trying to reduce symptoms. A systematic review was carried out to bring together and evaluate existing studies of these therapies for people with PVFS. While the evidence base is still small and often of limited quality, the preliminary results were encouraging. Many studies showed improvements in fatigue, anxiety, and quality of life, although the evidence was less consistent in other areas, such as depression and mindfulness. Where present, benefits often lasted for several months. However, because the studies varied widely in their design and quality, firm conclusions cannot yet be drawn, and further high-quality research is needed.

Less was known about how people with Long Covid themselves have experienced receiving psychological support in the National Health Service (NHS). To address this, a qualitative study was carried out with eight people who had received one-to-one psychological input from the NHS. The study used an exploratory approach to understand how participants made sense of their experiences. Their accounts highlighted the emotional weight of waiting for support to begin. They also emphasised the importance of feeling believed and validated within sessions, and having a good "fit" and collaborative relationship with their therapist. Many spoke about the value of having the space to grieve losses in their lives, while gradually adjusting to life with Long Covid.

Taken together, these two studies provide new insights into psychological support for people living with ME/CFS and Long Covid. They suggest that psychological therapies

focused on acceptance and mindfulness-based models may be helpful, but also show that support must be delivered in ways that are sensitive to the lived realities of these conditions. The research points toward possible clinical recommendations that reflect this lived experience.

Portfolio Thesis Abstract

Post-viral fatigue syndromes (PVFS), including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and Long Covid, are persistent conditions associated with substantial functional impairment and no definitive treatments. Psychological support has been one area of interest, but its role has been debated, particularly in relation to Cognitive Behavioural Therapy (CBT). This has led to growing interest in alternative approaches, such as 'third-wave' therapies. However, the evidence base for these approaches in PVFS has not previously been systematically reviewed. In addition, while psychological input is increasingly offered to people with Long Covid in the National Health Service (NHS), little is known about how such support is experienced by individuals with lived experience of PVFS.

This thesis therefore aimed to advance understanding of psychological approaches to PVFS by: (1) systematically reviewing the evidence for third-wave therapies in this population and (2) qualitatively exploring how people with Long Covid experience one-to-one psychological or other mental health support within the NHS.

The systematic review identified ten eligible studies (two randomised controlled trials [RCTs], two quasi-experimental, four pre–post, two case series) investigating interventions including acceptance and commitment therapy (ACT), mindfulness-based cognitive therapy (MBCT), and mindfulness-based stress reduction (MBSR). Findings indicated improvements in fatigue and quality of life in several studies, with large effect sizes in some studies and sustained gains at 3-12 month follow-up. Anxiety outcomes improved across most studies, whereas evidence for depression and mindfulness were less consistent. However, study quality was low to moderate, with small samples, heterogeneous designs and interventions, and limited fidelity checks, such as therapist competence. The review concluded that third-wave therapies show preliminary promise but require further high-quality investigation.

The empirical study adopted an Interpretative Phenomenological Analysis (IPA) approach to explore the lived experience of adults with Long Covid who had received one-to-one psychological or other mental health support. Semi-structured interviews were conducted with eight participants with a diagnosis of Long Covid. Analysis identified four themes. The first, *The Weight of Waiting*, described the emotional distress during the waiting period for

accessing support. The second, *Being Believed and Validated*, captured the relief and significance of having symptoms acknowledged and taken seriously within therapeutic encounters. The third, *Therapeutic Fit*, reflected the importance of relational connection, collaboration, and flexibility in shaping whether support felt helpful or misaligned. The fourth, *Grief, Adjustment and Acceptance*, outlined how mental health support provided space to process losses associated with the impact of Long Covid on everyday life and to gradually adapt to life with ongoing symptoms. Findings highlighted the importance of responsive, person-centred support for individuals with Long Covid.

Taken together, these studies contribute nuanced insights into the role of psychological support for individuals living with PVFS. Findings provide a preliminary indication that acceptance- and mindfulness-based approaches may benefit this population, while the lived experience research underscores the need for person-centred psychological interventions that are collaborative, validating, and responsive to the challenges of living with Long Covid. This thesis portfolio highlights the importance of integrating patient perspectives into service development and points toward clinical recommendations that prioritise evidence-based, person-centred care.

Chapter 1: Systematic Review

Third-wave interventions for the management of post-viral fatigue syndrome: A systematic review

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Abstract

Post-viral fatigue syndromes (PVFS), including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and Long Covid, are persistent conditions associated with significant functional impairment which lack curative treatments. Third-wave psychological therapies—such as acceptance and commitment therapy (ACT), mindfulness-based cognitive therapy (MBCT) / Mindfulness-Based Stress Reduction (MBSR), and compassion-focused therapy (CFT) – emphasise processes such as acceptance, mindfulness, and compassion and may offer a better fit for the chronic nature of PVFS than earlier cognitive-behavioural approaches. **Objective:** This systematic review evaluated the methodological quality and effectiveness of third-wave interventions for PVFS. **Methods:** Eight databases were searched up to August 2024. Eligible studies included quantitative investigation of third-wave therapies targeting health, quality of life, or related processes in PVFS populations. Study quality was assessed independently by two reviewers. **Results:** Ten studies met criteria (two randomised controlled trials [RCTs], two quasi-experimental, four pre–post, two case series). Interventions were predominantly ACT or MBCT/MBSR, typically delivered in group formats, with some condition-specific adaptations. Findings indicate consistent improvements in fatigue and quality of life, with large effect sizes in several studies, and sustained gains at 3- to 12-month follow-up. Anxiety outcomes improved across most studies, whereas evidence for depression and mindfulness was mixed. Study quality was generally low to moderate, with small sample sizes, heterogeneous designs, and limited fidelity checks. **Conclusion:** Third-wave therapies show promise in reducing fatigue and anxiety and improving quality of life for individuals with PVFS. However, the current evidence base is methodologically weak. Therefore, high-quality, adequately powered RCTs using standardised diagnostic criteria and PVFS-specific outcome measures are needed.

Keywords: post-viral fatigue; chronic fatigue syndrome; myalgic encephalomyelitis; long covid; post-covid-19 syndrome; psychological interventions; systematic review

Highlights:

- A small body of heterogeneous work (10 studies) has evaluated third-wave interventions in PVFS.

- Study quality is weak to moderate.
- Some preliminary evidence for improvements in fatigue, anxiety, and quality of life following ACT and MBSR/MBCT in ME/CFS and Long Covid populations. Evidence for depression and mindfulness outcomes is mixed.
- High-quality RCTs with larger samples and condition-specific outcome measures are required before firmer conclusions can be drawn.

Introduction

Post-viral fatigue syndromes (PVFS), including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and Long Covid, are long-term health conditions characterised most prominently by fatigue alongside symptoms such as cognitive impairment, unrefreshing sleep, and autonomic dysfunction (Slavin et al., 2023; Natarajan et al., 2023). PVFS can affect individuals of any gender or age, though studies indicate that prevalence is higher amongst women (Shah et al., 2025; Bai et al., 2022) and working-age adults (Shi et al., 2025; Davis et al., 2023). Symptom severity ranges from mild to profound; however, even milder presentations can be associated with substantial impairments in functioning – for example, some individuals may be able to sustain employment, but often at the expense of energy for leisure and social activities due to the need to rest and recover (Nacul et al., 2011). PVFS has been associated with elevated rates of anxiety and depression (Houben-Wilke et al., 2022; Goodman et al., 2023) and reduced quality of life (Malik et al., 2022; Vyas et al., 2022).

The Covid-19 pandemic has increased attention towards PVFS, specifically ME/CFS, through the emergence of Long Covid, which affects many individuals after infection with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) (Ballering et al., 2024). Similarities in symptom profile and trajectory between ME/CFS and Long Covid led to its recognition as a form of PVFS early in the pandemic (Lapp & John, 2021; Komaroff & Lipkin, 2023). Multiple systematic reviews have confirmed that fatigue is the most prevalent Long Covid symptom (Natarajan et al., 2023; Fernandez-de-Las-Peñas et al., 2024).

There are currently no curative treatments for PVFS. Accordingly, treatment approaches focus primarily on symptom management (National Institute for Health and Care Excellence [NICE], 2021). Earlier NICE guidelines (NICE, 2007) recommended cognitive behavioural therapy (CBT) as one of the primary interventions for ME/CFS. However, this recommendation was met with criticism from patient groups and researchers alike (Geraghty et al., 2019; Wilshire et al., 2018) due to concerns regarding the theoretical emphasis of earlier CBT formulations, as well as the robustness of the evidence base.

Historically, CBT interventions for ME/CFS were underpinned by cognitive behavioural models (e.g., Wessely et al., 1989; Surawy et al., 1995; Vercoulen et al., 1998). These models typically acknowledged an initial viral infection but proposed that ongoing symptoms were maintained by cognitive and behavioural processes, including unhelpful illness beliefs, avoidance behaviours, and physical deconditioning. Critics have argued that such formulations risk oversimplifying the multifaceted and poorly understood pathophysiology of PVFS and may frame persistent symptoms as perpetuated by patients' cognitive style or behaviours rather than ongoing biological processes (Geraghty et al., 2019).

From the patient perspective, the implications of this formulation have been reported as invalidating and, at times, stigmatising (Froehlich et al., 2022). Qualitative and patient-led research suggests that CBT has, in some instances, been experienced as minimising the physical reality of symptoms, reinforcing perceptions of disbelief, or placing responsibility for recovery onto individuals who continue to experience severe functional limitations (Geraghty & Blease, 2018; Geraghty et al., 2019; Froehlich et al., 2022). In addition, certain strategies – such as graded increases in activity or cognitive reinterpretation of post-exertional symptoms – have been described as incompatible with features of PVFS (e.g., post-exertional malaise), raising concerns about symptom exacerbation and potential harm (NICE, 2021; Vink & Vink-Niese, 2020). Although CBT models for ME/CFS have since evolved, the legacy of earlier formulations may continue to shape some patients' expectations of psychological support (Geraghty & Blease, 2018; Geraghty et al., 2019).

Alongside patient concerns, methodological criticisms have also been raised regarding the evidence base supporting CBT for ME/CFS. While several trials and systematic reviews have reported improvements following CBT (e.g., Janse et al., 2018; Maas genannt Bermpohl et al., 2024), high-profile trials, including PACE (Pacing, graded Activity, and Cognitive behaviour therapy: a randomised Evaluation; White et al., 2011), have been criticised for methodological limitations, including post-hoc changes to primary outcome definitions and recovery thresholds, limited reporting of adverse events, and a lack of sustained between-group differences at long-term follow-up (Wilshire et al., 2018; Vink & Vink-Niese, 2019). Such concerns contributed to the 2021 revision of the NICE guidelines (NICE, 2021), which no longer recommend CBT as a curative or primary treatment for ME/CFS. Instead, CBT is

positioned as a supportive intervention to help individuals cope with symptoms and the psychological impact of living with a long-term health condition, within a multi-disciplinary model of care (NICE, 2021).

Given the overlapping symptoms between ME/CFS and Long Covid, it has been proposed that CBT may also be beneficial for individuals with Long Covid (Kuut et al., 2023). However, historical controversies regarding the use of CBT in ME/CFS, together with the limited evidence currently available for its effectiveness in Long Covid (Huth et al., 2024; Biere-Rafi et al., 2023), suggest a need to explore alternative therapeutic approaches for PVFS. In addition, the legacy of earlier CBT formulations for ME/CFS may continue to shape patient expectations of psychological support. In light of reported experiences of invalidation and stigma (Froehlich et al., 2022; Geraghty et al., 2019), it may be appropriate to examine therapeutic approaches that prioritise coping with and relating differently to ongoing symptoms, rather than primarily aiming to reduce them.

In line with this suggestion, there has been growing interest in the use of 'third-wave' interventions—such as acceptance and commitment therapy (ACT; Hayes et al., 1999), mindfulness-based cognitive therapy (MBCT; Segal et al., 2002), compassion-focused therapy (CFT; Gilbert, 2009), dialectical behaviour therapy (DBT; Linehan, 1993), and metacognitive therapy (MCT; Wells, 2009). Conceptualised as process-oriented models of change, these approaches share an emphasis on the context and function of internal experiences (e.g., thoughts, emotions, and physical sensations) rather than on their form, content or frequency (Hayes & Hofmann, 2021). Accordingly, they aim to modify individuals' relationship to their internal experiences, rather than attempting to alter the form or frequency of thoughts and emotions to reduce distress. Across models, this includes various processes such as acceptance, compassion, mindfulness, and valued living, even in the presence of ongoing distress (Hayes et al., 2004, 2006; Gilbert, 2009; Segal et al., 2002).

These contextual, process-based approaches may be particularly relevant to PVFS. In long-term health conditions, experiences of distress, fear, or negative appraisals of illness may reflect realistic and understandable responses to ongoing physical limitations and uncertainty about the future (Graham et al., 2016; Maunick et al., 2023). In the context of

PVFS, where symptoms are often fluctuating and recovery trajectories are uncertain, attempts to directly challenge or modify such experiences may be less helpful than approaches that aim to support purposeful engagement in life alongside them (Graham et al., 2016). By focusing on processes such as acceptance, compassion, and valued living rather than primarily targeting symptom reduction, these interventions may offer a framework that closely reflects the lived realities of PVFS.

Further support for examining third-wave approaches in PVFS comes from evidence indicating their effectiveness across a range of long-term health conditions. Benefits have been demonstrated in chronic pain, cancer, and multiple sclerosis, including improvements in quality of life (Dochat et al., 2021; Konstantinou et al., 2023), fatigue (Maunick et al., 2023), and functional adjustment (Hughes et al., 2017). Given the parallels between PVFS and chronic conditions in terms of long-term symptom burden, uncertainty about the future, and psychosocial impact, these findings provide a rationale for examining their applicability within PVFS populations.

Although heterogeneous in technique, third-wave interventions are conceptualised as a "family" of contextual cognitive behavioural therapies (Hayes & Hofmann, 2021). Given their shared theoretical foundations, it is considered conceptually coherent to synthesise these interventions together in the present review. This approach is consistent with prior systematic reviews that have grouped third-wave interventions together when examining efficacy (e.g., Robinson et al., 2019; Öst, 2008). In the context of PVFS, where trials remain limited, a broader synthesis allows preliminary evidence to be considered collectively.

Present review

Despite growing interest, the evidence base for third-wave psychological interventions in PVFS has not yet been systematically reviewed. This review aimed to address this gap by collating available studies, evaluating their methodological quality, and assessing outcomes in health, quality of life, and related processes. A transdiagnostic perspective is adopted, focusing on intervention targets and outcomes rather than PVFS subtype. Given the diversity of therapies encompassed within the third-wave framework, the review took a

broad and inclusive approach. Recommendations for future research and clinical practice are provided.

Methods

Search Strategy

This systematic review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020; Page et al., 2021). An intended protocol was registered with PROSPERO: CRD42024629759 (see Appendix 2). A comprehensive search strategy was developed in consultation with an information specialist, drawing on terminology and subject headings from similar reviews and relevant literature.

A systematic search was performed in eight electronic databases for relevant published literature: PsycINFO, Embase, MEDLINE, AMED, CINAHL, Web of Science, Scopus and the Cochrane Library, from inception to 26th August 2024. The selected databases were chosen to maximise coverage of both psychological intervention research and biomedical literature relevant to PVFS. PsycINFO was included for its coverage of psychological therapies and behavioural science, while MEDLINE and Embase were searched to capture clinical and biomedical research on ME/CFS and Long Covid. CINAHL was included to ensure coverage of allied health literature relevant to the multi-disciplinary management of PVFS. AMED was included to identify relevant allied health literature. Web of Science and Scopus were searched as multi-disciplinary databases with broad journal coverage. Finally, the Cochrane Library was searched to identify controlled trials. In addition, reference lists of systematic reviews identified through this search were screened for additional studies.

Search terms covered third-wave psychological therapies (e.g., “acceptance and commitment therap*”, “compassion*”, “mindful*”, “dialectical behavio* therap*”, “metacognitive therap*”, “psychological flexibility”, “third wave”, “third generation”) and PVFS-related conditions (e.g., “post-viral fatigue,” “chronic fatigue,” “myalgic encephalomyelitis,” “long covid*,” “post-covid*,” “long-haul covid*,” “post-acute sequelae

of COVID*”). No restrictions were applied to date or language of publication. The full search strategy is provided in Appendix 3.

Grey literature (e.g., theses, reports, preprints) was not systematically searched. This decision was made to prioritise peer-reviewed studies with sufficient methodological detail and statistical reporting to allow robust quality appraisal and effect size extraction. However, eligible grey literature identified through database searching (e.g., doctoral theses) was considered for inclusion where it met the review’s inclusion criteria and provided sufficient quantitative data. While this approach may increase the risk of publication bias, the limited and heterogeneous evidence base meant that a systematic grey literature search was considered unlikely to substantially alter the overall conclusions.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were developed using the PICO (Population, Intervention, Comparison and Outcome) framework. Eligible studies were quantitative in design and involved populations with PVFS, including ME/CFS and Long COVID. Interventions were required to be third-wave psychological therapies. A broad definition was adopted, encompassing acceptance- and mindfulness-based approaches such as acceptance and commitment therapy (ACT), mindfulness-based cognitive therapy (MBCT), mindfulness-based stress reduction (MBSR), compassion-focused therapy (CFT), dialectical behaviour therapy (DBT), and metacognitive therapy (MCT). Outcome measures included measures related to physical health (e.g., fatigue), mental health, quality of life, or intervention-related processes, such as psychological flexibility, mindfulness, acceptance, self-compassion, or valued living. Full details are provided in Table 1. Comparators were not specified as an inclusion criterion to allow inclusion of uncontrolled designs (e.g., pre–post studies without a control condition and case series). Where a control condition was included (e.g., waitlist or treatment as usual), this was extracted and reported.

Although PVFS can affect children and adolescents, the review focused on studies involving participants aged 16 years and older (i.e., older adolescents and adults). This decision was taken to maximise comparability across studies, as psychological interventions delivered to those aged 16 years and over often resemble adult interventions in terms of structure,

therapeutic content, and outcome domains. In contrast, interventions for younger adolescents and children require developmentally tailored adaptations and may involve systemic components that are less commonly included in adult psychological interventions.

Consideration was given to whether mindfulness practice alone should be classified as a third-wave intervention. While mindfulness is a core component of third-wave approaches, particularly in fostering present-moment awareness and acceptance of internal experiences (Kabat-Zinn, 2003), these interventions typically incorporate additional structured therapeutic components. For example, ACT places values as central to the therapeutic work (Hayes, 2004), while DBT integrates mindfulness with emotional regulation and interpersonal effectiveness skills (Wu et al., 2023). Accordingly, studies involving mindfulness alone, without additional third-wave intervention components, were excluded.

Finally, studies referring to “chronic fatigue” without specifying CFS or ME were also excluded. Although ME/CFS diagnosis remains challenging due to the lack of definitive biomarkers and limited pathophysiological understanding, the literature distinguishes it from general chronic fatigue in terms of diagnostic criteria, symptomatology, and underlying mechanisms (Darbishire et al., 2003; Son et al., 2019). As reflected in Table 1, fatigue which is attributed to another condition (including ‘chronic fatigue’, unless followed by ‘syndrome’) was therefore excluded.

Table 1

Inclusion and Exclusion Criteria Based on PICO Framework

Population	**Include**	**Exclude**
	Participants aged ≥16 years living with post-viral fatigue syndrome (e.g., Long Covid, ME/CFS).	Fatigue related to another condition (e.g., fatigue related to cancer). Studies providing data for a transdiagnostic group (e.g., somatization disorder, bodily distress syndrome) where sub-group data is not provided for the post-viral fatigue syndrome. Studies that refer to chronic fatigue as opposed to ME/CFS.
Interventions	**Include**	**Exclude**
	Any third-wave therapies, including: ACT, MBSR, MBCT, DBT, CFT, and Metacognitive Therapy.	Studies investigating other therapeutic models (e.g., CBT) as the main intervention (as opposed to a comparison group). Studies which include a multi-disciplinary/rehabilitation approach where the third-wave intervention (e.g., MBSR, ACT, CFT) is not the major component of the intervention being evaluated.
Comparators	**Include**	**Exclude**
	Not required for inclusion. Studies with any comparator (e.g., waitlist, treatment as usual, active control) or no comparator were eligible.	Not applicable.
Outcomes	**Include**	**Exclude**
	Outcome measures based on mental health, physical health (e.g., fatigue measure scores) and quality of life. Measures may include those associated with the intervention, such as psychological flexibility (for ACT studies).	Outcomes that are not based on mental health, physical health (e.g., fatigue) or quality of life, such as economic costings. Studies where pre- and post-data are not provided.
Study design	**Include**	**Exclude**
	Quantitative studies. Studies can include: case studies,	Qualitative studies, protocol papers, and papers describing

	feasibility studies (where data is presented), quasi-experimental research designs, and RCTs.	hypothetical interventions.

Screening

At each stage of the review, papers were assessed for inclusion according to the criteria outlined in Table 1. Title and abstract screening was conducted by the lead reviewer (AC) only using Covidence software (Covidence, 2025). Where an abstract was available but no full text could be located (e.g., conference proceedings or letters to the editor), corresponding authors were contacted to enquire whether the study had subsequently been published and, if not, whether relevant data could be provided for inclusion in the review.

Full-text articles were reviewed against the eligibility criteria by the lead reviewer, with a subset of 50% independently assessed by a second reviewer (RM). Discrepancies were resolved through discussion; two studies required further deliberation to reach consensus, resulting in one exclusion after agreement on application of the eligibility criteria and one inclusion after resolving initial uncertainty at full-text review. Consensus was reached for all studies.

Data Extraction and Synthesis

Data extraction was performed by the lead reviewer using a standardised form. The lead reviewer then cross-checked extracted entries against the full-text study reports to enhance accuracy.

Data were extracted on study characteristics (e.g., authors, year of publication, country), sample characteristics (e.g., demographics, clinical condition), study design, intervention details (e.g., therapeutic approach, delivery format, dosage, adaptations), and outcomes (e.g., fatigue, mental health, quality of life, intervention-related processes).

The primary effect measure for continuous outcomes (e.g., fatigue, anxiety, depression, quality of life) was Cohen's *d*. Where possible, effect sizes were presented for both within-group (pre-post intervention) and, where relevant, between-group (post-intervention) comparisons. Where these were not reported, they were calculated using means and standard deviations (SDs) reported in the articles. When an alternative effect size indicator was used (i.e., ηp2), these were converted to Cohen's *d* to enable direct comparison (Cohen, 1988). Effect sizes were classified as small ($0.2 \leq d \leq 0.5$), moderate ($0.5 \leq d \leq 0.8$) or large ($d \geq 0.8$) (Cohen, 1988), with statistical significance set at $p < 0.05$. Results for case series designs were reported as the number of participants demonstrating clinically significant change from baseline. All analyses were conducted using data available in the published reports.

Given the limited number of studies and heterogeneity in intervention dosage, modality, delivery format, outcome measures, and control conditions, meta-analysis was not considered feasible. Instead, a narrative synthesis was undertaken following established guidance (Popay et al., 2006). A preliminary synthesis was developed through structured tabulation of study characteristics and outcomes (Tables 2 and 3), with studies grouped by intervention type (e.g., ACT, MBCT/MBSR) and outcome domain (e.g., fatigue, mental health, quality of life, and intervention-related processes). Patterns of findings were compared across studies, taking into account study design (e.g., RCTs, quasi-experimental designs with waitlist control groups, and uncontrolled pre–post designs) and follow-up period (where reported). The strength of conclusions drawn from the synthesis was interpreted in relation to methodological quality and risk of bias ratings.

Quality Appraisal and Risk of Bias

Study quality and risk of bias was assessed using an adapted tool combining items from the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (Thomas et al., 2004) and the Psychotherapy Outcome Measures and Research Fidelity (POMRF) checklist (Öst, 2008). The EPHPP is an established tool designed for evaluating methodological quality and risk of bias across a range of health-related studies. It assesses domains such as study design, selection bias, and statistical analysis, each rated as strong, moderate, or weak, with a global score derived from the number of weak ratings.

Two further domains—intervention integrity and data analysis—are assessed by the EPHPP but are not included in its global rating. Moreover, the level of detail provided in these domains is insufficient for the purposes of this review, which focused on psychological interventions. To address this limitation, intervention integrity and data analysis were further appraised using relevant items from the POMRF, which provides detailed criteria specific to psychotherapy trials. The adapted quality appraisal tool is provided in Appendix 4. Quality appraisal was conducted by the lead reviewer, with the second reviewer independently assessing 60% of included studies to evaluate inter-rater agreement. Disagreements were resolved through discussion before these were confirmed by the lead reviewer. Inter-rater reliability was calculated on pre-consensus assessments using Cohen's κ (quadratic weights). For the EPHPP, agreement was calculated across the six domains, with the global ratings assessed separately. For the POMRF, Cohen's κ was calculated for item-level ratings. Percentage agreement was also reported to aid interpretation.

Although the Surawy et al. (2005a, 2005b, 2005c) studies were published two decades ago and were rated as having low methodological quality, they were retained to reflect the full range of available mindfulness-based studies in ME/CFS within a limited evidence base, with findings interpreted cautiously in light of their age and quality.

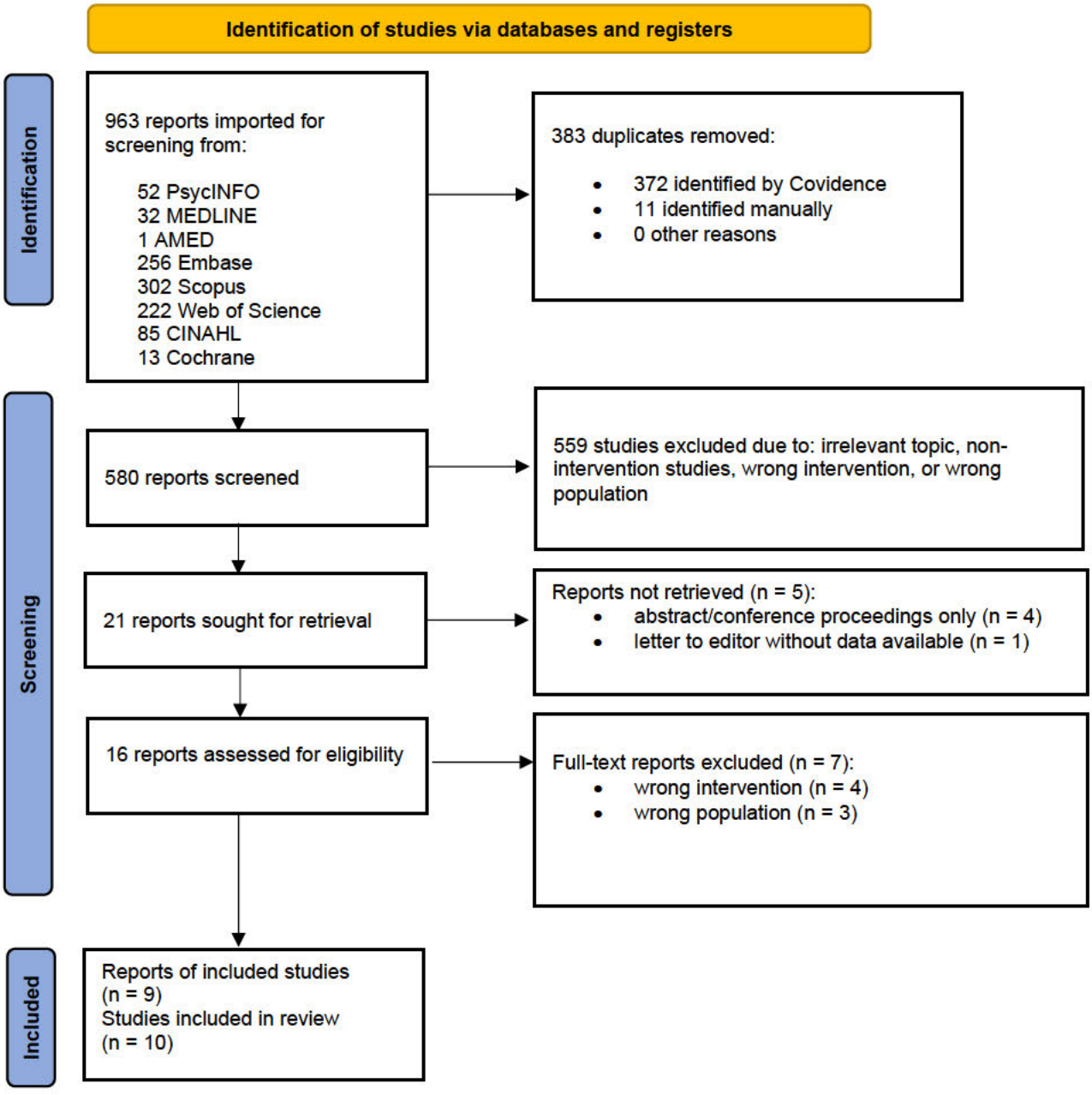
Results

The search returned 963 records, of which 383 were identified as duplicates and removed. The lead author screened the remaining 580 titles and abstracts, resulting in the exclusion of 559 records that did not meet the inclusion criteria. Five reports were not retrieved: four were available only as abstracts or conference proceedings, and one was a letter to the editor without sufficient data. One author confirmed that a full paper was under review and therefore not yet available. 16 reports were assessed at full-text review, with 50% reviewed in duplicate by a second reviewer (RM). Seven reports were excluded at this stage: two included participants with chronic fatigue only (i.e., not meeting ME/CFS diagnostic criteria), one investigated fatigue secondary to another condition, and four used an ineligible

intervention (e.g., mindfulness only or multi-component rehabilitation). The results of the screening and eligibility process are shown in Figure 1.

Figure 1

PRISMA Flowchart Showing the Process of Selecting Studies to Include in the Review



Nine reports met inclusion criteria. One report presented three separate studies (Surawy et al., 2005), and one doctoral thesis and its subsequent published paper reported findings from the same participant sample; these were therefore treated as a single study in the synthesis. Consequently, 10 individual studies were included in the review. Study characteristics, including sample features, design and therapeutic intervention details are summarised in Table 2, with the study results presented in Table 3. Studies are grouped by intervention (i.e., ACT, MBCT).

