**Holding the Hope? Therapist and Client Perspectives on Long Covid Recovery: A Q-Methodology**

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Thesis submitted in partial fulfilment of the requirements of Staffordshire University for the degree of Doctorate in Clinical Psychology

April 2023

Total word count (excluding references and appendices): 18,549

**THESIS PORTFOLIO: CANDIDATE DECLARATION**

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| --- | --- |
| **Title of degree programme** | Professional Doctorate in Clinical Psychology |
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| **Initial date of registration** | October 2020 |

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| **Declaration and signature of candidate** |
| I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.  I confirm that the decision to submit this thesis is my own.  I confirm that except where explicitly stated, the work has not been submitted for another academic award.  I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.  A pair of glasses  Description automatically generated with medium confidence  Signed: Date: 21/04/2023 |

**Acknowledgments**

This thesis would not have been possible without the support and guidance of many people. Thank you to the professionals and people with lived experience who shared their thoughts and experiences with me at the outset of this project. I hope I have represented you well.

Thank you to the services involved in this study. From the study’s inception, you have been enthusiastic in your support and very helpful with recruitment. I had the privilege of being placed within the local IAPT services and know how hard you work on a day-to-day basis. I have been inspired by your efforts to be responsive to local needs and I am grateful to you for finding some time for me and this project.

Thank you also to my research and clinical supervisors. This thesis would not have been possible without your thorough feedback, dedicated time, and support with both personal and academic issues. I have benefited greatly from your direction, wisdom and listening ears.

I have also been fortunate to be part of a very supportive university cohort – the ‘covid year’. We have faced some unique challenges together and I am grateful for your persistent source of warmth and comfort.

I am grateful also to my husband, family, friends, and cats. Outside of this process, you have offered me the belongingness, normality and respite I have needed and I am lucky to have you in my life.

Finally, a special thank you to the participants of this study. For therapists, I know how precious every working moment is and I appreciate you sharing them with me. For those of you living with Long covid, I sincerely appreciate your time contributing to this study, despite the physical and psychological challenges you may have endured. I am hopeful that this project, in some small way, helps continue the conversation around Long covid and broader chronic illnesses. I wish you strength on your journey with recovery, however you choose to define it.

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# **Thesis Abstract**

The aim of this thesis is to explore the role of psychological understanding and support for people living with Long covid in the United Kingdom. It is made up of three components in pursuit of this aim, including a synthesis of literature pertaining to psychological wellbeing and Long covid; an empirical study exploring recovery from Long covid, and an executive summary which presents these findings to the target groups.

Paper One is a literature review which synthesises current literature pertaining to Long covid and its potential impact on mental health and wellbeing. It utilises Ryff’s model of psychological wellbeing as a tool to formulate and understand the distress experienced by people living with the illness. The literature used is largely qualitative, representing the voices of those living with Long covid. The quality of the research is assessed using the Critical Appraisal Skills Program (CASP) qualitative checklist, alongside the Mixed-Methods Assessment Tool. Clinical implications and future research recommendations are then made.

Paper Two is an empirical study, reporting on the results of research into Long covid using Q-Methodology. This study consists of two sets of participants: therapists working within a Long covid Hub, and service users who had received talking therapies for Long covid. Their responses are analysed using factor analysis and compared within and between subjects, using participants’ qualitative feedback to give context to their perspectives. From the factor analysis, four key statements arose including *Psychological Pathways to Recovery*, *Social Context and Agency*, *Physiological Recovery Goals* and *Personal Meaning Making*. These factors are considered within a Hope theory framework, with clinical implications and recommendations for future research offered.

Paper Three is an executive summary designed to summarise the findings of the research project. This will be shared with local services, the sponsoring Trust, and interested client groups.

Paper One: Literature Review

**Psychological Wellbeing and Long covid: A Literature Review**

Will Burton-Fisher

April 2023

**Word Count: 7631**

**(Including abstract, excluding title page, references and appendices)**

**Literature review has been prepared for publication in the Clinical Psychology Review. Author guidelines can be found in Appendix A.**

## Abstract

**Introduction:** Long covid is a condition characterised by symptoms including breathlessness, loss of sense of smell or taste, chronic fatigue, headaches and muscle pain. Symptoms, which persist for weeks or months, have a high psychological and economic burden on the individual and nation. Psychological support is offered to people with Long covid through NHS ‘Long covid hubs’, but specific treatment approaches are not yet well understood. This literature review seeks to contribute to the evidence base by thematically synthesising available evidence using Ryff’s model of Psychological Wellbeing.

**Method:** Studies into Long covid were selected from several databases and were included if they referenced psychological wellbeing/mental health and Long covid. After screening, included studies were critically appraised and their data synthesised to consider the relationship between psychological wellbeing and Long covid.

**Results:** Twelve studies were included and had varying degrees of quality. Research generally used digital recruitment and participation methods, which limited the ecological validity of the samples. Applying findings to Ryff’s Psychological Wellbeing model indicated significant conceptual overlap between the six domains (autonomy, environmental mastery, personal growth, positive relations, purpose in life, self-acceptance), yet offered a pragmatic framework for understanding Long covid.

**Recommendations:** It is recommended that future research explores the concept of hope and relationships between therapist and clients in further detail. A number of therapeutic interventions are suggested for further investigation.

## Introduction

The Covid-19 pandemic has been the most significant global health emergency in a generation, causing symptoms such as sore throat, cough, high temperature, headache, muscle pain, fatigue, loss/change of sense of smell and taste and breathlessness (Struyf et al., 2022). For the clinically extremely vulnerable (e.g. older adults or those with physical health problems such as diabetes), severe and fatal infection becomes more probable (Wolff et al., 2021). At the time of writing, around a third (21 million) of United Kingdom citizens have been infected with the virus, and almost 200,000 people have died of the disease (Gov.uk, 2022). Whilst vaccination programmes have greatly reduced the number of Covid-19 related fatalities (e.g., Harris & Scwartzbaum, 2021; Passarelli-Araujo et al., 2022; Rearte et al., 2022), another more chronic symptomatology coined ‘Long covid’ persists.

### Long covid

The term ‘long covid’ originally emerged in 2020, from people who were experiencing prolonged symptoms which were unrecognised by health professionals (Callard & Perego, 2020). These chronic symptoms mirror the acute stage (or ‘short covid’) of the disease, including breathlessness, loss of sense of smell or taste, chronic fatigue, headaches, muscle pains and reduced libido (Carfi et al., 2020; Subramanian et al., 2022).

Debate exists within the scientific community regarding long covid’s veracity. For instance, the National Institute of Health Research’s research review (NIHR, 2021) found evidence that Long covid may in fact represent four different conditions, namely post-ICU syndrome, long-term organ damage, post-viral syndrome, and the novel condition termed ‘Long covid’. The National Health Service have demarcated long covid (or Post-Covid-19 Syndrome) as a persistence of symptoms for twelve or more weeks, with periods shorter than this being referred to as ‘ongoing symptomatic COVID-19’ (NHS, 2021).

However, research is yet to fully employ these criteria, with many allowing for self-diagnosis. This poses a problem for scientific rigour, in that any two studies might operationalise ‘long covid’ differently. Nevertheless, the literature so far indicates that long covid, in its various guises, may have myriad negative implications.

From an economic and workforce perspective, an estimated two million people experience Long covid in any given four-week period (Office of National Statistics, 2022), pushing over 120,000 people into long-term sickness and at least 80,000 people into unemployment (Reuschke & Houston, 2022). Beyond the headline costs to the economy of £8 billion in 2022 alone (Institute for Public Policy Research, 2022), the reduction of workforces across sectors (for instance, healthcare workers; ONS, 2021) poses a threat to the safe functioning of public services.

From a more personal perspective, the debilitating physical symptoms of long covid are negatively impacting people’s mental health. Whilst short covid might pose less of a threat to psychological wellbeing (Bourmistrova et al., 2022), those with long covid are at a comparatively higher risk (Fancourt, Steptoe & Bu, 2022). Research into this disparity is in its infancy, but early indications suggest that the debilitating nature of long covid increases mental health problems by reducing quality of life (Malik et al., 2021).

### Risk Factors for Long Covid

Risk factors associated with a lower quality of life, and its implications for long covid, must therefore be considered. A recent review of 73 studies implicated numerous biopsychosocial risk factors, such as being female, experiencing discrimination, being socially isolated, having previous traumatic experiences, and having a higher severity of Short Covid (Thye et al., 2022). Thus far, the found gender differences (with men more likely to experience short covid, and women more likely to experience long covid), have centred around the idea that the female immune response is stronger (Sylvester et al., 2022).

However, this does not explain the found influences of social malaises, or the potential interactions between risk factors. For instance, it is well documented that women face more structural oppression than men, are more frequently the target of abuse, and more often work in public-facing caring roles which might increase their risk of Covid-19 infection (Andrew et al., 2021; ONS, 2020). If, as the evidence suggests, such factors influence the risk for long covid, further exploration of these non-biological factors is warranted. The aim of this literature review is to contribute to this broader knowledge base, by exploring these psychosocial aspects.

### The Psychology of Long covid

Whilst research suggests that people with long covid are more likely to experience depression, anxiety and post-traumatic stress disorder (Huang et al., 2021; Janiri et al., 2021), the finer details are less understood. For instance, it is unclear what specific illness experiences (e.g. fatigue; Fava et al., 2014) might be contributing to psychological distress. No known review has yet sought to understand these intricacies, meaning there is limited guidance for psychological practitioners supporting those with long covid.

This has not prevented a rapid provision of psychological treatment. In recognition of long covid’s multi-systemic presentation, the UK health service has developed ‘long covid hubs’, which seek to offer treatments from a range of disciplines including psychology, pharmacology and occupational therapy (National Health Service, 2021). It is hoped that these multi-faceted hubs can support people with long covid holistically, so that their wellbeing and quality of life improve (Harenwall et al, 2021).

### Wellbeing

Definitions of wellbeing must therefore be considered, which has historically proven difficult. Theories have varyingly regarded wellbeing as the presence of happiness and positive emotions (Bradburn, 1969), a subjectively defined satisfaction with life (Diener et al., 2018), or a combination of these factors (Tennant et al., 2007). Whilst the scales typically used to measure these conceptualisations of wellbeing (e.g. the Satisfaction with Life Scale; Larsen, et al., 1985**,** Warwick Edinburgh Mental Well Being Scale; Tennant et al., 2007) may be useful for population studies, their definitions may be less useful in retrospective literature reviews such as the present. With the goal of offering a framework for understanding wellbeing in long covid, a more robust and detailed conceptualisation appears appropriate. For this reason, the model selected for use in this review is Ryff’s (1989) Psychological Wellbeing model.

### Psychological Wellbeing

Ryff’s psychological wellbeing model, influenced by Maslow’s self-actualisation (1943), Erikson’s psychosocial stages of development (1950) and Rogers’ fully-functioning person (1963), seeks to offer a practitioner-informed framework to understand “What [it] mean[s] to be well psychologically” (Ryff & Keyes, 1995, p. 719). Through a process of synthesis and factor analysis, Ryff proposed a six-factor solution for this question. These dimensions, detailed in table 1, include: Personal Growth; Autonomy; Environmental Mastery; Self-Acceptance; Positive Relations with Others and Purpose in Life (Ryff & Keyes, 1995; Ryff & Singer, 1996).

**Table 1**

*The Six Dimensions of Psychological Wellbeing: Adapted from Ryff & Keyes (1995)*

|  |  |
| --- | --- |
| **Dimension** | **Definition** |
| Autonomy | Having self-determination, independence, the ability to act in one’s own interests and being able to evaluate oneself by one’s own standards (e.g. not heavily relying on the reassurance or support of others) |
| Environmental Mastery | Feeling competent in managing the environment and everyday affairs, such as balancing home and work life. Having the resources available (e.g. finances) to cope with potential stressors. |
| Personal Growth | Having a sense of continuously developing and growing as a person. Being open to new experiences, able to reach one’s potential and seeing improvements in the self over time. Developing more self-knowledge. |
| Positive Relations with Others | Having close, loving and trusting relationships with others. Being able to empathise with and care for others, identifying with people and feeling a sense of intimacy and belonging. Recognising the reciprocal nature of relationships. |
| Purpose in Life | Finding a meaning and purpose to one’s life, having a sense of direction and setting and achieving goals. Having a reason to live and finding meaning in past experiences. |
| Self-Acceptance | Being able to accept ourselves for who we are and having positive attitudes towards ourselves. Recognising that there are multiple, positive and negative aspects of the self. |

In taking a multi-dimensional perspective, PWB can be researched as a whole or of its individual parts, meaning interventions can be targeted appropriately. For instance, research into fibromyalgia suggests that the illness might specifically affect the constructs of self-acceptance, environmental mastery, purpose in life, and positive relationships (Schleicher et al., 2005). As such, interventions to improve these areas of wellbeing (e.g. building self-esteem) might prove effective in managing the psychological consequences of chronic illness.

Despite its practical benefits, PWB and its associated ‘Psychological Well-Being Scale’, which seeks to measure these six domains (Ryff & Keyes, 1995) has had mixed results under empirical scrutiny. Whilst some research suggests that PWB’s factor structure is valid across age, sex, ethnicity and geographical location (Dierendonck et al., 2008; Linley et al., 2009; Opree, Buijzen & Reijmersdal, 2018; Yoo & Ryff, 2019), others have been unable to replicate the six-domain model, arguing there exists considerable overlap in the domains (specifically, personal growth, purpose in life, self-acceptance, and environmental mastery; Springer, Hauser & Freese, 2006).

There is therefore a need to balance the clinical utility of PWB with an awareness of its empirical limitations. This literature review aims to achieve this, by using PWB as a model to formulate wellbeing and long covid, whilst critically analysing the research and model. It is hoped that the subsequent synthesis of findings can be used to inform psychological interventions provided by long covid hubs.

## Method

The topic under review (psychological wellbeing and long covid) was initially identified through discussions with the clinical lead of South Staffordshire’s Improving Access to Psychological Therapies service (IAPT). As a lead service in the local ‘long covid’ hubs, IAPT hopes to understand the relationship between psychological wellbeing and long covid, so that their therapeutic offer can be enhanced and targeted.

A literature search strategy was therefore devised which aimed to identify the experiences and perspectives of people living with Long covid, which could later be formulated within Ryff’s psychological wellbeing framework. To achieve this, research was included based on the following criteria:

* Specifically relates, in whole or in parts, to long covid
* Has reference to psychological wellbeing or mental health
* Is available in the English language
* Cover the period 1st January 2020 – 1st May 2022 (i.e. within the pandemic time frame)

To support this focus on detail, a number of exclusion criteria were employed, including:

* Diagnostic (e.g. depression) prevalence studies
* Studies related to short covid only
* Studies solely focussed on other aspects of the pandemic (e.g. ‘lockdowns’)

### Search Terms

A number of search terms were developed based on existing literature. Alongside the common name ‘long covid’, ‘Post-Acute Sequalae of Covid-19 (PASC) was included as the technical medical term. The asterisk truncation ‘psychol\*’ was used as a broad method of finding relevant terms (e.g. ‘psychological wellbeing, psychological distress’), and ‘mental health’ was selected to provide for studies which did not specifically use psychological terms. Abstracts were the main search area, based on the assumption that studies focussed on this topic would make them prominent.