Characteristics of Included Studies

Study Characteristics

Included reports were published between 2005 and 2024. One report (Surawy et al., 2005) reported three individual studies. Eight studies investigated populations with ME/CFS, while two focused on post-viral fatigue related to Covid-19 syndrome (Post-acute Covid-19 syndrome [PCS] and Long Covid). Study designs comprised two randomised controlled trials (RCTs; Rimes & Wingrove, 2013; González-Moreno et al., 2024), two quasi-experimental designs with waitlist control groups (Surawy et al., 2005a; Nikrah et al., 2023), four pre-post study designs without a control condition (Jonsjö et al., 2019; Surawy et al., 2005b, 2005c; Stubhaug et al., 2018), and two case series (Roche et al., 2017; Sollie et al., 2017). Sample sizes ranged from 9 (Surawy et al., 2005a) to 305 (Stubhaug et al., 2018). Across included studies, the total sample size was 539 participants. Where reported, participant ages ranged from 18 to 65 years. Ethnicity was described in only one study (Rimes & Wingrove, 2013), which reported that the majority of participants identified as white (77.1%). Across studies, participants were predominantly female (81.6%), with male participants comprising 18.4%. Studies were conducted across five countries: the United Kingdom (UK), Norway, Sweden, Spain, and Iran. Where specified, recruitment and delivery most often took place in specialist CFS services, hospital outpatient clinics, or other clinical facilities. One study recruited through non-clinical channels (newspaper advertisement and snowball sampling) and did not report the intervention site (Sollie et al., 2017). Most studies applied established diagnostic criteria, such as the Fukuda definition (Fukuda et al., 1994) for ME/CFS or the World Health Organization (WHO, 2021) case definition for Long Covid, though criteria varied across studies, reflecting the evolving nature of diagnostic standards over time.

Intervention Characteristics

The majority of interventions were delivered in a group format (n = 8), including one study that used an online group approach (González-Moreno et al., 2024). One study delivered ACT individually (Jonsjö et al., 2019), with another employing guided bibliotherapy supported by weekly telephone contact (Roche et al., 2017). A further study implemented a brief, intensive four-day programme combining psychoeducation, mindfulness-based practices, ACT components, writing exercises, and physical activity (Stubhaug et al., 2018).

Across studies, the mean number of sessions was 8.3 (range = 4 to 13), with an average total intervention time of 16.5 hours (range = 9.8 to 29.5 hours). Three studies did not report session duration (Surawy et al., 2005a, 2005b, 2005c). Two studies included follow-up sessions: Surawy et al. (2005c) offered a three-month follow-up meeting, and Rimes and Wingrove (2013) delivered a two-month mindfulness practice review class focusing on current and future practice.

Several studies reported adaptations to accommodate the needs of individuals with PVFS. Sollie et al. (2017) shortened exercises and movements to reduce physical demands, while Rimes and Wingrove (2013) revised psychoeducation and cognitive elements to align with a cognitive behavioural model of ME/CFS (Surawy et al., 1995) and encouraged participants to take breaks or imagine movements instead of performing them when fatigued. Stubhaug et al. (2018) condensed their intervention into a four-day programme that integrated MBCT, ACT, writing tasks, and physical activity, likely to minimise treatment burden. Jonsjö et al. (2019) tailored individual ACT sessions according to illness severity, incorporating physician-led psychoeducation and a shift in focus from symptom reduction to valued living. Similarly, Nikrah et al. (2023) adapted ACT for PCS by integrating psychoeducation and promoting acceptance of ongoing symptoms. No adaptations were described in the remaining studies (González-Moreno et al., 2024; Surawy et al., 2005a, 2005b, 2005c; Roche et al., 2017).

Heterogeneity Across Included Studies

The included studies demonstrated substantial heterogeneity across multiple dimensions, including intervention modality (e.g., ACT, MBSR/MBCT, and multi-component programmes), format (individual, group, online, and bibliotherapy-based delivery), duration and intensity of intervention, study design, and outcome measurement. This heterogeneity

represents an important finding of the review and underpinned the decision to adopt a narrative synthesis approach rather than a meta-analysis. Consequently, findings are presented and interpreted by outcome domain and intervention type, with caution in making general claims about the effectiveness across the broader PVFS population.

Table 2

Characteristics of Included Studies

Author/year	**Study country (setting)**	**Design**	**Condition (range of duration in years, mean) & whether diagnosis was confirmed**	**Main objective**	**No. of participants (n) included in analysis (age range, mean age (*SD*).**	**No. of controls (n) (age range, mean age *(SD)*).**	**Females; males**	**Ethnicity**	**Therapeutic intervention**	**Format of intervention**	**No. of sessions (total hours) & professionals delivered by**	**Comparator**
Jonsjö et al. (2019)	Sweden (clinic setting)	Single-arm feasibility trial	CFS/ME (12.22 (*6.99*)) All fulfilled the 1994 Centers for Disease Control and Prevention and 2003 Canadian criteria for ME/CFS (Carruthers et al., 2003; Fukuda et al., 1994).	To evaluate the feasibility and efficacy of an ACT-based protocol for ME/CFS.	n = 40 (age range = 28 to 72 years, 49.02 (*10.78)*)	N/A	77.5% females; 22.5% males	Not reported	ACT	Individual therapy	13 sessions (9.75 hours) 10 sessions delivered by a Clinical Psychologist; 3 sessions by a physician.	No control group
González-Moreno et al. (2024)	Spain (clinic setting)	RCT	Persistent Covid / Long Covid Diagnosis of Persistent Covid required for participation	To evaluate the efficacy of the PsiCoRes program for improving psychological and emotional needs of patients with Long Covid.	n = 38 (age range = 34 to 65 years, 46.3 (*7.9*))	n = 32 (age range = 24 to 61, 45.6 (*9.1*))	92.9% females; 7.1% males	Not reported	ACT and mindfulness	Group online intervention program	10 sessions (15).	Waitlist
Nikrah et al. (2023)	Iran (specialised facility)	Quasi-experimental (with random assignment).	Post-acute Covid-19 syndrome (PCS). PCS diagnosis confirmed by a specialist.	To evaluate the efficacy of ACT on resilience and health-related quality of life in patients with PCS.	n = 15 (38.12 (*11.58*))	n = 15 (35.6 (*12.51*))	60% females; 40% males	Not reported	ACT	Group intervention	7 sessions (10.5)	Waitlist
Surawy et al. (2005a)	UK (hospital outpatient setting)	Quasi-experimental (with random assignment).	ME/CFS Diagnosis confirmed using the Oxford criteria (Sharpe, 1991).	To assess the efficacy and acceptability of group MBSR/MBCT on mood,	n = 9 (age range = 18 to 65 years)	n = 9 (age range = 18 to 65 years)	55.6% females; 44.4% males	Not reported	MBSR / MBCT	Group intervention	8 sessions	Waitlist

				functioning and fatigue in patients with CFS.								
Surawy et al. (2005b)	UK (hospital outpatient setting)	Uncontrolled / pre-post design	ME/CFS	To assess the efficacy and acceptability of group MBSR/MBCT on mood, functioning, fatigue and quality of life in patients with CFS.	n = 12 (ages not provided)	N/A	75% females; 25% males	Not reported	MBSR / MBCT	Group intervention	8 sessions	No control group
Surawy et al. (2005c)	UK (hospital outpatient setting)	Uncontrolled / pre-post design	ME/CFS	To assess the efficacy and acceptability of group MBSR/MBCT on mood, functioning, fatigue and quality of life in patients with CFS and whether improvements were maintained at 3-month follow-up.	n = 11 (ages not provided)	N/A	63.6% females; 36.4% males	Not reported	MBSR / MBCT	Group intervention	9 sessions (8 sessions + 3 month follow-up session)	No control group
Rimes & Wingrove (2013)	UK (specialist CFS service)	Pilot RCT	ME/CFS. Diagnosed according to the Fukuda et al. (1994) criteria or Oxford criteria (Sharpe et al., 1991). Required to have excessive fatigue (score of 4 or more) on the CFS.	To assess the acceptability, feasibility and preliminary efficacy of an MBCT intervention adapted for people with CFS who are still experiencing excessive fatigue after CBT.	n = 18 (41.4 (*10.9*))	n = 19 (45.2 (*9.4*))	82.9% females; 17.1% males	White - 27 (77.1%); Other white - 6 (17.1%); Black African - 1 (2.9%); Other (not specified) - 1 (2.9%)	MBCT Participants had previously received CBT sessions prior to this study (12 fortnightly sessions and follow-ups every 3 months for the	Group intervention (two groups of 11 and 7 participants).	8 sessions (18 hours) + 2-month follow-up mindfulness class and a review of the participant's current mindfulness practice and future practice intentions. Mean of 7.3 sessions out of the 8 attended.	Waitlist

									subsequent year).			
Roche et al. (2017)	UK (specialist CFS service)	Mixed-method multiple single case-series study	ME/CFS (range of 2 to 29 years) Participants were considered to have a diagnosis of CFS in line with CDC	To examine the effects of an ACT self-help intervention on behavioural measures of change in people with CFS.	n = 6 (age range = 19 to 62, 38.5 (*15.22*))	N/A	83.3% females; 16.7% males	Not reported	ACT	Guided bibliotherapy self-help intervention. 10-week group programme (psychoeducation and socialisation to a neurobiological model of CFS) had been completed by all participants within the past 12 months.	6 weeks of materials provided. Weekly 10 min phone calls with researcher to check comprehension and adherence each week.	Within-subject: Baseline acted as control period.
Sollie et al. (2017)	Norway (recruitment via newspaper advertisement and snowball sampling (delivery site not specified).	Single case series with A-B design and 3-month follow-up	ME/CFS (range of 1-19 years, 9.80) Diagnosis of CFS based on the Canada criteria (Carruthers et al., 2003).	To examine the efficacy and acceptability of MBCT for patients with CFS on CFS symptomatology and mental health and quality of life.	n = 10 (age range = 31 to 58 years, 43.50 (*9.90*))	N/A	80% females; 20% males	Not reported	MBCT	Group intervention	8 sessions (16)	Within-subject: Baseline acted as control period.
Stubhaug et al. (2018)	Norway (specialist outpatient clinic)	Uncontrolled / pre-post design	ME/CFS. Participants fulfilled the Oxford criteria for CFS (Sharpe et al., 1991).	To explore the clinical course and satisfaction for patients with ME/CFS who participated in a 4-day treatment program.	n = 305 (39.0 (*11.4*))	N/A	83.9% females; 16.1% males	Not reported	MBCT with integrated ACT, psychoeducation, writing tasks and physical activity (with integrated mindfulness practice and reflection)	Group intervention (45 x 4-day group intervention program, with 8-10 patients in each group) + 1 individual session.	4 days (29.5)	No control

Table 3

Study Results

	Quality appraisal overall rating	Assessment time-points	No. of treatment completers (% finished)	Outcome measures	Improvement post-intervention (ES)	Improvement compared to control (ES)	Maintained at follow-up (time)	Summary of results
Jonsjö et al. (2019)		Pre-, mid- and post-treatment. Follow-up at 3- and 6-months post-treatment.	32 (80%) Mean no. of sessions for treatment completers was 12.38 (SD 3.26).	Disability (PDI)	Significant reduction (d = 0.80)	-	Maintained at follow-up (6-month).	Improvements in disability, psychological inflexibility, ME/CFS symptoms, fatigue (with the exception of mental fatigue, which sig. increased), and anxiety. No changes observed in mood/depression, the SF-36 Mental sub-scale or the EQ-5D. The improvements were maintained at 6-month follow-up, with the exception of general fatigue, which showed a slight remission (i.e., small increase) at 6-month follow-up.
				Psychological Inflexibility (PIFS)	Significant reduction (d = 1.07)	-	Maintained at follow-up (6-month).	
				ME/CFS symptoms	Significant reduction (d = 0.41)	-	Maintained at follow-up (6-month).	
				Fatigue (MFI-20)	General fatigue – significant reduction (d = 0.20); Physical fatigue – significant reduction (d = 0.24); Mental fatigue – significant increase (d = 0.35); Reduced activity – significant reduction (d = 0.27); Reduced motivation - significant reduction (d = 0.34).	-	Maintained at follow-up (6-month follow-up), with the exception of general fatigue at 6-month follow-up, which showed a small, significant increase at 6-month follow-up compared to post-intervention (d = 0.10).	
				Mood & anxiety	Depression – No significant change	-	Not significant	
					Anxiety - Significant reduction (d = 0.62).		Maintained at follow-up (6-month).	
				Health-related quality of Life (SF-36, EQ-5D-3L)	SF-36 Physical – significant increase (i.e., indicating better physical health) (d = 0.56);	-	Maintained at follow-up (6-month)	
					SF-36 Mental – no significant change;		Not significant;	

					EQ-5D Index – no significant change		Not significant.	
González-Moreno et al. (2024)		Pre- and post-treatment	38 (100% included in analysis)	Subjective wellbeing (SHS)	Significant increase based on time x group interaction; Cohen's d not calculable due to missing SDs	Significant increase (d = 1.10)	Not assessed	Improvements in subjective wellbeing, self-compassion (specifically in reduced self-judgement) and anxiety (both state and trait). No significant differences found in stress and mood.
				Self-Compassion (SCS)	SCS total – significant increase based on time x group interaction; self-judgment subscale showed the only significant change. Cohen's d not calculable due to missing SDs.	Total SCS - significant increase (d = 0.75); Self-judgement - significant reduction (d = 0.62)		
				Stress (PSS)	Not significant	Not significant		
				Anxiety (STAI)	State anxiety (STAI-E) - significant reduction based on time x group interaction; Trait anxiety (STAI-R) - significant reduction based on time x group interaction; Cohen's d not calculable due to missing SDs	State anxiety (STAI-E) - significant reduction (d = 1.04); Trait anxiety (STAI-R) - significant reduction (d = 0.83)		
				Mood (BDI-II)	Not significant	Not significant		
Nikrah et al. (2023)		Pre- and post- and follow-up at 3-months	30 (100%)	Resilience (CD-RISC)	Significant improvement (d = 2.78)	Significant improvement in resilience (d = 2.43).	Maintained at follow-up (3 months)	Improvements observed in resilience and QoL, including the physical health, psychological health and social relationships sub-scales; no significant change was observed with the environment sub-scale.
				HRQoL (WHOQOL-BRIEF)	Significant increase in HRQoL total score and the following sub-scales: physical health (d = 0.77), psychological health (d = 1.1) and social relationships (d =	HRQoL Total Score (d = 1.52) and physical health (d = 0.81), psychological health (d = 1.3) and social	Maintained at follow-up (3 months). Environment sub-scale - remained non-significant.	

					0.92). No significant change in the environment sub-scale.	relationship (d = 1.05) sub-scales.		
Surawy et al. (2005a)		Pre- and post-intervention	All participants attended at least 4 (50%) of sessions. (1 participant in control group did not return questionnaires)	Fatigue (CFS)	No significant change	No significant change	Not assessed.	Improvement in anxiety only.
				Physical functioning (SF-36 subscale)	No significant change	No significant change		
				Anxiety and mood (HADS)	Anxiety - significant improvement (d = 0.85); Depression - no significant change	Significant improvement (d = 0.85) (no change in control group); Depression - no significant change.		
Surawy et al. (2005 b)		Pre- and post-intervention	75% (1 DNA, 2 dropped out after 2 sessions). The remaining 9 participants attended at least 5 sessions.	Fatigue (CFS)	No significant change	-	Not assessed	Improvement in anxiety and impact of fatigue on quality of life.
				Physical functioning (SF-36 subscale)	No significant change	-		
				Anxiety and mood (HADS)	Anxiety - significant improvement (d = 1.32); Depression - no significant change	-		
				QoL (FIS)	Significant improvement (d = 0.68)	-		
Surawy et al. (2005c)		Pre- and post-intervention, and 3-month follow-up	82% (2 dropped out before the second session). Nine participants attended at least 5 sessions (5/9 attended the follow-up session, 4/5 returned questionnaires at 3-month time point).	Fatigue (CFS)	Significant improvement (d = 1.6)	-	Maintained at follow-up (3 months)	Significant improvement in fatigue, physical functioning, anxiety, depression and impact of fatigue on QoL; all maintained at 3-month follow-up
				Physical functioning (SF-36 subscale)	Significant improvement (d = 0.76)	-	Maintained at follow-up (3 months)	
				Anxiety and mood (HADS)	Anxiety - significant improvement (d = 0.84); Depression - significant improvement (d = 1.13)	-	Maintained at follow-up (3 months)	
				QoL (FIS)	Significant improvement (d = 0.86)	-	Maintained at follow-up (3 months)	
Rimes & Wingrove (2013)		Pre-treatment, Post-treatment, 2-	17 (94.4%), one lost to follow-up (88.9%). N= 16	Fatigue (CFS)	Not provided	Significant improvement (d = 0.94)	Maintained at follow-up (6 months)	MBCT led to significant improvements compared with control in fatigue, impairment,

		month follow-up, 6-month follow-up (MBCT only)	included in analysis. Mean of 7.3 sessions out of the 8 sessions.	Impairment (WSAS)	Not provided	Significant improvement (d = 0.77)	Maintained at follow-up (6 months)	self-compassion, all-or-nothing behaviour and catastrophic thinking at post-treatment, with large effect sizes; gains were generally maintained at follow-up. No significant changes were found with anxiety or physical functioning with MBCT intervention. Delayed improvement in mindfulness in the MBCT group.
				Physical functioning (PF-10)	Not provided	Not significant	No significant change (pre- to 6-month follow-up)	
				Emotion beliefs (BES)	Not provided	Significant improvement (d = 0.97)	Maintained at follow-up (6 months)	
				Self-Compassion (SCSb)	Not provided	Significant improvement (d = 1.03)	Maintained at follow-up (6 months)	
				Mindfulness (FFMQ)	Not provided	Not significant	Significant improvement (compared to control) at 2-month follow-up, maintained at 6-month follow-up *	
				Anxiety and mood (HADS)	Not provided	Anxiety - not significant; Depression - significantly lower scores than control group at post-treatment (d = 0.77)	Anxiety - not significant; Depression - no significant within-group change (i.e., MBCT group) from pre-treatment to 6-month follow-up.	
				Responses to symptoms (CBRQ sub-scales)	Not provided	Significant improvement (d = 1.09)	Maintained at follow-up (6 months)	
Roche et al. (2017)		Baseline, intervention, post-intervention, 3-month follow-up	100% analysed	Psychological Flexibility composite score	3 of 6 improved	-	3 of 6 maintained at follow-up (3 months)	Improvement in psychological flexibility in 3/6; clinically significant improvements in valued living (4/6), acceptance (4/6), mindfulness (3/6), fatigue (5/6), while there was a clinically significant increase in cognitive fusion (2/6). Increased physical activity. ("clinically significant" changes determined using Jacobson & Truax (1991) criteria).
				Acceptance (PHLMS)	4 of 6 clinically significant improvement	-	2 of 6 maintained at follow-up (3 months)	
				Cognitive Fusion (CFQ)	2 of 6 clinically significant higher scores	-	2 of 6 (higher scores) maintained at follow-up (3 months)	
				Mindfulness (MAAS)	3 of 6 clinically significant	-	2 of 6 maintained at follow-up (3 months)	
				Valued living (ELS)	4 of 6 clinically significant improvement	-	4 of 6 maintained at follow-up (3 months)	
				HRQOL (SF-12 - Physical function sub-scale)	5 of 6 improved	-	3 of 6 maintained at follow-up (3 months)	

				Fatigue (CFQb)	5 of 6 clinically significant improvement	-	4 of 6 maintained or further improved at follow-up (3 months)	
				Activity Tracker ('Fitbit Flex')	5 of 5 (of usable data) improved	-	3 of 6 maintained	
Sollie et al. (2017)		Baseline, pre- and post-intervention, and 3-month follow-up	100% analysed	Fatigue (CFS)	1 of 10 clinically significant improvement	-	1 of 10 (different participant) clinically significant improvement at follow-up (3 months).	MBCT showed small to moderate effects on anxiety and depression, largely maintained at follow-up; mixed results for CFS symptoms. No significant change in rumination or mindfulness observed (*50% change in score was considered clinically) significant (using Hiller et al., 2012)
				ME/CFS symptoms	1 of 10 clinically significant improvement; 2 of 10 clinically significant increase in CFS symptoms	-	1 of 10 improvement maintained; increase in symptoms maintained for 1 participant (noted as being low at each time-point) at follow-up (3 months)	
				Anxiety and mood (HADS)	Anxiety - 4 of 10 clinically significant improvement; Depression - 3 of 10 clinically significant improvement; 1 of 10 clinically significant increase in depression (all scores within 'normal' limits).	-	Anxiety - 3/10 clinically significant at follow-up (3 months); Depression - maintained at follow-up (3 months).	
				Rumination (RRS)	No significant change	-	No significant change	
				Mindfulness (FFMQ)	No significant change	-	No significant change	
				QoL (SWLS)	1 of 10 clinically significant reduction	-	Reduction maintained at follow-up (3 months).	
Stubhaug et al. (2018)		Baseline, 1 week pre-treatment, 1 week post-treatment; follow-up at 3 months and 1 year	219 (72% completed) completed all assessments. 305 (100%) completed the programme.	Fatigue (CFS)	Significant improvement (d = 1.53); mental fatigue subscale - significant improvement (d = 1.05); physical fatigue sub-scale - significant improvement (d = 1.6)	-	Maintained at follow-up (1 week, 3 months, 1 year*) *means and SDs only provided for 1 year follow-up	Significant improvements observed in fatigue, physical functioning, depression and anxiety. These improvements were evident at all time points (1 week, 3 months and 1 year) and were maintained at 1 year follow-up.
				HRQoL (SF-36)	Significant improvement (d = 0.79)	-	Improvements were significant at all follow-up time points and maintained at 1 year	

				Mood (BDI-II)	Significant improvement (d = 0.81)	-	Improvements were significant at all follow-up time points and maintained at 1 year	
				Anxiety (BAI)	Significant improvement (d = 0.54)	-	Improvements were significant at all follow-up time points and maintained at 1 year	

PDI = Pain Disability Index; PIFS = Psychological Inflexibility in Fatigue Scale; MFI-20 = Multidimensional Fatigue Inventory; HADS = Hospital Anxiety and Depression Scale; SF-36 = Short-Form Health Survey; SHS = Subjective Happiness Scale; SCSa = Self-Compassion Scale (Spanish version); PSS = Perceived Stress Scale; CD-RISC (Connor-Davidson Resilience Scale); WHOQOL-BRIEF = World Health Organization's Quality of Life Questionnaire; PHLMS = Philadelphia Mindfulness Scale; CFQa = Cognitive Fusion Questionnaire; MAAS = Mindfulness Attention and Awareness Scale; CFQb = Chalder Fatigue Questionnaire; ELS = Engaged Living Scale; SF-12 = SF-12 Physical Function sub-scale of the SF-36; CFS = Chalder Fatigue Scale; WSAS = Work and Social Adjustment Scale; PF-10 = Physical functioning; BES = Beliefs about Emotions Scale; SCSb = Self-Compassion Scale; FFMQ = Five-Facet Mindfulness Questionnaire; CBRQ = Cognitive and Behaviour Responses to Symptoms Questionnaire; RRS = Ruminative Response Scale; SWLS = Satisfaction With Life Scale; BDI-II – Beck Depression Inventory; BAI = Beck Anxiety Inventory; FIS = Fatigue Impact Scale

Quality Appraisal and Risk of Bias

EPHPP Quality Appraisal

Inter-rater reliability across the EPHPP domains was substantial (weighted Cohen's κ = 0.82; 83.3% agreement), indicating strong consistency between reviewers. Agreement for the global rating was perfect (κ = 1.00; 100% agreement). Overall study quality was low to moderate, with half of included studies receiving a global rating of 'weak', while the remainder were rated as 'moderate'. EPHPP ratings by both reviewers are presented in Appendix 5, while the final consensus ratings are summarised in Table 4.

Selection bias was rated as moderate to weak, as most studies relied on convenience samples recruited through clinics or advertisements rather than random or representative sampling. Study design was also a frequent limitation, with many studies employing non-controlled designs or case series methodologies. As a result, confounding variables were often not addressed or reported, leading to consistent weak ratings in this domain (e.g., Jonsjö et al., 2019; Sollie et al., 2017). In some studies that included a comparison group, analyses of potential confounders were not reported (e.g., Nikrah et al., 2023; Surawy et al., 2005a).

A consistent methodological strength was the selection of well-established, valid, and reliable outcome measures. An exception was Nikrah et al. (2023), which received a moderate rating because the translated version of the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) demonstrated lower split-half reliability (0.669), indicating that further validation in the post-Covid population may be warranted. However, none of the included studies employed outcome measures specifically developed for ME/CFS or Long Covid, raising the possibility that some tools may lack sensitivity to condition-specific symptoms such as post-exertional malaise or cognitive dysfunction. Furthermore, while the RCTs (Jonsjö et al., 2019; Rimes & Wingrove, 2013) identified primary and secondary outcomes in line with standard RCT reporting standards, this level of detail was not evident in the non-randomised studies.

POMRF Quality Appraisal

Inter-rater reliability for the POMRF item-level ratings was substantial (weighted Cohen's κ = 0.85; 85.2% agreement), indicating strong consistency between reviewers. Total POMRF scores ranged from 3 to 10 out of 18. Reviewer POMRF ratings are presented in Appendix 6, with consensus ratings summarised in Table 5.

Interventions were generally well described and based on established ACT or MBSR/MBCT protocols. For example, Roche et al. (2017) evaluated a bibliotherapy-based ACT intervention that was not tailored to ME/CFS, and three studies by Surawy et al. (2005a, 2005b, 2005c) referenced MBSR/MBCT manuals but did not report any adaptations for the target population.

Reporting of therapist involvement was limited; several studies did not specify the number of therapists delivering the intervention. In one pre-post design (Stubhaug et al., 2018), the intervention was delivered by a single therapist, making it difficult to distinguish treatment effects from therapist-specific influences. Three studies involved two therapists but did not analyse therapist-related outcomes (Jonsjö et al., 2019; Sollie et al., 2017). None of the studies reported formal assessments of treatment fidelity or therapist competence, such as rating a sample of therapy sessions. Two studies mentioned supervision (Jonsjö et al., 2019; Rimes & Wingrove, 2013), but without sufficient detail to meet fidelity criteria. One ACT bibliotherapy-based intervention (Roche et al., 2017) did not involve a therapist; instead, one researcher provided weekly telephone calls to check participants' comprehension and adherence.

Statistical analyses were generally appropriate and clearly reported. However, some studies lacked key statistical details. For example, González-Moreno et al. (2024) did not report standard deviations, limiting calculation of effect sizes, while Stubhaug et al. (2018) reported means and standard deviations inconsistently for one outcome measure. Roche et al. (2017) presented an increase in cognitive fusion in two cases graphically, but did not discuss this result, raising some concerns about potential selective interpretation of results.

Sample size was another common limitation across studies. Only one study (González-Moreno et al., 2024) conducted a priori power calculation. Several of the RCT and pre-post studies (e.g., Surawy et al., 2005 a, 2005b, 2005c) appeared underpowered, thereby increasing the risk of both Type I and Type II errors. In addition, most studies did not report on clinical significance, limiting interpretation of the practical impact of findings.

Finally, attrition and its handling was often poorly reported. In several cases, attrition could only be inferred from the data or statistical analysis. Only two studies (Stubhaug et al., 2018; Jonsjö et al., 2019) conducted dropout analyses or applied an intention-to-treat approach.

Table 4

Quality Appraisal Ratings Using the EPHPP

	EPHPP						
Study	**Selection Bias**	**Study Design**	**Confounders**	**Blinding**	**Data Collection**	**Withdrawals & Dropouts**	**Global rating**
Jonsjö et al. (2019)	Moderate	Moderate	Weak	Moderate	Strong	Strong	**Moderate**
González-Moreno et al. (2024)	Moderate	Strong	Strong	Weak	Strong	Strong	**Moderate**
Nikrah et al. (2023)	Moderate	Strong	Weak	Moderate	Moderate	Weak	**Weak**
Roche et al. (2017)	Weak	Weak	Weak	Moderate	Strong	Strong	**Weak**
Surawy et al. (2005a)	Weak	Strong	Weak	Moderate	Strong	Strong	**Moderate**
Surawy et al. (2005b)	Weak	Moderate	Weak	Moderate	Strong	Strong	**Weak**
Surawy et al. (2005c)	Weak	Moderate	Weak	Moderate	Strong	Moderate	**Weak**
Rimes & Wingrove (2013)	Weak	Strong	Strong	Moderate	Strong	Strong	**Moderate**
Sollie et al. (2017)	Weak	Moderate	Weak	Moderate	Strong	Strong	**Weak**
Stubhaug et al. (2018)	Moderate	Moderate	Weak	Moderate	Strong	Moderate	**Moderate**

Table 5

Quality Appraisal Ratings Using the POMRF

	POMRF									
Study	Intervention integrity					Data analyses				
	Manualised	No. of therapists	Training/ experience	Adherence	Competence	Power analysis	Attrition	Analyses & presentation of results	Clinical significance	Total score (out of a possible 18)
Jonsjö et al. (2019)	**2**	**1**	**2**	**0**	**0**	**0**	**2**	**2**	**0**	**9**
González-Moreno et al. (2024)	**2**	**0**	**0**	**0**	**0**	**1**	**2**	**1**	**0**	**6**
Nikrah et al. (2023)	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**0**	**4**
Roche et al. (2017)	**1**	**0**	**0**	**0**	**0**	**0**	**2**	**1**	**2**	**6**
Surawy et al. (2005a)	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**0**	**3**
Surawy et al. (2005b)	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**0**	**3**

Surawy et al. (2005c)	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**0**	**3**
Rimes & Wingrove (2013)	**2**	**1**	**2**	**0**	**0**	**0**	**1**	**2**	**0**	**8**
Sollie et al. (2017)	**2**	**1**	**2**	**0**	**0**	**0**	**2**	**2**	**1**	**10**
Stubhaug et al. (2018)	**2**	**0**	**2**	**0**	**0**	**0**	**1**	**2**	**1**	**8**

Effectiveness of Third-wave Interventions

This section summarises the effectiveness of interventions on key domains assessed across the included studies (see Table 3 for a detailed summary of outcomes).

Fatigue

Fatigue was the most commonly assessed outcome, included in all ME/CFS studies but not in the two examining PCS/Long Covid (González-Moreno et al., 2024; Nikrah et al., 2023). Among pre-post and RCT designs, four studies reported significant improvements in fatigue, including ACT (Jonsjö et al., 2019), MBCT (Surawy et al., 2005c; Rimes & Wingrove, 2013, relative to waitlist control), and a multi-component programme combining MBCT with elements of ACT, psychoeducation, writing tasks, and physical activity (Stubhaug et al., 2018). Reported effect sizes were typically large (*d* = 0.94–1.6), although the ACT study by Jonsjö et al. (2019) reported only small-to-medium effects (*d* = 0.20-0.34), and also reported an increase in mental fatigue. Two studies of MBCT (Surawy et al., 2005a, 2005b) found no significant change in fatigue.

Findings from case series were mixed. In the ACT case series (Roche et al., 2017), five of six participants showed clinically significant improvements, whereas only one of ten improved in the MBCT case series (Sollie et al., 2017).

Six studies included follow-up assessment. Across RCTs and pre-post designs, gains in fatigue were sustained at 3 months (Surawy et al., 2005c), 6 months (Rimes & Wingrove, 2013; Jonsjö et al., 2019), and 12 months (Stubhaug et al., 2018). However, findings were inconsistent; for example, Jonsjö et al. (2019) reported a small but significant increase in general fatigue at 6 months. In the case series, four of six participants in Roche et al. (2017) maintained improvements, but the only responder in Sollie et al. (2017) did not.