This resulted in the search string: ((((AB=("Long covid")) OR AB=("Long covid")) OR (AB=post-acute sequalae of Covid 19)) AND (((AB=("Psychol\*")) OR AB=("Mental Health")))).

This search string was then inputted to the following databases: EBSCOHost (covering MEDLINE, CINAHL Plus, APA Psycinfo and Regional Business News); Web of Science, SCOPUS, Google Scholar and OpenGrey, covering peer reviewed papers and grey literature

### Screening

Studies were screened out if they did not meet inclusion/exclusion criteria. Studies which potentially met the criteria but required further investigation were read in full before screening. Remaining studies were read in full according to the same criteria.

### Quality Assessment

Included studies were subjected to a formal, standardised quality assessment. Depending on the nature of the research method, this was either the qualitative checklist of the Critical Appraisal Skills Programme (2018), or the Mixed Methods Appraisal Tool (MMAT, Hong et al., 2018). These tools employ a scoring method of ‘No, Can’t Tell or Yes’ on a range of domains, including consideration of ethical implications, the appropriateness of methodology used and if data analysis was sufficiently rigorous (ibid). Appendices B and C give a full overview of the appraisal tools used. Appendices D and E give appraisal scores for each article. The ‘Quality Appraisal’ section gives a full overview of these findings.

### Publication Bias

It is a known issue that empirical research is subject to a publication bias, where articles finding results considered as significant are more likely to be published than those which are not (Kuhberger et al., 2014). Reviews of literature are therefore subject to these same biases, and may not represent the full array of potential perspectives on a given topic.

## Results

### Search Results

This search method returned a total of 877 records from the named databases. No grey literature met the inclusion criteria. After screening of abstracts and full text readings, 12 studies in total were selected for review. The systematic process is outlined below using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart (2020; Figure 1). Data were extracted from the listed studies and are presented below in the ‘characteristics of included studies’ table (See Table 2)**.**

Diagram

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**Figure 1:** *PRISMA guidelines*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Table 2:** *Characteristics of Included Studies* | **Author; Year & Place** | **Participants** | **Aims & Methodology** | **Main Findings** | **Strengths** | **Limitations** |
| **1** | Kingstone et al (2020)  UK | 24 people self-identifying as having long covid. None hospitalised. | Exploring the lived experience of long covid. Semi-structured interviews via telephone/video call. Thematic analysis with constant comparison. | Uncertainty/hopelessness for recovery Feeling invalidated  Uncertainty acceptable when validated by GPs Loss of meaningful activity Feeling isolated Social media groups as helpful and unhelpful GET as worsening symptoms Pacing activities helpful | First qualitative exploration  Includes experts by experience  Saturation reached  Practical applications (UK)  Divergent perspectives considered | Inconsistent definition of long covid – self definition  Lacking details on ethics (but gained approval)  Potential selection bias |
| **2** | Ladds et al (2020)  UK | 114 Long covid patients, 8 hospitalised. | Understanding Experiences of being a patient with long covid. Narrative interviews and focus groups (telephone or video), thematic analysis informed by clinical insights and sociological theories | Uncertainty of recovery  Loss of meaningful activity  Feeling invalidated  Loss of confidence in career  Guilt for accessing services  Peer groups as helpful (connection and belonging)  Loss of trust in healthcare  Shame and stigma  Varied therapeutic relationships  Self-advocacy | More consistent definition of long covid (3+ weeks persistent symptoms).  Includes experts by experience.  Practical applications (UK)  Multiple rounds of invitations to promote diversity  Use of triangulation  Divergent perspectives considered | Potential selection bias |
| **3** | Buttery et al (2022)  UK | 3290 people with long covid. 12.7% hospitalised. | Patient symptoms and experiences of Long covid. Mixed methods analysis of a UK wide survey (April 2020 – December 2020) | Uncertainty of recovery – cyclical relapse  Loneliness and isolation  Feeling invalidated  Fear of being infectious  Varying healthcare support and gratitude  Loss of meaningful activity  Financial stress/worry | Large scale and rigorous  Compared symptoms with length of onset  Involved experts by experience  Practical applications (UK)  Considers interaction of qualitative and quantitative aspects  Reflection on selection bias | Little detail on recruitment strategy.  Few divergent views represented  Potential selection bias |
| **4** | Humphreys et al (2021)  UK & USA | 18 people living with long covid. None hospitalised. | Long covid and physical activity. Semi-structured telephone interviews, reflexive thematic analysis with semantic coding | Uncertainty for recovery – cyclical relapse  Fear of exercise worsening symptoms  Feeling like a burden on others  Identity changes contingent on previous exercise engagement  Online social groups promoting connectedness | Saturation reached  Reflection on selection bias  Use of experts by experience  Numerous researchers used in a reflexive process  Divergent perspectives considered  Use of triangulation | Inconsistent definition of long covid – self definition  Potential selection bias |
| **5** | Ladds et al (2021)  UK | 43 healthcare workers living with Long covid. None hospitalised. | Healthcare workers’ experiences of long covid. Narrative interviews and focus groups (telephone and video), thematic analysis | Uncertainty for recovery  Social support from colleagues  Loneliness and isolation  Healthcare social identity promoting belonging  Need to feel validated  Dilemma between patient and carer roles  Sense of responsibility to advocate | More consistent definition of long covid (3+ weeks persistent symptoms).  Specific sample of interest useful for comparison  Practical applications (UK)  Use of experts by experience  Use of triangulation | Article signposts elsewhere for in depth ethics and analysis procedures  Potential selection bias |
| **6** | Santiago-Rodriquez et al (2021)  USA | 24 people who have had Covid-19, an unspecified number of which had long covid. 9 hospitalised. | The covid-19 illness experience (including long covid). Thematic analysis of qualitative interviews | Uncertainty for recovery – cyclical relapse  Loss of self and meaningful activity  Fear of stigma (related to HIV status)  Proactive health information seeking | More consistent definition of long covid (3+ weeks persistent symptoms, plus confirmed test)  Saturation reached  Multiple experts consulted  Reflection on selection bias  Triangulation with other experts | Potential selection bias  No consideration of researcher/participant relationship  Difficult to relate to UK healthcare |
| **7** | Taylor et al (2021)  UK | 13 doctors with long covid. Hospital status not recorded. | Doctors’ experience as patients with long covid. Semi-structured interviews via telephone/video. Thematic analysis with inductive and constant comparison. | Uncertainty for recovery  Feeling invalidated  Online groups offering belonging and support  Fear online groups could worsen symptoms  Sharing of medical knowledge with peers  Fear of stigma from health professionals  Accessing healthcare through colleagues  Threat to professional identity  Dual identity as promoting empathy  Growth through contributing to research  Resentment for being put at risk (PPE) | Specific sample of interest useful for comparison  Researchers as experts by experience  Saturation reached  Multiple authors with reflexive analysis  Divergent perspectives considered | Inconsistent definition of long covid – self-definition.  Ethical approval received but otherwise lack of detail  Potential selection bias |
| **8** | Watson et al (2021).  UK based – international cohort | 9,000 users of the ‘absent Covid-19 Smell and Taste Loss Facebook support group. Hospital status not recorded. | The impact of long covid alterations to taste and smell. Thematic analysis of user-generated text on social media | Uncertainty for recovery  Purpose in participating in research  Feeling invalidated  Online groups offering empathy and sense-making  Online groups causing self-comparisons  Medical diagnoses as validating  Loss of control and enjoyment  Negative impacts on social relationships  Change to professional competence | Co-produced with experts by experience throughout collection and analysis  Reflected on selection bias  Use of triangulation  Clear consideration of ethics  Divergent perspectives considered | Inconsistent definition of long covid – self-definition  Potential selection bias |
| **9** | Santarossa et al (2022).  USA based international cohort | 2010 ‘tweets’ about long covid, 490 of which were by people with long covid. Hospital status not recorded. | ‘Narratives of long covid in Twitter. Theme identification and network analysis of user-generated text on social media | Loneliness and isolation  Online groups offering support and belonging  Feeling invalidated  Struggle to access healthcare  Self-advocacy  Loss of employment | Use of public domain data promotes ecological validity  Reflect on selection bias  Multiple authors with reflexive analysis | Inconsistent definition of long covid – self definition  Potential selection bias  Software used limited to 2,500 tweets – unclear if saturation achieved  Ethical approval deemed unnecessary, but lacks ethical considerations  Potential selection bias |
| **10** | Schiavi et al (2022)  Italy | 56 adults discharged from hospital after acute covid with ongoing symptoms | The lived experience of long covid in people who were previously hospitalized. Qualitative telephone interviews with empirical phenomenological analysis | Fear of acute relapse  Uncertainty for recovery  Helplessness for future  Stigma and shame  Fear of infecting others  Loss of interest in previously enjoyed activities  Learning to adapt to new abilities | More consistent definition of long covid (>3 months ongoing symptoms)  Use of reflexive analytical process  Multiple authors use of reflexive analysis  Considered divergent perspectives | Exclusion criteria (e.g. other illnesses) might undermine generalisability  No consideration of researcher/participant relationship |
| **11** | Thompson et al (2022)  USA based  International cohort | 31,892 ‘posts’ on long covid subreddit ‘r/covidlonghaulers’  Hospital status not recorded | Using social media to manage uncertainty of long covid. Social media forum text analysis, using the Meaning Extraction Method | Feeling invalidated  Uncertainty for recovery  Online groups offering support and belonging | Use of public domain data promotes ecological validity  Multiple authors engaged in analysis  Use of factor analysis to identify themes  Reflects on selection bias | Inconsistent definition of long covid – self definition  Ethical approval or considerations not discussed  Potential selection bias  No consideration of researcher/participant relationship |
| **12** | Wurz et al (2022)  Canada based – international cohort | 213 people with long covid. Hospital status not recorded | People’s experiences of living with long covid. Thematic analysis of open-ended survey | Uncertainty for recovery – cyclical relapse  Loss of meaningful activity and occupation  Loss of autonomy  Loneliness and isolation  Exercise worsening symptoms  Feeling invalidated  Inability to work | More consistent definition of long covid (>4 weeks persistent symptoms, with or without a test)  Involved expert by experience  Reflected on selection bias | Divergent perspectives not considered  Potential selection bias |

### Quality Appraisal

Two studies were assessed using the Mixed Methods Appraisal Tool (MMAT, Hong et al., 2018, appendix 2), and ten were assessed using the qualitative checklist of the Critical Appraisal Skills Programme (CASP; 2018, appendix 3).

All studies were regarded as sufficiently rigorous and had clear statements of aims. Half the studies explicitly considered the relationship between researcher and participant, including potential researcher bias or validation by experts by experience. This might reflect the lived experience of some people living with long covid, who have felt unheard within the medical community (Callard & Perego, 2020). Whilst there are advantages to coproduction, such as empowering service users to validate research (Buchbinder, 2010, Jo & Nabatchi, 2018).), there may also be benefits from not taking this approach.

For example, Santarossa and colleagues (2021) collected pre-existing data from social media, rather than seeking it through surveys or interviews. This possibly allowed for more accurate reflections of participants’ beliefs, rather than being influenced by researcher opinions or hypotheses (i.e. demand characteristics; Nichols & Maner, 2010). The combination of naturalistic and co-produced studies might therefore offer general benefits, as a broader range of perspectives are considered.

Most studies followed an ethical approval process, such as via their educational institution or the National Health Service (in the United Kingdom). Instances to the contrary were those which used secondary data, such as posts on social media networks (Santarossa et al, 2021; Thompson et al**,** 2022).Debate surrounds the ethics of using secondary data, and whilst it is generally accepted that ethical approval is not required in such instances, consideration must still be given to a person’s privacy (Stommel & de Rijk, 2021). Indeed, some studies included direct quotes which can be internet searched and traced back to individual posters, meaning further ethical considerations may have been appropriate (ibid.).

Most data also reflected specific demographics, namely White-British, female, self-selecting participants. Females are at a higher risk of contracting long covid (Thye et al., 2022), which might explain their representation here. However, some groups are likely to be underrepresented due to the methodologies used. For example, British social media users are generally younger, have higher levels of education and are more politically liberal than those who do not use social media (Mellon & Prosser, 2017). Older people and those on lower incomes are also less likely to have access to the internet (Choi & Dinitto, 2013; Estacio, Whittle & Protheroe, 2017). As most studies in this review were conducted online, there is a significant chance that these groups are underrepresented.

Studies also defined long covid differently. Some required a positive covid test (Santiago-Rodriquez et al., 2021), others accepted self-definition (Kingstone et al., 2020; Humphreys et al., 2021; Taylor et al., 2021; Watson et al., 2021; Thompson et al., 2022) and some relied on periods of symptom presence, including over three weeks (Ladds et al., 2020 & 2021) or three months (Schiavi et al., 2022). The lack of a standardised definition perhaps represents the time periods in which these studies were undertaken, as the NHS’s definitions (i.e. ‘ongoing symptomatic’ and ‘post-COVID-19 syndrome’) were not operationalised until a year after the pandemic began (NHS, 2021). This means that the reviewed studies might in fact represent different experiences and must be interpreted with flexibility and caution.

Despite these various disadvantages, multiple strengths exist in the current literature. Perhaps the biggest of these is the speed at which participant’s experiences have been recorded, and the number of participants across the studies. The breadth and diversity of opinions this offers enables a thorough and thoughtful analysis.

Analysis of the literature was conducted through a process of thematic synthesis (Thomas & Harden, 2008). Where traditional thematic synthesis involves the line-by-line coding of text to generate themes, the approach for this literature review involved using pre-determined themes (the six dimensions of psychological wellbeing), and an exploration of the data to identify where its content fits within this model. Below is an overview of the findings using this approach.

## Synthesis of Findings

### Autonomy

Autonomy refers to an individual’s independence and ability to make choices important for their wellbeing. Those who score highly on autonomy are more able to evaluate themselves according to their own standards and are less influenced by social pressures (Ryff & Keyes, 1995). Ten of the reviewed studies referred to issues which conceptually fell within this domain.

The most frequent issue in this respect was participants’ attempts to access healthcare. Many participants reported being refused a service, based on the limited medical knowledge of long covid at the time, and the experience of doctors “blaming what they don’t know on anxiety”(Thompson et al, 2022, p. 327; Wurz et al., 2022; Humphreys et al., 2021; Kingstone et al., 2020; Ladds et al., 2020; Ladds et al., 2021; Buttery et al, 2021; Burge-Watson et al., 2021; Santarossa et al., 2022; Taylor et al., 2021). The reports therefore suggest that, where medical knowledge was lacking, doctors often turned to more psychological explanations of disease, which was experienced as an undermining of autonomous help seeking.

It is within this context that many study participants sought support elsewhere. Six of the studies reflect on their participants’ use of social media, as a method of information seeking and social support (Kingstone et al., 2020; Ladds et al., 2020; Humphreys et al., 2021; Taylor et al., 2021; Watson et al., 2021; Santarossa et al., 2022; Thompson et al., 2022). In some instances, these online relationships helped to promote self-advocacy, with advice such as “If someone tells you it’s just anxiety, get up and walk out”(Thompson et al, 2022, p. 327) serving to encourage continued assertion of one’s medical needs. Thus, whilst an absence of medical intervention was disempowering for some; autonomy was maintained for others through social channels.

However, as discussed in the introduction, internet and social media use is not ubiquitous, meaning it is unclear how people might assert autonomy outside of the online context. The results also call into question the validity of autonomy in isolation. In the above examples, participants’ autonomy was contingent on the opinion or validation of another (i.e. healthcare or social groups). Considering this need to be supported, autonomy (i.e. self-validating and acting in one’s own interests; Ryff & Keyes, 1995) may be somewhat fallacious. This issue is considered further in the final discussion.

### Environmental Mastery

If ‘autonomy’ describes a person’s self-determination and self-reliance, ‘environmental mastery’ considers one’s relationship with the external world, such as being able to change situations and having the resources needed to cope with stressors (Ryff & Keyes, 1995). As discussed in the previous dimension, many who were denied medical intervention (i.e. an external resource) maintained a level of wellbeing through autonomous support and advice seeking (e.g. Kingstone et al., 2020; Thompson et al., 2022).

However, multiple studies indicated that participants did not always feel able to change their environment. For instance, some doctors who had contracted long covid (Taylor et al., 2021) felt that a lack of personal protective equipment (PPE; Hoernke et al., 2021) meant they were inadequately protected from the disease. For these doctors, the knowledge that they had been put at risk, and that they could not change their environments to mitigate this, led to feelings of resentment and increased distress.

In contrast, another study of healthcare workers with long covid (Ladds et al., 2021) highlighted how their professional positions might assist with environmental mastery. Here, some workers sought out advice from their professional contacts and arranged for further medical tests. For this group, the resources available to them were actively pursued in order to address their challenging situations.

These two studies of healthcare workers highlight how environmental mastery might in part be a matter of perspective. In Taylor et al’s study (2021), these doctors focussed on the causes of their illness and their inability to change this, whereas the healthcare workers in Ladds and colleagues’ research (2021) emphasised their active participation in finding treatments.

However, some aspects of long covid and environmental mastery were less easily framed as a matter of perspective, such as the symptoms of long covid themselves. For instance, Watson and colleagues’ (2021) study into the loss or change of sense of smell and taste (anosmia/parosmia and ageusia/ parageusia, respectively) found these sensory experiences were often intrusive and nauseating. In response, some chose to socially withdraw, such as by avoiding situations where strong smells (e.g. food, perfume) would be present. As such, whilst they exerted some form of environmental mastery (i.e. changing their social environment), this did not resolve their symptoms and risked increasing distress through social isolation (Robb et al., 2020).

Buttery and colleagues (2021) also noted that long covid had caused people to take time off work, leading to financial stress and worries. Finances provide the resources to seek out opportunities, such as sourcing alternative healthcare or engaging in activities that contribute to positive wellbeing (Johnson & Krueger, 2006). As such, a loss of financial wellbeing serves to separate us from our external environment and necessarily reduces our ability to master it.

It thus appears that the physical realities of living with long covid threatened participants’ perceived and real ability to master their environment which, from Ryff’s perspective, threatens their psychological wellbeing (PWB). These physical realities of the disease were also implicated in other PWB domains, including ‘personal growth’.

### Personal Growth

Ryff conceptualises personal growth as a sense of continuous development, growing as a person and being open to new experiences (Ryff & Keyes, 1995). Long covid appeared to influence this in both positive and negative ways.

For instance, negative personal growth was presented in nine studies which highlighted participants’ uncertainty for their future recovery, due to the unpredictable, relapsing nature of their symptoms or the general unknown prognosis (Buttery et al., 2021; Kingstone et al., 2020; Wurz et al., 2022; Ladds et al, 2020; Ladds et al, 2021; Schiavi et al, 2022; Wilson et al, 2021; Taylor et al, 2021; Santiago-Rodriquez et al., 2021). The unpredictability of these symptoms, and the distress they caused, meant many participants could not adequately plan future activities or events. Some treatment approaches, such as gradually increasing exercise, were also said to exacerbate rather than improve symptoms (Kingstone et al., 2020), meaning few effective treatment options seemed available.

The combined effects of unpredictable relapses, loss of meaningful activity, and lack of promising treatment approaches, caused many to feel hopeless for their future. Instead, an overarching sense of stagnation prevailed, with personal growth (e.g. pursuing new experiences or continuous development) put ‘on hold’ until recovery, which could not be guaranteed, was achieved.

However, not all groups described this feeling of stagnation and some sought to harness their illness experience as a source of positive personal growth. For instance, in studies of healthcare workers with Long covid, the awareness that research was limited motivated some to share their stories, contribute to an evidence base and learn how to self-advocate (Ladds et al., 2021; Taylor et al., 2021). Some of these even reflected on the specific problem of prognosis uncertainty, and how their own illness had enhanced their empathy for people they care for (Taylor et al., 2021).

These contrasting positions, between stagnation and growth, may be underscored by the participants’ professional identities. Specifically, healthcare workers, who seek to treat illness as part of their professional roles, more readily spoke to illness as an opportunity for self-improvement (e.g. through learning to self-advocate, or have empathy for patients). Of course, this does not negate the potential personal growth of non-medical professionals, and many people with lived experience have sought to share their illness stories (see, for example, longcovid.org). However, the availability of pre-existing professional identities offered a framework from which to build hope for future growth, in the absence of symptom remission.

### Positive Relations with Others

Ryff and Keyes (1995) propose that positive relations with others involves reciprocal trust, love and empathy with others. In doing so, people feel a sense of belonging and avoid the detrimental effects of loneliness and isolation (Robb et al., 2020). Nine of the reviewed studies referenced Long covid’s influence on people’s pre-existing and newfound relationships.

For instance, a number of studies noted that people felt lonely when experiencing long covid, either due to their struggles with leaving home and meeting others (Wurz et al., 2022), isolating themselves out of a fear of being infectious (Buttery et al., 2021), feeling a lack of empathy from others (Santarossa et al., 2022), or being unable to engage in previously shared activities such as cooking (Watson et al., 2021).

For many, their loneliness led them to seek other people with Long covid, most often online. Doing so promoted feelings of validation, connectedness, managing uncertainty, sharing emotional support and making sense of their experience (Thompson et al., 2022; Humphreys et al., 2021; Ladds et al., 2020; Santarossa et al., 2022; Watson et al., 2021). As explored in the personal growth dimension, these groups sometimes reflected pre-existing identities, such that healthcare workers were able to maintain positive relations with their colleagues by sharing support and medical knowledge (Ladds et al., 2021; Taylor et al., 2021). In this way, meeting others with Long covid was a development of new alliances, where support and validation were more abundant than in people’s everyday social contexts.

One exception to this was for those who found other people’s experiences distressing. In these instances, hearing others’ stories of the protracted nature of long covid worsened anxiety and uncertainty for their own recovery – “the more it’s gone on, it’s scary; I try not to read that group too much because it depresses me, makes me a bit anxious” (Kingstone et al., 2020, p.6).

By examining the nature of positive relations with others, clear links can be made to other dimensions in Ryff’s model of psychological wellbeing. For instance, if participants sought out validation from their peers, queries can be raised as to the limits of autonomy and ‘self-validation’ (Ryff & Keyes, 1995). For others, these alliances promoted hope, through the sharing of advice and recovery stories. In rarer instances, the opposite was true, and online social groups threatened the notion of personal growth.

### Purpose in Life

Ryff and Keyes (1995) define purpose in life as the ability to find life’s meaning, including making sense of past experiences, achieving goals and having a reason to live. Multiple studies referred to participants’ sense of direction, or purpose they either lost or found through acquiring long covid.

As described within previous domains, some participants were unable to work or engage in leisure activities due to their symptoms (Wurz et al., 2022; Ladds er al, 2020, Buttery et al., 2021, Watson et al, 2021; Santarossa et al, 2022; Taylor et al, 2022). These activities were sometimes framed in identity terms, such that someone who previously used to exercise, or worked in healthcare, had a greater sense of loss when this was no longer possible (Humphreys et al., 2021; Watson et al., 2021). For some people, their identity and purpose in life were intrinsically linked, meaning the loss of one led to the loss of the other.

There are clear connections here with environmental mastery, where illness experiences threatened one’s ability to engage with their environment. This subsequently undermined their purpose in life and psychological wellbeing: “I’m the wrong generation not to go to work…I felt guilty about not going…I’d get really anxious”(Humphreys et al., 2021, p3-4).

Yet for others, the interaction between environment and identity became constructive. In Ladds and colleagues’ study (2021), some doctors living with long covid sought to assimilate their new challenges into their existing care-provider identity. Specifically, they cite their unique position and responsibility to advocate for people living with long covid, so that they are believed and validated. Similarly, the study into anosmia (Watson et al., 2021) noted how some participants expressed that they had become “pioneers of a new phenomenon” who “are the research” (Watson et al., 2021, p. 5).

Clear connections and potential overlaps can be observed here between a purposeful life and the dimension of personal growth. For those who managed to reframe their experience into what they could, rather than could not, achieve (e.g. advocating for others), new meanings and goals could be identified (e.g. ‘becoming the research’). The final area of psychological wellbeing, self-acceptance, exhibited similar connections with other domains within Ryff’s model.

### Self-Acceptance

Self-acceptance refers to having a positive attitude towards oneself, by acknowledging and being satisfied with our positive and negative attributes (Ryff & Keyes,1995). Seven of the reviewed studies suggested that Long covid in some way influenced self-acceptance in this way.

For instance, some participants reported a lowered self-esteem, either due to feelings of guilt by not working or relying on others (Humphreys et al, 2021; Taylor et al., 2021), shame for contracting the virus and seeking support (Ladds et al, 2020; Schiavi et al, 2020), or concerns that they were infectious to others (Buttery et al, 2021; Schiavi et al., 2020).

There are clear links here with the concept of autonomy (i.e. seeking validation from others). Where participants felt disbelieved or unheard, their self-acceptance also appeared to suffer. For instance, in the study of loss/changes to smell and taste (Watson et al., 2021), the use of specific medical terms (e.g. anosmia/parosmia) gave participants a credible, scientific language to discuss their problems with others. In doing so, they were able to feel validated and more confident in their own perspectives.

As discussed in the Purpose in Life dimension, some healthcare workers with long covid straddled their dual identities, where their lived experience of the illness informed their advocacy for medical access and awareness. However, for others, the value they placed in medical testing undermined their self-acceptance when they received unexpected results: *“*[the test] came back negative. That day was really bad. I thought I was going mad…would anyone believe I that I had COVID?” (Ladds et al., 2021, p.61).

Thus, beliefs and willingness to accept oneself could not be completely divorced from the perceived opinions of others, or the previous abilities a person had. Where illness marked a significant change to one’s prior identities and relationships, and where new meaning could not be found in this, self-deprecating comments often came to the fore. The final discussion attempts to explore the interactions between these domains further, and what implications these may have for therapeutic practice.

## Discussion

Although interest in long covid has peaked in the past two years, research into the relationship between long covid and psychological wellbeing remains limited. Whilst intervention studies are underway (Hawke et al., 2022; Kuut et al., 2021; Skillbeck, 2022), it remains “urgently incumbent on researchers to expand upon [this]”(Hawke et al., 2022; p1). This review aimed to contribute to this need, by thematically synthesising existing literature into a framework useful for practicing clinicians and policy makers.

In pursuit of this goal, Ryff’s Psychological Wellbeing (PWB) model (Ryff & Keyes, 1995) was employed. As discussed in the introduction, debate remains surrounding the validity of this model, particularly in terms of the conceptual distinctiveness of the six dimensions (Abbot et al., 2010; Ryff, 2014; Torabi et al., 2022).The potential overlap between these factors was borne out in this review, with clear interactions between each dimension of PWB. Whilst these overlaps might prove problematic for construct validity and research purposes (ibid), it may be less relevant from a psychological intervention perspective. Specifically, psychological formulation intends to “make sense of people problems” (Johnstone & Dallos, 2014, p.3) by exploring the interactions between each aspect of someone’s experience (e.g. how self-defeating beliefs might influence social behaviours; ibid).

With respect to long covid, such interactions were numerous. For example, threats to environmental mastery, including limited access to medical care and knowledge, motivated some to participate in research, finding personal growth and purpose in this endeavour. Whereas for others, threats to environmental mastery (e.g. lack of personal protective equipment) led to feelings of resentment and autonomy loss. These examples implicate the role of perspective taking, and that reframing exercises (such as challenging a person’s belief that they are no longer useful) may be helpful. Reframing exercises echo cognitive behavioural therapy’s emphasis on thought challenging (Beck, 2011) and so may be easily applied within IAPT services.

Another theme within the studies was that participants sought validation from healthcare professionals, families and peers which, when received, promoted self-acceptance and positive connections with others. Peer support groups can often promote feelings of validation through the sharing of emotional and practical support (Repper & Carter, 2011), and this literature review suggests similar groups may offer therapeutic opportunities to people with long covid. The rarer findings, that some avoided these groups due to potentially distressing stories (Kingstone et al., 2020), might be somewhat mediated with active facilitation by separate, psychological services.

Finally, several studies noted how personal growth and meaning in life were both found and lost through long covid. For some, a sense of stagnation arose due to an inability to pursue meaningful and valued activities. For others, their experiences of long covid offered a new source of meaning and value. These internal dynamics resonate well with ‘positive psychology’ approaches, which consider the role of positive emotions and behaviour arising from illness and trauma, and how these might be harnessed to improve psychological wellbeing (Tedeschi & Calhoun, 2004). Evidence suggests that positive psychology interventions (PPIs), which focus on the potential positive thoughts, feelings and behaviours arising from illness, may have small to medium effect sizes on psychological wellbeing (Hendricks et al., 2020). As IAPT currently largely employ cognitive behavioural models, which similarly focus on thoughts, feelings and behaviours (National Collaborating Centre for Mental Health, 2020) PPIs may therefore be a compatible and helpful adjunct.

### Limitations

Long covid was inconsistently defined within the reviewed studies, with some relying on self-definition and others using specific timeframes of symptom presence. This means that interpretations are tentative, as other factors (e.g. the influence of being hospitalised) may have played a significant role in some participants’ experiences of long covid.

The research also reflects a specific time within the pandemic, with most interviews occurring during the first lockdown in 2020. Research into long covid is increasing on an almost daily basis, meaning the understandings of its impacts are in a constant state of refinement. Specifically, feelings of invalidation by healthcare professionals might not fully represent the current landscape, as long covid hubs are now actively delivering multi-system support (NHS, 2021).

A note of caution must also be made in regards to Ryff’s psychological wellbeing framework, as models of wellbeing and happiness are often problematic due to their ‘WEIRD’ nature (Westernised, Educated, Industrialized, Rich and Democratic), meaning their applicability to other cultures may be limited (Hendricks et al., 2018).