Overall, most studies reported improvements in fatigue, and where observed, these gains were usually maintained at follow-up.

Quality of Life

Six studies included a quality of life measure, most commonly health-related quality of life (HRQoL), though the specific tools and subdomains varied across studies. Among pre-post and RCT designs, four studies reported improvements following ACT (Jonsjö et al., 2019; Nikrah et al., 2023), MBSR/MBCT (Surawy et al., 2005b, 2005c), or a multi-component programme combining MBCT with ACT components (Stubhaug et al., 2018). Reported effect sizes were moderate to large (d = 0.56–1.1). However, not all subdomains improved: for example, Jonsjö et al. (2019) found no significant change on the Medical Outcomes Study 36-Item Short Form (SF-36; Ware & Sherbourne, 1992) mental health subscale or the EuroQol 5-Dimension Questionnaire (EuroQol Group, 1990) Index, and Nikrah et al. (2023) found no effect on the WHO Quality of Life questionnaire – brief version (WHOQOL-BREF; The WHOQOL Group, 1998) environmental subscale. Where gains were observed, they were generally sustained at follow-up at 3 months (Nikrah et al., 2023; Surawy et al., 2005c), 6 months (Jonsjö et al., 2019), and 12 months (Stubhaug et al., 2018).

Findings from the case series were mixed. In the ACT bibliotherapy case series (Roche et al., 2017), five of six participants improved post-intervention, three of whom maintained gains at 3 months. By contrast, in the MBCT case series (Sollie et al., 2017), only one of ten participants demonstrated clinically significant improvement, which was maintained at follow-up.

In addition, the ACT trial with a PCS/Long Covid population (González-Moreno et al., 2024) reported a significant improvement in subjective wellbeing compared to the control group, with a large effect size (d = 1.10). This aligns with the broader pattern of quality of life gains observed across controlled trials, though measured using a distinct construct.

In summary, across most controlled trials, third-wave interventions were associated with moderate to large improvements in quality of life, which were sustained over time. However, effects were inconsistent across subdomains, and evidence from case series was less robust.

Psychological Symptoms

Several studies assessed psychological symptoms, focusing primarily on depression and anxiety, with a smaller number examining stress and rumination.

For depression, four pre-post or RCT studies reported no significant improvements following ACT (Jonsjö et al., 2019; González-Moreno et al., 2024) or MBSR/MBCT interventions (Surawy et al., 2005a, 2005b). In contrast, significant reductions in depression were reported in an RCT of MBCT (Rimes & Wingrove, 2013), a pre-post MBSR/MBCT study (Surawy et al., 2005c), and a pre-post multi-component intervention integrating MBCT with ACT (Stubhaug et al., 2018), with moderate to large effect sizes (d = 0.77–1.13) compared to baseline or waitlist control. In the MBCT case series (Sollie et al., 2017), three out of ten participants showed clinically significant improvement in mood, while one participant showed a clinically significant increase in low mood, though scores remained within the 'normal' range.

For anxiety, seven of the nine studies that assessed this outcome reported significant improvements across ACT, MBSR/MBCT, or multi-component approaches (Jonsjö et al., 2019; González-Moreno et al., 2024; Surawy et al., 2005a, 2005b, 2005c; Stubhaug et al., 2018), with effect sizes ranging from moderate to large (d = 0.54–1.32). Where follow-up assessments were conducted, gains were sustained at 3 months (Surawy et al., 2005c), 6 months (Jonsjö et al., 2019), and 12 months (Stubhaug et al., 2018). One exception was the MBCT study (Rimes & Wingrove, 2013), which found no significant improvement in anxiety relative to the waitlist control. In the MBCT case series (Sollie et al., 2017), four of ten participants showed clinically significant improvement in anxiety, maintained in three participants at 3 months.

For other psychological outcomes, no significant reductions were observed for stress (González-Moreno et al., 2024) or rumination (Sollie et al., 2017).

In summary, findings for depression were mixed, whereas anxiety showed more consistent improvement across intervention types. There was no evidence of intervention-related change in stress or rumination.

Disability and Functional Impairment

Five studies assessed disability or functional impairment. In an ACT trial for ME/CFS, Jonsjö et al. (2019) reported a significant reduction in disability (*d* = 0.80) and ME/CFS symptoms (*d* = 0.41), both maintained at 6-month follow-up. The MBCT RCT by Rimes and Wingrove (2013) found significant improvements in work and social adjustment compared to a waitlist control group (*d* = 0.77), with gains maintained at 6-month follow-up. Across the three MBSR/MBCT studies by Surawy et al. (2005a, 2005b, 2005c), findings were inconsistent: no significant changes were observed in the first two studies, whereas the third reported improvements in physical functioning (*d* = 0.76), sustained at 3-month follow-up. In contrast, results from the MBCT case series by Sollie et al. (2017) were mixed — one of ten participants showed clinically significant improvement in ME/CFS symptoms post-intervention, while two reported deterioration.

In summary, evidence for improvements in disability and functional impairment was mixed. While some interventions demonstrated improvements that were maintained at follow-up, results from the MBSR/MBCT studies were inconsistent, and evidence from case series was limited.

Psychological Processes

A range of psychological mechanisms were assessed across studies, including psychological flexibility, mindfulness, acceptance, self-compassion, valued living, and cognitive appraisals of symptoms.

Psychological flexibility was assessed in two ACT interventions. Jonsjö et al. (2019) reported a significant reduction in psychological inflexibility among individuals with ME/CFS, with a large effect size (*d* = 1.07), maintained at 6-month follow-up. In the ACT bibliotherapy case series, Roche et al. (2017) found improvements in psychological flexibility in three of six participants, all of whom maintained gains at 3-month follow-up, though these did not meet criteria for clinical significance.

Three studies measured mindfulness. In their RCT of MBCT, Rimes and Wingrove (2013) found no immediate post-intervention improvement relative to waitlist control, but significant improvements emerged at 2 months and were maintained at 6 months. Roche et al. (2017) reported clinically significant improvements in mindfulness in three of six participants following ACT guided bibliotherapy, with two maintaining gains at 3-month follow-up. In contrast, Sollie et al. (2017) reported no significant changes in mindfulness in their MBCT case series. Overall, findings on mindfulness were mixed, with limited evidence for consistent improvement.

Acceptance and valued living were assessed only in the ACT bibliotherapy case series by Roche et al. (2017). Four participants showed clinically significant improvement in acceptance, with two maintaining gains at 3-month follow-up. Similarly, four of six reported clinically significant improvements in valued living, which was sustained at follow-up. However, the same study also reported clinically significant increases in cognitive fusion (i.e., entangled with thoughts) in two participants, which persisted at follow-up.

Self-compassion was assessed in the two RCT studies. In an ACT and mindfulness intervention for PCS/Long Covid, González-Moreno et al. (2024) reported significant improvements in self-compassion (d = 0.75), driven in part by reductions in self-judgement (d = 0.62). Similarly, Rimes and Wingrove (2013) observed large improvements in self-compassion in an MBCT trial (d = 1.03) relative to controls, maintained at 6-month follow-up.

Finally, cognitive appraisal of symptoms were assessed through emotion beliefs and response to symptoms. The Emotional Beliefs Scale (BES) (Rimes & Chalder, 2010) evaluates maladaptive attitudes about emotions (e.g., perceiving them as uncontrollable or dangerous), while the Cognitive and Behavioural Response to Symptoms Questionnaire (CBRQ) (Moss-Morris & Chalder, 2003) captures unhelpful behavioural and cognitive responses to fatigue (e.g., avoidance, catastrophizing, all-or-nothing behaviour). In their RCT of MBCT, Rimes and Wingrove (2013) reported significant improvements in both domains (d = 0.97-1.09) relative to controls, with gains maintained at 6 months.

Additional Outcomes

A small number of studies assessed additional outcomes beyond these core domains, such as resilience and activity tracking. In an ACT trial for PCS/Long Covid, Nikrah et al. (2023) reported a significant improvement in resilience (*d* = 2.43), which was maintained at 3-month follow-up. In the ACT bibliotherapy case series, Roche et al. (2017) found that all five participants with usable data demonstrated increased activity levels, as measured by a wearable activity tracker (Fitbit Flex).

Discussion

The review identified ten eligible studies examining third-wave interventions for PVFS. Across studies, preliminary evidence suggested improvements in a number of outcomes, including fatigue, quality of life, and anxiety, with less consistent findings for depression and mindfulness outcomes. However, the same heterogeneity that precluded meta-analysis – including variation in intervention type, dosage, delivery format, study design, and outcome measurement – also limits the strength and generalisability of the systematic review's conclusions. While a pattern of potential benefit is evident, the nascent evidence base, diversity of methodologies and small, predominantly uncontrolled samples mean that robust claims about the overall effectiveness of third-wave interventions in PVFS cannot be made. Rather, the findings of the current review indicate that there are areas of promise that require further investigation through methodologically rigorous trials.

Methodological Limitations of Included Studies

These findings must be considered in the context of generally low methodological quality and small sample sizes. Most included studies were uncontrolled and likely underpowered, raising the risk of bias and limited generalisability, and resulting in many being rated of low or moderate quality. Sample size is particularly problematic, as smaller studies often inflate effect sizes, with larger, more rigorous trials typically finding more modest effects (Button et al., 2013). Such a phenomenon may have skewed the results of the present review. In addition, fewer than half of the studies were RCTs or controlled clinical trials, limiting confidence that observed effects were attributed to the intervention rather than non-

specific factors. The lack of standardised, condition-specific outcome measures may have reduced sensitivity to symptoms central to PVFS – such as post-exertional malaise and cognitive impairment. Fidelity and therapist competence were rarely assessed, and adaptations to intervention were inconsistently reported. Finally, heterogeneity across interventions (e.g., format, number of hours/sessions), study designs and outcomes precluded meta-analysis.

Comparison to the Wider Literature

The methodological weaknesses identified in this review mirror those seen in the wider field of third-wave interventions literature for long-term health conditions. Common limitations reported in the literature include small sample sizes, lack of active comparators, and poor reporting of fidelity (e.g., Graham et al., 2016; Frisvoll, 2022). Such issues are common across psychological intervention research, particularly when an approach is in its infancy (Gaudiano, 2009), suggesting that the challenges observed in PVFS research are not unique to this population but reflect broader patterns in the field.

With respect to outcomes, the wider third-wave literature is itself characterised by heterogeneity in effect sizes and outcomes. Systematic reviews in third-wave interventions for long-term health conditions such as chronic pain, multiple sclerosis and cancer commonly report improvements in psychological distress (e.g., anxiety, stress) (Hughes et al., 2017; Hann & McCracken, 2014) and quality of life (Han, 2022; McCracken et al., 2022). However, findings for core physical health symptoms, such as pain intensity in chronic pain, tend to be less consistent (e.g., Ye et al., 2024; Hughes et al., 2017). This latter pattern is evident in systematic reviews of ACT for chronic pain, where effects have been more robust for pain interference than for pain intensity itself (Hughes et al., 2017; Trindade et al., 2021), indicating that this approach may influence the impact of symptoms rather than their severity. This distinction aligns with the theoretical foundations of ACT, which emphasises shifting the relationship to symptoms rather than directly targeting symptom reduction.

The findings of the present review broadly align with the variability observed in the wider third-wave literature. Improvements were observed in anxiety and quality of life across several studies. Notably, improvement in fatigue was identified in multiple studies, often

with moderate to large effect sizes. As discussed, symptom reduction is not a primary target of third-wave interventions, although changes in symptom experience may occur indirectly. Improvements in fatigue may therefore reflect shifts in how individuals relate to and manage their symptoms; however, in the absence of further analysis to explore mechanisms of change, this interpretation remains tentative. Furthermore, as noted, methodological limitations and heterogeneity across studies precludes firm conclusions.

Finally, although several studies included at least one measure of psychological processes (e.g., psychological flexibility, mindfulness, or self-compassion), none conducted formal mediation analyses to determine whether changes in these processes accounted for improvements in outcomes. As a result, it remains unclear whether observed effects reflect theoretically specified mechanisms or broader non-specific therapeutic factors. This absence of mechanism testing represents a notable gap in the PVFS literature. While mediation analyses have become more established within parts of the ACT literature (e.g., McCracken & Jones, 2012; De Jong et al., 2016), it has been suggested they remain less consistently applied within MBCT and MBSR research across health conditions (Alsubaie et al., 2017). Addressing this gap will be an important priority for future PVFS trials.

Feasibility and Acceptability

Attrition rates were generally low to moderate across included studies, with most reporting retention between 75% and 100%. Retention was comparable to ACT-based interventions in other long-term conditions based on a recent review reporting an average completion rate of approximately 90% (Frisvoll, 2022). This suggests that third-wave interventions may be acceptable and feasible for people with PVFS, despite the fatigue and energy limitations characteristic of the condition. However, inconsistent reporting of attrition and session attendance in the current review limit the strength of conclusions. Some studies provided detailed information on session completion, while others conflated treatment completion with analysis inclusion, hindering cross-study comparison. Greater consistency in reporting engagement would enhance measurement of feasibility and acceptability in future trials.

Conceptual Issues

Beyond methodological limitations, some conceptual issues also emerged. Several studies (Surawy et al., 2005a, 2005b, 2005c; Rimes & Wingrove, 2013) drew on an earlier cognitive behavioural model of ME/CFS (Surawy et al., 1995), which emphasised unhelpful thoughts and behaviours. While the interventions themselves were based on MBSR/MBCT protocols, this framing reflects an outdated conceptualisation that has been criticised for oversimplifying the biomedical complexity of ME/CFS and is no longer consistent with current clinical guidelines (NICE, 2021).

The Surawy et al. (2005) studies were retained to capture the breadth of mindfulness-based applications within post-viral fatigue populations, particularly in light of the limited number of available studies. However, their age, low methodological quality, and theoretical framing mean that their findings should be considered cautiously and within the context of subsequent developments in the field, with greater weight given to more recent and methodologically robust studies when considering implications for current practice.

In another study (Nikrah et al., 2023), the ACT intervention appeared to deviate from standard practice, such as encouraging patients to "accept medical arrangements without overthinking." While this may partly reflect translation issues or cultural adaptations, such guidance risks reinforcing compliance rather than fostering genuine psychological flexibility, which is central to ACT's theoretical model.

Taken together, these examples highlight the importance of ensuring that interventions are both culturally sensitive and conceptually aligned with contemporary evidence on ME/CFS and Long Covid, as outdated or non-standard framings may undermine both acceptability and effectiveness.

Methodological Recommendations and Future Research

Based on the limitations identified in the current evidence base, several steps could strengthen the design and reporting of future studies. Key recommendations include:

- Use clear, standardised diagnostic criteria for ME/CFS and Long Covid to ensure sample comparability and transparency.
- Develop and include PVFS-specific outcome measures that capture hallmark symptoms such as post-exertional malaise, cognitive dysfunction, and activity limitation, as generic fatigue or quality of life scales may lack sensitivity.
- Conduct a priori power calculations to ensure adequate sample sizes, as several existing studies appeared underpowered.
- Incorporate long-term follow-up (at least 12 months) to assess the sustainability of effects.
- Record concomitant treatments to allow clearer interpretation of outcomes.
- Report complete descriptive statistics (means and standard deviations or standard errors) for pre- and post-intervention measurements, to facilitate calculation of effect sizes.
- Include at least two therapists per intervention arm to help disentangle intervention effects from individual clinician effects.
- Assess treatment fidelity and therapist competence, for example through independent rating of recorded sessions and reporting of therapist training.
- Use active control conditions (e.g., supportive counselling, psychoeducation) rather than waitlist controls, to better test intervention-specific effects.

Future research should explore how intervention delivery influences outcomes. The format of intervention delivery may be particularly important in PVFS, where energy limitations and mobility barriers pose significant challenges. Within the current review, one RCT evaluated an online group intervention (González-Moreno et al., 2024), which demonstrated large between-group improvements in subjective wellbeing, anxiety, and self-compassion (particularly reduced self-judgement). In addition, a guided bibliotherapy intervention supported by brief weekly telephone calls (Roche et al., 2017) reported clinically significant improvements in several domains (including quality of life and valued living), although this was based on a small case series design. These findings suggest that remote or low-intensity formats may be feasible and potentially beneficial for this population. However, the small number of studies and heterogeneity in design mean that it remains unclear whether remote delivery is equivalent to face-to-face individual or group-based interventions.

Intervention intensity is another key consideration. Evidence from ACT research in other populations suggests that brief or low-intensity interventions produce weaker effects (Graham et al., 2016). However, there are exceptions; for example, Dochat et al. (2021) found preliminary efficacy and acceptability for a single-session ACT intervention for patients with chronic health conditions. The mixed findings in PVFS trials may reflect the same variability in intervention intensity observed in ACT research more broadly. Tailoring the "dose" of therapy – for instance, by offering shorter sessions extended over a longer period, or self-paced digital programmes – may improve both feasibility and effectiveness for this group.

Finally, as previously highlighted, the mechanisms of change underlying third-wave interventions in PVFS remain unclear. Future trials should incorporate process measures and mediation analyses to clarify how third-wave interventions exert their effects in PVFS populations. In addition, future work could broaden the scope of interventions examined. For instance, CFT and other emerging third-wave approaches have not yet been systematically studied in PVFS, but may hold promise and warrant investigation.

It is also important to acknowledge that research on Long Covid is still at an early stage, reflecting its relatively recent recognition. The volume of studies is likely to increase in the coming years and, as such, ongoing reviews will need to incorporate this emerging evidence to provide a more comprehensive understanding of third-wave interventions in Long Covid.

Strengths and Limitations of the Current Review

To our knowledge, this is the first review to synthesise evidence for third-wave interventions in PVFS, offering an early snapshot of a developing field. This was supported by a broad and inclusive search across eight databases, which maximised the likelihood of capturing all relevant studies and provided a transdiagnostic overview of intervention approaches. Methodological rigour was further enhanced by independent quality appraisal conducted by two reviewers.

Several limitations should be acknowledged. Heterogeneity in study design, intervention format, and outcome measures was a significant constraint, precluding meta-analysis and

limiting the ability to make direct comparisons between interventions. In addition, due to resource limitations, initial screening was conducted by a single reviewer and data extraction was not conducted by two reviewers, which may have introduced potential bias or error.

The review did not attempt to compare the relative effectiveness of different third-wave approaches (e.g. ACT vs MBCT vs MBSR). The number of available studies was small, methodologies were heterogeneous, and outcomes were inconsistently reported, meaning that direct comparisons were unlikely to be informative. Instead, the review synthesised third-wave interventions at the level of their shared theoretical and process-oriented foundations. Although these approaches differ in their emphasis and specific techniques, they share a focus on promoting more flexible and adaptive patterns of responding to internal experiences. At the current stage of the evidence base, this level of synthesis was considered more appropriate than modality-level comparison. As the evidence base grows, future research may be better positioned to examine whether specific third-wave modalities offer different benefits for this population.

Clinical Practice Implications

Given the limited and heterogeneous nature of the current evidence base, clinicians should remain mindful of its preliminary nature when considering third-wave therapies in practice. Nonetheless, these approaches may have value as supportive interventions for some individuals with PVFS, particularly when embedded within a broader multi-disciplinary model of care. Their emphasis on shifting individuals' relationship to internal experiences – through processes such as acceptance, mindfulness, compassion, and values-based action – may offer a useful therapeutic framing in such contexts where symptom management and quality of life, rather than cure, are the primary therapeutic goals.

CBT remains recommended within current NICE guidelines (NICE, 2021) as a supportive (rather than curative) intervention. It is important to note that third-wave approaches would similarly be conceptualised as supportive rather than curative in this context. The potential distinction between CBT and third-wave approaches therefore lies not in curative intent, but in therapeutic stance. In the context of PVFS, such a stance may offer a useful

framing that emphasises adjustment and meaningful engagement alongside ongoing symptoms. However, given the current limitations in the evidence base, such recommendations require further empirical investigation.

Conclusion

Third-wave psychological interventions, such as ACT, MBSR and MBCT, show preliminary promise for improving some outcomes in PVFS, particularly fatigue and anxiety, and quality of life. While these findings are encouraging, the current evidence base remains nascent and methodologically limited. To advance understanding and inform clinical practice, future adequately powered RCTs using consistent diagnostic criteria and standardised, PVFS-specific outcome measures are needed to establish effectiveness, test underlying mechanisms of change, and ensure transparent reporting. Until then, these interventions should be considered promising but still at an early stage of evidence in the management of PVFS.

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Chapter 2: Empirical Project

The perspectives of people with Long Covid on receiving individual psychology or other mental health input for management of the condition in NHS services: An Interpretative Phenomenological Analysis (IPA).

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Abstract

Background: Long Covid is a multi-system condition with varied and often debilitating symptoms. Psychological therapies are increasingly offered within the National Health Service (NHS), yet their role remains contested, reflecting earlier debates about similar interventions for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a condition with overlapping features. Little is known about how people with Long Covid experience one-to-one psychological or mental health support. **Aim:** This study explored the lived experiences of individuals with Long Covid who accessed one-to-one psychological or other mental health support through NHS services. **Method:** Eight adults with a diagnosis of Long Covid were recruited from across the UK via third-sector organisations, support groups, and social media. Semi-structured interviews were conducted online or by telephone and analysed using Interpretative Phenomenological Analysis (IPA). **Results:** Analysis identified four themes: *The Weight of Waiting*, which described the emotional distress during the waiting period for accessing support; *Being Believed and Validated*, which captured the relief and significance of having symptoms acknowledged and taken seriously; *Therapeutic Fit*, reflecting the importance of relational connection, collaboration, and flexibility; and *Grief, Adjustment and Acceptance*, which outlined how mental health support provided space to process losses and gradually adapt to life with ongoing symptoms. **Conclusion:** Findings provide novel insights into how people with Long Covid engage with and make sense of psychological support. These insights, while not generalisable, suggest important considerations for the design and delivery of NHS services that are evidence-based, patient-centred, and responsive to lived experience.

Introduction

As the Covid-19 pandemic unfolded, it became apparent that a proportion of individuals who contracted SARS-CoV-2 infection continued to experience symptoms for weeks or months beyond the acute infection (Carfì et al., 2020). These prolonged symptoms have been described in the literature using a range of terms, including Post-Covid-19 Syndrome (National Institute for Health and Care Excellence [NICE] et al., 2020), Post-acute Sequelae of SARS-CoV-2 infection (Thaweethai et al., 2023), Long Haul Covid (Yong, 2021), and Post-Covid Condition (World Health Organization [WHO], 2021). Notably, "Long Covid"—a patient-coined term—has become the most widely used, both in public discourse and within patient communities, to capture the diverse and often debilitating array of ongoing symptoms (Callard & Perego, 2021).

Long Covid is a multi-system condition with heterogeneous presentations, and over 200 symptoms have been identified in clinical and patient-led research. Common symptoms include fatigue, cognitive impairment ("brain fog"), and pain (Davis et al., 2021; Taquet et al., 2021). Alongside these physical and cognitive symptoms, Long Covid has been associated with pronounced psychological, social, and financial consequences. Common psychological difficulties include anxiety, depression, sleep disturbance, and post-traumatic stress symptoms (Marchi et al., 2023; Fancourt et al., 2023), alongside reduced quality of life (Orrù et al., 2021). It has also been linked to financial losses arising from reduced working capacity, including working fewer hours and prolonged periods of sickness absence (Ayoubkhani et al., 2024; Leitner et al., 2024; Schwartz et al., 2024).

A hallmark of many people's experience with Long Covid is the unpredictable nature of symptoms, which can fluctuate over days and even hours (Greenwood et al., 2024). Due to this complexity, no consistent case definition has yet been established (Goldowitz et al., 2024), with recent guidance suggesting that Long Covid may consist of multiple overlapping conditions with differing biological mechanisms, risk factors, and outcomes (Agency for Healthcare Research and Quality [AHRQ], 2023). Studies further suggest that symptom clusters overlap with recognised conditions such as postural orthostatic tachycardia syndrome (POTS) (Cantrell et al., 2024). Long Covid has been observed across all age groups, though prevalence appears highest among adults aged 36–50 years (Davis et al., 2021).

Reported risk factors include female sex (Shah et al., 2025), ethnic minority background (Mkoma et al., 2024), pre-existing health conditions (e.g., type 2 diabetes) (Wang et al., 2024), and lower socioeconomic status (Subramanian et al., 2022).

The physiological basis of Long Covid has been a key area of research, with several mechanisms proposed, including immune dysregulation, impaired cellular signalling, and autonomic dysfunction (Peluso & Deeks, 2024; Marques et al., 2023). However, none fully account for the wide-ranging symptomatology, and no definitive biomarkers or treatments for the overall condition currently exist (Eckey et al., 2025; Davis et al., 2021). As such, clinical guidelines focus on the management of specific symptoms rather than the overarching syndrome (NICE et al., 2020; WHO, 2021). This lack of clarity has led researchers and patients to draw comparisons with related conditions.

Parallels with Related Conditions

Parallels have been drawn between Long Covid and other post-viral fatigue conditions, particularly myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), with which it shares features such as fatigue, post-exertional malaise, and cognitive difficulties (Wong & Weitzer, 2021). Like Long Covid, ME/CFS lacks biomarkers or diagnostic tests and definitive treatments, and its aetiology remains unclear. Patients with ME/CFS have historically reported feeling disbelieved or stigmatised, particularly when symptoms are framed in primarily psychological terms (Froehlich et al., 2022). Evidence to date suggests that people with Long Covid face similar challenges of stigma, dismissal, and difficulties accessing appropriate care (Hunt et al., 2022; Burton-Fisher & Gordon, 2024).

Psychological Support

Psychological therapies are commonly offered to people living with chronic health conditions, where they can support adjustment, coping, and the management of associated psychological difficulties (Akyirem et al., 2022). However, the use of psychological therapies in ME/CFS has been the subject of considerable debate. Earlier cognitive behavioural models of ME/CFS conceptualised persistent symptoms as maintained by unhelpful illness beliefs, avoidance behaviours, and physical deconditioning (Wessely et al., 1989; Surawy et al., 1995; Vercoulen et al., 1998). Critics argued that this formulation risked oversimplifying

the complex and poorly understood pathophysiological nature of ME/CFS and may frame persistent symptoms as perpetuated by patients' cognitive style or behaviours rather than ongoing biological processes (Geraghty et al., 2019). Qualitative research indicates that some individuals experienced such formulations as invalidating and, at times, stigmatising (Froehlich et al., 2022). Alongside experiential concerns, aspects of the CBT evidence base for ME/CFS were also subject to methodological criticism (e.g., Wilshire et al., 2018), contributing to ongoing controversy. Although CBT has since been repositioned as a supportive rather than curative intervention in updated NICE guidelines (NICE, 2021a) and models have evolved, it is possible that the legacy of earlier models continues to shape patient expectations and experiences of psychological support.

In the context of Long Covid, CBT has been suggested as a potentially useful intervention (Kuut et al., 2023). However, given the historical controversies surrounding its use in ME/CFS, patient experiences and the limited evidence currently available, its applicability and acceptability remain in question (Huth et al., 2024; Biere-Rafi et al., 2023; Hawke et al., 2022; Burton-Fisher & Gordon, 2024). While psychological difficulties such as anxiety, depression, and adjustment challenges are common and warrant appropriate support within this population, these uncertainties highlight the need for caution in how therapies are framed and delivered within services. In the UK, psychological support is now offered within National Health Service (NHS) services, but the evidence base for such provision remains sparse (Hawke et al., 2022; Burton-Fisher & Gordon, 2024). It is therefore considered vital to learn from past experiences with ME/CFS to ensure that psychological support for Long Covid is both evidence-based and sensitive to patient perspectives.

Value of Lived Experience Research

As a relatively new condition, Long Covid presents challenges for building a robust evidence base, with limited clinical trials and no established treatment pathways. In such contexts, qualitative research is particularly valuable; it can illuminate patient experiences, identify priorities, and generate insights that help to shape and inform future quantitative research. Lived experience research is valuable for deepening our understanding and ensuring that health and social care services are responsive, validating, and patient-centred (Sartor, 2023).

Quantitative studies have documented prevalence, risk factors, and clinical outcomes in Long Covid. However, such approaches are less well equipped to capture nuanced psychological consequences, such as stigma, disruption to identity, and uncertainty about recovery. In this context, qualitative research has played a vital role in bringing patient perspectives to the fore. Notably, patient-led research has been instrumental in shaping recognition of the condition (Callard & Perego, 2021), with subsequent work highlighting how patients have attempted to navigate healthcare services (MacEwan et al., 2024; Kingstone et al., 2020), manage symptoms (Leggat et al., 2024), and deal with uncertainty (Moretti et al., 2022). Yet little is known about how people with Long Covid experience one-to-one psychology support or other forms of mental health support within NHS services.

Present Study

The present qualitative study sought to address this gap by exploring the lived experience of people with Long Covid who accessed one-to-one psychology or other mental health support through NHS services. Interpretative Phenomenological Analysis (IPA) was used to capture in-depth accounts of how participants made sense of their experiences. The guiding research question was: What is the lived experience of people with Long Covid receiving one-to-one psychology/mental health support for the management of the condition?

Methodology

Design

This study drew upon the principles of Interpretative Phenomenological Analysis (IPA). IPA is a qualitative methodology that aims to provide detailed examination of personal lived experience (Smith & Osborn, 2015). It is grounded in three key theoretical underpinnings. First, it is phenomenological in its focus on exploring experience on its own terms rather than preconceptions derived from existing theory. Second, it is interpretative, applying a "double hermeneutic", whereby the researcher seeks to make sense of the participant making sense of their experience (Smith et al., 2022). Finally, it is idiographic, in that it is committed to in-depth exploration of each individual case before identifying patterns of convergence and divergence across cases to develop more general themes (Eatough & Smith, 2017).

IPA has been widely applied in health research to explore personal experiences of illness and is considered particularly suited to topics that are complex, ambiguous, and emotionally laden (Smith et al., 2022). Long Covid, as a relatively new and heterogeneous condition characterised by fluctuating symptoms and uncertainty, represents such a topic. In a context where standardised treatment pathways remain limited, an approach that prioritises patients' perspectives and attends closely to how they make sense of support is particularly valuable. IPA was therefore selected to enable an in-depth exploration of participants' experiences of accessing and engaging in one-to-one psychological support for Long Covid.

Central to this choice is IPA's idiographic commitment. By prioritising personal narratives over pre-defined categories, IPA allows for a nuanced examination of complex biopsychosocial experiences grounded in lived accounts (Biggerstaff & Thompson, 2008). In the present study, such an approach supports exploration of how engagement with support may be shaped by the emotional, relational, and identity-related impacts associated with Long Covid, as these intersect with experiences of healthcare.