Finally, participants were often self-selecting and recruited via digital pathways, meaning some voices may be underrepresented in this review.

### Future research

Based on this review’s findings, it is recommended that future research employs a standardised measurement of long covid. The National Health Service’s definitions of ‘Post-COVID-19 syndrome’ (12+ weeks of symptoms) and ‘ongoing symptomatic Covid-19’ (less than 12 weeks), offer the practical benefits of being in line with current clinical practice (NHS, 2021).

As most of the reviewed studies were qualitative in nature, it may be beneficial to employ quantitative methods for exploring psychological wellbeing. Several validated measures are available for this purpose, some of which are already in use in certain NHS services. For instance, alongside Ryff’s own PWB scale,the Short Warwick Edinburgh Mental Wellbeing Scale offers a well-validated method of assessment, measuring items including feeling useful and connected to others, which might align well with positive psychological approaches (Tennant et al., 2007). In doing so, the findings here might be supported with more generalisable evidence for future policy planning.

Finally, it is recommended to implement a contemporaneous evaluation of therapist and client perspectives of long covid and psychological wellbeing. As noted in this study, competing beliefs and attitudes towards long covid often left clients feeling invalidated, which led to a deterioration in autonomy and hopefulness for the future. Understanding how client and therapist groups approach and understand long covid now might therefore offer useful opportunities for promoting hope, and broader psychological wellbeing, in the future.

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## Appendices

### Appendix A: Clinical Psychology Review Author Guidelines

The target journal for publication is Clinical Psychology Review. A full link to the author guidelines can be found here: <https://www.elsevier.com/journals/clinical-psychology-review/0272-7358/guide-for-authors>

Clinical Psychology Review recommends use of APA referencing and formatting styles. Submissions must be no longer than 50 pages long including references.

### Appendix B: Mixed Methods Appraisal Tool Scores

Mixed Methods Appraisal Tool scores (Hong et al., 2018). Numbers in the white cells indicate how many research articles met each criteria.

*Mixed Methods Appraisal Tool Checklist (MMAT)*

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes (/2) | Can't Tell (/2) | No (/2) |
| 5.1 Is there an adequate rationale for using a mixed methods design to address the research question? | 2 |  |  |
| 5.2. Are the different components of the study effectively integrated to answer the research question? | 2 |  |  |
| 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? | 2 |  |  |
| 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? | 1 | 1 |  |
| 5.5. Do the different components of the study adhere to the quality criteria of each tradition in the methods involved? | 2 |  |  |
| Have ethical issues been considered? | 1 | 1 |  |

### Appendix C: Critical Appraisal Skills Programme Qualitative Checklist Scores

Qualitative checklist of the Critical Appraisal Skills Programme (CASP) scores (CASP, 2018). Numbers in the white cells indicate how many research articles met each criteria.

*Qualitative checklist of the Critical Appraisal Skills Programme (CASP)*

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes (/10) | Can't Tell (/10) | No (/10) |
| 1. Was there a clear statement of the aims of the research? | 10 |  |  |
| 2. Is a qualitative methodology appropriate? | 10 |  |  |
| 3. Was the research design appropriate to address the aims of the research? | 10 |  |  |
| 4. Was the recruitment strategy appropriate to the aims of the research? | 9 | 1 |  |
| 5. Was the data collected in a way that addressed the research issue? | 10 |  |  |
| 6. Has the relationship between researcher and participants adequately considered? | 5 | 2 | 3 |
| 7. Have ethical issues been taken into consideration? | 9 | 1 |  |
| 8. Was the data analysis sufficiently rigorous? | 9 | 1 |  |
| 9. Is there a clear statement of findings? | 10 |  |  |
| 10. Is the research valuable? | 7 | 3 |  |

### Appendix D: MMAT Scores by Article

2 = Criteria Met, 1= Can’t Tell if Criteria Met, 0 = Criteria Not Met

|  |  |  |
| --- | --- | --- |
|  | Buttery et al., 2022 | Thompson et al., 2022 |
| 5.1 Is there an adequate rationale for using a mixed methods design to address the research question? | 2 | 2 |
| 5.2. Are the different components of the study effectively integrated to answer the research question? | 2 | 2 |
| 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? | 2 | 2 |
| 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? | 2 | 1 |
| 5.5. Do the different components of the study adhere to the quality criteria of each tradition in the methods involved? | 2 | 2 |
| Have ethical issues been considered? | 2 | 1 |
| Total | 12 | 10 |
| % | 100 | 83 |

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Kingstone et al, 2020 | Ladds et al., 2020 | Humphreys et al., 2021 | Ladds et al., 2021 | Santiago-Rodriguez et al., 2021 | Taylor et al., 2021 | Watson et al., 2021 | Santarossa et al., 2022 | Schiavi et al., 2022 | Wurz et al., 2022 |
| 1. Was there a clear statement of the aims of the research? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 2. Is a qualitative methodology appropriate? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 3. Was the research design appropriate to address the aims of the research? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 4. Was the recruitment strategy appropriate to the aims of the research? | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 5. Was the data collected in a way that addressed the research issue? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 | 2 |
| 6. Has the relationship between researcher and participants adequately considered? | 2 | 2 | 1 | 1 | 0 | 2 | 2 | 0 | 0 | 2 |
| 7. Have ethical issues been taken into consideration? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 | 2 |
| 8. Was the data analysis sufficiently rigorous? | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 2 |
| 9. Is there a clear statement of findings? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 10. How valuable is the research? | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 1 | 1 | 2 |
| Total | 20 | 20 | 18 | 18 | 17 | 20 | 20 | 15 | 17 | 20 |
| % | 100 | 100 | 90 | 90 | 85 | 100 | 100 | 75 | 85 | 100 |

### Appendix E: CASP Scores by Article

2 = Criteria Met, 1= Can’ t Tell if Criteria Met, 0 = Criteria Not Met

# Paper Two: **Empirical Report**

**Holding the Hope? Therapist and Client Perspectives on Long covid Recovery: A Q-Methodology**

**Word Count: 8146**

**(Including abstract, excluding title page, references and appendices)**

**This empirical paper has been prepared for publication in The British Journal of Health Psychology. Author guidelines can be found in Appendix 5.**

## Abstract

**Purpose:** Long covid is a global health concern which has debilitating effects on the individual experiencing it. In the United Kingdom, psychological therapies are being offered to people with long covid, although the evidence for these therapies is yet to be demonstrated. This research aims to understand how therapists and clients define and understand recovery from long covid, and uses hope theory to interpret the results.

**Methods:** An online Q-methodology was employed, where participants sorted a range of statements pertaining to long covid recovery based on their level of agreement with them. These arranged statements (Q-sorts) were collated and factor analysed to explore and compare underlying perspectives.

**Results:** Sixteen participants were recruited for the study, including eleven clients, four IAPT therapists and one therapist working in the broader long covid pathway. A four-factor model is reported, including 1) *Psychological Pathways to Recovery*, 2) *Social Context and Agency*, 3) *Physiological Goals of Recovery* and 4) *Personal Meaning Making*. All IAPT therapists loaded onto the psychological pathways factor, whereas the remaining participants shared more diverse perspectives.

**Conclusions:** The belief that long covid recovery was possible, taken as an indicator of hopefulness, was rated highest for factor one, *Psychological Pathways to Recovery,* and factor three, *Physiological Recovery Goals.* This suggested that having a clear definition of recovery, or clear guidance on how to intervene, promoted hopefulness and, theoretically, wellbeing. However, clients reported experiences of being invalidated and disbelieved by health professionals, with psychological explanations sometimes being experienced as dismissive and invalidating. Clinical implications and future research directions are discussed.

**Holding the Hope? Therapist and Client Perspectives on Long covid Recovery: A Q-Methodology**

## Introduction

As healthcare services move beyond the acute stages of the Covid-19 pandemic,attention has turned to its longer-term consequences. ‘Long covid’ is one such consequence, which is a chronic (months or years) form of the illness characterised by over 200 symptoms, including loss of sense of smell, chronic fatigue, headaches and muscle pains (Carfi et al., 2020; University College London [UCL], 2021). Although the causes of long covid are still being researched, early evidence suggests the illness may in part arise due to organ damage, functional deconditioning, persistent immune response activations and/or chronic inflammation of mitochondrial cells (Kersten et al., 2021; Vallee, 2021; Nunn et al., 2022).

Whilst the specific causes and perpetuating factors of long covid remain under review, individuals’ lived experiences of the illness are well documented. People living with long covid have described it as “like a tornado living inside my body” (Gahan, 2023, p.17); with symptoms such as tachycardia manifesting at seemingly unpredictable times. Alongside the chronic and painful nature of the illness, this unpredictability means people can struggle to plan and engage with social, leisure and work activities, leading to loneliness, isolation, and unemployment (ibid). Psychological consequences of acquiring and living with these “tornadoes” are therefore common, with many people experiencing depression, anxiety and/or post-traumatic stress (Huang et al, 2021; Janiri et al., 2021).

The United Kingdom’s National Health Service (NHS) has developed a series of ‘long covid hubs’, aimed at addressing the physical and psychological impacts of long covid. Including specialisms such as occupational therapy, physiotherapy and psychology, these hubs aim to offer triaging and intervention services based on the needs of the individual accessing them (NHS, 2020).

However, the role of psychology in long covid has become a contentious issue, in part due to its comparison to, and potential conflation with, other chronic illnesses (also termed ‘invisible illnesses’; Vink & Vink-Nese, 2020; Gahan, 2023). For instance, Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) are post-viral illnesses producing similar symptoms and lived experiences to those with long covid (Wong & Weitzer, 2021). On this basis, and in the absence of contemporaneous long covid research, early reports suggested long covid and CFS/ME may have similar aetiologies (Komaroff & Bateman, 2021). Despite these reports implicating viral causes, concern has arisen that people with long covid will be thought of as malingering, or experiencing somatised anxiety due to adverse childhood experiences, as has long (and controversially) been the case for people with CFS/ME (Thompson et al., 2022; Kempke et al., 2013). People in the CFS/ME community have strongly disputed these claims, citing them as barriers to appropriate physical healthcare due to assumptions that their problems are psychological in nature (Rehmeyer, 2016). On the background of psychological attitudes towards invisible illnesses, and direct comparisons being made to CFS/ME, it is perhaps unsurprising that people with long covid have also felt disbelieved and turned away from physical healthcare services (Callard & Perego, 2020; Kingstone et al., 2020; Ladds et al., 2021; Watson et a., 2021).

Consequent to these comparisons is the assumption that psychological interventions, such as cognitive behavioural therapy, might play a role in recovering from long covid (Kuut et al., 2021). Concern has arisen here that such arguments may perpetuate the psychological-aetiological argument and the barriers this may bring (Skillbeck, 2022; Vink & Vink-Niese, 2020). Moreover, the National Institute for Health and Care Excellence (NICE) recently withdrew pre-existing psychological intervention guidance (CBT and graded exercise therapy) due to its potential to harm people with chronic fatigue (Wiltshire et al., 2018; Tisk & Maes, 2009; Turner-Stokes & Wade, 2020). This means that there is a limited evidence base from which long covid interventions might be informed.

The issues outlined above indicate that, whilst acquiring long covid might lead to significant psychological consequences, there are hazards associated with taking a psychological perspective. Lessons from CFS/ME communities, alongside emerging reports from people with long covid, indicate that psychological perspectives may be experienced as invalidating, whilst interventions to promote wellbeing remain limited. In respect of the cumulative issues outlined here, the current study seeks to explore the concept of hope (Snyder, 2002) and if this might offer an adjunctive understanding of how to promote psychological wellbeing for people with long covid.

### Hope

From Snyder’s hope theory perspective (Snyder et al., 1991; 2002),hopefulness reflects the belief that a personal goal is achievable, that one knows how to achieve that goal (termed ‘pathways’), and that an individual has the agency (i.e. motivation and ability) to achieve them. Hopefulness might promote psychological wellbeing by encouraging people to engage in healthful behaviours (e.g. exercise; Venning et al., 2011), promoting positive emotions and buffering against debilitating distress (Snyder, 2002). Cognitively, people experiencing hopefulness might perceive challenges as temporary and feel motivated to explore alternative routes to achieving their goals, thereby encouraging them to persist in the face of adversity (Leite et al., 2019). In contrast, those experiencing hopelessness might struggle to identify means of improving their life circumstances, leading to a sense of futility and, at times, suicidality (Beck et al., 2006; Knowles et al., 2022).

Hope theorists frame the three elements of hope (goals, pathways and agency) as somewhat flexible. For instance, where an individual is unclear about a goal (e.g. being unclear what long covid recovery is), hopefulness might persist if their personal agency is high, reflecting a belief that they can learn more about the topic in order to clarify their goals (Balen & Merluzzi, 2021). Furthermore, this sense of agency can be derived from either external or internal sources, meaning that if a person is struggling to find the personal motivation to persist (internal), systems including family, friends and support services can offer emotional and practical assistance. In so doing, support systems might maintain a person’s sense of agency and hopefulness, thereby supporting wellbeing (Bernardo, 2010). In instances where agency and goal certainty both remain subdued, a person might seek to make sense of their illness (e.g. understanding how they became ill and how it is affecting them now), in order to develop a coherent narrative which might later lead to alternative solutions (Balen & Merluzzi, 2021). This then suggests that hopefulness is a state-like experience, which may be malleable and promoted through psychological therapy. Consideration is now given to how hope might play a role with specific relation to invisible illnesses.

### Hope in Invisible Illnesses

As their name suggests, invisible illnesses can be difficult to understand and formulate, leading to conflicting hypotheses as to their aetiology and prognosis. From a hope theory perspective, this means there may be a lack of consensus on the goalsof recovery and the pathwaysto achieving them (Tryon et al., 2018). For instance, the PACE trials for CFS/ME advocated goalsof physical and psychological recovery (i.e., overcoming physical deconditioning and anxiety; Van Houdenhove, 2006), using CBT and GET as their intervention/pathway*.* In contrast, more biomedical perspectives (e.g., Goldberg, 2022) focus on symptom reduction goals,achieved through pathways including pharmacological intervention (Jarrot et al., 2022).

For long covid, neither psychological nor biomedical approaches have yet achieved their goals. For some, this elusiveness of a ‘cure’ might lead to more nuanced goals of living a meaningful life *despite* illness – a sentiment reminiscent of the broader ‘recovery movement’ (Piat, Seida & Sabetti, 2017). In this perspective, pathways involve engaging in personally meaningful activities, whilst learning to “exist in a space somewhere between illness and wellness” (Gahan, 2023, p.58). From a hope theory perspective, the uncertainty surrounding recovery may lead to more personal meaning making and agentic processes (Balen & Merluzzi, 2021).

However, as discussed, people with long covid may experience barriers to exerting personal agency. For instance, healthcare services’ disbelief or misunderstandings of invisible illnesses have prevented people from accessing support (Guise, McVittie & McKinlay, 2010; Gahan, 2023). Agency might also be undermined by the lived experience of long covid, such as post-exertional malaise (extreme physical and cognitive exhaustion following effort), and unpredictable symptoms disrupting goal planning and pursual (Twomey et al., 2002; Ladds et al., 2021; Devendorf, 2020).