In addition to generating in-depth analysis, IPA offers potential for theoretical and practical transferability. Findings may illuminate existing psychological literature, including prior quantitative research, by providing rich and nuanced accounts of how key constructs are experienced and understood in context (Smith & Nizza, 2022). Such insights may also be drawn upon by clinicians to assist in designing and making sense of their interactions and interventions with clients (Smith & Nizza, 2022). Furthermore, by attending closely to lived experience, IPA research may offer insights that support recovery-oriented approaches, such as fostering hope, reflection, and shared understanding (Honey et al., 2020).

Sampling and Recruitment

Consistent with IPA's methodological approach, purposive sampling was used to recruit individuals who had direct experience of the phenomenon under investigation and were able to offer reflective accounts of engaging in one-to-one psychology or other mental health support in relation to Long Covid. Unlike probability sampling methods, which aim for representativeness, purposive sampling in IPA prioritises experiential depth within a

relatively homogeneous group (Smith et al., 2022). This approach reflects IPA's epistemological commitment to idiographic analysis, which emphasises exploration of lived experience rather than statistical generalisability.

Recruitment continued until a small sample appropriate for detailed idiographic analysis was achieved, consistent with methodological guidance for IPA studies, which emphasises depth and richness of data over sample size. For professional doctorate research, IPA studies typically include between six and ten participants (Smith et al., 2022).

The study aimed to recruit adults with a diagnosis of Long Covid who had accessed one-to-one psychology or other mental health support within NHS services. Recruitment took place across the United Kingdom (UK) through advertisements shared by third-sector organisations (e.g., Chest, Heart & Stroke Scotland, ME Action), volunteer-led Long Covid support groups and charities (e.g., Long Covid Scotland), a Long Covid wellbeing company recommended by a participant (Rest, Repair, Recover) and social media platforms (e.g., BlueSky, Facebook, Instagram) across the UK. Recruitment materials included a participant information sheet and study advert (see Appendices 8 and 9).

Inclusion criteria required participants to: a) have experienced symptoms of Long Covid for at least 12 weeks following initial Covid-19 infection, in line with the World Health Organization's clinical case definition (WHO, 2021), and b) not have been hospitalised in relation to Covid-19 infection. Although obtaining a formal diagnosis of Long Covid may have presented barriers to participation, this requirement was retained to ensure a relatively homogeneous group experience, consistent with IPA's idiographic focus. At the time of study design, much of the emerging research on Long Covid focused on individuals who had been hospitalised with Covid-19. To address this imbalance, the present study specifically included only non-hospitalised patients. Furthermore, this aligns with IPA's emphasis on idiographic and relatively homogeneous samples (Smith et al., 2022).

Homogeneity was defined at the level of the shared phenomenon under investigation, namely, the experience of receiving one-to-one psychology or other mental health support for Long Covid, rather than at the level of professional discipline, therapeutic modality, or

duration of support. While different professional groups may practise in different ways, variation may also occur within the same discipline (e.g., clinical psychology), depending upon therapeutic approach, clinician style, and service context. As such, restricting inclusion based on professional background may not necessarily produce a more homogeneous group. The shared experience of engaging in one-to-one psychology or other mental health support for Long Covid was therefore considered sufficiently homogeneous for idiographic analysis. Variation in professional background and duration of support were therefore understood as contextual within cases rather than as criteria for inclusion.

Individuals who were interested in the study were invited to complete a brief online screening survey (presented in Appendix 10). The survey was used to confirm eligibility against the study criteria, register interest in participation, and collect preliminary demographic and contextual information. The survey included its own consent form, which respondents completed before providing personal details. While most participants completed the online screening survey, a small number contacted the researcher directly by email. In these cases, eligibility was confirmed individually and the required information was collected during the pre-interview telephone call, at which point consent was also taken.

All participants reported having received a formal diagnosis of Long Covid, with this information accepted on trust rather than independently verified via a healthcare professional or records. This decision reflected a commitment to respecting participants' accounts and avoiding the reproduction of disbelief that many encounter across different contexts. It was also consistent with the epistemological stance of IPA, which prioritises lived experience and participants' meaning-making as the central focus of analysis.

Eligible participants were then invited to take part in a pre-interview telephone call. This call was designed to reduce the burden of data collection during the research interview itself and to provide an opportunity to build rapport with participants, in line with guidance from Smith and Nizza (2022). During this call, eligibility was confirmed, verbal consent was audio-recorded, and further information was gathered (e.g., demographic details and postcode, which was used to derive Index of Multiple Deprivation [IMD] deciles as a contextual indicator of socioeconomic background and was not retained in identifiable form).

Participants were also given the opportunity to ask questions about the study and request adjustments to the research interview format (e.g., taking breaks, receiving interview questions in advance). As part of the consent process, participants were also informed of their right to withdraw from the study for up to two weeks following their initial interview. A two-week withdrawal window was used to support ongoing voluntary participation and informed consent while enabling timely progression to data analysis.

Finally, participants were socialised to the style of the forthcoming interview. They were informed that they would be asked some very open questions about their experience of receiving one-to-one mental health support in relation to having Long Covid, that the interview was expected to last between 30 and 60 minutes, and that they could choose how to respond to these questions. They were informed that the interview was a space to share and so the researcher may be quite quiet throughout the interview. A convenient time for the interview was then arranged. A full telephone call schedule is provided in Appendix 11.

To support participants and minimise fatigue, they were informed that they could take breaks whenever needed or stop the interview at any time without giving a reason. In recognition of the cognitive difficulties often associated with Long Covid (e.g., memory lapses, brain fog), participants were informed that if they were to recall additional information after the interview, they were welcome to share this by email within two weeks of the interview. Three participants emailed further information within this period. One participant shared additional reflective material related to their experience of receiving psychological support; this was appended to the interview transcript and incorporated into the analysis. Two participants provided information in the form of lists outlining the content of their therapy sessions and clarification of factual details, such as the number of sessions attended. This descriptive material was retained as transcript addenda for completeness but did not shape the analysis.

Expert by Experience Involvement

In line with IPA's commitment to centring lived experience, the study was informed by input from people living with Long Covid at multiple stages of its development. Early in the research process, the researcher held informal exploratory conversations with several

individuals with Long Covid to discuss potential research ideas and priorities. These discussions provided valuable insight into the day-to-day challenges of living with the condition, including fatigue, cognitive difficulties, and barriers to accessing support, and helped to raise the researcher's awareness of issues related to accessibility and participant burden. While these conversations did not directly determine the final research question, they shaped subsequent research decisions by foregrounding the lived realities of Long Covid.

Following refinement of the research question, three Experts by Experience (EbE) with lived experience of Long Covid were consulted more formally. Their input influenced several key aspects of the study design. First, EbE contributors reviewed and provided feedback on study materials, including the participant information sheet and consent forms, with a focus on accessibility and cognitive load. Feedback largely confirmed the clarity and appropriateness of the materials, including the use of concise formatting and images, while recognising the need to retain ethically required information. Minor refinements were made where appropriate.

Second, EbE feedback informed the development of the semi-structured interview schedule. One EbE in particular highlighted the potential burden of overly broad or abstract opening questions and suggested a more focused initial question to support engagement without expending unnecessary energy. This input led to the refinement of the interview schedule to ensure questions were meaningful and sensitive to participants' limited cognitive and physical resources.

Third, EbE contributors advised on practical adjustments to the interview process itself, including the importance of offering breaks, sharing the interview schedule in advance, and allowing participants the opportunity to share additional reflections after the interview if relevant information was later recalled. These suggestions were incorporated into the study protocol and consent process with the intention of reducing burden and increasing accessibility.

During data collection, the researcher remained attentive to participants' energy levels, adapting interviews flexibly in response to participants' needs. Collectively, EbE input helped

to ensure that the study design, materials, and procedures were sensitive to the lived realities of Long Covid, and that participation was kept as inclusive as possible.

Participant Characteristics

Eight participants (one man, seven women) took part in the research study. One additional individual consented to participate but withdrew from the study before the interview took place. All participants identified as White British or White Scottish and were living in areas spanning IMD deciles 5-10, representing areas of average to relatively low deprivation. While duration of illness varied (approximately 11 months to over 4 years), the sample was unified by the shared experience of engaging with one-to-one psychology or other mental health support for Long Covid in NHS services. This shared clinical pathway ensured a relatively homogeneous sample appropriate for IPA. Pen portraits are provided below to offer orientation to each participant's lived experience.

Andrew (50s)

Andrew had been living with Long Covid for over three years at the time of interview. Previously active and engaged in hobbies such as motorcycling and gardening, he described a significant narrowing of life due to fatigue and post-exertional malaise. He had accessed counselling and support from a mental health nurse within NHS services. His account was marked by themes of grief, loss of social roles, adjusting to pacing, and gradual shifts toward acceptance, alongside a strong appreciation for therapeutic support. Andrew made reference to societal expectations that men should not cry or seek emotional support, while also expressing defiance towards these views if accessing support was helping him.

Catriona (50s)

Catriona had experienced Long Covid for approximately 11 months. She was referred to a Long Covid service and allocated to a clinical psychologist. She described relief at being believed and understood within the specialist service. Living with fatigue, pain, and suspected POTS, she drew on prior pain management strategies and engaged in structured pacing work. Together, they developed ways of explaining the impact of her symptoms to her employer, using "spoon theory" to communicate the limits of her energy in discussions about returning to work. Her narrative highlighted validation, collaborative problem-solving,

and the challenges of regulating activity in the context of fluctuating symptoms.

Dee (40s)

Dee had experienced Long Covid for around 11 months. She was referred to NHS Talking Therapies but faced a 14-16 week wait for CBT. In the interim, she sought private clinical psychology support. When she later accessed CBT through the NHS, she experienced these approaches as vastly different. With a professional background in healthcare, she reflected on these experiences from the perspective of both a patient and professional. Her account highlighted a sense of urgency, experiences of waiting, and the importance she placed on relational depth and understanding of the lived realities of Long Covid.

Emily (40s)

Emily had been living with Long Covid for over four years. After limited input from an early Long Covid clinic, she was referred to a specialist ME/CFS service where she accessed psychology, occupational therapy, and group interventions. In her sessions with the clinical psychologist, she explored ways of managing difficult thoughts related to loss. Her narrative reflected the effort involved in participating in sessions while experiencing considerable cognitive fatigue, including difficulties retaining information and engaging with written materials. She also described struggling with some therapeutic terminology used in sessions.

Fiona (60s)

Fiona had experienced Long Covid following reinfection with Covid-19 and described both practical and emotional impacts of prolonged illness. She accessed NHS-supported programmes including the Hope Programme for Long Covid and counselling support. Practical adaptations (e.g., pacing, physical modifications) intersected with emotional themes of anger and sadness after feeling dismissed in previous healthcare interactions, particularly with her General Practitioner (GP). Her account foregrounded the importance of being understood by someone with lived experience and the relational validation this provided. She reflected that NHS services was part of a combination of support drawn upon.

Gillian (50s)

Gillian had engaged with multiple NHS mental health services, including CBT, group

interventions, Interpersonal Psychotherapy (IPT), and later psychological support for long-term health conditions. Following the onset of Long Covid, she experienced profound mood changes, including frequent crying. Across services, she reflected on differences in approaches and how well they fit her needs. Group interventions felt content-heavy and poorly adapted to cognitive fatigue, whereas one-to-one sessions provided space to process grief. Her narrative centred on issues of fit, the cognitive burden of engaging with support, and the tension between psychological framing and the realities of living with Long Covid.

Hillary (50s)

Hillary self-referred to Improving Access to Psychological Therapies (IAPT) counselling after experiencing a prolonged wait for support. With a professional background in mental health services herself, she sought non-directive space rather than structured techniques. She described feeling heard and validated through reflective listening, which supported insight and emotional processing. Her account highlighted therapeutic alliance, containment, and the value of protected space to articulate the broader life impact of Long Covid.

Issy (40s)

Issy was a healthcare professional who accessed health psychology through an NHS service after a prolonged period of crisis-level distress. A previously committed runner, she described intense psychological deterioration following loss of physical functioning. Early sessions focused on normalising the physiological–psychological interaction of symptoms, particularly shortness of breath and fight-or-flight responses, which helped her begin to make sense of these experiences. Her narrative emphasised normalisation, identity disruption, and gradual understanding of mind–body interactions.

Data Collection

Data were collected between July 2024 and February 2025 using semi-structured interviews. Interviews took place online via Microsoft Teams, or by telephone where preferred, to maximise accessibility. All interviews were conducted by the lead author (AC), with each participant completing the interview in a single session. Interviews followed a topic guide with open-ended questions and prompts (Appendix 12), allowing flexibility to follow areas

raised by participants, as per guidance by Smith et al. (2022). Questions were open-ended in nature to allow for rich data to be gathered. Interviews lasted an average of 55 minutes, ranging from 43 minutes to 1 hour 14 minutes.

A secure digital audio-recorder was used to record the interviews to allow for transcription and analysis. Where available, Microsoft Teams' auto-transcription function was used to generate an initial transcript. To protect confidentiality, the auto-generated transcript was anonymised immediately following the interview, with identifying information removed and replaced with bracketed descriptors (e.g., [name], [service], [location]) before being saved. The original identifiable Microsoft Teams auto-transcription output was deleted immediately thereafter. The anonymised transcript was then checked line-by-line against the audio-recording to ensure accuracy. In other cases, transcripts were produced manually from the audio recordings and anonymised in the same way. All transcripts (auto-generated and manually produced) were reviewed against the audio recording and corrected as required prior to analysis. Member checking (i.e., sharing transcripts or interpretations to participants for comment) was not undertaken. Instead, rigour was supported through reflexive notetaking and discussion of interpretations with supervisors.

Following each interview, participants were provided with a short verbal debrief, which included a summary of the study aims and space to ask questions. Participants were also provided with a written post-interview debrief sheet, which included study information and signposting to relevant support resources (see Appendix 14). This was intended to ensure participants felt supported after sharing potentially sensitive experiences.

Reflective notes were written immediately following each interview to capture initial impressions, thoughts about participants' accounts, and the meaning they attributed to their experiences.

Ethics

Ethical approval was obtained from the School of Health in Social Sciences, University of Edinburgh (CAHSS240102; see Appendix 13a for Sponsorship confirmation, 13b for the full ethics application, and 13c for the ethics confirmation email). All participants provided

informed consent prior to participation. Consent included agreement to audio-recording and optional agreement to the use of Microsoft Teams' auto-transcription function (where applicable) for transcription purposes. The researcher accessed training in Good Clinical Practice (GCP). Confidentiality and secure data handling were maintained throughout the study. Procedures were adapted to support accessibility, for example allowing participants to provide follow-up reflections after their interview if needed, in recognition of the cognitive difficulties often associated with Long Covid.

The post-interview debrief sheet included study information and signposting to relevant support services as an additional safeguard.

Data Analysis

Analysis followed the steps outlined by Smith and colleagues (Smith et al., 2022; Smith & Nizza, 2022). Each transcript was read and re-read alongside the audio recording to ensure immersion in the data. Initial noting included descriptive, linguistic, and conceptual comments, from which experiential statements were then developed. According to Smith and Nizza (2022), experiential statements should highlight both the psychological processes at play and the contextual or content-based features invoked by participants' responses. The experiential statements were clustered into meaningful groups, before being elaborated into Personal Experiential Themes (PETs) for each case. Once each participant's transcript had been analysed in this way, cross-case analysis then identified patterns of convergence and divergence across PETs, which were clustered into Group Experiential Themes (GETs) to represent shared meanings across the dataset. This analytical process remained iterative in nature rather than strictly linear, involving repeated movement back and forth between the transcripts, experiential statements, and themes (PETs and GETs), consistent with IPA's hermeneutic circle.

To enhance transparency of the analytic process, an example transcript with the initial steps of this process is presented in Appendix 15. This demonstrates the analytic process, from exploratory noting (descriptive, linguistic, and conceptual comments) to experiential statements. The progression from experiential statements to the development of PETs for the same participant is provided in Appendix 16.

Rigour and Reflexivity

In IPA, the researcher is considered an integral part of the analysis, becoming part of the research process. As noted by Sydor (2019), in order to ensure that analysis is rooted in the data, the researcher must be reflexive by being aware of their own preconceptions and the influence on the process of analysis. To enhance rigour, several strategies were adopted. Reflexive notes were kept throughout data collection and analysis to document the researcher's assumptions and evolving interpretations. Discussion of developing interpretations took place with supervisors (CB and ER), which helped to check interpretations, enhance reflexivity, and ensure transparency in the analytic process.

The researcher was aware that Long Covid and post-viral fatigue syndromes more generally are subject to ongoing debate, both in terms of their aetiology and the extent to which symptoms are understood through different lenses (e.g., biologically, psychologically). The potential stigma attached to patients' experiences formed part of the interpretative context in which the analysis was conducted. It was recognised that participants' accounts may have been shaped by experiences of validation or invalidation within healthcare settings and wider society. Discussions with supervisors helped to ensure that interpretations remained grounded in the participants' meaning-making while acknowledging this broader context.

Power dynamics were also considered in relation to the researcher's role as a trainee clinical psychologist. It was recognised that participants may have perceived the researcher as bringing professional biases or assumptions into the interviews. Reflexive awareness was maintained throughout to acknowledge this potential imbalance. From the outset, participants were reminded that the interviews were intended to hear about their own experiences, and the researcher sought to foster a comfortable and open environment in which participants felt able to share their perspectives freely.

Finally, given the context of the study, the researcher remained aware that cognitive difficulties, such as memory lapses and brain fog, may have shaped how participants articulated their experiences. Allowing participants the opportunity to provide additional reflections after the interview was one way of mitigating this. During analysis, attention was

paid not only to what was said in the moment, but also to hesitations, gaps, and the ways participants sometimes struggled to recall or find words, recognising these as meaningful aspects of the lived experience of Long Covid rather than simply limitations in data quality.

Results

The analysis generated four GETs capturing participants' lived experience of receiving one-to-one psychology or other mental health support in the context of Long Covid. Table 1 presents each of the GETs alongside its associated sub-themes and highlights the transcripts in which the themes were present. Themes are presented in a sequence that reflects the analytic flow of participants' journeys: beginning with *The Weight of Waiting*, followed by experiences of *Being Believed and Validated* and *Therapeutic Fit,* and concluding with accounts of *Grief, Adjustment and Acceptance*. Sub-themes are illustrated with participant quotes (with pseudonyms used to protect anonymity) to highlight both convergence and divergence across participants' experiences.

Regarding terminology, participants received one-to-one sessions with a range of professionals, including clinical psychologists (one of whom was a trainee), counsellors, a mental health nurse, a health psychologist, and a CBT therapist. When reporting their accounts, terms such as 'therapist' are used interchangeably with specific professional roles.

Table 1

Group Experiential Themes (GETs) and Sub-themes Across Participant Interviews

	Andrew	Catriona	Dee	Emily	Fiona	Gillian	Hillary	Issy
The Weight of Waiting								
Waiting with urgency and distress	✓		✓			✓	✓	✓
Navigating the system		✓	✓	✓		✓		✓
Being Believed and Validated								
Being believed vs. being dismissed	✓	✓		✓	✓	✓	✓	✓
Different routes to recognition	✓	✓			✓	✓		✓
Therapeutic Fit								
Connection			✓			✓	✓	✓
Safety	✓	✓	✓		✓	✓	✓	
Collaboration	✓	✓	✓			✓		✓
Grief, Adjustment and Acceptance								
Grieving the past self: experience of loss	✓		✓	✓	✓	✓	✓	✓
Toward adjustment and acceptance	✓			✓	✓	✓	✓	✓

1 The Weight of Waiting

The theme of *The Weight of Waiting* was evident across seven transcripts and captured participants' early experiences of accessing one-to-one mental health support. While referral was often described as relatively straightforward, the transition from referral to first session was less predictable.

1.1 Waiting with Urgency and Distress

For several participants, waiting coincided with periods of acute distress linked to Long Covid symptoms and was often characterised by urgency – a sense of needing support now – combined with limited clarity about when, or whether, support would arrive.

Dee recalled the intensity of this period in stark terms:

> "I wasn't going out, I wasn't working … I was desperate and I was waiting for that call back from the service. Literally waiting by the phone." (Dee, lines 87-91)

What had initially felt reassuring for her – a sense of being "in the system" – quickly shifted when she was informed of a wait of 14 to 16 weeks for NHS Talking Therapies:

> "I'm not sure if devastated is too strong a word, but I was so disappointed, because I was so desperate at that time. And I remember, just thinking "I just can't, I need this now, I can't wait." (Dee, lines 59-62)

She reflected that this realisation was not only disappointing and distressing, but also felt unhelpful, as it delayed her in seeking alternative support sooner.

Issy similarly described waiting during a period of mounting crisis, recalling being in a "really bad state in that waiting period", including experiencing suicidal thoughts while also feeling uncertain about whether she would meet service criteria for the health psychology service.

For others, waiting was experienced as a frustrating period but was understood through their own processes of meaning-making. Andrew, for instance, articulated experiencing frustration during his wait for counselling, yet tempered this by positioning his needs in relation to the needs of others who were also waiting:

> "Em, there was nothin' I could really do about it. It was a bit frustrating because I knew I had to see somebody … But as I say I mean I wasnae gonna go bangin' on the door demandin' I get seen because there's other people … could do wae help an' that." (Andrew, lines 830-843)

These accounts indicated that waiting was often experienced as emotionally demanding and, at times, destabilising, shaping how support was eventually received.

1.2 Navigating the System

For several participants, waiting was compounded by the need to navigate service pathways that felt unclear, inconsistent or effortful to move through. Accessing support was therefore not only a matter of waiting but also of continued effort, as participants attempted to make sense of and navigate services while also managing the ongoing symptoms of Long Covid.

Dee described that she had to "take matters into [her] own hands", drawing upon financial support from family to bridge the waiting period. For her, the prolonged wait led her to seek alternative provision outside the NHS with a private clinical psychologist. She recognised that this option had only been possible because such support was available to her.

Others experienced the system itself as difficult to make sense of. Emily described waiting for the Long Covid service to be established and initially "pinning all [her] hopes on it" as a source of support. However, following an initial assessment, she was unexpectedly discharged despite being told that she would be referred onward:

> "… it was just going through like a questionnaire … they said that I'd be referred to a psychologist… and then the next thing I heard … was the discharge letter. And when I phoned them … they said they'd get back to me and then they never got back to me, and then I didn't have the energy to chase them so I gave up (laughs). So that was a bit pointless." (Emily, lines 8-18)

Her words convey how service processes could feel futile, with the decision of whether to chase support becoming another demand on her already limited energy.

In a similar vein, Gillian described the effort of working within a structured "hierarchy of therapies". While she had initially hoped to access support tailored to living with a physical health condition, she understood access as contingent on progressing through CBT before being considered for further intervention. This meant that she experienced extended gaps without support, punctuated by return visits to her GP to demonstrate continued need:

> "It was explained to me that there was like this kind of hierarchy… you start with the CBT and then if that doesn't work then you can get … I think I had to wait 5 or 6 months and go back to the GP and say … these are still my symptoms, this is how it's making me feel ... So, so there was a gap where I had to not have anything, unless I was like, in crisis or something." (Gillian, lines 139-146)

While she eventually accessed support that felt helpful, she reflected upon the energy cost of this process:

> "It was … pretty tiring and probably … I don't want to use as strong a word as damaging, but there's another word that isn't quite as strong." (Gillian, lines 657-659)

Her account illustrates how navigating this structured pathway required continued effort which took its toll as she worked through the system to reach the support she had initially hoped to access.

For a small number of participants, navigation was further shaped by Long Covid services that were still being established. During this period, accessing support also depended upon determining which services existed and how they could be accessed. This often unfolded through repeated visits to their GP, as participants sought to identify available pathways.

Catriona reflected on a period in which routes into support were unclear, noting that neither she nor her GP had been aware of the Long Covid service for several months and that she had little information about what the service involved prior to referral. In hindsight, she reflected that earlier input "might have made dealing with fatigue easier". Similarly,

Emily described repeated GP visits while waiting on Long Covid services to be set up, recalling being told that there was little that could be done until it opened:

> "… every time I went to the doctors, they were like, 'Don't know what to do, um, just waiting for the Long Covid service to be set up." (Emily, lines 29-31)

Across these accounts, the effort of navigating an evolving system added another layer to the experience of waiting, but involved sustained effort and decision-making.

2 Being Believed and Validated

The theme of *Being Believed and Validated* was evident across seven participant accounts and was central to what made one-to-one mental health support particularly impactful. Participants often mentioned one therapist in particular who made them feel understood and validated, both in relation to Long Covid as an illness and its emotional challenges. This recognition was experienced as profoundly different from many wider encounters. In this context, being believed in therapy was not taken for granted but described as deeply meaningful, offering both relief and a renewed sense of legitimacy.

2.1 Being Believed vs. Being Dismissed

The significance of being believed was sharpened when set against prior experiences of dismissal or minimisation. Several participants described Long Covid as an "invisible illness", with few biomarkers or visible signs, leaving them feeling unseen, minimised or doubted in their interactions with others. Andrew captured the frustration of appearing outwardly "normal" while internally suffering debilitating symptoms:

> "Em it's like, people see it, because you've not got like em a pink horn sticking out your head tae be different from the crowd. They're like, 'Oh look at you, there's nothin' wrong wi' you'. And I'm like, 'If only if youse knew eh'." (Andrew, lines 409-412)

His words convey the exhaustion of carrying an invisible condition without external markers. The aside, "If only youse knew", reflects his strong desire to be recognised. Others similarly described how the invisibility of Long Covid allowed assumptions of wellness to persist.

Hillary reflected on how therapy enabled her to articulate the dissonance between her outward functioning and internal struggle:

> "But it always allowed space to come back to really what, how Long Covid was affecting me and my life. And really getting, a lot of empathy, for that. Because … it's an invisible illness … you're still out there functioning to a certain level, people forget you're unwell. So … they assume you're okay now, so you're just getting on with life, but you're not, and you're stuck in this and don't feel like you can get out of it. And, yeah, I was able to kind of share all that and feel really heard and understood and get, get the empathy for that about how hard that is." (Hillary, lines 169-180)

This sense of being overlooked was often compounded by "normal" test results and invalidating encounters with healthcare professionals and wider society. Fiona reflected on the paradox of being "lucky" not to have been hospitalised, yet feeling dismissed as a result:

> "… I was lucky, I wasn't hospitalised. But on the other hand, it kind of meant that I and many, many other people felt totally dismissed. And in actual fact, I think, I feel a little bit like that in the general world now still." (Fiona, lines 88-91)

Her words highlight the double-edged nature of being fortunate in one respect, yet more easily minimised in another. Encounters in which she felt her illness was questioned or framed as psychological by her GP left a lasting imprint of sadness and anger. In this light, the empathy she later encountered in therapy gained particular significance.

Similarly, Catriona valued speaking to professionals who acknowledged Long Covid, particularly after advice experienced as dismissive elsewhere:

> "… it's been really welcome to speak to people that do acknowledge that it exists … I've had so many people just say, "Oh, just get a better night's sleep and you'll be fine". So to be speaking to people that actually understand it … the main thing is having somebody that actually gets what I'm talking about." (Catriona, lines 16-43)

For her, validation extended beyond being believed; it included sensing that her struggles were met with visible efforts from the clinical psychologist and the wider Long Covid service team to support her, even amid the emerging nature of Long Covid knowledge:

> "… trying to specialise in helping us and who were hopefully going to be like up-to-date with any sort of ideas that had come out for managing it." (Catriona, lines 248-250)

Taken together, these accounts highlight how validation in mental health support acted as an antidote to invisibility, dismissal, and minimisation often encountered elsewhere. Recognition within sessions was not experienced as incidental but as foundational to the impact of therapy itself, offering a rare and meaningful sense of being "seen". However, not all participants experienced their condition as fully recognised and validated within sessions.

For Dee, the difficulty was that CBT felt script-like and emotionally superficial, while Long Covid itself seemed peripheral within the work. Even when the therapist showed interest in Long Covid, she felt her lived reality was not meaningfully integrated into the sessions:

> "It's just the experience I had, the therapist didn't know what Long Covid was, he didn't – he, he, you know he was interested, don't get me wrong – but it was like, I felt like (sigh), it wasn't really part of the session, if you know what I mean; part of the therapy." (Dee, lines 331-334)

In Dee's account, the absence of meaningful recognition within sessions limited the extent to which therapy felt relevant to her experience of Long Covid.

2.2 Different Routes to Recognition

Participants described different ways in which therapists conveyed recognition and validation. Validation was not experienced as one-dimensional but layered, with each route offering a sense of being seen. These routes included professional knowledge, shared experience, normalising explanations, and practical adaptations within sessions.

For some participants, recognition initially involved acknowledging the limits of professional understanding. Andrew reflected that professionals could only "understand tae an extent" his experience of Long Covid, recognising that full understanding was constrained without lived experience, such as that shared within his peer support group. However, this did not diminish the value placed on the mental health support. He described clinicians as being "on a different level", with their training offering another important form of understanding:

> "They've obviously had their trainin', an', they'll know signs ..." (Andrew, lines 744-745)

Similarly, Catriona acknowledged that it was "difficult for people that don't have it to understand it", yet valued the willingness of her clinical psychologist and the wider Long Covid service team to listen and support her in navigating parts of the health service:

> "The main thing is that … it's somebody that understands what Long Covid can be … and is kind of like willing to like listen, and also to try and … sort out things with other people within the health service that I need …." (Catriona, lines 34-40)

In both accounts, recognising the limits of professional understanding was not expressed as criticism. Rather, appreciation centred on clinicians who made the efforts to "try to get it" and apply their specialist knowledge in supportive ways.

For one participant, shared lived experience carried particular significance. Fiona described the significance of being supported by a therapist who also had Long Covid:

> "… she understood the situation of somebody who'd had it herself…and that really helped." (Fiona, lines 78-107)

Here, understanding was grounded in shared experience, offering reassurance that her struggles were not only acknowledged but genuinely understood.

Recognition was also conveyed through how participants' difficulties were conceptualised and responded to in practice. For some, this involved the normalisation of symptoms. Issy

described arriving to sessions with a health psychologist confused and self-critical, unable to reconcile her suffering with a life that appeared outwardly "perfect". What proved most helpful was the psychologist's explanation of how symptoms such as shortness of breath could trigger a physiological fight-or-flight response:

> "She was the first person that said to me, you know, actually what you're going through is a normal physiological response … she sort of normalised it for me." (Issy, lines 127-146)

This normalisation reduced her self-blame and helped her to make sense of the links between her physiological and psychological experiences.