Whilst no known research has yet linked hope theory to long covid, the issues outlined above implicate such associations. It therefore appears that goal uncertainty, unclear intervention pathways, and barriers to personal agency might contribute to hopelessness (and therefore distress) in people with long covid. In these instances, the role of the therapist may be of “holding hope”for their clients(Bartholomew et al., 2019, p.501).

### Therapist Hope and Agency

“Holding hope” involves the therapist envisaging what recovery means for their client and guiding them through an intervention package aimed at achieving this (ibid). In this respect, therapists believe that recovery for their client is possible, even when the client cannot. Research suggests that holding hope for clients in this way can itself lead to recovery, as clients come to accept and adopt their therapist’s hopefulness (Coppock et al., 2010).

However, therapist hopefulness relies on their sense of competence (Larsen et al., 2013), which may be threatened due to the absence of long covid research. This may be of particular concern to an IAPT model of service, where interventions are often pre-determined based on a person’s presenting problem (e.g. matching anxiety with ‘worry management’ workbooks; Richard & White, 2011). Although IAPT long terms conditions practitioners may have more confidence in adapting their approach to support people with physical illnesses (Panchal et al., 2020),the paucity of long covid research inevitably remains a threat to this. Moreover, if a therapist’s recovery goals are not respectful of a client’s view of a problem, a lack of goal consensus may arise which undermines the transferability of hopefulness (Tryon et al., 2018). It therefore remains to be seen if therapist and clients hold similar views on long covid causes and recovery, and how these might influence a therapist’s ability to hold hope for their clients.

### The Current Study

A social constructionist epistemology was adopted for this study, which takes the position that understandings of a given topic are interpreted and culturally ascribed (Leeds-Hurwitz, 2009). As outlined in the introduction, various beliefs pertaining to recovery from invisible illnesses exist, which have historically led to feelings of disenfranchisement and invalidation (Rehmeyer, 2016; Thompson et al., 2022).In this respect, this study is less concerned with uncovering an objectively true definition of ‘long covid recovery’ or how to achieve it. Rather, it seeks to understand the diverse beliefs social groups might hold regarding recovery, and what hazards might arise should these beliefs diverge.

This study seeks to understand how therapists and clients perceive recovery from long covid, using hope theory to interpret the results. A long covid pathway providing psychological therapies (most of which take a cognitive behavioural perspective) is the setting of the study. In the absence of clear guidance, and on the background of physical and social barriers to change, the research question asks: Can (and if so, how) therapists and clients hold hope for long covid recovery?

## Method

### Q-Methodology

Q-Methodology aims to undertake a “systematic study of human subjectivity” (Brown, 1986, p.58), whereby potential opinions on a given subject (e.g. long covid recovery) are recorded, individually sorted into grids, scored and statistically compared against others’ sorted statements (ibid). In doing so, shared and individual opinions can be compared, with underlying ‘factors’ representing main areas of agreement and divergence. Historically, this method has been used to compared perspectives on topics including therapeutic relationships (Dziopa & Ahern, 2009), mental health client needs (Papworth & Walker, 2008), outcome measurement in paediatrics (Morris et al., 2015) and in learning disabilities (Combes, Hardy & Buchan, 2004).

Q-methodology was selected over other qualitative methods as it may be deployed across cohorts (i.e. staff and client groups) with relative flexibility and accessibility. Its positivist, statistical element also allows for the within and between-group comparisons with reliability, meaning it may be repeated in future studies to support or reject the findings. Its ability to compare various groups’ beliefs also supports the social constructionist perspective taken by this research, where the divergence and convergence of opinion is of main concern.

This method involves participants arranging a set of statements (the Q-set) into a fixed sorting distribution. These statements are then given a score (ranging from -3 to +3), which allow for statistical comparison with other participants’ scores. Once all participants have completed the activity, these collated scores are factor-analysed to identify patterns of beliefs based on participant groups. Further details of the Q-set and sorting procedure are given below.

## Design

### Ethics

This study was approved by the Staffordshire University Ethics Committee and the NHS Research Ethics Committee. All participants were given information sheets outlining the study before they consented to participate, including information about withdrawal (Appendices 7a, 7c, 8a and 8b).

Research may need adapting to promote the inclusion of people with complex health needs, for instance by using concise statements and allowing for breaks (Banks et al., 2022). To reduce the risk of causing post-exertional malaise in participants with Long covid (Twomey et al., 2022), several adaptations were made to this study. These are described throughout and reflected upon within the discussion section.

### Q-Set

Q-sets (the statements to be sorted within the activity) aim to achieve “coverage and balance” (Watts & Stenner, 2012, p.58), meaning they broadly represent all potential perspectives on the topic of choice (long covid recovery). This coverage and balance can only be achieved through a closeness with relevant literature, theories and lived experiences, which are then used to inform the statements. To achieve this closeness, the author consulted with professionals working in the field, read numerous articles, and attended long covid workshops and training. These workshops and training were delivered, wholly or partly, by people living with long covid. Alongside broader media sources and qualitative articles referred to in this thesis’ literature review, these workshops and training ensured a broad representation of client perspectives.

An unstructured approach to q-set development was employed, which involved describing recovery perspectives and identifying themes which had arisen from the literature review and broader sources. This resulted in 70 initial items, which were then screened for duplicates and condensed to 50 statements. These statements were then taken to an online focus group, consisting of staff working within the long covid pathway (recruitment attempts for client participants were unsuccessful). Focus groups were able to suggest removing, changing or adding to the statements, leading to a final Q-set of 54 statements which were subsequently verified by the focus group via email (see Appendix 11).

### Q-Sort Procedure

This was an online-only study, consisting of two phases, using the free Q-Sort software ‘QSortware’ (2022). In the first phase, the Q-Set was sorted into three columns (Disagree, Neither/Nor, Agree). In the second phase, participants re-sorted these statements into further categories on a 7-point scale (or ‘sorting distribution’), ranging from ‘agree least with’ to ‘agree most with’ in a two-five-ten-twenty-ten-five-two pattern (See figure 1.). Many Q-studies have wider or shallower sorting distributions (e.g. 15 point scales with ten statements around the middle), aimed at promoting finer-grained decisions (Watts & Stenner, 2012). However, these require more time and cognitive demand, which may have put undue strain on participants with post-exertional malaise (Twomey et al., 2022). Steeper distributions might also be considered if the topic “is relatively complex” (Watts & Stenner, p. 80), leading to the decision to adopt a leptokurtic design. This required less time and cognitive decision making, as more statements could be arranged around the middle. Each statement is scored based on its position in the sorting distribution.

**Figure 1***Sorting Distribution Design Including Scores*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Agree Least** | **Agree Less** | **Agree Slightly Less** | **Neither/Nor** | **Agree Slightly More** | **Agree More** | **Agree Most** |
| -3 | -2 | -1 | 0 | 1 | 2 | 3 |
| -3 | -2 | -1 | 0 | 1 | 2 | 3 |
|  | -2 | -1 | 0 | 1 | 2 |  |
|  | -2 | -1 | 0 | 1 | 2 |  |
|  | -2 | -1 | 0 | 1 | 2 |  |
|  |  | -1 | 0 | 1 |  |  |
|  |  | -1 | 0 | 1 |  |  |
|  |  | -1 | 0 | 1 |  |  |
|  |  | -1 | 0 | 1 |  |  |
|  |  | -1 | 0 | 1 |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |
|  |  |  | 0 |  |  |  |

After statement sorting, participants were invited to give context to their answers via written qualitative feedback. This method of qualitative feedback was selected over more traditional post-activity interviews (ibid) to reduce overall physical and cognitive demand. Qualitative responses were used to assist the interpretation of factor structures and are reported verbatim in the results section.

### Analytic Method

Following collection, data were factor analysed using SPSS version 28 and Ken-Q, an online statistical analysis package specifically designed for Q-methodology (Banasick, 2016). Watts and Stenner’s (2012) Principle Components Analysis (PCA) technique was employed, which involved comparing PCA eigenvalues with those from a parallel analysis of random computer-generated data. PCA (real data) eigenvalues scoring higher than the 95th percentile of randomly generated eigenvalues are considered as representing a better-than-chance occurrence (O’Conner, 2000). Eigenvalues above one are then considered as potential factors (ibid).

After identifying potential factors, KenQ (Banasick, 2016) was used to conduct a varimax rotation and examine the specific statement placements for each factor (termed factor arrays; Watts & Stenner, 2012). These factors arrays offer insights into which statements were most and least agreed with according to each factor (see appendices 13a – 13d for full factor arrays). Along with qualitative feedback, these factor arrays allowed the researcher to interpret the results into coherent narratives for reporting. In this respect, other researchers may have reached different conclusions regarding the factors presented. However, the statistical element of the methodology, and the correlations between responses, offers a level of objectivity which can promote reliability, credibility and generalisability (Watts & Stenner, 2012).

### Participants

Sixteen participants were recruited for the study. This included four therapists working within the sponsoring Trust’s Improving Access to Psychological Therapies Service, one therapist working within the Trust’s long covid pathway, and eleven people (‘clients’) who had received therapy for long covid through the Trust’s IAPT services. This therapy typically consisted of cognitive behavioural therapy lasting approximately twelve weeks.

Study advertisements were shared via IAPT services (who emailed the adverts to previous clients and current staff), the Trust’s intranet and on social media (see appendix 10). Potential participants initially completed a ‘consent for contact’ form (Appendix 6), which gave their informed consent to be contacted by the researcher about either stage of the study (focus group or Q-sort). At the respective times, invitations were sent to all consenting people (Appendices 7 – 8). Table 1 shows the inclusion and exclusion criteria for each participant group.

Table 1

|  |  |  |
| --- | --- | --- |
|  | Client Group | Therapist Group |
| Inclusion Criteria | Personal experience of long covid | Work for the sponsoring Trust |
|  | Received therapy for long covid via local IAPT | Trained in long term conditions |
|  |  | Delivered therapy for long covid |
|  |  |  |
| Exclusion Criteria | IAPT Therapy for long covid is ongoing | Working for a different Trust |
|  | Under 18 | Trained in therapies not including long term conditions |

*Inclusion and Exclusion criteria for* client*s and therapists*

Recruitment focused on therapists working within the local IAPT services, however psychological practitioners within the broader sponsoring trust’s long covid pathway were not excluded. To offer reassurance of anonymity and limit participation time, demographics beyond a person’s status as therapist or client were not recorded. As discussed in the literature review, long covid definitions can differ across research studies. By virtue of having received therapy for long covid via the NHS, client participants in this group are considered as meeting the standardised definition (symptoms of at least twelve weeks; NHS, 2021). Limitations to omitting other demographics are considered in the final discussion.

## Results

A total of sixteen participants were recruited for the study, including four IAPT therapists, one Long covid pathway therapist and eleven clients. For therapists, the average (mean) time taken to complete the activity was 43 minutes, ranging between 6 and 117 minutes. The staff member who completed it quickest had attended the previous focus group and had some prior understanding of the task. For clients, the average (mean) time taken to complete the activity was 30 minutes, ranging between 17 and 49 minutes.

All sixteen Q sorts correlated with at least one other Q sort (see appendix 12a). The analytic method prior described suggested a four-factor solution. Table 2 shows the eigenvalues of each factor, parallel (by chance) eigenvalue, and the total variance explained within the model. Table 3 gives an overview of the correlation between factors, indicating that each factor was distinct.

**Table 2**   
*Initial PCA Factor and Parallel Analyses*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Component** | **Eigenvalue (Actual)** | **Eigenvalue (Parallel)** | **Variance explained (%)** | **Cumulative**  **Variance (%)** |
| **1** | 5.415 | 1.585 | 34 | 34 |
| **2** | 2.265 | 1.274 | 14 | 48 |
| **3** | 1.439 | 1.081 | 9 | 57 |
| **4** | 1.056 | 0.926 | 7 | 64 |

**Table 3***Correlations between Factors*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Factor 1** | **Factor 2** | **Factor 3** | **Factor 4** |
| **Factor 1** | 1 | 0.2469 | 0.1804 | 0.2727 |
| **Factor 2** | 0.2469 | 1 | 0.3028 | 0.2831 |
| **Factor 3** | 0.1804 | 0.3028 | 1 | 0.2655 |
| **Factor 4** | 0.2727 | 0.2831 | 0.2655 | 1 |

### Four Factor Solution

The final four-factor model included: Factor One – Psychological Pathways to Recovery; Factor Two – Social Context and Agency; Factor Three – Physiological Recovery Goals; Factor Four – Personal Meaning Making

Full factor arrays and grids are available in Appendix 13. Following is an overview of each factor. Where Q-statements are presented in quotes to support analysis, their statement number and scores are given alongside them (e.g. “is different for everyone” (S16, +1))”. Where quotes are given, the participant number (‘U’) is used to identify them (e.g., ‘U1, ‘U9’).

#### Factor One – Psychological Pathways to Recovery

Factor one accounted for 34% of the found variance, with six participants loading significantly onto this factor. All four of the therapists working within Improving Access to Psychological Therapies services, and two of the eleven clients, loaded onto this factor. This offers some indication that taking the role of therapist, at least within an IAPT context, influences concepts of recovery.

Statements of recovery showed that it was “different for everyone” (S16, +2), but most often involved “learning to pace yourself (boom and bust)” (S11, +3). Factor one loaders advocated for accepting how you feel (S14. +2, S15, -3) and doing things despite illness (S33, +2) suggesting that the goal of recovery was living alongside the illness, rather than ‘curing’ it (as discussed in factor three).

In contrast to psychological perspectives, physical health related statements were ranked lower in this factor. These included “having less pain” (S30, -1), “taking medication for your physical health” (S39, -1), having less brain fog (S32, 0) and having less fatigue (S31, 0).

Participant one, a cognitive behavioural therapist working in an IAPT service, offered context to this position*:* *“I have found that underlying core beliefs/ rules (often linked to perfectionism) play a definite role in how well people adapt to living with long covid”* (U1). From a cognitive-behavioural perspective, perfectionism involves unhelpful beliefs that one must achieve the highest standards, with these beliefs worsening distress when standards are unachievable (Hirsch & Hayward, 1998). Perfectionism in long covid might therefore be understood as a distress arising from the physical inability to complete tasks to a level the client believes necessary.

It thus follows that therapeutic techniques aimed at overcoming these beliefs (a central tenet of cognitive behavioural approaches; Beck, 2011) were prioritised in this factor. For instance, factor one participants prioritised the following statements on long covid recovery: “Can be achieved through psychological therapy” (S1, +2); “managing anxiety” (S5,+1); “overcoming the fear of moving your body” (S20, +1); “gradually increasing your movement” (S50, +1); “managing unhelpful thoughts” (S48, +1; S49, +1) and “addressing core beliefs” (S19, +1).

Quotes from other therapists, such as *“it’s multidisciplinary”* (U7) and *“it depends on the relationship with the practitioner”* (U4) suggest professional intervention, and the nature of this, holds some importance. A client loading onto this factor further suggested that *“it would be better if doctors pay more attention to the patients with long covid”* (U11), suggesting that a lack of attention from healthcare professionals may serve as a barrier to recovery.

Despite this potential external locus of agency, participants loading onto factor one scored “long covid recovery is possible” as the highest (S37, +3) and “long covid recovery is not possible” as the lowest (S36, -3). This suggests that participants loading onto factor one experienced hopefulness for recovery, or at least held on to the possibility for recovery irrespective. From the IAPT therapist perspectives, all of whom loaded onto factor one, it may be that their clearly defined roles and training offer them the distinct pathways (i.e., psychological interventions) needed to experience hope. Speculatively, the two client participants loading onto this factor may have similarly associated therapeutic approaches to their beliefs for recovery.

#### Factor Two – Social Context and Agency

Factor two accounted for 14% of the explained variance, with three participants loading on to this factor. Participants included two clients who had received talking therapies through IAPT provision, and one psychological practitioner. Notably, this practitioner was providing psychological therapies in the broader long covid pathway and did not follow an IAPT model.

Factor two shared some similarities to factor one, in that “learning to pace yourself (boom and bust)” was scored highest (S11, +3) and “is different for everyone” remained high (S16, +2). However, the emphasis here shifted from psychological interventions to the social experiences of having long covid. Participants loading onto this factor expressed that long covid recovery “requires your friends and family to believe you” (S21, +3) and “requires professionals to believe you” (S22, +2), and that recovery from long covid “is made harder due to society’s stigma towards it” (S38, +1).

These statements suggest participants with long covid have experienced invalidation and/or rejection by those around them. One participant explained, *“I feel very let down by the medical profession as I was not believed and made to feel stupid”* (U12). Another stated *“*[long covid] *takes away so much of what is important to someone, which often includes supportive relationships and expectations that a medical professional you consult will be able to help, or even believe your symptoms in the first place”* (U4). For these people, the social contexts around them were experienced as barriers to recovery, which undermined their self-esteem and identity.

With exception to having less brain fog (S32, +2), these participants broadly saw long covid recovery as *“one size does not fit all”* and that *“the meaning of recovery and how to achieve it is different for everyone”* (U14). Where recovery goals/pathways were noted, they remained couched within these broader social contexts. As described by one client, *“*[I] *manage my symptoms through yoga, breathing techniques, meditation, walking my dog and good nutrition. Every day is a struggle and although my family are incredibly supportive, none of them fully appreciate just how hard it is living with long covid”*(U12).

Factor two opposed factor one in its broad rejection of psychological intervention, with low agreement for managing unhelpful thoughts caused by the illness (S48, -3), thoughts existing before the illness (S49, -2) and addressing core beliefs (S19, -2), alongside strongly agreeing with it *not* being a psychological issue (S52, +1). Again, qualitative responses suggest a social element to these, based on the stigma or invalidation people have experienced: *“Long covid is not a psychological issue – however, it is extremely psychologically challenging and these two ideas are easily and frequently mixed up”* (U4).

As identified in previous literature, many people living with long covid have been told *“it’s just anxiety”* (Thompson et al., 2022, p.327). This proved to be a barrier to psychological and physical healthcare and understanding, which from a hope theory perspective might reduce a sense of agency and, therefore, hopefulness (Bernardo, 2010; 2015). Factor two participants’ experiences reflected this, which might therefore explain their tentativeness around the idea that long covid recovery “is possible” (S37, 0) and “is not possible” (S36, -1).

#### Factor Three – Physiological Recovery Goals

Factor three accounted for 9% of the total variance with five significantly loading Q sorts, all of whom were client participants.

Factor three was characterised by the physical experience of having long covid, with potential recovery goals and pathways reflecting this. For this group, recovery meant having less fatigue (S31, +3), brain fog (S32, +2) and pain (S30, +2). Other high scoring statements reflected this position, in that increasing physical movement was seen to hamper recovery (S10, +2) and taking medication for physical health was seen as more important here than in other factors (S39, +1). Qualitative responses also reflected the focus on long covid as a physiological problem “*There appears to me to be a potential overlap between long covid and anaemia”* (U14).

In contrast, ideas of acceptance were rejected in this factor. For instance, pacing oneself (boom and bust) was rated lower than the previous factors (S11, 0), accepting how one feels was seen as giving up (S14, -1; S15, +2), and learning to live with pain was rejected (S45, -2). There was also less attention given to social issues, such as feeling close to people again (S23, -1), feeling less lonely (S4, -1) or a need to feel believed by friends and family (S21, -1).

Similar sentiment was noted for psychological interventions, with participants rejecting the idea that recovery was a psychological issue (S52, +1) or that it involved addressing one’s core beliefs (S19, -2), overcoming the fear of moving their body (S20, -1) or managing anxiety (S5, -1). As one client simply put, *“we need more groups talking about it. It’s not just mental health issues”* (U5).

The overall sense from these responses is that long covid recovery is a medical task, where the goal is symptom elimination using physiologically curative pathways. This suggestion is confirmed by one participant’s written feedback: *“Covid infected our bodies. Long covid is the result of the original infection which remains in our bodies not yet 100% removed. We did not cure Covid. The remaining infection impacts our lives our mobility & abilities and our breathing […] Cure the route cause kill the infection 100% and allow for us* *to recover with support and assistance if required”* (U12).

Notably, this group appeared very hopeful for their recovery in the future (is possible, +3; is not possible, -3); it was simply a matter of finding a cure for their illness and, perhaps, sitting with uncertainty until then.

#### Factor Four – Personal Meaning Making

Factor four accounted for 7% of the variance, with two client participants significantly loading onto the factor.

This factor represented a striving to live a personally meaningful and valued life, represented by the statement “means doing things that are important to you in spite of the illness” (S33, +3). For these participants, the disability caused by the illness led them to seek new meanings in life (S24, +2) and finding meaning in having the illness (S35, +2).

Where factor one noted the potential harm of perfectionist beliefs (i.e. attempts to uphold unattainable standards; Hirsch & Hayward, 1998) factor four represented attempts to change these beliefs in order to live alongside illness. However, unlike factor one, psychological therapy was not considered as the route to achieving these changes (S1, -2), suggesting that this was a personal endeavour representing an internal locus-of-hope (Bernardo, 2010; 2015). Yoga, an intervention suggested as beneficial for long covid (Venugopal & Venkateswaran, 2022) was strongly rejected here (S34, -3) whilst breathing techniques, a central tenet of yoga (Capello Santos et al, 2023) were strongly supported (S41, +3). No qualitative data remarked on this distinction, however it may be an artifact of the statement wording (*“long covid recovery is achieved through yoga”* vs *“long covid recovery involves learning breathing techniques”*). Other qualitative feedback appears to support the notion that recovery cannot be ‘achieved’ but is a process of persistence: *“It is difficult**. There are good days and bad days. Setbacks are very frustrating and lead me to low times. Deciding to get on and live life anyway is helpful but hard”* (U6)

To support this idea, many highly ranked statements represented the actions and broader contexts conducive to living a meaningful life, such as “involves taking medication for your mental health” (S46, +2), “Involves living alongside pain (S45, +1), “includes building your self-esteem” (S25, +1), “requires professionals to believe you” (S22, +2) and “feeling less lonely” (S4, +1).

Other social elements were ranked lower than in other factors. For instance, society’s stigma was ranked as less relevant in factor four (S38, -1) and both participants rejected the idea that sharing self-management tips with others is helpful (S3, -2). Without further details on individual circumstances (a limitation of the study discussed later), it is difficult to interpret the reasons for these responses. However, it may be that this small cohort have experienced a more supportive social context as outlined in factor two, and have therefore prioritised personal meaning making processes. Indeed, both participants had low and non-significant loading correlations with the social context and agency factor (U9=0.257, U13=0.117).

Hopefulness in this factor, measured by the statements “is not possible” (S36, -2) and “is possible” (S37, +1) suggested that the personal meaning making perspective fostered some hope for these people. However, these statements were not as pronounced as within factors one and three, which more strongly supported the ideas of hopefulness. This suggests that, whilst objective and external ideas (e.g. ‘cure’) may be unattainable, personal and subjective definitions of recovery may still be present.

### Consensus Statements

Consensus statements are those which are non-significant at P>0.01 and P>0.05 levels, meaning they did not distinguish between any of the factors. Quoted statements are presented with their statement (‘S’) number and scores for all four factors (F1, F2, F3, F4 respectively). All of these consensus statements fell around 0 (i.e. neither strongly agree nor disagree), indicating that there were no priority rankings within them (see appendix 12c).

Several of these consensus statements related to therapist factors, including: “long covid recovery is more likely if your therapist has had it” (S6, 0, 0, 0, 0), “treatments are shaped by a therapist’s own experience of Covid-19” (S47, 0, 0, 0, 0) and “practitioners know how to support people” (S53, -1, 0, 0, 0). These scores might reflect a general unknowing of the therapist’s personal circumstances and a recognition of ability being a case-by-case basis.

Similarly, “having better mental health” (S29, 1, 0, 0, 1) and “can make you feel stronger than you were before the illness” (S26, 0, 0, 0, 0) were neither strongly agreed nor disagreed with across the factors. This perhaps indicates a broad acknowledgment that mental health might play a role, but as a symptom rather than a cause of the issue.

Finally, “is easier if you meet other people with long covid” (S2, 0,1,0,0) was a consensus statement. When compared to other statements mentioned in Factor two it may be that these statements lacked the specificity upon which participants agreed or disagreed.

## Discussion

### Summary of Findings

A variety of recovery perspectives were found in this study. Therapists working within IAPT services mostly represented recovery as a psychological task and advocated for aligning therapeutic interventions. Whilst their factor array did not negate other aspects of recovery, such as the influence of personal meaning and social inclusion, the emphasis on psychological tasks reflected their roles and identities as psychological practitioners. Additionally, participant U4, a psychological practitioner working within the broader long covid hub, significantly loaded onto the Social Context and Agency factor. This suggests that the psychological factor might be more accurately attributed to an IAPT model of treatment as opposed to a ‘professional’ perspective or practice.

Clients held more diverse opinions, with just two loading onto factor one. Clients more commonly emphasised a medical symptom-reduction version of recovery, or reflected the perceived stigma and invalidation they had experienced from society and healthcare professionals. For two people, meaning making processes on a more personal basis were advocated. This demonstrated that clients’ definitions of recovery were individual and subjective, which may contrast with the more model-driven (e.g. specific formulations and interventions for specific problems) format of low intensity IAPT approaches (Richard & White, 2011; National Collaborating Centre for Mental Health, 2020).

Imperatively, participants loading on to factor one did not *reject* the idea that Long covid is a physical illness with physical causes. Indeed, responses such as *“it’s multidisciplinary”* (U7)suggest a holistic understanding of the illness, with therapists offering support specifically for its psychological sequalae. However, broader social and historical contexts mean this position must be carefully explained and demonstrated, should hopefulness be promoted.

### Hope in Recovery

Hopefulness is thought to be an active ingredient for psychological and physical wellbeing, as it encourages perseverance in the face of adversity, promotes positive emotions and offers resilience against feelings of futility, negative affect, and suicide (Bartholomew, 2019). Snyder (2002) proposed that hopefulness requires clearly defined goals, foreseeable pathways to achieving those goals, and the ability and motivation (agency) to pursue these pathways. Later theories suggested agency may be supported by also external sources (e.g. social and healthcare services), which may become more relevant if there is uncertainty surrounding a goal (Bernardo, 2010; Balen & Merluzzi, 2021). Statements intended to measure participants’ hopefulness for recovery (S36 and S37) indicated that all factors disagreed with the idea that recovery was not possible. However, only the psychological (factor one) and physiological (factor three) factors were emphatic in their agreement that it *is* possible.

From a hope theory perspective, factor one, *Psychological Pathways to Recovery,* had clear goalsof recovery (living alongside illness), pathwaysto achieving them (various psychological interventions) and well-defined agencyroles (personal responsibility with less expectation for therapist expertise). For this group, most of whom were therapist practitioners, a shared and clear understanding of the direction and definition of recovery might explain the high score of hopefulness. This aligns with previous literature, which suggests that when therapeutic approaches provide a coherent framework, the enacting therapists really are capable of “holding hope”(Bartholomew et al., 2019, p. 501)

In factor three, *Physiological Recovery Goals,* respondents similarly had clearly defined goals(physical recovery) achieved through medical pathways(i.e. finding cures), with a more shared idea of agencybetween individuals and professionals. Their belief that recovery is possible was also strong, suggesting they too were hopeful. It is particularly striking that such hopefulness for recovery existed, considering the lack of an available medical cure. Balen and Merluzzi’s (2021) theory of uncertainty and agency might go some way to explaining this finding, as in the face of an uncertain goal, this group emphasised personal agency and control (e.g. avoiding increasing movement, taking medication). As such, their hope may arise from the recognition that there were things they *could* do whilst waiting for healthcare developments (ibid).

The starkly different ideas of recovery, yet equal levels of hopefulness, offer a word of caution to psychological practitioners. The results suggest that therapists must be cognisant of what specifically makes clients feel hopeful, and challenging the belief a cure can be found could have the unintended consequence of increasing client hopelessness. As previous research shows, hopelessness might reduce psychological wellbeing and exacerbate suicidal feelings (Venning et al., 2011). Therapists’ ideas of therapeutic goals and recovery outcomes might therefore risk undermining the needs or goals of the person they are supporting, should these not be aligned or explained carefully.

Factor Two, *Social Context and Agency*, might offer more insights in this respect. In contrast to the above factors, recovery goals and pathways were less well defined here. Rather, the social context was emphasised, including a need to be believed by family, friends, and professionals. In this respect, societal attitudes and dismissal were presented as barriers to agency,in that personal validation and access to healthcare was prevented. Participant U4’s quote that *“*[long covid] *takes away so much of what is important to someone, which often includes supportive relationships and expectations that a medical professional you consult will be able to help, or even believe your symptoms in the first place”* speaks to this idea, reflecting broader historical and social contexts faced by people with invisible illnesses. Alongside the general threat to recovery a lack of goal consensus poses (Tryon et al., 2018), the privileging of psychological explanations might carry a risk of repeating historically invalidating experiences (e.g. *“it’s just anxiety*”; Thompson et al., 2022, p.327), thereby undermining personal agency and increasing hopelessness.

Factor four, *Personal Meaning Making,* outlines how some participants navigated the reality that no physical cure yet exists. For this group, physical symptom amelioration remained a goal of recovery, yet the pathwaysrepresented an acceptance and living alongside the illness. Participants here were more tentative about the possibility for recovery, and had resorted to personal meaning making (agency) as a means of seeking wellbeing. This factor supports Balen and Merluzzi’s (2021) theory that, where uncertainty is high and control is low, people with illnesses might more readily turn to meaning making processes.