Similarly, for others, recognition was conveyed through a holistic understanding of illness as both physical and psychological. In contrast with earlier encounters in which she experienced her difficulties as being interpreted as depression rather than a response to the losses associated with Long Covid, Gillian valued working with a trainee clinical psychologist who did not reduce her struggles to "depression", but instead understood them as illness and grief bound together:

> "There was none of this 'I believe you're depressed' and [treating that] as distinct from Long Covid … It was like she completely understood I'm physically ill, I've got limitations. My life is changed and, there's a lot of grief with that." (Gillian, lines 279-311)

This framing was reinforced through the trainee clinical psychologist's willingness to make adaptations within sessions that recognised these physical realities. Gillian described the relief of having her clinician adjust expectations to her fluctuating energy and cognitive limits. These adjustments extended beyond session content to the physical environment and pacing of therapy:

> "She brought a chair for me to put my legs on … was careful with 'Did I need the lights off?' '… the air con on?' '… the blinds closed?' … she would make sure I had water and tissues — all of that was catered for me, which was part of making me, helping me feel cared for." (Gillian, lines 346-351)

Practical breaks during sessions were also built in, reinforcing this sense of recognition.

Taken together, these accounts illustrate how recognition was communicated through multiple layers: partial but still valued understanding; physiological explanations that normalised distress; adaptations that respected physical limits within sessions; and, in one case, the deeper resonance of shared lived experience.

3 Therapeutic Fit

The theme of *Therapeutic Fit* was evident across seven participant accounts. Participants described mental health support as most helpful when there was a sense of connection, safety, collaboration, and responsiveness. Where these elements were absent, sessions could feel misaligned, rigid, or emotionally flat.

3.1 Connection

Participants often described a genuine sense of felt connection with a therapist. This was often conveyed through warmth, empathy, and a sense of being emotionally held.

For Dee, this sense of connection was instant in her sessions with her clinical psychologist:

> "And I think I just felt instantly listened to and heard and seen and held…I just instantly felt like she was holding that space for me – um, I felt genuinely cared for – and that she was, you know, there for me … I genuinely felt that she had huge empathy and that is what I needed at that time." (Dee, lines 224-236)

The phrase "holding space" conveys a sense of emotional containment. Dee also described this connection as extending beyond the session, helping her to regulate her nervous system. Knowing that she would be seen the following week helped her manage difficult experiences, such as the "waves of adrenaline" she experienced at night. She described "hanging on" to speak to the clinical psychologist about these experiences, suggesting an ongoing relational support between sessions.

Hillary described a similar immediacy:

> "But luckily, I got someone that I gelled with quite quickly. And, yeah, I felt that it was, right from the start. I felt quite, um, heard." (Hillary, lines 119-121)

The phrase "gelled with" captures a fit that suggests a level of ease in their relationship.

Others described connection as sustained over time, through a steady presence that offered them continuity and support. Catriona's account conveyed the value of having someone alongside her, "checking in". Across accounts, this relational presence appeared to reduce isolation and enabled participants to feel accompanied in navigating illness.

However, this sense of connection was not always experienced within one-to-one support encounters. Where connection was absent or superficial, sessions were described as lacking warmth and depth. Dee characterised her work with one CBT therapist, following earlier support with a clinical psychologist, as "superficial", "cold", and "mechanical", explaining that although there was a "superficial connection", she did not feel able to fully express herself. Similarly, while Gillian later described a strong sense of connection with the trainee clinical psychologist, earlier therapeutic relationships were experienced as less connected.

In these instances, where connection felt absent, sessions appeared to lack the relational warmth and depth that facilitated engagement with the therapeutic work.

3.2 Safety

Participants valued therapeutic spaces in which difficult emotions linked to grief, anger, and vulnerability could be expressed without fear of judgement. Across accounts, safety was associated with a non-judgemental stance from therapists and the freedom to speak openly.

For Andrew, non-judgement was central to this sense of psychological safety, reflected in his comment, "They're no here tae judge me." This created a safe space in which he could release emotions he had not fully recognised in himself:

> "As I say when I first started goin', just had a wee cry tae ma'self sometimes… it was gettin' it out of the system … Just sittin' there talkin's absolutely amazin' … I'd never realised how bad I was actually feelin'." (Andrew, lines 863-865)

Similarly, Fiona described therapy as providing a “safe outlet for anger”, particularly following earlier experiences in primary care in which she felt her illness had been questioned or dismissed. Hillary valued being able to speak in a contained space without worrying about burdening loved ones:

> “…without me having to worry that I'm burdening them, upsetting them … if you share with a friend or family member, you're always concerned that they're going to be worrying about you.” (Hillary, lines 129-132)

For Catriona, safety was conveyed through the non-judgemental stance of her clinical psychologist, which enabled her to voice her “list of things wrong” without being perceived as “crazy”.

Across these accounts, psychological safety appeared to facilitate emotional expression and meaning-making.

However, this sense of psychological safety appeared to falter when participants felt their experiences were steered toward particular interpretations that did not fully reflect their own understanding. Gillian described feeling pressured to “admit” that she was experiencing depression in an earlier encounter with an earlier therapist, reflecting:

> “It feels like you’re wanting, this is what you keep pressing me for … you’re saying that I’m depressed and you’re wanting me to admit it.” (Gillian, lines 167-170)

In this instance, she conveyed a sense that her wider experience of grief and the impact of physical illness on her life were not fully addressed.

Dee also described an exposure exercise used in CBT sessions focused on “hypothetical worry” about relapse in her Long Covid symptoms. For Dee, relapse was not hypothetical but grounded in lived experience. She reflected that the exercise was not adapted to her experience and described this piece of work as distressing. In these instances, the work was experienced as less safe and responsive to their lived realities.

3.3 Collaboration

Participants' accounts illustrated that collaboration with the therapist was another marker of therapeutic fit. Sessions were experienced as most helpful when they felt like a shared process, shaped by participants' priorities and were responsive to fluctuating needs.

Across several accounts, there was an appreciation for therapists who did not bring a fixed agenda, but instead responded in the moment with reflections, questions or practical ideas that emerged organically from dialogue. This created a sense of a co-created process rather than a fixed intervention.

For Catriona and Issy in particular, collaboration was conveyed through language of joint problem-solving. Catriona often spoke in terms of "we" when describing her work with the clinical psychologist:

> "I think having somebody that you can, like, sort of say, 'Right, OK, I'm struggling with this aspect, what can we do to try and work on that?" (Catriona, lines 427-428)

She described logging daily activity and fatigue patterns, asking, "Can we do things in a different order?". The repeated use of "we" suggested strategies were co-developed and reviewed together. Similarly, Issy emphasised that her health psychologist did not simply provide suggestions but helped identify what might be most useful alongside her:

> "She was really supporting me to find things that would work in my individual circumstances. And, it was a very ... we were working together on it. I didn't feel like … she was suggesting things and I'd go off and do them. It was more, you know, me coming up with ideas and then exploring together how that could support my mental and (emphasised) physical health; Because it was so joined up, and it still is." (Issy, lines 191-198)

In this sense, collaboration extended beyond emotional support to include practical strategies that acknowledged both psychological and physical dimensions of Long Covid.

Others highlighted valuing flexibility and pacing in the format of sessions. Andrew described experiencing a balance between being given space and direction within sessions:

> "No, she never pushes you. At times a' just sit there an' "Na, na, nah", just talk away. And other times she'll hit me with questions, and stuff like that … So, really good." (Andrew, lines 876-879)

This flexibility extended to practical adjustments, such as changing to telephone appointments or re-arranging sessions to accommodate fatigue, further reinforcing this sense of flexibility and helping him to avoid feeling that he was "letting down" the counsellor.

Gillian similarly valued sessions that were open-ended yet gently guided, likening the trainee clinical psychologist's responsiveness to having a "key" that could "open something":

> "I was very grateful for how open-ended the sessions were…she might say something quite small and then I might cry (laughs), then I might then talk a bit more and she might give a prompt or give a little bit of kind of theory, and that might open something else up; … sometimes they were a bit more structured ... but she would say things – it was like, it was like she had a key – she would maybe just say a sentence and that would be it – and really open something." (Gillian, lines 312-325)

The metaphor of a "key" suggests moments of unlocking reflection or meaning-making.

In contrast, where sessions felt driven by adherence to technique rather than shared formulation, the work felt less collaborative. Dee described CBT sessions as "script-like" and almost too structured, explaining that there was not a lot of room to move beyond the model. She described the reality of her Long Covid feeling flattened to a series of techniques, with limited space for emotional depth.

Similarly, Gillian recalled feeling steered towards accepting particular interpretations with her IPT therapist, leaving her feeling like there was little room for the experiences she

wished to focus on in sessions. In these instances, participants described a direction and focus that could feel imposed rather than co-created.

These accounts suggest that collaboration depended upon responsiveness to the emotional and practical realities of living with Long Covid. Where such responsiveness was present, sessions felt aligned; where it was limited, this appeared to impact upon engagement and felt less useful.

4 Grief, Adjustment and Acceptance

The theme of *Grief, Adjustment and Acceptance* was evident across seven transcripts and captured participants' reflections on the profound personal changes brought about by living with Long Covid. Participants described experiences of loss that disrupted their sense of identity, roles, routines, and valued activities.

4.1 Grieving the Past: Experience of Loss

For many participants, loss was experienced as a longing for aspects of their life that had previously shaped their identity and daily routines. These were often ordinary activities that had carried meaning to them prior to life with Long Covid. Andrew's narrative often returned to the loss of simple, everyday pleasures:

> "… like my motorbike, I love my motorbike, just jumping on it and going away … I used to grow my own vegetables … but not anymore … It just really turns your life upside down, it really does ... it's like you're grieving for my past life to come back..." (Andrew, lines 45-51)

For Andrew, these activities represented autonomy and enjoyment. His use of the language "grieving" suggests the loss of a former way of being rather than simply reduced activity. He later reflected that "it's just the silly things that really really get tae yeah," highlighting how the loss of ordinary aspects of everyday life carried particular emotional weight.

A similar sense of change was evident in Emily's account. She spoke of previously having engaged in "fun and exciting things", including adventurous pursuits and qualifications:

> "… things that I used to, you know, do, that I no longer do." (Emily, lines 487-488).

Her emphasis on what she "used" to do positions her life as divided into a before and after, foregrounding the gap between her former and current capacity.

Others described the disruption to work, volunteering, and family roles as equally painful. For Gillian, the loss was framed explicitly as "grief", while for Issy the removal of running represented the loss of a key way of managing her mental health.

For Fiona, loss extended into her self-perceptions of productivity and identity within her relationship. She described seeing herself as "someone who…isn't productive, so what's my value?" and reflected that her husband was "sort of becoming my carer", leaving her feeling guilty and that she had "lost a lot of the person [she] was".

4.2 Toward Adjustment and Acceptance

Most participants described movements towards adjusting to, and in some cases accepting, life with Long Covid. These shifts were sometimes fluctuating rather than linear and were reflected upon in the context of engaging in psychological support.

For some participants, the idea of acceptance initially felt incompatible with their lived reality of Long Covid. In an early session, Gillian's trainee clinical psychologist introduced the Acceptance and Commitment Therapy (ACT) "finger trap" metaphor, inviting her to contemplate the idea of acceptance. Her immediate response was to resist:

> "I can't accept this, I can't be ill, I can't accept the change it's brought, I can't accept the loss, I can't accept the pain …" (Gillian, lines 380-382)

The repetition of "I can't" in her account conveys how distant acceptance felt within her lived reality. Following the session, she reflected on this through the lens of her faith:

> "I can easily surrender my whole life and my whole self to God … so I'd said that in the moment and then afterwards as I left, I thought, 'Oh, that's funny, I can't accept

> like humanly but I can in prayer with God say, "I'm, I surrender to you" … And then I just could … I could accept it. And that was very important – that has been probably the most important thing …" (Gillian, lines 383-392)

Framing acceptance as surrender allowed her to draw on an existing spiritual practice, making the concept personally meaningful. She later described Long Covid illness as feeling more "real" and "solid", explaining that the "double thinking" of questioning her symptoms subsided once acceptance "kicked in", providing a sense of legitimacy to her experience of illness. As such, acceptance was experienced as a release from her internal struggle.

A similar challenge was evident in Issy's account. She described being unable to accept the loss of running, which had been a central part of her wellbeing prior to Long Covid. With support, she began to learn to sustain her wellbeing in alternative ways:

> "At the start … I definitely wasn't accepting my situation at all … I couldn't accept that I needed to rest … So then to have [running] taken away, I just couldn't accept that I wasn't going to get back to [it] … So … we did a lot of work around acceptance and how I need to find other things … that can support me to manage my mental health. And I think, accepting Long Covid and where I was in that moment was … I'm much better at understanding that this is just where I am now … So, although I can't go out and run, I can walk 3 miles … that for me now I can accept. You know, that, that feels like a positive." (Issy, lines 209-227)

She later described learning to see fluctuations as part of the condition – "like mountain ranges…you have to go up and down" – with her health psychologist helping her to notice these patterns in herself. Acceptance here was more about recalibration.

For others, adjustment came more gradually. In Andrew's account, adopting his counsellor's language of "grieving for [his] past life", he began to recalibrate his expectations:

> "If I don't do it, I don't do it; it doesnae bother me …" (Andrew, lines 52-59).

This marked a shift from a previous boom-and-bust cycle. Yet his narrative continued to oscillate between tentative adjustment and a sense of resignation and longing for his past life.

Emily, who spoke of previously living an active and adventurous life, similarly described therapy as lightening the emotional weight of what she could no longer do. Previously preoccupied with thoughts such as "I can't do anything now", she described a shift toward a more present-focused stance through the support of her psychologist:

> "… I can't do it at the moment but I will be able to in the future. But … I'm not just waiting for that, I'm, you know, making the most of like finding things I enjoy doing now. Um, focusing on those rather than focusing on things that I can't do." (Emily, lines 590-594)

This reframing was also reinforced by her partner, who encouraged her to view life as unfolding in "chapters", supporting a shared re-authoring of her identity.

For Fiona, adjustment centred on a re-evaluation of productivity as a marker of worth. With support, she began to consider that "being" might be enough rather than "doing", reflecting a reorientation away from productivity as a marker of value.

Across accounts, adjustment took different forms, often involving a gradual process of recalibrating expectations, identities, and ways of living with Long Covid.

Discussion

This study explored how individuals with Long Covid experienced one-to-one psychological or other mental health support within NHS services. By drawing upon the methodological principles of IPA, four GETs were identified in the data*: The Weight of Waiting*, *Being Believed and Validated*, *Therapeutic Fit*, and *Grief, Adjustment and Acceptance*.

The study highlighted the significance of the waiting period between referral and access to mental health services. Participants described long and uncertain waits for their first

appointment, which were often experienced with urgency and distress. This finding resonates with broader literature linking prolonged wait periods for access to mental health services with increased anxiety, stress, and symptom exacerbation (Reichert & Jacobs, 2018; Subotic-Kerry et al., 2025), and behavioural responses such as non-attendance or seeking alternative forms of support (Swift et al., 2012; Reitzel et al., 2006; Loumidis & Shropshire, 1997). A recent IPA study exploring young adults' experiences of waiting for mental health services similarly found that delays could intensify distress and prompt individuals to seek alternative coping strategies (Punton et al., 2022). In this sense, the present findings echo existing research in suggesting that waiting can have meaningful psychological consequences.

The present study also extends this literature by illustrating how waiting for mental health support in the context of Long Covid occurs alongside symptoms such as fatigue and cognitive impairment. Participants described expending effort to pursue referrals, clarify available services, or consider alternative routes to support at a time when their energy and cognitive capacity were limited. For some participants, the waiting period also involved attempts to make sense of evolving services and actively pursue pathways to support. This finding aligns with research exploring healthcare access for people living with Long Covid, which highlights the level of effort and perseverance often required to secure appropriate support. For instance, qualitative studies have described how individuals with Long Covid frequently needed to exercise persistence (Baz et al., 2023), self-advocacy (McNabb et al., 2023), and sustained effort to navigate emerging or fragmented care pathways (Turk et al., 2024; Kingstone et al., 2020) – efforts that are often difficult to sustain (McNabb et al., 2023; Turk et al., 2024). Together, these findings suggest that waiting for and navigating access to mental health support may require considerable personal effort at a time when individuals' physical and cognitive resources are already constrained.

Beyond access to services, another key finding concerned the significance of feeling believed and validated within therapeutic encounters. For many participants, when supportive therapeutic relationships were present, they served as a positive counterbalance to earlier encounters in which their symptoms had been doubted, minimised or reduced to psychological explanations. Similar experiences have been documented in the wider Long

Covid literature, where individuals report feeling unheard or disbelieved when attributing ongoing symptoms to Long Covid (Ireson et al., 2022). In some cases, these encounters may also involve experiences of trivialisation or blame within healthcare settings (Kennelly et al., 2023; MacPherson et al., 2022), contributing to perceptions that the illness is not recognised as legitimate (Büchner et al., 2025; Logue, 2025). Conversely, research suggests that having symptoms acknowledged and taken seriously by healthcare professionals can generate reassurance and relief (Ireson et al., 2022), with such validation identified as an important component of supportive care for people with Long Covid (Turk et al., 2024; Ladds et al., 2020; MacEwan et al., 2024).

The present study extends this literature by highlighting the layered nature of validation within mental health support. Participants' accounts illustrated multiple ways in which validation was experienced, including feeling heard and understood, having symptoms recognised and normalised, and encountering practical adaptations that acknowledged physical and cognitive limitations. Consistent with research highlighting the importance of feeling listened to and taken seriously by healthcare professionals (Ladds et al., 2020; MacEwan et al., 2024), the present findings add nuance by demonstrating how validation can be enacted through a range of therapeutic practices. Taken together, these findings suggest that validation may play a foundational role in engagement with mental health support for individuals with Long Covid, and may also be important within wider healthcare contexts, particularly where previous interactions have been experienced as dismissive.

Participants consistently emphasised relational qualities associated with therapeutic fit within psychological support, particularly connection, safety, and collaboration. These accounts align with literature on therapeutic alliance, which has long been identified as a powerful predictor of treatment outcomes across psychological therapies (Baier et al., 2020; Martin et al., 2000). Therapeutic alliance is typically conceptualised as encompassing trust, collaboration, and shared goals (Prusiński, 2022). In this sense, participants' emphasis on connection, safety, and collaborative working reflects broader evidence that the quality of the therapeutic relationship plays a key role in shaping engagement with mental health support and treatment outcomes.

At the same time, participants' accounts highlighted that relational fit was not guaranteed. Experiences of misalignment were also described, particularly where therapists appeared to prioritise diagnostic framing or apply structured interventions with limited adaptation. In these instances, sessions could feel rigid or emotionally unsafe. In line with this, some participants described sessions as lacking the depth required to explore the realities of living with Long Covid. This finding suggests that therapeutic alliance may depend not only on relational qualities such as trust and collaboration, but also on clinicians' attunement to the fluctuating physical, cognitive, and emotional challenges associated with the condition.

These findings also resonate with recent Long Covid research highlighting the importance of collaborative, person-centred relationships between healthcare professionals and patients. For example, Turk et al. (2024) highlight how trust and collaboration within healthcare encounters can support recognition of patients' experiences and enable care to be tailored to their needs. The present study extends this literature by illustrating how these relational processes unfold within one-to-one mental health support, suggesting that therapeutic fit may be particularly important for individuals navigating a condition characterised by uncertainty, fluctuating symptoms, and limited biomedical recognition.

Alongside participants' experiences of psychological support, accounts also highlighted the profound personal impact of living with Long Covid. Participants described significant experiences of loss, including loss of employment, social roles, hobbies, independence, and aspects of their pre-illness identity. These accounts are consistent with existing qualitative literature highlighting disruption to roles, relationships, and everyday life in Long Covid (Kingstone et al., 2020; Ladds et al., 2020; Taylor et al., 2021), including research reporting experiences of grief for a former identity and efforts to reconcile past and present identities following Long Covid (Kennelly et al., 2023; MacPherson et al., 2022). Adjustment to life with Long Covid was typically conveyed as gradual and fluctuating rather than linear. In some accounts, conversations and practices within therapy enabled participants to acknowledge grief for their pre-illness self while tentatively rebuilding aspects of their sense of identity. This aligns with chronic illness literature conceptualising acceptance as a dynamic and ongoing process (McCracken & Eccleston, 2003; Sharpe & Curran, 2006; Telford et al., 2006). The present study extends this literature by illustrating how

psychological support can scaffold this process of adjustment when support feels safe, validating, and responsive to the needs of individuals living with Long Covid.

Transferability

While IPA does not aim for generalisability, it offers insights that are situated and contextual. As Smith et al. (2022) explain, claims are necessarily bounded by the group studied, but they can have value beyond the immediate sample through theoretical generalisability. This means it is ultimately up to the reader—whether clinician, researcher, or someone with lived experience—to consider how the findings may resonate with, or illuminate, similar contexts based on their own professional and experiential knowledge. In this spirit, the present study does not claim universality but highlights what was meaningful for this particular group of eight participants living with Long Covid.

Tentative Clinical Implications

Although the findings are not generalisable, they suggest several considerations for clinical practice when supporting individuals living with Long Covid.

Prioritising Validation

Clinicians may benefit from adopting an explicitly validating stance that acknowledges the physiological basis of Long Covid symptoms while also recognising its psychological and social impact. NICE guidelines recommend discussing individuals' experience of symptoms and how these affect their daily life, including work, education, mobility, and independence, while responding with empathy to any associated distress (NICE et al., 2020). In practice, this may involve giving space for individuals to describe the impact of symptoms on their lives, explicitly acknowledging the legitimacy of their experiences, recognising that emotional distress can coexist with physical illness, and avoiding premature framing of symptoms with diagnostic labels (e.g., attributing distress primarily to depression without acknowledging the broader impact of Long Covid).

Such approaches align with research highlighting the importance of listening and validation in improving care for people with Long Covid (Brennan et al., 2022). Similarly, a co-design study developing a personalised support intervention for people living with Long Covid

emphasised the importance of clinicians creating psychologically safe, non-judgemental spaces in which individuals feel able to share their experiences (Jones et al., 2024). Participants in the study also highlighted that feeling heard and believed contributed to the development of trusting relationships with healthcare professionals.

Collaboration

The findings of the present study highlighted the importance of collaboration. Both NICE and NHS guidelines recommend using shared decision-making approaches when planning care, including working with individuals to identify priorities and set realistic goals (NICE et al., 2020; NICE, 2021b). These principles are also reflected in the Scottish Government's Realistic Medicine strategy, which emphasises collaborative conversations between individuals and clinicians that focus on "what matters to you" when making decisions about care (Smith, 2024). In practice, this may involve inviting individuals to discuss what matters most to them, using clear and accessible language, and collaboratively exploring strategies that feel manageable within the context of fluctuating symptoms.

Research developing personalised support interventions for people with Long Covid similarly emphasises the importance of person-centred approaches in which clinicians work alongside clients to collaboratively produce solutions and problem-solve together (Jones et al., 2024). Participants in the study highlighted the value of clinicians acknowledging uncertainty and engaging in a collaborative trial-and-error approach to identifying strategies that are feasible for the individual. This was similarly reflected in the present study.

Offering Adaptations

Services may also enhance accessibility by adapting therapeutic approaches to accommodate the cognitive and physical symptoms associated with Long Covid. NICE guidelines highlight that symptoms may be wide-ranging and fluctuate over time, and that support may therefore need to vary accordingly (NICE et al., 2020). In practice, adaptations might include offering shorter sessions, incorporating breaks during sessions, reducing cognitive or practical demands, such as written homework tasks, or providing flexible formats (e.g., telephone or video consultations).

Research with people with Long Covid similarly emphasises the importance of tailoring support to individuals' current priorities and symptom burden, rather than assuming which aspects of illness are most impactful for the individual (Jones et al., 2024).

Framing of Support

How psychological support is framed may also influence engagement. Framing psychological intervention as supportive – focusing on coping, identity changes, adjustment, and emotional responses to illness – rather than as a curative intervention may help to avoid misunderstanding regarding the role of psychological support in Long Covid. This distinction is particularly relevant given historical controversies surrounding psychological interventions in post-viral conditions such as ME/CFS (NICE, 2021).

In the context of Long Covid, rehabilitation literature highlights that recovery may be slow, unpredictable, and non-linear. As such, clinicians may need to adjust expectations of recovery and support individuals in anticipating and managing setbacks, rather than assuming steady progress towards predefined goals (DeMars et al., 2023). In practice, this may involve collaboratively identifying flexible and meaningful goals, while recognising that fluctuations in symptoms may require plans to be revisited over time. For some individuals, this may include focusing on small achievable goals or identifying activities that support moments of enjoyment or meaning within current limitations (Jones et al., 2024).

Supporting Grief and Identity Change

Participants' accounts suggest that clinicians may find it helpful to explicitly acknowledge and explore experiences of loss associated with Long Covid. This may include changes to employment, social roles, independence, and aspects of identity. Therapeutic approaches that allow space for processing grief, meaning-making, and identity change – such as compassion-focused, narrative, or acceptance-based approaches – may be helpful when delivered in a flexible and collaborative manner. Inviting discussions of these experiences may help individuals feel understood while supporting adjustment to the longer-term impact of illness.

Long Covid Knowledge

Developing clinicians' knowledge of Long Covid may also support effective care. NICE guidelines recommend adopting a holistic, person-centred approach that considers the physical, cognitive, psychological, and functional impacts of the condition (NICE et al., 2020). Clinicians are also encouraged to recognise that symptoms can be wide-ranging, fluctuate over time, and affect individuals' ability to engage in everyday activities.

National commissioning guidance similarly highlights the importance of ongoing workforce training and multi-disciplinary collaboration in the management of Long Covid (NHS England, 2023). Access to multi-disciplinary training and opportunities for knowledge sharing across services may help clinicians develop confidence in recognising and responding to the complex nature of the condition. In practice, this may include developing greater awareness of symptoms such as post-exertional malaise, cognitive impairment ("brain fog"), the episodic nature of disability associated with Long Covid, and the psychosocial impact of an illness with limited external signs. Rehabilitation literature further emphasises the importance of building knowledge of post-infectious and energy-limiting conditions to support safe and effective management of Long Covid (DeMars et al., 2023). Greater understanding of the condition may help clinicians adapt therapeutic approaches and avoid inadvertently minimising or misinterpreting individuals' experiences.

Reducing the Burden of Waiting

Finally, the findings highlight the potential psychological burden associated with waiting for support. At a service level, clear communication regarding waiting times, interim updates where feasible, and improved co-ordination between services may mitigate distress during this period. Such practices align with broader NHS commitments to patient-centred care and clear communication across services (NICE et al., 2020; NHS England, 2023).

Contributions

To the author's knowledge, this is the first qualitative study to explore the experiences of people with Long Covid, or other post-viral fatigue syndromes, in relation to engaging in one-to-one psychological or other mental health support. This study contributes to the emerging literature on Long Covid in several ways. First, it highlights the psychological burden associated with waiting for and navigating mental health services in the context of a

condition characterised by fatigue and cognitive impairment. Second, it demonstrates the central importance of validation within therapeutic encounters, particularly in counterbalancing wider experiences of dismissal or disbelief in healthcare. Third, the findings emphasise the importance of therapeutic fit, suggesting that engagement with support may depend upon relational qualities such as connection, psychological safety, and responsiveness to the lived realities of Long Covid. Finally, the study contributes to an understanding of psychological adjustment to Long Covid by illustrating how therapy can support processes of grief, identity change, and gradual adaptation to life with a long-term condition. Taken together, these insights extend existing qualitative research by highlighting how psychological support may provide a relational space for validation, meaning-making, and adjustment for individuals living with Long Covid when it aligns with their needs.

Strengths

A key strength of the current study lies in its focus on the lived experience of Long Covid. To date, little research has explored this condition qualitatively, with even fewer studies having considered how individuals with Long Covid experience one-to-one psychological or mental health support. By adopting an IPA approach, the study was able to capture idiographic, context-rich accounts of meaning-making, offering insights that may be less accessible through quantitative designs.

The involvement of Experts by Experience throughout the research design represents an additional strength. Input from people with lived experience shaped the participant information sheet, consent procedures, and interview schedule, helping to ensure, as far as possible, that materials were accessible. This approach enhanced the study's credibility and alignment with the principles of patient-centred research. Flexibility in interview delivery (telephone or online, with breaks available) further supported accessibility, making it more feasible for participants to take part despite the challenges of Long Covid.

Limitations

Limitations of this study should also be acknowledged. It is possible that the researcher's role as a trainee clinical psychologist may have shaped how participants perceived and took part in the interviews, for example by positioning the researcher as someone with

professional authority or as holding particular views about Long Covid and the role of psychological therapies. This creates a potential risk that participants might moderate their accounts. However, many participants were open and candid in sharing their perspectives, appearing to feel able to speak freely despite this dynamic.

Recruitment through Long Covid support groups, charities, and social media may have biased the sample towards individuals already engaged in advocacy or peer support networks, whose experiences might differ from those not connected to such groups. However, this approach was considered more appropriate than recruiting through NHS services, as it reduced the risk of participants being selectively identified by staff and helped to ensure that individuals felt able to speak freely about their experiences of NHS care.

In addition, the time-intensive nature of participating in the study may have disproportionately excluded individuals living with more severe forms of Long Covid or with particular symptom profiles (e.g., profound fatigue, breathlessness), which can act as barriers to participation in research interviews. Indeed, this was provided as feedback by someone living with Long Covid who saw the study advert. Future studies could consider alternative formats, such as inviting participants to provide audio-recorded or written responses, to help ensure that a wider range of perspectives is represented.

The sample was predominantly female and adults of working age. While this may limit the extent to which men's perspectives are captured, IPA does not seek representativeness but rather an in-depth, idiographic exploration of lived experience. Further studies could examine whether similar patterns are evident across different demographics, including people from ethnic minority backgrounds, who appear to be disproportionately affected by Long Covid (Mkoma et al., 2024).

Conclusion

This study provides a novel qualitative account of how people with Long Covid experienced one-to-one psychological or other mental health support within NHS services. The findings suggest that support was experienced as most helpful when it was validating, collaborative,

and responsive to the physical, cognitive, and emotional realities of living with Long Covid. In particular, feeling believed and having symptoms recognised emerged as central to participants' engagement with support, especially in the context of prior experiences of dismissal or minimisation. Psychological support also appeared to offer an important space for processing grief, changes in sense of identity, and ongoing adjustment to life with a fluctuating and unpredictable long-term condition. Although the findings are not intended to be generalisable, they highlight considerations for the delivery of patient-centred, evidence-informed psychological support for people living with Long Covid. As services continue to develop responses to Long Covid, incorporating patient perspectives may be essential in shaping services that reflect the complex realities of the condition.

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Appendices

Appendix 1 Clinical Psychology Review Author Guidelines

About the journal
Aims and scope

Clinical Psychology Review publishes substantive reviews of topics germane to **clinical psychology**. Papers cover diverse issues including: psychopathology, psychotherapy, behavior therapy, cognition and cognitive therapies, behavioral medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology.
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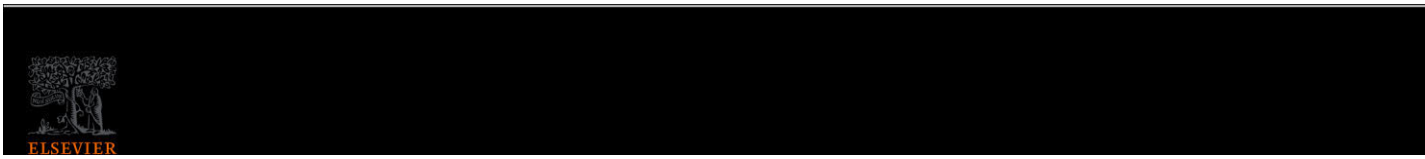

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Appendix 2 PROSPERO Protocol

The efficacy of acceptance and compassion-based interventions for post-viral fatigue (including Long Covid and Chronic Fatigue Syndrome/Myalgic Encephalomyelitis): A systematic review.

To enable PROSPERO to focus on COVID-19 submissions, this registration record has undergone basic automated checks for eligibility and is published exactly as submitted. PROSPERO has never provided peer review, and usual checking by the PROSPERO team does not endorse content. Therefore, automatically published records should be treated as any other PROSPERO registration. Further detail is provided here.

Citation

Andrea Clark, Ronan McGrath. The efficacy of acceptance and compassion-based interventions for post-viral fatigue (including Long Covid and Chronic Fatigue Syndrome/Myalgic Encephalomyelitis): A systematic review.. PROSPERO 2024 CRD42024629759 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42024629759

Review question

Is there evidence to support the use of third wave psychological therapies (i.e., therapies which take an acceptance and compassion-based approach) in the treatment of post-viral fatigue syndrome?

Searches

PsycINFO, MEDLINE, EMBASE, AMED, Scopus, Web of Science & Cochrane Library.

Types of study to be included

Inclusion: Quantiative studies. Studies can include case studies, feasibility trials (where data is presented), quasiexperimental research designs, and Randomised Controlled Trials (RCTs).

Exclusion: Qualitative research studies, protocol papers and papers describing hypothetical interventions.

Condition or domain being studied

Post-viral fatigue syndrome

Participants/population

Inclusion: Children and adults with post-viral fatigue syndrome, including those with Long Covid/Post-COVID-19 Syndrome and Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME).

Exclusion: Studies which include participants who have fatigue related to another condition (e.g., fatigue related to cancer).

Intervention(s), exposure(s)
Inclusion: Studies which investigate the effectiveness of any third-wave therapy for the above patient group. This will include: Acceptance and Commitment Therapy (ACT), Mindfulness Based Stress Reduction (MBSR), Mindfulness Based Cognitive Therapy (MBCT), mindfulness practice, Dialectical Behaviour Therapy (DBT), Compassion Focused Therapy (CFT), Metacognitive therapy, Behavioural Activation and Functional Analytic Psychotherapy.
Interventions that are primarily based on mindfulness (e.g., Mindfulness Based Stress Reduction, Mindfulness Based Cognitive Therapy) or take an acceptance and compassion-focused approach included.

Excluded: Studies including other therapeutic models (e.g., CBT) as the main intervention as opposed to a comparison group.

Studies which include a multi-disciplinary/rehabilitation approach where the third-wave psychological intervention (e.g., mindfulness, ACT, CFT) is not the major component of the intervention being evaluated.

Comparator(s)/control
Inclusion: Comparison groups, where they exist, are likely to include groups receiving CBT, waitlist control or psychological therapy/tasks. A control or comparison group is not mandatory.

Exclusion: None aware of

Context

No specific setting.

Main outcome(s)
Outcome measures that are based on mental health, physical health (e.g., fatigue measures scores) and quality of life. Measures may include those associated with the intervention, such as psychological flexibility (for ACT studies). Variability in outcomes is anticipated.

Measure of effect

This will be determined when full-text papers are reviewed.

Additional outcome(s)
Not
applicable
Measures of
effect
As above.

Data extraction (selection and coding)
Titles and/or abstracts of studies retrieved using the search strategy and those from additional sources will be screened by one reviewer (using Covidence) to identify studies

that potentially meet the inclusion criteria outlined above. The full text of these potentially eligible studies will be retrieved and independently assessed for eligibility by two review team members using the same software. Any disagreement between them over the eligibility of particular studies will be resolved through discussion with a third reviewer.

A standardised, pre-piloted form will be used to extract data from the included studies for assessment of study quality and evidence synthesis. Data to be extracted is likely to include: Study (author), post-viral fatigue condition, design, participants (included in the analysis)/controls (mean age), post-viral fatigue condition, therapeutic intervention, format of intervention (e.g., group and/or individual), outcome measures N (% finished), control, outcome measures, improvement post-intervention (mean ES), improvement compared to control (mean ES), maintained at follow-up.

Software (Covidence) will be used for data extraction by a single reviewer.

Risk of bias (quality) assessment
Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project 2007) or a similar tool which assesses quantitative studies of various types (e.g., RCTs, case-series).

Strategy for data synthesis
Meta-analysis will be completed if possible; however, it is anticipated that a narrative synthesis of the data will be completed due to the variation expected in study methods and the nature of this field of research still being in its infancy.

Analysis of subgroups or subsets
Data will be organised based upon the most salient and cohesive manner.

Analysis would compare pre- and post- outcome measure scores across the psychological intervention types (i.e., ACT, MBSR, metacognitive therapy) (if possible).

Descriptive accounts will look to compile the results by each model of third wave psychological interventions, or potentially by diagnosis (i.e., Long Covid, CFS/MS) dependent upon the emergent data.

Contact details for further information
Andrea Clark

Organisational affiliation of the review
University of Edinburgh
https://www.ed.ac.uk/

Review team members and their organisational affiliations
Miss Andrea Clark. University of Edinburgh

Mr Ronan McGrath. University of Edinburgh

Collaborators
Dr Caroline Brett. University of Edinburgh

Type and method of review
Intervention, Narrative synthesis, Systematic review

Anticipated or actual start date
26 August 2024

Anticipated completion date
01 August 2025

Funding sources/sponsors
Undertaken as part of the Doctorate in Clinical Psychology at University of Edinburgh. No funding or sponsorship for the work.

Conflicts of interest

Language
English

Country
Scotland

Stage of review
Review Ongoing

Subject index terms status
Subject indexing assigned by CRD

Subject index terms
COVID-19; Distance Counseling; Empathy; Fatigue Syndrome, Chronic; Humans; Post-Acute COVID-19 Syndrome

Date of registration in PROSPERO
30 December 2024

Date of first submission

19 December 2024

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.
The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

30 December 2024
30 December 2024

Appendix 3 Full Search Strategy for All Databases

The following terms were used to search for studies on the databases: ("Acceptance and commitment therap*" or Compassion* or Mindful* or MBSR or MBCT or "Dialectical behavio* therap*" or "metacognitive therap*" or "Psychological flexibility" or "third wave" or "third generation") AND ("post-viral fatigue" or "postviral fatigue" or "chronic fatigue" or "myalgic encephalomyelitis" or "long covid*" or "post-covid*" or "long-haul covid*" or postcovid* or "post-sequelae of COVID*" or "post-acute COVID*" or "chronic COVID*" or "long-term effect* of COVID*" or "post-acute sequelae of SARS*"). When conducting the search, no limits were applied to the date or language of publication.

Appendix 4 Adapted Quality Appraisal Tool Using EPHPP and POMRF

COMPONENT RATINGS

A) **SELECTION BIAS**

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

1. Very likely
2. Somewhat likely
3. Not likely
4. Can't tell

(Q2) What percentage of selected individuals agreed to participate?

1. 80 – 100% agreement
2. 60 – 79% agreement
3. less than 60% agreement
4. Not applicable
5. Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

1. Randomized controlled trial
2. Controlled clinical trial
3. Cohort analytic (two group pre + post)
4. Case-control
5. Cohort (one group pre + post (before and after))
6. Interrupted time series
7. Other specify _____
8. Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1. Yes
2. No
3. Can't tell

The following are examples of confounders:

1. Race
2. Sex
3. Marital status/family
4. Age
5. SES (income or class)
6. Education
7. Health status
8. Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1. 80 – 100% (most)
2. 60 – 79% (some)
3. Less than 60% (few or none)
4. Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1. Yes
2. No
3. Can't tell

(Q2) Were the study participants aware of the research question?

1. Yes
2. No
3. Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1. Yes
2. No
3. Can't tell

(Q2) Were data collection tools shown to be reliable?

1. Yes
2. No
3. Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1. Yes
2. No
3. Can't tell
4. Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1. 80 -100%
2. 60 – 79%
3. less than 60%
4. Can't tell
5. Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	**SELECTION BIAS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
B	**STUDY DESIGN**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
C	**CONFOUNDERS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
D	**BLINDING**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
E	**DATA COLLECTION METHOD**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
F	**WITHDRAWALS AND DROPOUTS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1. STRONG (no WEAK ratings)
2. MODERATE (one WEAK rating)
3. WEAK (two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

1. Oversight
2. Differences in interpretation of criteria
3. Differences in interpretation of study

Final decision of both reviewers (circle one):

1. **STRONG**
2. **MODERATE**
3. **WEAK**

Psychotherapy outcome study methodology rating form

Note: if not enough information is given regarding a specific item a rating of 0 is given.

Intervention Integrity

Manualized, replicable, specific treatment programs

0 Poor. Description of treatment procedure is unclear, and treatment is not based on a publicly available, detailed treatment manual. Patients may be receiving multiple forms of treatment at once in an uncontrolled manner.

1 Fair. Treatment is not designed for the disorder, or description of the treatment is generally clear and based on a publicly available, detailed treatment manual, but there are some ambiguities about the procedure. Patients may have received additional forms of treatment, but this is balanced between groups or otherwise controlled.

2 Good. Treatment is designed for the disorder. A detailed treatment manual is available, and/or treatment is explained in sufficient detail for replication. No ambiguities about the treatment procedure. Patients receive only the treatment in question.

Comment:

Number of therapists

0 Poor. Only one therapist, i.e. complete confounding between therapy and therapist.
1 Fair. At least two therapists, but the effect of therapist on outcome is not analyzed.
2 Good. Three, or more therapists, and the effect of therapist on outcome is analyzed.
Comment:

Therapist training/experience

0 Poor. Very limited clinical experience of the treatment and/or disorder (e.g. students).
1 Fair. Some clinical experience of the treatment and/or disorder.
2 Good. Long clinical experience of the treatment and the disorder (e.g. practicing therapists).

Comment:

Checks for treatment adherence

0 Poor. No checks were made to assure that the intervention was consistent with protocol.

1 Fair. Some checks were made (e.g. assessed a proportion of therapy tapes).
2 Good. Frequent checks were made (e.g. weekly supervision of each session using a detailed rating form).

Comment:

Checks for therapist competence

0 Poor. No checks were made to assure that the intervention was delivered competently.
1 Fair. Some checks were made (e.g. assessed a proportion of therapy tapes).
2 Good. Frequent checks were made (e.g. weekly supervision of each session using a detailed rating form).

Comment:

Equality of therapy hours (for non-WLC designs only)

0 Poor. Conditions differ markedly (⩾20% difference in therapy hours).
1 Fair. Conditions differ somewhat (10–19% difference in therapy hours).
2 Good. Conditions do not differ (<10% difference in therapy hours).

Comment:

Data analyses

Power analysis
0 Poor. No power analysis was made prior to the initiation of the study.
1 Fair. A power analysis based on an estimated effect size was used.
2 Good. A data-informed power analysis was made and the sample size was decided accordingly.

Comment:

Handling of attrition

0 Poor. Proportions of attrition are not described, or described but no dropout analysis is performed.
1 Fair. Proportions of attrition are described, and dropout analysis or intent-to-treat analysis is performed.
2 Good. No attrition, or proportions of attrition are described, dropout analysis is performed, and results are presented as intent-to-treat analysis.

Comment:

Statistical analyses and presentation of results

0 Poor. Inadequate statistical methods are used and/or data are not fully presented.
1 Fair. Adequate statistical methods are used but data are not fully presented.
2 Good. Adequate statistical methods are used and data are presented with M and SD.

Comment:

Clinical significance

0 Poor. No presentation of clinical significance was done.
1 Fair. An arbitrary criterion for clinical significance was used and the conditions were compared regarding percent clinically improved.
2 Good. Jacobson's criteria for clinical significance were used and presented for a selection (or all) of the outcome measures, and conditions were compared regarding percent clinically improved.

Comment:

Appendix 5 EPHPP Ratings by Both Reviewers

	Jonjso			Gonzalez-Moreno			Nikrah			Roche			Sollie			Stubhaugh		
Items	AC rating	RMc rating	New rating	AC rating	RMc ratin	New ratin	AC rating	RMc rating	New rating	AC rating	RMc rating	New ratin	AC rating	RMc rating	New rating	AC rating	RMc rating	New rating
1. Selection bias	2	2	2	2	2	2	2	3	3	3	3	3	3	3	3	2	3	2
2. Design	2	2	2	1	1	1	1	1	1	3	3	3	2	3	3	2	2	2
3. Confounders	3	3	3	1	1	1	3	3	3	3	3	3	3	3	3	3	3	3
4. Blinding	2	2	2	3	3	3	2	2	2	2	2	2	2	2	2	2	3	2
5. Data collection	1	1	1	1	1	1	2	1	3	1	1	1	1	1	1	1	1	1
6. Withdrawals	1	1	1	1	1	1	3	3	3	1	1	1	2	1	1	1	1	1
7. Global	2	2	2	2	2	2	3	3	3	3	3	3	3	3	3	3	3	3
Number agreed		100%			100%			71.40%			100%			85.70%			71.40%	
Number changed			0			0			1			0			1			0

Appendix 6 POMRF Ratings by Both Reviewers

	Jonso			Gonzalez-Moreno			Nikrah			Roche			Sollie			Stubhaug		
Items	AC rating	RMc ratin	New ratin	AC rating	RMc ratin	New ratin	AC rating	RMc ratin	New ratin	AC rating	RMc ratin	New ratin	AC rating	RMc ratin	New ratin	AC rating	RMc ratin	New rating
1. Manualised/replicable/specfic treatments	2	2	2	2	2	2	2	2	2	1	2	2	2	1	2	2	2	2
2. Number of therapists	1	0	1	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0
3. Therapist training/experience	2	2	2	0	0	0	0	0	0	0	0	0	2	2	2	2	0	2
4. Treatment adherence	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
5. Therapist competence	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
6. Power analysis	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
7. Handling of attrition	2	2	2	1	2	1	0	0	0	2	2	2	2	2	2	1	1	1
8. Analysis/presentation of results	2	2	2	2	2	2	2	2	2	1	0	1	2	1	2	2	2	2
9. Clinical significance	0	0	0	1	1	1	0	0	0	2	2	2	1	1	1	1	1	1
TOTAL	10	8	9	6	7	6	4	4	4	6	6	7	10	8	10	8	6	8
Number agreed		77.8%			88.9%			100.0%			77.8%			77.8%			88.9%	
Number changed			1			0			0			1			0			0

Appendix 7 Qualitative Research in Psychology Author Guidelines

Qualitative Research in Psychology author guidelines

Instructions for authors

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Contents

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This work was supported by the [Funding Agency] under Grant [number xxxx].

For multiple agency grants

This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

6. **Disclosure statement.** This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare*. Further guidance on what is a conflict of interest and how to disclose it.

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Updated 8th July 2025

Participant information sheet

Project title: The perspectives of people with Long Covid on receiving individual psychology or other mental health input for management of the condition in NHS services.

Invitation to take part in the research

- You are being invited to take part in a research study.
- It is important for you to understand why the research is being done and what it will involve.
- Please ask if there is anything that is not clear, or if you would like more information.

Who is organising the research?

- The research study is being conducted by Andrea Clark, a 3rd year student on the Doctorate of Clinical Psychology course at the University of Edinburgh.
- The research is supervised by Dr Caroline Brett (Health Psychologist) and Dr Emily Revell (Clinical Psychologist).
- It is sponsored by the University of Edinburgh.

What is the purpose of the study?

- The aim of the study is to listen to people's experiences of having input from either a psychologist or other mental health professional (such as a counsellor or mental health nurse) in NHS services in relation to having Long Covid.
- This will be useful as it might indicate how mental health professionals (and other healthcare professionals) can best support people who are living with Long Covid.

Who is being invited to take part in this research study?

We would like to hear from you if your answers are 'yes' to the following:

- You are aged 18 years or older
- You live in the U.K.
- You have experienced symptoms of Long Covid for a period of 12 weeks or longer
- You have been told you have Long Covid by a healthcare professional

Appendix 9 Recruitment Advert

Do you have Long Covid? Share Your Experience!

Hi, my name is Andrea, I am a trainee clinical psychologist. I am researching people's experiences of receiving mental health support as part of their treatment for Long Covid within NHS services.

Long Covid Research Study

Are you 18 or older and living in the U.K.? Have you experienced Long Covid symptoms for 12 weeks or more? Have you been diagnosed with Long Covid by a healthcare professional and received mental health support (for example, been seen by a psychologist, counsellor or mental health nurse) from an NHS service? Were you able to stay out of hospital while you had COVID-19?
If you answered yes to these questions, I want to hear from you!

What's Involved:

1. A brief telephone call
2. An online interview taken at your own pace over one or more sessions with plenty space for breaks

How to Participate:

Find out more and register your interest by emailing me or using the link or QR code

Email: A.I.Clark-1@sms.ed.ac.uk

Link: https://edinburgh.eu.qualtrics.com/jfe/form/SV_5gAmY5UqE1xqIDk

Lived experience of Long Covid and NHS mental health care, V6 20.11.24
Ethical approval granted by University of Edinburgh Ethics Committee

Appendix 10 Brief Online Survey (including Participant Information Sheet and Consent Form)

Brief online survey

Research study title: The perspective of people with Long Covid on receiving individual or other mental health input for management of the condition in NHS Services.

Thank you very much for your interest in this research study being carried out by Andrea Clark (student and trainee clinical psychologist at the University of Edinburgh). Information on the research study and what it involves is provided on the next page (click 'next page' below).

This online survey has three purposes:
1) You can confirm that you are eligible to take part in the research study; and
2) If you wish to, you can register your interest in taking part in it.
3) As part of the survey, you will also be asked to provide brief details about yourself (please see further information about the reason for this below). Before you provide these details, you will be asked to complete a short consent form within this survey. Please ensure that you have read the participant information sheet on the next page before completing this consent form.

People will be selected for the research study in a way that allows us to make sure that we hear from a range of people living with Long Covid in the U.K. . For instance, we would like to include people from across different age groups and locations. As such, you are asked to provide a few details about yourself within this survey to allow us to do this.

Next page >

Participant information sheet

Brief online survey

Research study title: The perspective of people with Long Covid on receiving individual or other mental health input for management of the condition in NHS Services.

Thank you very much for your interest in this research study being carried out by Andrea Clark (student and trainee clinical psychologist at the University of Edinburgh). Information on the research study and what it involves is provided on the next page (click 'next page' below).

This online survey has three purposes:

1) You can **confirm that you are eligible to take part** in the research study; and
2) If you wish to, you can **register your interest in taking part** in it.
3) As part of the survey, you will also be asked to provide **brief details about yourself** (please see further information about the reason for this below). Before you provide these details, you will be asked to complete a short consent form within this survey. Please ensure that you have read the participant information sheet on the next page before completing this consent form.

People will be selected for the research study in a way that allows us to make sure that we hear from a range of people living with Long Covid in the U.K. . For instance, we would like to include people from across different age groups and locations. As such, you are asked to provide a few details about yourself within this survey to allow us to do this.

Next page >

Participant information sheet

Project title: The perspectives of people with Long Covid on receiving individual psychology or other mental health input for management of the condition in NHS services.

Invitation to take part in the research

- You are being invited to take part in a research study.
- It is important for you to understand why the research is being done and what it will involve.
- Please ask if there is anything that is not clear, or if you would like more information.

Who is organising the research?

- The research study is being conducted by Andrea Clark, a 3rd year student on the Doctorate of Clinical Psychology course at the University of Edinburgh.
- The research is supervised by Dr Caroline Brett (Health Psychologist) and Dr Emily Revell (Clinical Psychologist).
- It is sponsored by the University of Edinburgh.

What is the purpose of the study?

- The aim of the study is to listen to people's experiences of having input from either a psychologist or other mental health professional (such as a counsellor or mental health nurse) in NHS services in relation to having Long Covid.
- This will be useful as it might indicate how mental health professionals (and other healthcare professionals) can best support people who are living with Long Covid.

Who is being invited to take part in this research study?

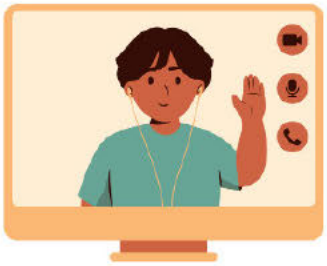
We would like to hear from you if your answers are 'yes' to the following:

- You are aged 18 years or older
- You live in the U.K.
- You have experienced symptoms of Long Covid for a period of 12 weeks or longer
- You have been told you have Long Covid by a healthcare professional
- You were not hospitalised in relation to your Covid-19 infection(s)
- You have received individual sessions with a psychologist or other mental health professional (e.g., counsellor or mental health nurse) in an NHS service in relation to having Long Covid.

Do I have to take part?

- No. It is up to you to decide if you want to take part in the study or not.
- You are free to withdraw from taking part in the study at any time and without giving a reason. You can request to withdraw your data from the study up to 2 weeks after the research interview date.
- Deciding not to take part or withdrawing from the study will not affect your medical care or legal rights

What does taking part involve?



- You will be asked to fill in an online survey to **register your interest** in the study and **provide brief details** about yourself, such as your age category and the type of service(s) accessed. You will be asked to complete a brief consent form before providing this information. The online survey link is here: https://bit.ly/SurveyLC
- If selected for interview, a **telephone call** will be arranged (via email), where you will be asked to complete a consent form for taking part in the research study. This shows that you are agreeing to take part in the study. At this time, you will be asked some **further brief questions** about yourself, including your gender, ethnicity and length of time living with Long Covid.
- The study involves a **video call interview** on Microsoft Teams at time that is convenient for you. (This can be arranged as a **telephone call** if preferred).
- We would like to audio record your responses (and will require your consent for this).
- The interview is likely to last between **30 minutes and 1 hour.** You will be welcome to take breaks during the interview. You can finish the interview at any time.
- Following the interview, participants are welcome to get in touch with the researcher (by email) within a 2 week period from their interview date should they later remember information they wish to share.

Extra information about the interview

The interview provides a chance for you to share thoughts and reflections on your experience of receiving individual psychology or other mental health input from NHS services in relation to your Long Covid. Some questions which *may* be asked include questions about your experience of accessing the service, what your expectations of the input was, and what you found helpful or unhelpful about the input received.

What happens to my information?

- The personal information you provide in the online survey may be kept for a period of up to 6 weeks, as this will allow the researcher to contact you during the recruitment period. Your identifiable information (i.e., first name, email address) will be kept in a separate, password-protected file to the other details you provide (e.g., your age category). Your postcode will only be stored temporarily. It will be used to calculate the Index for Multiple Deprivation (IMD) data for the area you reside in (which cannot be used to identify you), with your postcode being deleted within 7 days of being received. You can find out more about IMD for the country you live in here should you wish:
- Scotland: https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/

- England: https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019
- Wales: https://www.gov.wales/welsh-index-multiple-deprivation
- Northern Ireland: https://www.gov.uk/government/statistics/northern-ireland-multiple-deprivation-measures-2017

- If you also take part in the research study, which includes the telephone call and research interview, the identifiable information you provide (including your first name, email address and telephone number) will be deleted 2 weeks after the date of your research interview. The one exception to this is if you tell us that you would like to receive a summary of the findings, in which case, your email address will be stored for a period of up to 18 months until the research finishes. You can contact us at any time to let us know if you would like your email address to be removed from our records.
- A password-protected digital recorder (Dictaphone) will be used to record the interviews. Your interview recording and transcript (written interview record) will always be kept separately from any personal information you provide.
- Recordings will be transferred to a secure online storage space (provided by the University of Edinburgh), after which the recording will be deleted from the digital recorder.
- The live transcription feature on Microsoft Teams will be used. This writes out (or 'transcribes') what is said during the interview. This will then allow the researcher to analyse the interview. Your name and any identifying information (e.g., place or service names) mentioned during the interview, will be removed from the written record before it is saved.

- The information that is obtained will be held in accordance with the Data Protection Act in University of Edinburgh, which means that we keep it safely and cannot reveal it to other people.

- The results of this study will be used in the researcher's report ('thesis') may also be used in other formal reports (e.g., journal articles, conference papers). Interview quotes from the recordings may be included in these, but all information will be anonymised and it will not be possible to personally identify you from this information. With your consent, your anonymised information may also be kept for future research.

- A summary of the findings from the study will be made available to participants who indicate they would like to receive this. This summary will be sent to participants by email.

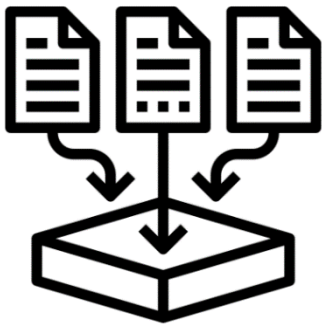
What are the possible benefits of taking part?

- There are no direct benefits to taking part in the study, but by sharing your experiences, you will be helping Andrea Clark and the University of Edinburgh to better understand how people with Long Covid have experienced mental health input in NHS services.

Are there any risks or disadvantages of taking part?

- There are no significant risks identified with taking part in this study. There is a small risk that you may find some of the topics covered in the interview to be distressing. For example, if it reminds you of a difficult situation.
- We are aware that participants may experience fatigue during the interview and/or after the interview is finished. Please keep in mind that you can take breaks and/or decide to finish the interview at any point.
- At the end of the interview, some sources of support will be shared should you wish to discuss or explore any topics further.

What are your choices about how your information is used?



- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have, unless you tell us in the 2-week period following your research interview date that you would like to withdraw your data.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep identifiable information about you for up to 6 weeks (with your email address being stored for 18 months if you tell us that you wish to receive a summary of findings) and your anonymised data for a minimum of 10 years.

Who has reviewed this study?

The study has been reviewed by the School of Health in Social Sciences Ethics Committee at the University of Edinburgh.

What should I do if I have any further questions?

If you have any further questions about the study, please contact the lead researcher, Andrea Clark at

If you would like to discuss this study with someone who is not involved in the study, please contact
(Lecturer in Clinical Psychology).

If you wish to make a complaint about the study, please contact:
Professor Matthias Schwannauer, headofschool.health@ed.ac.uk

In your communication, please provide the study title and detail the nature of your complaint.

For general information about how we use your data go to:
https://www.ed.ac.uk/records-management/privact-notice-research

Thank you for taking time to read this information sheet.

Next page >

Please confirm that you meet all of the criteria for taking part in the study:

* Are you aged 18 years or older?

- Yes
- No

*Do you live in the U.K.?

- Yes
- No

*Have you experienced symptoms of Long Covid for a period of 12 weeks or longer?

- Yes
- No

*Have you been told you have Long Covid by a healthcare professional?

- Yes
- No

*Were you **not** hospitalised in relation to your Covid-19 infection(s)?

- Yes
- No

*Have you received individual sessions with a psychology or other mental health professional (e.g., counsellor or mental health nurse) in an NHS service in relation to having Long Covid?

- Yes
- No

Next page >

* I have read the Participant Information Sheet (v6 dated 20.11.24) and I would like to register my interest in taking part in the study.

- Yes
- No

*I understand that the information I provide in this survey will be used to inform if I am invited to take part in the study and that my details will be deleted within 6 weeks.

- Yes
- No

*I understand that the information I provide in this survey will be used for the researcher (Andrea Clark) to contact me.

- Yes
- No

Next page >

First name (only)

Email address

Further information

As mentioned at the start of this survey, we are looking to include a representative group of people living with Long Covid in Scotland in this research. To help with this, we would appreciate some further information about yourself.

*Age category

- 18-29 years
- 30-39 years
- 40-49 years
- 50-59 years
- 60-69 years
- 70 + years

*Postcode

Please note, your postcode will only be stored temporarily (for a maximum of 7 days). It will be used to calculate the Index for Multiple Deprivation (IMD) data for the area you reside in (which cannot

be used to identify you) before being deleted. You can find out more about IMD for the country you live in here should you wish to:

- Scotland: https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/
- England: https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019
- Wales: https://www.gov.wales/welsh-index-multiple-deprivation
- Northern Ireland: https://www.gov.uk/government/statistics/northern-ireland-multiple-deprivation-measures-2017

Please provide brief details about the type(s) of psychology and/or mental health support service you have accessed in relation to having Long Covid. This might include details about the type of service (e.g., Long Covid service, chronic fatigue service) or the professional(s) you saw for the one-to-one sessions (such as a psychologist, counsellor, mental health nurse, CBT therapist etc.):

Next page >

Thank you very much for registering your interest in this research study and for providing additional information. Andrea Clark will be in touch with you in the coming weeks by email.

[Survey respondents will be redirected to the following message if their answer to any item indicates they are not eligible for the study or if they did not answer 'yes' to the three consent items].

- Thank you very much for your interest in this research study into Long Covid.
  Your response indicates that you do not meet the criteria for taking part in the study *or* that you did not answer 'yes' to the three consent items. We really appreciate your interest in the research study and that you have taken the time to complete these intitial questions.

Looking out for any support resources for people with Long Covid?

Here is a list of resources that you might find helpful, most of which have been shared with the researcher (Andrea Clark) by people with Long CovidNuffield Health Long Covid Recovery Programme – a free service and is a 12-week programme – https://www.nuffieldhealth.com/about-us/our-impact/healthy-life/covid-19-rehabilitation-programme

- Breathing exercise (YouTube): https://youtu.be/YGXCPvzbnCA?si=lywDjd5SBzNBWUtm
- Chair based pilates exercise video: https://www.nhs.uk/conditions/nhs-fitness-studio/pilates-and-yoga/chair-based-pilates-exercise-video/
- Asthma + Lung UK - https://www.asthmaandlung.org.uk/conditions/long-covid
- The Rest Room Podcast – not specifically for Long Covid but deals with living with chronic illness.
- Mind – https://www.mind.org.uk
- Mental Health Foundation – https://www.mentalhealth.org.uk/

Specific to people living in Scotland:

- Chest, Heart and Stroke Scotland -- Long Covid - Chest Heart & Stroke Scotland (chss.org.uk)
- Information and advice on Long Covid (plus information on the NHS Greater Glasgow & Clyde service): https://www.nhsggc.scot/your-health/covid-19/long-covid-service/
- Life Link – https://www.lifelink.org.uk/

Specific to people living in England and Wales:

- Long Covid Support - https://www.longcovid.org/ (this includes information and different peer support groups)

Specific to people living in Northern Ireland:

- Long Covid Support Group Northern Ireland (peer support group).