### Implications for Clinical Practice

Reflecting previous literature into people with chronic illnesses (Rehmeyer, 2016; Thompson et al., 2022), some client participants experienced invalidation from others. From a practitioner perspective, it is imperative to recognise the validity and existence of long covid, as to promote agency and hopefulness. Indeed, this position is emphasised within IAPT training procedures and, therefore, will hopefully be acceptable to therapeutic professions (Taylor et al., 2023).

Moreover, examined through the lens of hope theory, these results suggest taking a cautious approach to offering psychological support. Whilst therapists did indeed hold the hope for their clients, most participants here did not wholly share the same recovery goals. This diversity of recovery goals, despite all clients having received IAPT support, underscores the personal and subjective nature of long covid recovery, thereby recommending careful exploration of a clients’ expectations for intervention. In doing so, a goal consensus, and therefore positive therapeutic outcome, may be promoted (Tryon et al., 2018).

The social constructionist perspective taken by this research, which sought to understand the potentially conflicting views between groups, provides a framework from which to make practice recommendations. For instance, initial assessments within the broader long covid pathway might include a focus on a person’s hopefulness and recovery goals, such as improving physical wellbeing or having closer relationships. Where indicated, alternative therapeutic models might also be considered. For instance, in respect of factor four *Personal Meaning Making,* Acceptance and Commitment Therapy (Hayes, 2004 [ACT]; 2019) can be used to support clients with living a valued life despite illness. Operating on the basis of “creative hopelessness” (Hayes et al., 2012, p.189) where clients feel hopeless in their goal pursuits, ACT promotes a willingness to accept difficult emotions in the service of one’s values (ibid). ACT has a growing evidence base for problems including health anxiety (Eilenberg et al., 2016), chronic muscle disease (Rose et al., 2022) and fibromyalgia (Simister et al., 2018), and might be useful for CBT has previously been unsuccessful (Clarke et al., 2014).

Similarly, Narrative Therapy (NT)can be helpful in supporting clients to make sense of their illness and change experiences (Brown & Scott, 2007), with promising results in areas such as strokes (Chow, 2018) and cancer (Sun et al., 2021). Through a process of putting their illness experience into a story format, NT can help clients understand who they were before the illness, how the illness may have changed them, the distress this brought, and how this might be assimilated into the next ‘chapters’ of their lives (Brown & Scott, 2007). Whilst both ACT and NT do not typically fall within the remit of IAPT services, these ‘third wave’ cognitive behavioural approaches they may prove useful sources of professional development for IAPT’s long terms conditions practitioners.

The results also indicate a therapeutic benefit to social support groups, reflecting previous literature which finds such groups may promote feelings of validation, inclusion and support seeking (Day, 2022). A clinical implication, then, is to advertise such groups widely (e.g. during sessions, on social media channels), as to promote agency and hopefulness. Moreover, involving these groups in service design, such as assessment and intervention models used is recommended, as to ensure the broad range of perspectives are heard and goal consensus is promoted (Akerblom & Ness, 2022).

Finally, despite the evidence suggesting hope may be an active ingredient for recovery (Leite et al., 2019), hopefulness must not be considered as a pre-requisite for receiving support. Concerns exist regarding an over-emphasis of client personal responsibility, and how this might leave the sometimes-harmful systems surrounding clients (e.g. societal stigma, healthcare inequality) unacknowledged (Cosgrove & Carter, 2018). It is hoped that the framing of therapists ‘holding hope’ for clients, alongside an emphasis on *external* sources of agency, has gone some way to demonstrating this position.

### Limitations

There are a number of limitations to the current study. Firstly, the study design was atypical of Q-methodology, in that it used a leptokurtic sorting distribution and omitted participant demographics and interviews. These adaptations were made to reduce the time taken to complete the task, thereby limiting the possibility of inducing post-exertional malaise (Twomey et al., 2022). However, the relatively limited demographic and contextual detail meant finer-grained analysis (e.g. if factors differed by age, sex, ethnicity or length of long covid) could not be made.

Moreover, a failure to recruit clients for the initial focus groups may have limited the potential perspectives covered in the initial Q-set (cohort of statements). Similarly, the online-only nature of the study may have disproportionately excluded groups with less access to the internet, including older people (Choi & Dinitto, 2013), and people on lower incomes (Estacio et al., 2017). However, it is hoped that the reference to lived experience texts (e.g. Gahan, 2023) and training went some way to ensuring these client perspectives were thoroughly represented.

### Future Research

To overcome the limitations mentioned, it is recommended that demographics are measured in future studies, alongside conducting qualitative interviews which can offer more detailed and nuanced perspectives.

Additionally, it may be that the four-factor structure uncovered a more latent phenomenon describing as ‘recovery’ in long covid. For instance, those who ranked the importance of social inclusion lower might have experienced less prior exclusion than others. Similarly, those emphasising the importance of physical recovery might have better overall psychological wellbeing after receiving IAPT intervention. To test this further, development of a long covid Recovery scale is suggested which, after confirmatory factor analysis, may be used as an assessment tool in long covid pathways.

As discussed, Acceptance and Commitment Therapy (ACT) and Narrative Therapy (NT), could be helpful alternatives to Cognitive Behaviour Therapy (CBT; Rose et al., 2022; Simister et al., 2018; Sun et al, 2021). It is recommended that a randomised controlled trial is conducted to test this, including a comparison of long covid recovery outcomes comparing ACT, NT and CBT, to explore alternatives and promote goal consensus (Tryon et al., 2018).

The literature review also indicated a therapeutic value of peer support groups, as has been found in groups ranging from substance use (Tracy & Wallace, 2016), mental health (Shalaby & Agyapong, 2020) and chronic illness (Kingod et al., 2017). Further research might explore the role of peer support in more detail, including testing for outcome predictors (e.g. online versus in person), in order to understand the specific mechanisms involved (Reif et al., 2014).

## Conclusion

The aims of this research were to explore therapist and client understandings of and hopefulness for long covid recovery. Results suggested varying perspectives, with participants prioritising either psychological, social, physical or meaning making notions of recovery. Where therapists might be more inclined to offer psychological explanations, these are not always shared by clients and must therefore be approached cautiously as to avoid creating feelings of invalidation. Alternative therapeutic models are implicated and future research suggested.

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## Appendices

### **Appendix 1 – Evidence of Sponsorship/Indemnity**

**Text, letter

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### Appendix 2 – Research Ethics Committee Approval Letter

**Text, letter

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### Appendix 3 – NHS Research and Development Approval Letter

From: Christopher Flanagan (RRE) MPFT <[Christopher.Flanagan@mpft.nhs.uk](mailto:Christopher.Flanagan@mpft.nhs.uk)>   
Sent: 03 November 2022 10:49  
To: William Burton Fisher (RRE) MPFT <[William.BurtonFisher@mpft.nhs.uk](mailto:William.BurtonFisher@mpft.nhs.uk)>  
Cc: Chantel-Lea Grocott (RRE) MPFT <[Chantel-Lea.Grocott@mpft.nhs.uk](mailto:Chantel-Lea.Grocott@mpft.nhs.uk)>; Frances Davies (RRE) MPFT <[Frances.Davies@mpft.nhs.uk](mailto:Frances.Davies@mpft.nhs.uk)>; Liz Glaves (RRE) MPFT <[Liz.Glaves@mpft.nhs.uk](mailto:Liz.Glaves@mpft.nhs.uk)>; GORDON Kim V <[Kim.Gordon@staffs.ac.uk](mailto:Kim.Gordon@staffs.ac.uk)>  
Subject: IRAS 313943 'Holding the Hope?' – Confirmation of Capacity and Capability at MPFT

Dear Will,

 RE: IRAS 313943 – Confirmation of Capacity and Capability at MPFT

Full Study Title: Holding the Hope? Therapist and Client Perspectives on the Psychological Aspects of Long-Covid. A Q-Methodology

On behalf of Ruth Lambley-Burke (Head of R&I), this email confirms that Midlands Partnership NHS Foundation Trust has the capacity and capability to deliver the above referenced study; please find the agreed Organisation Information Document attached as confirmation.

If you wish to discuss further, please do not hesitate to contact me; good luck with your study.

Many thanks,

Chris

Chris Flanagan  
He/him

Research Support Administrator  
Midlands Partnership NHS Foundation Trust

Research & Innovation

Block 7, St George’s Hospital

Corporation Street, Stafford, ST16 3AG

### Appendix 4 – Research Ethics Committee and Sponsoring Trust Approval for Amendments

**From:** New IRAS Dev <[no-reply-iras@hra.nhs.uk](mailto:no-reply-iras@hra.nhs.uk)>   
**Sent:** 15 December 2022 15:01  
**To:** BURTON-FISHER Will <[b024994k@student.staffs.ac.uk](mailto:b024994k@student.staffs.ac.uk)>  
**Subject:** IRAS 313943. Amendment

**IRAS Project ID:** 313943    
**Sponsor amendment reference:**20024994   
  
  
Thank you for submitting your study amendment.  In accordance with the outcome of your completed amendment tool, this amendment requires no further regulatory review. Please now share this amendment with your UK research sites, in accordance with the instructions in your completed amendment tool.  
  
For studies with more than one UK research site, your amendment will now be automatically shared with the R&D offices of any NHS/HSC research sites in Scotland and Northern Ireland, but you should share the amendment by email directly with those Research team/s.  
  
For all NHS research sites in England and Wales, please now share this amendment by email directly with those sites, including both the R&D offices and research teams.  
  
Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.

This message may contain confidential information. If you are not the intended recipient please inform the sender that you have received the message in error before deleting it. Please do not disclose, copy or distribute information in this e-mail or take any action in relation to its contents. To do so is strictly prohibited and may be unlawful. Thank you for your co-operation..

**From:** Christopher Flanagan (RRE) MPFT <[Christopher.Flanagan@mpft.nhs.uk](mailto:Christopher.Flanagan@mpft.nhs.uk)>   
**Sent:** 16 December 2022 09:51  
**To:** William Burton Fisher (RRE) MPFT <[William.BurtonFisher@mpft.nhs.uk](mailto:William.BurtonFisher@mpft.nhs.uk)>; Chantel-Lea Grocott (RRE) MPFT <[Chantel-Lea.Grocott@mpft.nhs.uk](mailto:Chantel-Lea.Grocott@mpft.nhs.uk)>  
**Cc:** GORDON Kim V <[Kim.Gordon@staffs.ac.uk](mailto:Kim.Gordon@staffs.ac.uk)>  
**Subject:** RE: \*\*\*EXTERNAL\*\*\* FW: IRAS 313943. Amendment

Dear Will,

**RE: IRAS 313943 – Amendment 20024994 Advertising Via Social Media**

**Full Study Title:** Holding the Hope

Following review of the above amendment, we have now received all of the necessary approvals and amendment number 20024994 Advertising Via Social Media can now be implemented at our site. The site files will be updated with the following documents:

|  |  |  |
| --- | --- | --- |
| Document | Version | Date |
| - | - | - |

Please do not hesitate to contact me if I can be of any further assistance.

Many thanks,

Chris

Chris Flanagan  
He/him

Research Support Administrator  
**Midlands Partnership NHS Foundation Trust**

Research & Innovation

Block 7, St George’s Hospital

Corporation Street, Stafford, ST16 3AG

**e:** [christopher.flanagan@mpft.nhs.uk](mailto:christopher.flanagan@mpft.nhs.uk)

Tel. 01785 783170 (internal ext: 7128770) / 07580 971489

### Appendix 5 – Author Guidelines for Submission to Specified Journal

The target journal for publication is the British Journal of Health Psychology. A full link to the author guidelines can be found here: <https://bpspsychub.onlinelibrary.wiley.com/hub/journal/20448287/homepage/forauthors.html>

Word Count for this journal is 5,000 words (quantitative) or 6,000 words (qualitative). This journal follows a ‘free format submission’ approach. An overview of this includes:

**Free Format Submission**

*British Journal of Health Psychology* now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

* Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer (if you do submit separate files, we encourage you to also include your figures within the main document to make it easier for editors and reviewers to read your manuscript, but this is not compulsory). All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
* The title page of the manuscript, including a data availability statement and your co-author details with affiliations. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)*You may like to use [this template](https://bpspsychub.onlinelibrary.wiley.com/pb-assets/assets/2044835X/Sample_Manuscript_Title_Page%20-%20revised-1556026160210.docx) for your title page.

### Logo, company name Description automatically generatedAppendix 6 – Consent for Contact Form

**Consent for Contact (C4C) information**

**Title of study**

Holding the Hope? Exploring Therapist and Client Perspectives on the Psychological Aspects of Long covid: A Q-Methodology

*Project Reference Number:* 313943 *University Reference:* WBF EJT 0190522

**What is Consent for Contact? (C4C)**

We are looking for people who are interested in taking part in research that contributes to better health for people who have/have had Long covid. We are creating a register of people who might be interested in taking part in a future research project and we need your help.

Volunteers who take part in research play a crucial role in improving the lives of thousands of people. Research is the only way to develop better treatments and nearly all research at some point needs the help of those affected by particular health conditions in order to develop these treatments. You can help us to achieve this. As a first step, we are creating a list of people who would be willing for researchers to contact them about agreeing to take part in a study.

All researchers work for or are approved by NHS Trusts in Shropshire, Telford, Wrekin and South Staffordshire (Midland Partnership NHS Foundation Trust).

When approached about any specific study you will be able to agree or not to participate. At any time you can ask to be removed from this register.

**What type of research could I be involved in?**

There are two elements to the planned future study. The first part would include participating in an online focus group with other people who have experienced Long covid, where you will be asked to share your opinions on a number of statements. The second part of the study involves asking people to sort a number of statements, based on how much they agree with them, using online software. You may be asked to participate in one or both elements of the study. If you agree to join this register, you are giving your consent for researchers to make contact with you regarding potential involvement. There is no commitment to participate in the study if you change your mind. Researchers will not have access to your medical records but will understand that you have experienced Long covid.

**What happens if I agree to be on the C4C register?**

If you agree to be on the register, we will record your permission on a confidential database. We’ll give you a copy of this information leaflet to keep. Even if you agree for your name to be on this register, there’s no commitment to take part in the research project. If you agree, it just means that you are allowing our researchers to contact you if they think you might be suitable for the particular project. It is possible that they may not contact you at all. Our researchers will discuss the particular project in more detail with you and give you time to think about taking part. You’re then free to agree to take part or not, without giving a reason.

You are free to leave the C4C research register at any time without giving a reason. If you want to leave, you can ask the register administrator to remove your recorded permission from the database (contact details below). This won’t affect your care in any way.

**What will happen if I don’t agree to be on the list?**

Nothing; it is entirely up to you to decide whether you want to be on the list. This is an ‘opt-in’ rather than an ‘opt-out’ system. You do not have to give a reason for not being on the list and it will not affect your care in any way.