Appendix 11 Telephone Call Schedule

Lived experience of Long Covid and NHS mental health care, V2 20 Nov 2024

TELEPHONE CALL SCHEDULE

Hi [participant name], my name is Andrea Clark, I'm a trainee clinical psychologist at the University of Edinburgh. I emailed you in connection with participating in my research study into Long Covid.
Thank you very much for your interest in this research study. As mentioned in my email, you are now being invited to take part in the research study. This involves today's phone call, which should last around 15 minutes, and a research interview, which we can arrange a date/time for today.

To summarise, the purpose of today's call is to:

- Confirm that you meet the criteria for the study;
- Provide an opportunity for you to ask any questions you may have about the study's consent form and taking part in the study;
- Complete the consent form and audio record your responses to this;
- Gather further information about yourself, your physical health and Long Covid.
- And finally, to arrange a suitable date/time for the research interview date/time.

We can also speak about what the research interview will be like in terms of its format.

Eligibility criteria

- Are you aged 18 years old or over?
- Do you currently live in the U.K.?
- Have you experienced symptoms of Long Covid for a period of 12 weeks or longer?
- Have you been told that you have Long Covid by a healthcare professional?
- Were you *not* hospitalised in relation to their Covid-19 infection(s);
- Have you received individual sessions with a psychologist or other mental health professional (e.g., counsellor or mental health nurse) in an NHS service in relation to having Long Covid?

Consent

Have you had a chance to look over the consent form? Would you like to ask any questions about the research study or your participation in the research? Did everything in the consent form make sense?

We will go through the consent form now. As mentioned in the study's information sheet, this will be audio recorded? Are you okay to go ahead with this?

[If participant is happy to be audio recorded, switch on the recorder for informed consent].
May I double-check that you are happy for this interview to be recorded?
[Continue recording, if participant has confirmed their consent.]

I will now go through each item on the consent form.
[Read through each item, checking that the participant answers 'yes' before continuing].

Further questions

I will now ask some further questions about your, your physical health and Long Covid.

- What age category are you in? (18-29 years; 30-39 years; 40-49 years; 50-59 years; 60-69 years; 70 + years).
- What is your gender? (e.g., man, woman, transman, transwoman, non-binary, different gender identity).
- How would you describe your ethnicity? (e.g., Asian or Asian British, Black, Black British, Caribbean or African, Mixed or multiple ethnic groups, White, or other ethnic group).
- What was the date of your initial Covid illness? [Prompt: a rough date is fine].
- When did you notice the onset of symptoms?
- How long have you had Long Covid for?
- What are your Long Covid symptoms? [Prompt: your main symptoms are fine].
- Do you have any other physical health conditions? (If relevant, what are these?).
- Which support services have you accessed?

Thank you very much for answering those questions.

Arrange research interview (and socialisation for the interview format)

The next step is to arrange a date and time for the research interview.
[Socialisation to interview style] In the research interview, I will ask you some very open questions about your experience of receiving one-to-one psychology or other mental health support in relation to having Long Covid. We expect the interview to last between 30 and 60 minutes. On the day, you can choose how to respond to these questions and you can share as much or as little as feels comfortable for you. There are no right or wrong answers. The space is a space for you to share and so I will likely be quite quiet throughout the interview. You can pause or stop at any point.

Seeking information on adjustments for the research interview

Lastly, is there anything I can do to make the research interview an easier process for you? (e.g., offer regular breaks, send out a copy of the interview questions ahead of time, include the questions I ask in the comments box in Teams?):

Thank you very much for your time today. I look forward to speak with you on [date/time] for the research interview. If you need to get in touch with me before then for any reason, my email is

Appendix 12 Interview Schedule with Prompts

INTERVIEW SCHEDULE

Project title: The perspective of people with Long Covid on receiving individual psychology or other mental health input for management of the condition in NHS services: An Interpretative Phenomenological Analysis (IPA).

Introduction script – 'I'm going to ask you some very open questions about your experience of receiving one-to-one psychology or other mental health support in relation to having Long Covid. We expect the interview to last between 30 and 60 minutes You can choose how to respond to these questions and you can share as much or as little as feels comfortable for you. There are no right or wrong answers. This is a space for you to share and so I will likely be quite quiet throughout the interview. You can pause or stop at any point'

[If participant has consented to be recorded, switch on the recorder]
May I double-check that you are happy for this interview to be recorded?
[Continue recording, if participant has confirmed their consent.]

Support offered
What psychology/mental health support were you offered with regards to Long Covid?
Prompts: Who made the referral for psychology/mental health support? Which service were you referred to?

Accessing the service
What was your experience of accessing the service?
Prompts: Tell me what was helpful/unhelpful about accessing the service.

Expectations
Did you have any expectations of psychology/mental health support for Long Covid beforehand?
Prompts: What were your expectations of psychology/mental health support for Long Covid beforehand? What did you think the sessions might offer?

The experience of psychology/mental health service(s)
What was your experience of the service(s) you received?
Prompt: What did you find helpful or unhelpful about your experience with the service(s)? Did your expectations differ from what you expected it to be like?

Outcome
Would you recommend accessing a psychology or mental health service to other people with Long Covid?
Prompt: What would you change about the input you received?

Interview closure
Is there anything I did not ask you and you would like to add?

Appendix 13a Sponsorship Letter

University of Edinburgh
College of Arts, Humanities and Social Sciences Research Governance Office
55 George Square
Edinb
urgh
EH8
9JU

24th January 2024

Andrea Clark
c/o School of Health in Social Science

Dear Andrea,

Study Title: The perspective of people with Long Covid on receiving individual psychology or other mental health input for management of the condition in NHS services: An Interpretative Phenomenological Analysis (IPA).
Sponsor number: CAHSS 2401/02

Under the requirements of the UK policy framework for health and social care research, the University of Edinburgh agrees in principle to act as Sponsor for this project. Sponsorship is subject to you obtaining institutional ethics for the project.

As Chief Investigator, you must ensure that the study does not commence until all applicable approvals have been obtained. Following receipt of all relevant approvals, you should ensure that any amendments to the project are notified to the Sponsor (including an extension to the study end date). Please note that there is a requirement to notify the sponsor once the study has ended.

Yours sincerely

Matt Erikson

Research Governance Coordinator

Appendix 13b Ethics Application

School of Health in Social Science Research Ethics Application
The supervisor or primary investigator must complete and sign this form after checking that all relevant sections are completed, and relevant documents are attached. For all undergraduate (UG) and MSc student projects, it is the supervisor's responsibility to submit this form and all attachments. Please note that failure to do this will result in the application being returned (and not processed) causing your research to be delayed.

Supervisor (name and UUN): Dr Caroline Brett	
Primary Investigator (name and UUN): Andrea Clark (S0978449)	
List of all collaborators (with affiliated institutions in brackets): Dr Emily Revell (NHS Lothian), Dr Paul Graham Morris (University of Edinburgh).	
Student's programme of study (if applicable): Doctorate of Clinical Psychology	
Project Title: The perspective of people with Long Covid on receiving individual psychology or other mental health input for management of the condition in NHS services: An Interpretative Phenomenological Analysis (IPA).	
Case Number (if known – assigned by Administrator at time of 1st submission): CAHSS2401/02	
Proposed Project Start Date: 1st May 2024	**Proposed Project End Date:** 31st Jan 2026

Please indicate whether the primary investigator on this project is staff or student and select your subject area:

☐ Staff ☐ UG or MSc Student ☒ DClin Student ☐ PhD Student
☐ CPASS ☒ Clinical Psychology ☐ Nursing Studies

This is a:

☐ New application for ethical review – first submission

☒ Resubmission following reviewer comments

☐ Resubmission with requested amendments

Has been reviewed by an external ethical board, such as NHS IRAS or a UK HEI (multi-site studies only) with a favourable opinion? Level 1 *

☐ IRAS (NHS research ethics) ☐ Other: _____

Please tick one option that best describes your application:

☒ Collecting or generating new data involving other people: Level 2

☐ Extracting, re-coding and analysing existing data that contains sensitive information (i.e. identifiable information): Level 2

☐ Analysing secondary (archival) data that is routinely collected or is an existing anonymised dataset: Level 1

☐ Collecting new data BUT an external ethical review board (such as NHS IRAS; UK HEI – for multi-site studies; etc) has fully reviewed this project and generated a favourable opinion: Level 1

This application is complete with the following attachments (tick all that apply):

Advert/flyer ☒	Caldicott application stating what data was requested ☐	Caldicott signed approval ☐		Consent form/s ☒
Data collection tools (e.g. interview guides) ☒	Debrief with signposting ☒	IRAS application ☐	IRAS opinion letter ☐	NGO or local authority letters ☐
Participant Information Sheet/s ☒	Participant Information Sheet (young person version) ☐	R&D application ☐	R&D approval ☐	Researcher Checklist (C-19) ☐
Risk assessment ☐	Standardised recruitment email ☒	Sponsorship Letter OR Email to confirm no sponsorship needed / statement explaining why sponsorship is not needed. ☒		

Other attachments (please specify):
Research study flowchart
Telephone call schedule

To be completed by primary investigator or project supervisor

By signing this front sheet, I confirm that I have prepared and/or reviewed this ethics application and related documents in accordance with ethical guidelines. I also confirm I have checked that all relevant sections of the application form are completed and relevant documents are attached.

Supervisor or/PI Signature:

Student signature:

Date: 08.07.25

On completion, this Word document along with the relevant attachments should be submitted to ethics.hiss@ed.ac.uk.

Note: **Please note all undergraduate and MSc applications MUST been signed and submitted by the project supervisor.**

Contents

This section is to be completed after review only

ISSUES ARISING FROM THE PROPOSAL – to be completed by Ethics Reviewer

Thank you for your application. The review process has generated the following queries regarding your application. Please address the following items, and provide a note underneath each comment letting us know how you have addressed them:

Application:

-Please have your supervisor(s) sign the form.

-Please fill in the very first question under Section 1 regarding external ethics approval. Item now answered.

-I am confused about the procedure. I believe that you are collecting data in the brief online survey (including identifiable information) before participants read the PIS and give consent. This raises problems regarding how potential participants could know for how long and where you store this information about them and whether they consent to this. Respondents to the brief online survey are provided with the Participant Information Sheet (PIS) ahead of them answering a brief consent form within the survey. (The PIS is shared as a link at the start of the brief online survey, as an attachment in the recruitment email, and an email copy can be requested). This is an initial consent form as part of the brief online survey, which is followed later by the main study consent form completed during the telephone call. I have added additional information to the online survey/PIS to try to make this clearer, and have added information on how data from the brief online survey will be used within the PIS, which respondents are provided with in the survey. I have created the Research Flowchart with the aim of making the process clearer.

-Q14: Have you really contacted the School's Research Ethics Officer? Re-visiting this question, I can see that I was not required to fill in this box based on my response to Q14 (i.e., I could skip this item and move on to Q15). I spoke with a Research Data Support Officers (Kerry Miller); which is why I had (mistakenly) ticked this box at the time.

-Q32: Please provide the rationale for the targeted sample size. Now added.

-Q43: You mention that participants can withdraw their data until data analysis. That means that you are keeping identifying information about them at least until then. Please be specific regarding when all identifying information will be deleted and transcripts anonymized both in the application and in the PIS. I have clarified that participants can withdraw their data until 2 weeks following the date of their research interview in the ethics form, PIS and consent form.

Flyer:

-Not all inclusion criteria are listed on the flyer (e.g. living in Scotland). The flyer had living in Scotland in the criteria ('Are you aged 18 years or over and living in Scotland?); however, I have separated these out to make this clearer. I have added in the criteria missed ('Have you experienced symptoms of Long Covid for a period of 12 weeks or longer?').

Brief online survey:

-The phrase "when no longer required" in the following statement is quite vague, please be more specific when this information will be deleted: "I understand that the information I provide in this survey will be used to inform if I am invited to take part in the study and that my details will be deleted when no longer required." Thank you, I have made this clearer with a specific time frame (6 months) and have added this information to the PIS.

PIS:

-Please keep titles consistent through all documents. I have changed the PIS title to the short title (in keeping with other documents).
-An explanation of what long COVID is might be helpful. Following further discussion with my thesis supervisor, we agreed that providing an explanation of long COVID may not be necessary in this instance for the following reasons:

- Prospective participants will be required to have been told by a healthcare professional that they have Long Covid, and so they will not be self-identifying as having the condition. We can see the place that a definition of Long Covid could have played if people were self-identifying with Long Covid; however, as this is not the case, we feel that this reduces the need for an explanation and would perhaps muddy the waters.
- Furthermore, the PIS (and other documents) were reviewed by people with lived experience of Long Covid. A definition of Long Covid was not suggested by those providing feedback.

-Please make sure to explain whether and, if so, how long after the interview participants have to withdraw (when is the recording transcribed and deleted?). I have added that they have 2 weeks to withdraw their data from the date of their research interview.
-You mention the following "Your name and any identifying information (e.g., place or service names) mentioned during the interview, will not be removed from the written record before it is saved" Did you mean to say these will be removed? Thank you, I have removed the 'not' to correct this.
-Please explain that you will collect postcodes and what you will do with this information. I have added a sentence on to the PIS.
-You state that identifiable information will be kept for 18 months. Can you please mention which of the identifiable information? Does this include names and audio recordings? This is quite a long time to store these information. Please justify why this is necessary. Or is it only the email addresses of participants who indicate that they wish to receive the summary? Yes, that latter is correct. Is it only the email addresses of people wishing to receive the summary. I have clarified this in the PIS.
-It is an optional point in the consent form whether participants consent to third-party transcription, while in the PIS the live transcription feature of Teams is presented as something that will happen and is not an option. Please be consistent throughout. Thanks, I have added 'With your consent, the live transcription feature…'.
-Please be consistent regarding for how long after the interview participants can withdraw their data.

Consent form:
-"Withdraw at any time": Please be more clear whether, and if so, for how long can participants withdraw after the interview. This has been updated to specific that participants can withdraw from the study up to 2 weeks following their research interview date.
-"copy of the results": Do you mean the research report? Yes, I have changed this to 'summary of the findings' since I have used this phrase in the PIS.

Emails:
-Please be clearer and concrete in the email for recruiting organizations. Thank you, I have made this more concrete and succinct.
-Please use lay language in the recruitment email for participants (e.g. IPA). Also, here you only mention interviews through Teams and not the option of a phone interview. Thanks, I have tried to adapt the email so that it is in plain English. I have added the option of a phone interview.

Signature: Zsofia Garai-Takacs (sig)

Position: Ethics & Integrity Lead

Date: 08/03/2024

APPLICANT'S SIGNATURE FOLLOWING REVISIONS – <u>to be completed by applicant</u>

I confirm that I have addressed all of the queries generated during the ethical review process of my application. I have outlined in the box above underneath each comment how each request was addressed and/or provided further clarification.

Supervisor/PI Signature:

Student signature:

Date: 23.04.24

CONCLUSION TO ETHICAL REVIEW – <u>to be completed by Ethics Lead</u>

Thank you for providing responses to our comments. Some outstanding questions remain:

-I am confused about the procedure. I believe that you are collecting data in the brief online survey (including identifiable information) before participants read the PIS and give consent. This raises problems regarding how potential participants could know for how long and where you store this information about them and whether they consent to this. Respondents to the brief online survey are provided with the Participant Information Sheet (PIS) ahead of them answering a brief consent form within the survey. (The PIS is shared as a link at the start of the brief online survey, as an attachment in the recruitment email, and an email copy can be requested). This is an initial consent form as part of the brief online survey, which is followed later by the main study consent form completed during the telephone call. I have added additional information to the online survey/PIS to try to make this clearer, and have added information on how data from the brief online survey will be used within the PIS, which respondents are provided with in the survey. I have created the Research Flowchart with the aim of making the process clearer.

I am still confused. In fact, when clicking on the link in the flyer, I did direct me to the brief questionnaire without having seen the PIS. Why not start with the PIS and then ask the questions of the brief survey?

I have now included the PIS at the start of the brief questionnaire. I had been keen to include images as part of the PIS (as per feedback from people with lived experience of Long Covid), which I was able to do via sharing a link to the PIS; however, I have now managed to add these to the start of the brief survey without a link being required.

-The phrase “when no longer required” in the following statement is quite vague, please be more specific when this information will be deleted: “I understand that the information I provide in this survey will be used to inform if I am invited to take part in the study and that my details will be deleted when no longer required.” Thank you, I have made this clearer with a specific time frame (6 months) and have added this information to the PIS.

6 months to store identifying information is quite long. Can you please give a rationale for why this is necessary?

I have spoken with my supervisor again and we agreed to change this to 6 weeks. I have changed this on the PIS. This would give me time to purposively sample participants and respond to people to let them know if they are being invited to take part in the study or not.

Signature: Zsofia Garai-Takacs (sig)

Position: Ethics & Integrity Lead

Date: 29/04/2024

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

If you are applying for amendments to a previously reviewed and processed project, please use the below form to detail the amendments you wish to make:

This section is to be completed for amendments only
AMENDMENT/S: REQUEST FOR APPROVAL – to be completed by applicant
I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion: To boost recruitment, it would be helpful to share recruitment information (recruitment flyer) via social media platforms, including 'X' (formerly known as Twitter), Facebook and Instagram. I have added this additional information to section Q1 under methodology and Q43 using tracked changes. **Supervisor/PI Signature:** **Student signature:** **Date:** 19.08.24
CONCLUSION TO ETHICAL REVIEW OF AMENDMENT – to be completed by Ethics Lead

The requested amendment satisfies the requirements for ethical practice and it has therefore received a favourable opinion.

Signature: Zsofia Garai-Takacs (sig)

Position: Ethics & Integrity Lead

Date: 27/08/2024

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

If you are applying for amendments to a previously reviewed and processed project, please use the below form to detail the amendments you wish to make:

This section is to be completed for amendments only
AMENDMENT/S: REQUEST FOR APPROVAL – to be completed by applicant
I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion: Unfortunately, recruitment to-date has been slow. With the aim of reducing perceived burden regarding participation in the research interviews, I have taken on board feedback from one of my research supervisors and re-designed by the flyer to particularly highlight adaptations that can be made to make sure this is accessible as possible for people with Long Covid (this information was previously only mentioned within the participant information sheet) – this includes details that the research interview can be completed over one or more sessions and with plenty space for breaks. In addition, the flyer features contact details more prominently to ensure that clients are aware they can get in touch directly with any questions or concerns, or to seek assistance with completing the online survey. **Supervisor/PI Signature:** **Student signature:** **Date:** 25.10.24
CONCLUSION TO ETHICAL REVIEW OF AMENDMENT – to be completed by Ethics Lead

The requested amendment satisfies the requirements for ethical practice and it has therefore received a favourable opinion.

Signature: Zsofia Garai-Takacs (sig)

Position: Ethics & Integrity Lead

Date: 07/11/2024

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

If you are applying for amendments to a previously reviewed and processed project, please use the below form to detail the amendments you wish to make:

This section is to be completed for amendments only

AMENDMENT/S: REQUEST FOR APPROVAL – to be completed by applicant

I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion:

Recruitment numbers for my research study continue to be low. With agreement from my research supervisors, I am seeking to lift the recruitment criteria restriction which currently seeks to only recruit those people who have accessed NHS Scotland services to include people who have accessed NHS services across the U.K. (England, Wales and Northern Ireland). As noted in Q1, recruitment would continue to be through third sector organisations and social media (as opposed to directly through NHS services themselves).

Supervisor/PI Signature:

Student signature:

Date: 25.11.24

CONCLUSION TO ETHICAL REVIEW OF AMENDMENT – to be completed by Ethics Lead

The requested amendment satisfies the requirements for ethical practice and it has therefore received a favourable opinion.

Signature: Zsofia Garai-Takacs (sig)

Position: Ethics & Integrity Lead

Date: 05/12/2024

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

LEVEL 1 and 2 – Confidentiality and Handling of Data

Section 1: Introduction

External Research Ethics Approval:

Does your research project require the approval of any other institution and/or ethics committee, nationally or internationally?

Note: It is each researcher's responsibility to check whether their project requires Sponsorship, Caldicott Approval, R&D approval, and/or IRAS (see https://www.ed.ac.uk/health/research/ethics/sponsorship-and-governance). The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

☒ This research project does not require external ethics approval.
OR

If you require external approval, please state the name of the review body:
☐ IRAS (NHS research ethics) ☐ Local Authority ☐ Other:
_____

NB: If you require external approval from IRAS/NHS/Caldicott, **you must have external approval before submitting your application for School of Health in Social Science Research Ethics approval**. You can only submit your application to us once external approval has been obtained, and you must include all documentation including your application to and approval of external approval as an attachment.

If you require approval from a **local authority**, you must first receive ethics approval from the School of Health in Social Science Research Ethics Committee, before submitting your application to the local authority.

Q1. Project summary

Please provide a brief summary of your proposed study. Do not exceed 1500 words. Our interest is in areas of your methodology where ethical issues may arise so please focus your detail on areas such as recruitment, consent, describing your participants and the nature of their involvement, and data handling.

Background

'Long Covid' is the term coined by people with lived experience of the illness (Callard & Peregro, 2020). As a relatively new illness, a lot is still unknown about it and ambiguity exists around its diagnosis and treatment. Since early in its recognition, Long Covid has been compared to other long-term conditions, such as Chronic Fatigue Syndrome (CFS)/Myalgic encephalomyelitis (ME). A subset of chronic conditions, including CFS/ME and Functional Neurological Disorder (FND), do not have physical signs of illness or biomarkers, and have a history of being given psychological explanations for symptoms. Within the CFS/ME literature, there is well-documented history of patients feeling stigmatised and disbelieved in their interactions with healthcare services (Froelich et al., 2022). Given that Long Covid has some overlaps with CFS/ME in terms of symptomatology (e.g., profound fatigue), there is a possibility that patients with Long Covid may also come across similar experiences (see Hunt et al., 2022). Psychological input for symptoms of low mood, anxiety and adjustment is recommended as part of Long Covid rehabilitation guidelines (NICE, Scottish Intercollegiate Guidelines Network & Royal College of General Practitioners, 2020).

Rationale and research question for the current study

Multiple calls have been made from patients, professional bodies (e.g., NICE, 2022b) and Government (e.g., The Scottish Parliament, 2023) for more lived experience research into Long Covid. The viewpoint of people with Long Covid on current or potential psychological therapies would be particularly useful as we learn more about the chronic condition and develop NHS services which take into account people's lived experience and perspectives. The research question for the current project is, 'What are the perspectives of people with Long Covid on one-to-one psychology or other mental health input received in relation to having Long Covid?'.

Design

A qualitative, exploratory method will be used to investigate the lived experience of adults with ongoing symptoms of Long Covid, with particular focus on psychology or other mental health input. To address the above research question, the researcher will carry out one-to-one semi-structured interviews with research participants to obtain in-depth accounts of personal experiences and perspectives using Interpretative Phenomenological Analysis (IPA). IPA is a qualitative approach which has been applied to the exploration of personal experience of health and illness (Smith et al., 2009). In order to purposively recruit a sample of up to 12 participants, a brief online screening survey (which includes its own specific consent form) will be used to enable individuals to confirm their eligibility for the research study, register their interest in taking part and provide basic details about themselves (e.g., name, email address, age category, postcode and types of psychology and/or other mental health services accessed). A pre-interview telephone call will used be to seek informed (verbal) consent and gather additional data (e.g., gender, length of time with Long Covid, Long Covid symptoms). A semi-structured interview schedule (see attached), which includes suggested prompts if required, will be used as a flexible guide during the interview.

Participants

Participants will be eligible for the proposed study if they: are 18-years of age or older; are living in any country within the UK (Scotland, Wales, England or Northern Ireland); have been told by a healthcare professional that they have Long Covid; have experienced symptoms of Long Covid for a period of 12- weeks or longer; if they were *not* hospitalised at the time of their Covid-19 infection(s),

and they have accessed individual psychological therapy and/or other mental health support (e.g., with a mental health nurse, counsellor, psychological therapist) for any length of time.

Procedure

The following procedure is outlined in the 'Research study flowchart' attachment.

1. Contact will be made with the Project Manager and Advice Line Nurses within the Long Covid Pathway at Chest, Heart & Stroke Scotland (CHSS) (see Email for CHSS attached). This email contact will include the Participant Information Sheet and flyer. Should recruitment rates via CHSS be low, the researcher will make contact Long Covid support groups, including Long Covid Scotland, a volunteer-led charity supporting those with Long Covid. In addition, study information will be shared on social media platforms, such as 'X', BlueSky, Facebook and Instagram. Third sector organisations and social media accounts relevant to people living in England, Wales and Northern Ireland will also be contacted. This will include organisations such as the M.E. Association (which reaches individuals with Long Covid) and voluntary organisations such as Long Covid Support.

2. The researcher will attend meetings and/or peer support groups within the organization(s) mentioned above to share information on the study and answer any questions about the research. Staff at CHSS will be encouraged to mention the study with people who access the Long Covid Pathway. In terms of Long Covid support groups, such as Long Covid Scotland, the researcher will email the organization(s) and request that study information is shared with its group members, as described below.

2. An easy-read flyer and Participant Information Sheet (both attached) describing the research, including the study's recruitment criteria, will be shared with the above contacts. The flyer includes a link and QR code for a brief online screening survey (see link here: https://bit.ly/SurveyLC) as well as the researcher's contact details. The flyer will be shared on social media in order to maximise recruitment.

3. People who are interested in the study will be invited to complete the brief online screening survey. This will allow them to: 1) confirm that they meet the criteria for taking part in the study, and 2) register their interest in taking part in the study and 3) provide brief details about themselves. Details requested will include their first name and email address, which allow the researcher to contact them. In addition, respondents will be asked to provide further details about themselves, including their age category (e.g., 18-29 years old), postcode (which will be used to calculate their Index of Multiple Deprivation), and the types of psychology and/or other mental health support services accessed. The brief online survey contains its own specific consent form, which respondents must complete before they can provide these personal details. Information on data storage is outlined in the PIS, which respondents will have access in the brief online survey, recruitment email and on request).

The purpose of asking for these personal details is to allow the researcher to purposively sample participants for the study based on these three characteristics/experiences, including age category, IMD and types of services accessed. Respondents are informed of this within the Participant Information Sheet and brief online survey, including that the information they provide will be used to select participants for the research study to ensure that people with a range of experiences and characteristics will be invited to participate in the research study.

4. Individuals who register their interest in the study will be contacted by email to confirm that they are being invited to take part in the research study (see Email for prospective participants, attached) or to inform them that they are not being invited to take part in the research study due to reaching capacity. (An interim email may be sent to let people know that the researcher will get back in touch with them as soon as possible to let them know the outcome). Participants who are invited to take part will receive the main study consent form as an attachment. They will be asked to provide a telephone number to be contacted for the pre-interview telephone call and will be given the opportunity to provide the best time to be contacted.

5. During the pre-interview telephone call, the person's eligibility to take part in the study will be confirmed, the participant will be given the opportunity to ask any questions they may have, verbal consent will be audio recorded, and further details will be collected (including ethnicity, gender, age category, date of initial Covid illness, onset of symptoms, duration of Long Covid, whether they have other physical health conditions, support services accessed and their Long Covid symptoms). The reason for arranging a separate, pre-interview telephone call is to reduce the burden on participants during the research interview. In addition, Smith and Nizza (2021) recommend having a telephone conversation with participants prior to the research interview to help with building rapport, as well it providing an opportunity to socialize the participant to the style of the research interview. A suitable time will be arranged for the research interview during this phone call. At this stage, information about reasonable adjustments to the research interview format (e.g., taking breaks, sharing the questions ahead of time) will be discussed with the participant. Participants will be reminded that they can get in touch with the researcher with any questions they may have. As part of the consent process, participants will be made aware that they have the right to withdraw from the study for a period of 2 weeks following their interview date.

6. The research interview will take place via video call on Microsoft Teams or, if preferred by the participant, by telephone call, on the pre-arranged date. Participants will be reminded that they can take breaks whenever they wish and/or stop the interview early if preferred. At the end of the interview, participants will be informed that they can get in touch if they wish to share any further reflections which they may have forgotten during the interview (N.B., this is to assist participants who may experience 'brain fog') within 2 weeks from the date of their research interview. At the end of the interview, participants will be offered a list of resources and contacts for support, which can be shared via MS Teams or email (see debrief attached).

7. Participants who responded 'Yes' on the main study consent form in relation to receiving a summary of the findings will be contacted by email at the research study's completion.

1. Data handling

Participants will be allocated a unique participant ID (e.g., PA, PB, PC etc.), which will be used when saving data (e.g., PA_interview_24.01.24).

Data from the brief online screening survey will be saved onto the University of Edinburgh's One Drive in two separate password-protected documents. Postcode data will be stored temporarily before it is converted into the client's Index for Multiple Deprivation (IMD) within 7 days. Once converted, the postcode data will be deleted. Identifiable data from the brief online survey (i.e., first name, email address) will be stored in a separate, password-protected file to the other data collected

within the survey (i.e., age category, IMD (which will have been converted from postcode) and type of services accessed). All data from the brief online survey will be deleted after a period of 6 weeks. This timeframe will allow the researcher to contact prospective participants within the recruitment period.

Data from the pre-interview telephone call and research interview will also be stored on the University of Edinburgh's One Drive across separate files to protect anonymity. Identifiable data (including first name, email address and telephone number) will be stored in a separate password-protected file to the other data collected from participants (e.g., age category, gender, ethnicity, length of time living with Long Covid). Identifiable data will be deleted for each participant two weeks following their research interview date. A participant key file will temporarily store participants' ID alongside their name and email address for two weeks following their research interview date. This will allow the researcher to connect the participants name/email address with their anonymized/unidentifiable data so that any additional information provided by participants in the two-week period following their research interview to be saved. The data in the participant key file will similarly be deleted for each participant 2 weeks after their research interview date.

Participants who tell us that they would like to receive a summary of the findings within the main study consent form will have their email addresses saved within a separate 'mailing list' file (which will include no other identifiers). This will be stored for a period of up to 18 months, unless participants inform us that they wish to have this deleted from our records.

Audio recordings (verbal consent and interview recordings) will be recorded using a password-protected Dictaphone provided by the University of Edinburgh. The verbal consent audio recordings will be made on a separate recording to participants' research interview recording, and will be stored in separate locations on the University of Edinburgh's One Drive to protect anonymity. Recordings will be will be clearly labelled using a unique participant number (as noted). In addition, the Live Transcription Feature on Microsoft Teams will also be used during the research interview (N.B., the use of this feature does not require video or audio recording). Transcripts will be anonymized before being saved, with identifying information such as people's names, place names or names of any services being redacted from transcripts.

Participants are informed in the PIS that the University of Edinburgh will keep their anonymized data for a minimum of 10 years.

Research supervisors, Dr Caroline Brett (CB) and Dr Emily Revell (ER), will review data being archived at the end of the project to ensure that every transcript has been fully anonymised. Data will be archived in a University of Edinburgh approved archive, such as Data Share or Data Vault.

Q2. Will you collect or use NHS data?

☐ Yes ☒ No

If "yes" – what NHS data will you collect or use?

Q3. What information about participants/data subjects will you collect and/or use?

Contact details: prospective participants' name, email address and phone number will be used for the purpose of contacting respondents to the brief online survey and for carrying out the pre-interview telephone call outlined in Q1 (includes checking eligibility, taking verbal informed consent, gathering further health data, and if appropriate, arranging an interview date/time and seeking information about adjustments to the interview).

Semi-structured interview – qualitative data will be collected in the form of individual semi-structured interviews.

Demographics – across the brief online screening survey and pre-interview telephone call, participants will be asked to provide basic information. This will include age category, ethnicity, gender and postcode, which will allow the identification of the participant's Index of Multiple Deprivation (IMD). Participants' postcode will only be stored temporarily (for a maximum of 7 days) before being converted into IMD data.

Health data – Details related to participants' Long Covid will also be sought from those who are invited to participate in the research study, including: the date of initial Covid illness, onset of symptoms, duration of Long Covid, whether they have other physical health conditions, which support services they have used, and their Long Covid symptoms.

Q4. What training will staff who have access to the data receive on their responsibilities for its safe handling? Have all staff and students who have access completed the mandatory data protection training on the self-enrolment page of Learn?

The following training has been completed:
- Introduction to Good Clinical Practice (GCP) eLearning.
- MANTRA – (research data in context; data management planning).
- Data Protection Essentials (University of Edinburgh Learn).
- Introduction to Research Ethics & Integrity

Q5. Will the information include special categories of personal data (health data, data relating to race or ethnicity, to political opinions or religious beliefs, trade union membership, criminal convictions, sexual orientations, genetic data and biometric data)?

☒ Yes ☐ No

If "yes" – Explain what safeguards e.g. technical or organisational you have in place; including any detailed protocols if this requires special and/or external processing, storage, and analysis.

Health data will include:
- Date of initial Covid illness
- Onset of symptoms
- Duration of Long Covid
- Whether they have other physical health conditions
- Which support services they have accessed
- Long Covid symptoms

In addition, the following information will also be collected:
- Age category
- Postcode (this will be stored as Index of Multiple Deprivation).
- Gender
- Ethnicity

This personal data will be stored securely in a password protected document. Participants will be allocated a unique participant ID number (e.g., PA, PB, PC etc.) which be used in the storage of personal data. Personal data will be kept in a separate document to participants' names and contact details.

Q6. Please indicate how your research is in the public interest:

☒ Your research is proportionate
☐ Your research is subject to a governance framework
☐ Research Ethics Committee (REC) review (does not have to be a European REC)
☐ Peer review from a funder
☐ Confidentiality Advisory Group (CAG) recommendation for support in England and Wales or support by the Public Benefit and Privacy Panel (PBPP) for Health and Social Care in Scotland
☐ Other

Q7. It is essential that you identify, and list all risks to the privacy of research participants. You will then need to consider the likelihood of the risks actually manifesting and the severity of harm if the risks actually manifest.

Risk	Likelihood of risk manifesting			Severity of harm		
	Remote	Possible	Probable	Minimal	Significant	Severe
Identifiable due to data linkage	☒	☐	☐	☐	☒	☐
Identifiable due to low participant numbers	☐	☒	☐	☐	☒	☐
Identifiable due to geographical location	☐	☒	☐	☐	☒	☐
Identifiable due to transfer of data	☒	☐	☐	☐	☒	☐
Identifiable due to access of data	☒	☐	☐	☐	☒	☐
Insert more rows as appropriate	☐	☐	☐	☐	☐	☐

Please use this text box to record any other risks and the likelihood of them occurring, along with the severity of harm. Please also use this when dealing with secondary data.

Please identify measures you could take to reduce or eliminate risks identified as possible/significant or probable/severe.

All interview transcripts will be anonymized before being save, including (but not limited to) any reference to people, places, health boards, or services. Both supervisors will check any quotes or demographics to be included in publications (including the thesis) to confirm that it is not possible to identify individual participants.

Q8. Will information containing personal, identifiable data be transferred to, shared with, supported by, or otherwise available to third parties outside the University?

☐ Yes ☒ No

If "yes" - Please explain why this necessary and how the transfer of the information will be made secure. If the third party is based outside the European Economic Area please obtain guidance from the Data Protection Officer.

Q9. Other than the use by third parties, will the data be used, accessed or stored away from University premises?

☐ Yes ☒ No

If "yes" - Describe the arrangements you have put in place to safeguard the data from accidental or deliberate access, amendment or deletion when it is not on University premises, including when it is in transit, and (where applicable) it is transferred outside the EEA.

Q10. Will feedback of findings be given to your research project participants or data subjects?

☒ Yes ☐ No

If "yes" - How and when will this feedback be provided?

A plain English summary will be shared with research project participants. This will be shared with participants shortly following the final thesis submission (on 1st May 2025) via email.

If "no" - Please provide rationale for this.

Q11. How do you intend to use/disseminate the results of your research project?

The report will be disseminated in the following ways: • The results will be written up as part of the Doctorate in Clinical Psychology thesis, which will be made publicly available by the University of Edinburgh. • The report will be written up in the style of a research paper with the aim of submitting this for publication. Journals will be reviewed for their suitability, and their potential impact considered. Open access options will also be explored to enable increased access to the paper. • The results will be shared with relevant Chest, Heart & Stroke service users and staff (i.e., within the Long Covid pathway/Advice Line), the NHS Lothian MACH service, and any other relevant organisations outwith Scotland that helped with recruitment. This will include a report written in plain English. • As mentioned, the research findings will be shared as a plain English summary to research project participants. • Opportunities to present the findings at conferences will be sought, including through liaising with research leads for relevant health boards.

Section 2: Security-sensitive material

The Terrorism Act (2006) outlaws the dissemination of records, statements and other documents that can be interpreted as promoting or endorsing terrorist acts.

Q12. Does your research involve the storage on a computer of any such records, statements or other documents?

☐ Yes ☒ No (if you answered no to this question please jump to section 3)

If "yes" - Please type 'Yes' to indicate that you agree to store all documents on that file store

Q**13. Might your research involve the electronic transmission (for example, as an email attachment) of such records or statements?**

☐ Yes ☒ No

If "yes" - Please type 'Yes' to indicate that you agree not to transmit electronically to any third party documents stored in the file store

Q14. Will your research involve visits to websites that might be associated with extremist, or terrorist, organisations?

☐ Yes ☒ No

If "no", please proceed to Question 15.

If "yes" - You are advised that such sites may be subject to surveillance by the police. Accessing those sites from University IP addresses might lead to police enquiries. Please type 'Yes' to acknowledge that you understand this risk

By submitting to the ethics process, you accept that your School Research Ethics Officer and the convener of the University's Compliance Group will have access to a list of titles of documents (but not the contents of documents) in your document store. *Please type 'Yes' to acknowledge that you accept this.*

Please confirm that you have contacted your School Research Ethics Officer to discuss security-sensitive material by ticking 'Yes'

☐ Yes, I have contacted my School's Research Ethics Officer

☐ No, I have not contacted my School's Research Ethics Officer

Section 3: Copyright

Q15. Does your project require use of copyrighted material?

☐ Yes ☒ No

If "yes" please give further details

Section 4: Good conduct in collaborative research

Q16. Does your project involve working collaboratively with other academic partners?

☐ Yes ☒ No (if you answered no to this question please jump to section 5)

If "yes" - Is there a formal agreement in place regarding a collaborative relationship with the academic partner(s)?

If "no" - Please explain why there is no formal agreement in place

Q17. Does your project involve working collaboratively with other non-academic partners?

☒ Yes ☒ No

If "yes" - Is there a formal agreement in place regarding a collaborative relationship with the non-academic partner(s)?

If "no" - Please explain why there is no formal agreement in place.

Q18. Does your project involve employing local field assistants (including guides/translators)?

☐ Yes ☒ No

If "yes" - Is there a formal agreement in place regarding the employment of local field assistants (including guides and translators)?

If "no" - Please explain why there is no formal agreement in place

Q19. Will care be taken to ensure that all individuals involved in implementing the research adhere to the ethical and research integrity standards set by the University of Edinburgh?

☒ Yes ☐ No

If "no" - Please explain why care will not be taken

Q20. Have you reached agreement relating to intellectual property?

☒ Yes ☐ No

If "no" - Please explain why you have not reached agreement

Intellectual property will be held by the lead researcher, Andrea Clark, and the University of Edinburgh.

Section 5: Good conduct in publication practice

In publication and authorship, as in all other aspects of research, researchers are expected to follow the University's guidance on integrity. https://www.ed.ac.uk/governance-strategic-planning/content-to-be-removed/research-integrity. By ticking yes, you confirm that full consideration of the items described in this Section will be addressed as applicable

☒ Yes ☐ No

If you intend to collect new data, please continue completing the Level 2 application in the next page.

If you are NOT collecting any new data, you have now completed the Level 1 application. Please submit this document alongside all attachments to ethics.hiss@ed.ac.uk .

LEVEL 2 ONLY – Participant Risk and Information

The following Sections are to be completed if you are collecting new data. Please do not complete it if you are using existing data.

Section 6: Potential risks to participants and researchers

Q21. Is your research project likely or possible to induce any psychological stress or discomfort in the participants or others, indirectly associated with the research?

☒ Yes ☐ No

If "yes" state the types of risk and what measures will be taken to deal with such problems

Due to the nature of the research interview, which focuses on people's experiences of receiving mental health and/or psychological input in relation to their Long Covid, there is a chance that research participants will find some topics covered sensitive or upsetting, thereby inducing psychological stress or discomfort. This is deemed to be of low to medium risk, particularly as people with Long Covid live with these experiences in their daily life. Should a research participant become distressed or uncomfortable during the interview process, they will be asked if they wish to take a break from the interview, or discontinue with the interview altogether. The debrief following the research interviews will signpost research participants to relevant support organisations.

It is important to note that while topics may cause stress or discomfort, the research interview experience may also be a positive experience for people with lived experience of Long Covid, due to being provided with the chance to share their experiences and perspective, which may not often occur within the context of research.

As participants will have Long Covid, and at a higher risk of experiencing fatigue during the interview, they will be reminded that they are welcome to take breaks at any stage of the interview, or finish the interview at any point.

The researcher has training in managing distress.
'

Q22. Does your research project require any physically-invasive or potentially physically harmful procedures?

☐ Yes ☒ No

If "yes" give details and outline procedures to be put in place to deal with potential problems.

Q23. Does your research project require the use of privacy-invasive technology, such as CCTV, biometrics, facial recognition, vehicle tracking software?

☐ Yes ☒ No

If "yes" - Give details and outline procedures to be put in place to deal with potential problems.

Q24. Does your research project involve the investigation of any illegal behaviour or activities?

☐ Yes ☒ No

If "yes" - Give details of any illegal behavior or activities you may investigate

Q25. Is it possible that your research project will lead to awareness or the disclosure of information about child abuse or neglect?

☐ Yes ☒ No

If "yes" - Indicate the likelihood of disclosure and the procedures to be followed if you become aware that a child has been or may be at risk of harm

Q26. Is it likely that dissemination of research findings or data could adversely affect participants or others indirectly associated with the research?

☐ Yes ☒ No

If "yes" - Describe the potential risk for participants/data subjects of this use of the data. Outline any steps that will be taken to protect participants.

Participants' quotes may be used in the researcher's thesis and in other published materials (e.g., journal article, conference paper); however, participants' names will be changed throughout and any other identifying information (e.g., NHS service name or area the participants lives in) will be redacted from quotes, where applicable.

Q27. Could participation in this research adversely affect participants and others associated with the research in any other way?

☐ Yes ☒ No

If "yes" - Describe the possible adverse effects and the procedures to be put in place to protect against them.

As mentioned in Q21, the interview may increase the chances that participants will experience fatigue and/or distress related to taking part in the interview. However, no significant adverse effects are anticipated.

Q28. Is this research expected to benefit the participants, directly or indirectly?

☒ Yes ☐ No

If "yes" - Give details of how this research is expected to benefit the participants.

There are no direct benefits to research participants taking part in this study. However, in terms of indirect benefits, participants may feel positive about their contribution to Long Covid research and/or in sharing their experiences and perspective on lived experience of Long Covid/a long-term health condition and receiving input for this.

Q29. Will the true purpose of the research be concealed from the participants/data subjects?

☐ Yes ☒ No

If "yes" - Explain what information will be concealed and why.

Q30. Will participants/data subjects be debriefed at the conclusion of the study?

☒ Yes ☐ No

If "no" – Why will participants / data subjects not be debriefed?

A debrief will include the researcher providing the names and contact details for relevant support organisations.

Q31. At any stage in this research could researchers' safety be compromised, or could the research induce emotional distress in the researchers?

☒ Yes ☐ No

If "yes" - Give details and outline procedures to be put in place to deal with potential problems.

It is possible that experiences shared by research participants in one-to-one interviews will induce emotional distress in the researcher. The researcher is a Trainee Clinical Psychologist who is on a semi-regular basis subject to information of a distressing nature being shared and who is able to seek supervision and/or support from multiple staff members at the University of Edinburgh, including Academic Supervisors, NHS Field Supervisor, clinical tutor and Line Manager.

In terms of physical safety, research interviews will take place on a video call platform (Microsoft Teams) or if necessary, by telephone call interview, and so no physical risks will be present.

Please tick to confirm you agree with the following:

I will adhere to School guidance on risk assessment and health and safety and will seek advice on project and travel insurance prior to project commencement.

☒ I agree

☐ I do not agree

☐ Not applicable

Section 7: Participants and data subjects.

Q32. How many participants or data subjects are expected to be included in your research project?

Purposive sampling will be used to recruit up to 12 people with Long Covid. Smith, Flowers and Larkin (2022) recommend that between six and ten interviews are adopted for a professional doctorate. Up to 12 participants has been chosen as an upper limit for recruitment, which would allow for 3-4 participants to be recruited within each section of the sampling grid (which includes age category, IMD and type(s) of services accessed).

IPA is noted as being an approach which benefits from engagement with a small sample in order to explore in-depth accounts fully.

Q33. What criteria will be used in deciding on the inclusion and exclusion of participants/data subjects in your research project?

Inclusion criteria:

- Aged 18 years old or over;
- Currently living in the U.K.
- Has experienced symptoms of Long Covid for a period of 12 weeks or longer;
- Has been told they have Long Covid by a healthcare professional;
- Was not hospitalised in relation to their Covid-19 infection(s);
- Has received individual sessions with a psychologist or other mental health professional (e.g., counsellor or mental health nurse) in an NHS service in relation to having Long Covid;

Exclusion criteria:

- Non-English speaker
- Unable to provide informed consent.
- Were hospitalized in relation to their Covid-19 infection(s)
- Have not received input from a psychologist or other mental health professional in relation to their long Covid
- Have not received a diagnosis of Long Covid from a healthcare professional
- Have experienced symptoms of Long Covid for less than 12 weeks

Q34. Are any of the participants or data subjects likely to be under 16 years of age?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q35. Are any of the participants or data subjects likely to be children in the care of a Local Authority?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q36. Are any of the participants or data subjects likely to be known to have additional support needs?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q37. In the case of participants with additional support needs, will arrangements be made to ensure informed consent?

☐ Yes ☐ No ☒ N/A

If "yes" – What arrangements will be made?

If "no" – Please explain why not

Q38. Are any of the participants or data subjects likely to be physically or mentally ill?

☒ Yes ☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Inclusion criteria for the research includes participants having been informed that they have Long Covid. It is possible that research participants will have a mental health diagnosis and/or challenges with their mental health or wellbeing, either as existing issues or following their experience of living with Long Covid. Participants may also be living with other long term physical health conditions or symptoms in addition to those associated with Long Covid.

Q39. Are any of the participants or data subjects likely to be vulnerable or likely exposed to harm in other ways?

☐ Yes ☒ No

If "yes" - Explain and describe the nature of the vulnerability and the measures that will be used to protect and/or inform participants/data subjects.

Q40. Are any of the participants or data subjects likely to be unable to communicate in the language in which the research is conducted?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q41. Are any of the participants or data subjects likely to be in a relationship (i.e., professional, student-teacher, other dependent relationship) with the researchers?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q42. Are any of the participants or data subjects likely to have difficulty in reading and/or comprehending any printed material distributed as part of the study?

☒ Yes ☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Due to symptoms of Long Covid (e.g., cognitive difficulties or "brain fog", profound fatigue, etc.)., some prospective participants might find it more challenging to read and comprehend printed material (e.g., flyer, participant information sheet, consent form). Measures have been taken to provide plain English documents, which include the use of headings, bullet points, visuals and shortened sentences. During the initial phone call, the researcher will offer to go through the information sheet and consent forms verbally, if preferred by participants.

Q43. Describe how the sample will be recruited.

1. 1. Contact will be made with the Project Manager and Advice Line Nurses within the Long Covid Pathway at Chest, Heart & Stroke Scotland (CHSS) (see Email for CHSS attached). This email contact will include the Participant Information Sheet and flyer. Should recruitment rates via CHSS be low, the researcher will make contact Long Covid support groups, including Long Covid Scotland, a volunteer-led charity supporting those with Long Covid. In addition, study information will be shared on social media platforms, such as 'X', Bluesky, Facebook and Instagram. Third sector organisations and social media accounts relevant to people living in England, Wales and Northern Ireland will also be contacted. This will include organisations such as the M.E. Association (which reaches individuals with Long Covid) and voluntary organisations such as Long Covid Support.

2. The researcher will attend meetings and/or peer support groups within the organization(s) mentioned above to share information on the study and answer any questions about the research. Staff at CHSS will be encouraged to mention the study with people who access the Long Covid Pathway. In terms of Long Covid support groups, such as Long Covid Scotland, the researcher will email the organization(s) and request that study information is shared with its group members, as described below.

3. An easy-read flyer and Participant Information Sheet (both attached) describing the research, including the study's recruitment criteria, will be shared with the above contacts. The flyer includes a link and QR code for a brief online screening survey (see link here: https://bit.ly/SurveyLC) as well as the researcher's contact details.The flyer will be shared on social media.

4. People who are interested in the study will be invited to complete the brief online screening survey. This will allow them to: 1) confirm that they meet the criteria for taking part in the study, and 2) register their interest in taking part in the study and 3) provide brief details about themselves. In relation to the latter, respondents will be asked to provide their first name and email address, which allow the researcher to contact them. In addition, respondents will be asked to provide further information about themselves, including their age category (e.g., 18-29 years old), postcode (which will be used to calculate their Index of Multiple Deprivation, IMD), and the types of psychology and/or other mental health support services accessed. The brief online survey contains its own specific consent form, which respondents must complete before they can provide these personal details.

The purpose of asking for these personal details is to allow the researcher to purposively sample participants for the study based on these three characteristics/experiences, including age category, IMD and types of services accessed. Respondents are informed of this within the Participant Information Sheet and brief online survey, including that the information they provide will be used to select participants for the research study to ensure that people with range of experiences and characteristics will be invited to participate in the research study.

5. Individuals who register their interest in the study will be contacted by email to confirm that they are being invited to take part in the research study (see Email for prospective participants attached) or to inform them that they are not being invited to take part in the research study due to reaching capacity. (An interim email may be sent to let people know that the researcher will get back in touch with them as soon as possible to let them know the outcome). Participants who are invited to take part will receive the main study consent form as an attachment. They will be asked to provide a telephone number to be contacted for the pre-interview telephone call and will be given the opportunity to provide the best time to be contacted.

6. During the pre-interview telephone call, the person's eligibility to take part in the study will be confirmed, the participant will be given the opportunity to ask any questions they may have, verbal consent will be audio recorded, and further details will be collected (including ethnicity, gender, age category, date of initial Covid illness, onset of symptoms, duration of Long Covid, whether they have other physical health conditions, support services accessed and their Long Covid symptoms). A suitable time will be arranged for the research interview during this phone call. At this stage, information about reasonable adjustments to the research interview format (e.g., taking breaks, sharing the questions ahead of time) will be discussed with the participant. Participants will be reminded that they can get in touch with the researcher with any questions they may have.

7. The research interview will take place via video call on Microsoft Teams or, if preferred by the participant, by telephone call, on the pre-arranged date. Participants will be reminded that they can take breaks whenever they wish and/or stop the interview early if preferred. At the end of the interview, participants will be informed that they can get in touch if they wish to share any further reflections which they may have forgotten during the interview (N.B., this is to assist participants who may experience 'brain fog') within 2 weeks from the date of their research interview. At the end of the interview, participants will be offered a list of resources and contacts for support, which can be shared via MS Teams or email (see debrief attached).

Q44. Will participants receive any financial or other material benefits as a result of participation?

☐ Yes ☒ No

If "yes" - What benefits will be offered to participants and why?

Section 8: Participant or data subject information and consent

Q45. Will written or oral consent be obtained from all participants or data subjects?

☒ Yes ☐ No

If "yes" – attach participant information sheet and consent form and detail the process you will follow.

If "no" – explain why not and what process you will follow regarding consent, or if consent cannot or should not be sought for some reason, please provide a clear case and rationale for this (e.g. in international contexts where speaking to foreign researchers is prohibited).

People completing the brief online survey will be asked to complete a short consent form. Verbal consent for taking part in the study will be also sought on the telephone call, prior to beginning the individual interviews with participants. Prior to the telephone call, prospective participants will have received an email with the consent form attached, giving them time to review this before informed consent is sought.

Q46. Have you made arrangements to tell participants what information you will hold about them and for how long?

☒ Yes ☐ No

If "yes" - what arrangements have been made?

This information has been provided in the participant information sheet (see attached).

If "no" – why not?

Q47. Have you made arrangements to tell participants whether you will disclose the information to other organisations?

☐ Yes ☐ No ☒ N/A

If "yes" - What arrangements have been made?

If "no" – why not?

Q48. Have you made arrangements to tell participants whether you will combine that information with other data?

☐ Yes ☐ No ☒ N/A

If "yes" - What arrangements have been made?

Q49. In the case of children participating in the research, will the consent or assent of parents be obtained?

☐ Yes ☐ No ☒ N/A

If "yes" - Explain how this consent or assent will be obtained

If "no" – Please explain why you won't be obtaining consent

Q50. Will the consent or assent of children participating in the research be obtained?

☐ Yes ☐ No ☒ N/A

If "yes" - Explain how this consent or assent will be obtained

If "no" – Please explain why not

Q51. In the case of participants who are not proficient in the language in which the research is conducted, will arrangements be made to ensure informed consent?

☐ Yes ☐ No ☒ N/A

If "yes" – What arrangements will be made?

If "no" – Please explain why not

Q52. Does the activity involve using cookies or tracking individual's activity on a website or the Internet in general?

☐ Yes ☒ No

If "yes" – Describe the arrangements you have put in place to obtain informed consent for the use of these tools

You have now completed the Level 2 application. Please submit this document alongside all attachments to ethics.hiss@ed.ac.uk .

Appendix 13c Ethics Confirmation Email

From: HiSS Research Ethics
Sent: 05 December 2024 10:08
To: Andrea Clark Subject:
Re: 23-24CLPS054 - Amendment to doctorate research
Dear Andrea,

Thank you for your Amendment application. Based on your responses the amendment meets the standards for favorable opinion from Clinical Psychology. The signed ethical response sheet/application is attached. If you need to make any changes to the study, you should return an amendment form to new ethics mailbox (ethics.hiss@ed.ac.uk) with the changes clearly noted in the relevant section of the form.

This is the perfect time to pre-register your study on OSF (Open Science Foundation): https://osf.io/dashboard You put a lot of time in your application and provided us with many details of your study, which could make preparing a pre-registration quite quick! To help this process, we mapped the forms and made suggestions regarding which sections of the form of our committee might contain the relevant information to the different sections of the pre-registration forms. You can find these enriched templates for quantitative and qualitative studies on the HiSS Research Ethics website: Ethics and Integrity | The University of Edinburgh Preregistration is the practice of registering the hypotheses, methods, and/or analyses of a scientific study before it is conducted and involves creating a time-stamped record of the study and analysis plan. So, when you preregister your research, you're simply specifying your research plan in advance of your study and submitting it to a registry. Pre-registration of studies is to be uploaded before you start any data analysis. That means that you can submit the pre-registration while you are collecting data. If anything should change, you can also update the pre-registration before starting the analyses. Why would I want to pre-register my study? See a list of benefits here: Ethics and Integrity | The University of Edinburgh

Good luck with your project.
Best wishes,
Zsofia
Dr Zsofia Garai-Takacs
Lecturer in Applied Psychology Ethics & Integrity Lead

Appendix 14 Post-interview Debrief Information

Post-interview debrief information

Thank you very much for taking part in this research project. Your time and contributions are greatly valued by Andrea Clark and the University of Edinburgh.

Here is a list of resources people with Long Covid have shared with the researcher (Andrea Clark) as having been useful for them, some of which you may have already come across:

- **Nuffield Health Long Covid Recovery Programme** – a free service and is a 12-week programme – https://www.nuffieldhealth.com/about-us/our-impact/healthy-life/covid-19-rehabilitation-programme
- **Breathing exercise (YouTube):** https://youtu.be/YGXCPvzbnCA?si=lywDjd5SBzNBWUtm
- **Chair based pilates exercise video:** https://www.nhs.uk/conditions/nhs-fitness-studio/pilates-and-yoga/chair-based-pilates-exercise-video/
- **Asthma + Lung UK** – https://www.asthmaandlung.org.uk/conditions/long-covid
- **The Rest Room Podcast** – not specifically for Long Covid but deals with living with chronic illness.
- **Mind** – https://www.mind.org.uk/
- **Mental Health Foundation –** https://www.mentalhealth.org.uk/

Specific to people living in Scotland:

- Chest, Heart and Stroke Scotland -- Long Covid - Chest Heart & Stroke Scotland (chss.org.uk)
- Information and advice on Long Covid (plus information on the NHS Greater Glasgow & Clyde service): https://www.nhsggc.scot/your-health/covid-19/long-covid-service/
- Life Link – https://www.lifelink.org.uk/

Specific to people living in England and Wales:

- Long Covid Support - https://www.longcovid.org/ (this includes information and different peer support groups)

Specific to people living in Northern Ireland:

- Long Covid Support Group Northern Ireland (peer support).

Should you wish to withdraw your data from the research study, you have a 2-week period from the date of your interview to request its withdrawal by emailing the lead researcher, Andrea Clark at

If you have any further questions about the study, please contact the lead researcher, Andrea Clark at . Similarly, if you remember something you would like to share after the reseach interview has taken place, you are welcome to share this information by email within a 2-week period from the date of your research interview.

If you requested a summary of the findings while completing the consent form, we will share this with you via email in due course. If you no longer wish to receive this, you can request to be removed from the mailing list at any time by contacting .

If you would like to discuss this study with someone who is not involved in the study, please contact (Lecturer in Clinical Psychology).

If you wish to make a complaint about the study, please contact:
Professor Matthias Schwannauer, headofschool.health@ed.ac.uk

Appendix 15 Transcript Example

Experiential statements	**Transcript**	**Exploratory notes (orange = descriptive; blue = linguistic; green = conceptual)**
Emotional resilience was tested during the wait period for psychology support (p3) Experiences a shift from certainty and relief ("I was in the system") to devastation and desperation when confronted reality of long wait (p3) Feels significant disappointment when her understanding of the process misaligns with the service's communication. (p3) A desperate plea for more immediate support is met with a response she perceives as insufficient given the intensity of her need. (p3) The need for support felt essential and time-sensitive in nature. (p3)	P: Oh, I see. Yeah – really tough. Um so once I was triaged, I spoke a trainee clinical psychologist and she offered me – or she went through a lot of questions – em and told me what my scores were at that point, which was moderate to severe anxiety and depression, em and that she would go away and speak to her team and then come back to me with, you know, what would happen next. So at that point, I thought (emphasised) in my head that I was *in* the system, I was going to get the support um, and she was going to go away and then come back and tell me that, you know, therapy was going to start or whatever it was was going to start. But when she came back to me and said "You will receive one-to-one CBT therapy but the waiting lists are 14-16 weeks", I was – sort of, I, I think, I'm not sure if devastated is is is too strong a word, but I was so (emphasised) disappointed, because I was so desperate at that time. And I remember just thinking 'I just can't, I need this now, I can't wait'. So, I said to her, what, you know like "really, is there anything that you can offer me in in	Difficult length of wait period between triage and 1st appointment. "really" – emphasises impact. Informed of long wait time, went against expectations "I thought", "in my head" – indicates her understanding/expectations/assumption; "devastated" "disappointed"– emotional toll highlighted. Experienced desperation for support. Shift from certainty ("I was in the system") to devastation/disappointment shows rupture in her narrative. Mismatch in understanding in communication with service led to significant level of disappointment. "I just can't", "need this now, I can't wait" – desperation / need. Short phrasing – unelaborated, urgency, possible overwhelm? "Just" – like limit reached. Sense of need / essential / time-sensitive nature of the need for support without delay.

Takes back agency out of necessity, feeling forced to seek private therapy — while aware that access depended on privilege (p4) Private therapy met her needs before NHS support became available, making the latter feel too late for meaningful intervention. (p4)	between, like is there is there any sort of other charity support or anything that I c- you know, anything?". She, she just said "not really" but she was going to go away again and see if there was anything extra – or additional – that she offer, but there wasn't so she sent me a couple of – I think it was a couple of em sort of webinars on sleep or anxiety or something like that. So, I had to take matters into my own hands at that point, and I was lucky that my mum agreed to pay for some private um psychotherapy. R: Okay, so that was started before you received the first appointment for the NHS? P: Yes, so I had 6 months of appointments with the private Clinical Psychologist before I heard back from the NHS therapy services. Um, and by the time I saw the CBT therapist uh, my anxiety and depression scores were pretty much back to normal, maybe slightly, mild. Um so it was, yeah! Most of the work had been done if you know what I mean.	Asks trainee CP for alternative or interim support. "really" – sense of pleading or dissatisfaction. Sense of grasping for support. Support was essential and time-sensitive, cannot wait. Trainee CP initially said no interim support available, then provided webinars. "Just said" – indicates perceived this as dismissive and/or it felt insufficient? "or something like that" – indicates low impact. Sense of being offered an insufficient response to request for support which is time-sensitive/essential to her. Decided to pursue private psychotherapy as a result "So" – indicates action taken as a result. 'Had to take matters into own hands – taking back control / agency. 'Had to' – necessity not by choice. Possibly indicating sense of being forced to. 'lucky' – indicates perceived inequity in access / awareness of privilege. Takes back agency as a result, out of necessity

	R: Yeah, yeah..	Waited for 6 months for NHS therapy, during which time she accessed private support; anxiety/depression had reduced by the time NHS care began. 'most of the work had been done' – private healthcare had met her needs in this time? Sense that the window for meaningful intervention had then passed. Diminished need for the NHS care; needs had been met by private care.

Appendix 16 Example PETs development