**How will we use information about you?**

* We will need to use information from you for this research project. This information will include your name and email address. People will use this information to do the research or to check your records to make sure that the research is being done properly.
* People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.
* We will keep all information about you safe and secure.
* Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

* You can stop being part of the register at any time, without giving a reason, but we will keep information about you that we already have. Personal data will not be kept for longer than three months after the study has finished.
* 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.
* If you agree to be part of this register, you will have the option to take part in future research using your data saved from this register.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

* at [www.hra.nhs.uk/information-about-patients/](https://www.hra.nhs.uk/information-about-patients/)
* our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
* by asking one of the research team
* by sending an email to [William.burtonfisher@mpft.nhs.uk](mailto:William.burtonfisher@mpft.nhs.uk)

If you are happy to be on the register, please complete the consent form below. You can either digitally sign and email this to [William.BurtonFisher@MPFT.nhs.uk](mailto:William.BurtonFisher@MPFT.nhs.uk), or alternatively, you can complete this form at the following link: <https://staffordshire.qualtrics.com/jfe/form/SV_2gVnehboM75v4DI>

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| I have read and understood this information sheet. | Yes |  | No |  |
| I have been given the opportunity to ask questions, and I have had any questions answered satisfactorily. | Yes |  | No |  |
| I understand that my inclusion on this register is entirely voluntary | Yes |  | No |  |
| I agree that data will only be used for this Long covid research, although the data may also be audited for quality control purposes | Yes |  | No |  |
| I understand that my data will be held in accordance with the General Data Protection Regulations (GDPR) and stored safely on a password protected computer. | Yes |  | No |  |
| I understand that I can withdraw my name from this database at any point. | Yes |  | No |  |
| I understand that my personal data (e.g. email address) will be stored for up to three months after the end of the study. | Yes |  | No |  |
| I hereby give consent to be included on the register | Yes |  | No |  |

Please complete the following personal information. This will allow us to contact you regarding future studies

|  |  |
| --- | --- |
| **Name:** |  |
| **Sign:** |  |
| **Date:** |  |
| **Email Address:** |  |

Please return via email to [William.BurtonFisher@MPFT.nhs.uk](mailto:William.BurtonFisher@MPFT.nhs.uk) or complete online at: <https://staffordshire.qualtrics.com/jfe/form/SV_2gVnehboM75v4DI>

**Thank you for taking the time to consider this research.**

Version 2 – 27/07/2022

### Logo, company name Description automatically generatedAppendix 7a - Focus Group Participant Information Form (Patient)

**FOCUS GROUP INFORMATION SHEET FOR PARTICIPANTS (Patient Version)**

*Project Reference Number:* 313943 *University Reference:* WBF EJT 0190522

**Title of study**

Holding the Hope: Exploring Therapist and Client Perspectives on the Psychological Aspects of Long covid: A Q-Methodology

**Invitation Paragraph**

Thank you for your interest in being part of this research, and for completing the consent to contact form. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

Long covid is a relatively new condition which has a potentially significant impact on someone’s physical and mental health. Shropshire, Telford, Wrekin and South Staffordshire Improving Access to Psychological Therapies services (IAPT) are currently offering therapy to those affected by Long covid. However, research into how it affects your mind and body, and what treatments are best for people, remain limited. Guidelines for therapists are also currently under review, meaning there is an opportunity to explore therapists’ and patients’ perspectives of Long covid.

**Why have I been invited to take part?**

You have been invited to take part because you have or have had Long covid, and have received psychological treatment for this through one of the named Improving Access to Psychological Therapies programme (also called IAPT).

**Who cannot take part?**

You cannot take part if you are still receiving therapy from IAPT for your Long covid. This is to ensure we only get opinions from people who have finished their course of treatment and that we are not adding to that burden. When you do finish your therapy, you are welcome to take part. You will also be unable to take part if you are under sixteen or do not live within Shropshire, Telford, Wrekin or South Staffordshire. This focus group will only be available to people who do not require language translation services.

**What will happen if I take part?**

Your participation would initially involve attending an online focus group held by the principal researcher. This would involve discussing and making comments on statements related to Long covid, alongside giving your own opinions that might not be covered by these statements. These statements will be brought by the researcher, derived from initial research into Long covid and related conditions. We expect this focus group to take no longer than one hour. Focus groups will be audio recorded and transcribed within two weeks of the group. Once recordings have been transcribed, audio recordings will be deleted.

**Do I have to take part?**

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

**What are the possible risks of taking part?**

As you have or have had Long covid, there is a risk that the activity could contribute to tiredness, screen fatigue or ‘brain fog’. To manage this risk, the activity will solely be conducted online. This allows you to take breaks as and when required. As the activity involves thinking about Long covid and its treatment, it is possible that you might feel some distress when thinking about your experiences. To help manage any potential distress, a list of local and national support organisations will be provided. You are also welcome to leave the focus group at any time. It will not be possible to maintain your privacy, as the nature of the focus group would mean that you are visible to other people in the group, who will similarly have received therapy for Long covid. Discussions about experiences will be kept within the focus group.

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

You may not receive any immediate benefits from taking part in the research, but you may find some benefit in recollecting and reflecting on the treatment you received for Long covid. It is also hoped that your experiences can help inform treatment approaches for others suffering from Long covid.

**How will we use information about you?**

We will need to use information from you for this research project. This information will include your name and email address. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

You can stop being part of the research at any time, but we will keep information about you that we already have. 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.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

* at [www.hra.nhs.uk/information-about-patients/](https://www.hra.nhs.uk/information-about-patients/)
* our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
* by asking one of the research team
* by sending an email to [William.burtonfisher@mpft.nhs.uk](mailto:William.burtonfisher@mpft.nhs.uk)

**What if I change my mind about taking part?**

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. However, we will keep information from you that we already have. If you agree to participate, you will be asked to develop a unique identifier code consisting of numbers and letters (e.g. EM198976) which will be used for all correspondence and record keeping of your data. To withdraw, please contact the researcher on the details below quoting this identifier.

**What will happen to the results of the study?**

The results of the study will be used to contribute to research into Long covid. This will primarily take the form of a written doctoral thesis, however may also be published in a peer reviewed journal. Other forms of dissemination, such as presentations, training and conferences, may be used to share the results. The results may also be used as part of a report which is publicly available. Your personal information and any identifying characteristics will be anonymised and your participant data will remain confidential. Any potential publication/dissemination of the researcher will not include sharing of personal information or participant data.

**Focus group ground rules**

To promote a safe and comfortable environment, we ask that you follow a number of ground rules when in the focus group. These include:

* Confidentiality – whatever is discussed in the focus group is not discussed with others who have not participated
* Respect – listen to others and avoid conflict. It is possible that people will have different opinions on the topic, and it is ok to disagree
* Self-care – participants are welcome to take a break or leave whenever they wish

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact me using the following contact details:

|  |  |
| --- | --- |
| **Name and Contact** | **Role** |
| Will Burton-Fisher  [William.BurtonFisher@mpft.nhs.uk](mailto:William.BurtonFisher@mpft.nhs.uk) | Principal Researcher – Trainee Clinical Psychologist |
| Dr Sarah Watts  [Sarah.Watts@mpft.nhs.uk](mailto:Sarah.Watts@mpft.nhs.uk) | Clinical Lead and Supervisor – Improving Access to Psychological Therapies Service |
| Dr Kim Gordon  [Kim.Gordon@staffs.ac.uk](mailto:Kim.Gordon@staffs.ac.uk) | Research Supervisor – Staffordshire University |

**What if I have further questions, or if something goes wrong?**

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

Dr. Tim Horne  
Research, Innovation and Impact Services  
Cadman Building, Staffordshire University  
College Road  
Stoke-on-Trent  
ST4 2DF  
[Tim.horne@staffs.ac.uk](mailto:Tim.horne@staffs.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research**

Version 2.0 – 27/07/2022

### Appendix 7b – Focus Group Topic Guide (client)

**Focus Group Topic Guide -** client**s**

*Research goals of the focus groups and Q Sort include:*

* Understanding therapists and clients’ perspectives on Long covid
* A focus on the psychological aspects – e.g. what makes people more vulnerable, how is it experienced, and what potential treatments work/have worked?
* Also want to understand if there are differences of opinion

**Part 1: Introductions & ground Rules** (Approx 10 minutes)

* Welcome and thank yous. Researcher to introduce themselves and their role.
* Put debrief sheet in chat
* “The goal of today’s focus group is to understand what your thoughts are on Long covid, including what its causes might be, how it affects people’s lives, and how psychological treatments might help. Within the next hour, we will aim to have a general group discussion about this, before I show you a list of statements. I would like you to give feedback on these statements, and if you think they cover the whole breadth of potential perspectives. We will do introductions shortly, but I just need to go over some ground rules before we do. “

1. Everything discussed in the focus group is kept confidential. There are limits to this, as some of you might know each other. However, please respect each other’s privacy.
2. We don’t anticipate this exercise to cause any distress, but you are welcome to take a break leave at any point if you do feel uncomfortable. Support information has been provided if you want follow up, or you can email my work email and I can arrange a debrief with you. We will have to end the session if it proves too upsetting.
3. This session will be audio recorded to help with transcription. No personal information (e.g. names) will be transcribed. The audio recording will be kept on an NHS password protected laptop, and destroyed after it has been transcribed (within two weeks)
4. You are welcome to withdraw from the study at any time, including leaving this session. But we will keep any data you have given us up until that point.
5. People do have different opinions on Long covid. It’s ok to disagree but please keep respectful.
6. You are welcome to have your video on or off, use the microphone, or just type in the chat box. I will read out any chat box messages to help with transcription.

**Instructions: Check everyone is happy with this (e.g. use thumbs up, say yes)**

* Introductions – ask the group to introduce themselves and briefly give an overview of their relationship to Long covid.

**Part 2: General Discussion (around 30 minutes)**

**Instructions –** reiterate the research. Focus group is to help inform the Q-Sort, to make sure that everybody’s perspectives are covered. There isn’t much national guidance for psychological treatments of Long covid yet, and of course there are the physical elements also. We are hoping to get a better idea of what might work for people who come to IAPT services. Does anyone have any questions before we start?

**Question 1:** (put hand up to answer question, or pop it in the chat if you prefer)

(Question prompts)

* When you hear ‘long covid’, what first comes to mind?
* What is your experience of having long covid?
* How, if at all, has long covid affected your life?
* What worked for you?
* What didn’t work?
* Could there be psychological factors which make people more vulnerable to it?
* Any specific thoughts on graded exercise therapy? Cognitive behavioural therapy?

**Part 3: Q-Sort statements (around 15 minutes)**

Here are some statements I have already put together, based on a literature review I have been writing. These reflect some of the opinions that people have, either from people living with Long covid or professionals who are trying to treat it. What do you think of these statements, and do you think anything is missing?

**Part 4: Endings**

Thank you for taking part, it’s really appreciated. Just a reminder that we are keeping things confidential, so please do not share details of what other people have said outside of this group. I have a record of people who have said they would be interested in doing the Q Sort part of the research. If you have changed your mind either way (i.e. if you said you weren’t interested but are now), please let me know and I can update your details and send you the link when it’s ready.

Version 1.0 – 29/07/2022

### Logo, company name Description automatically generatedAppendix 7c – Focus Group Participant Information Form (IAPT Therapist)

**FOCUS GROUP INFORMATION SHEET FOR PARTICIPANTS (Therapist Version)**

*Project Reference Number:* 313943 *University Reference:* WBF EJT 0190522

**Title of study**

Holding the Hope? Exploring Therapist and Client Perspectives on the Psychological Aspects of Long covid: A Q-Methodology

**Invitation Paragraph**

Thank you for your interest in being part of this research, and for completing the consent to contact form. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

Long covid is a relatively new condition which has a potentially significant impact on someone’s physical and mental health. Shropshire, Telford, Wrekin and South Staffordshire’s Improving Access to Psychological Therapies services (IAPT) are currently offering therapy to those affected by Long covid. However, research into how it affects your mind and body, and what treatments are best for people, remain limited. Guidelines for therapists are also currently under review, meaning there is an opportunity to explore therapists’ and patients’ perspectives of Long covid.

**Why have I been invited to take part?**

You have been invited to take part because you work for Shropshire, Telford & Wrekin or South Staffordshire’s Improving Access to Psychological Therapies service and have delivered therapy to people suffering with Long covid.

**Who cannot take part?**

You cannot take part if you have not provided an IAPT-based therapy to someone living with Long covid. You will also be unable to take part if you do not work for IAPT within Shropshire, Telford, Wrekin or South Staffordshire. This focus group will only be available to people who do not require language translation services.

**What will happen if I take part?**

Your participation would initially involve attending an online focus group held by the principal researcher. This would involve discussing and making comments on statements related to Long covid, alongside giving your own opinions that might not be covered by these statements. These statements will be brought by the researcher, derived from initial research into Long covid and related conditions. We expect this focus group to take no longer than one hour. Focus groups will be audio recorded and transcribed within two weeks of the group. Once recordings have been transcribed, audio recordings will be deleted.

**Do I have to take part?**

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

**What are the possible risks of taking part?**

No significant risks are anticipated from engaging in this study. However, there is a possibility that engaging in this research will have a negative impact on staff workload. Participants are encouraged to discuss the task with their clinical supervisor, so that appropriate time can be allocated to the activity during working hours. You are also welcome to leave the focus group at any time. It will not be possible to maintain your privacy, as the nature of the focus group would mean that you are visible to other people in the group, who will similarly have provided therapy for Long covid. Discussions about experiences will be kept within the focus group.

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

It is hoped that your experiences can help inform treatment approaches for people suffering from Long covid and to help shape guidance and policy for IAPT services.

**How will we use information about you?**

We will need to use information from you for this research project. This information will include your name and email address. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

You can stop being part of the research at any time, but we will keep information about you that we already have. 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.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

* at [www.hra.nhs.uk/information-about-patients/](https://www.hra.nhs.uk/information-about-patients/)
* our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
* by asking one of the research team
* by sending an email to [William.burtonfisher@mpft.nhs.uk](mailto:William.burtonfisher@mpft.nhs.uk)

**What if I change my mind about taking part?**

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. However, we will keep information from you that we already have. If you agree to participate, you will be asked to develop a unique identifier code consisting of numbers and letters (e.g. EM198976) which will be used for all correspondence and record keeping of your data. To withdraw, please contact the researcher on the details below quoting this identifier.

**What will happen to the results of the study?**

The results of the study will be used to contribute to research into Long covid. This will primarily take the form of a written doctoral thesis, however may also be published in a peer reviewed journal. Other forms of dissemination, such as presentations, training and conferences, may be used to share the results. The results may also be used as part of a report which is publicly available. Your personal information and any identifying characteristics will be anonymised and your participant data will remain confidential. Any potential publication/dissemination of the researcher will not include sharing of personal information or participant data.

**Focus group ground rules**

To ensure a safe and comfortable environment, we ask that you follow a number of ground rules when in the focus group. These include:

* Confidentiality – whatever is discussed in the focus group is not discussed with others who have not participated
* Respect – listen to others and avoid conflict. It is possible that people will have different opinions on the topic, and it is ok to disagree
* Self-care – participants are welcome to take a break when they wish

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact me using the following contact details:

|  |  |
| --- | --- |
| **Name and Contact** | **Role** |
| Will Burton-Fisher  [William.BurtonFisher@mpft.nhs.uk](mailto:William.BurtonFisher@mpft.nhs.uk) | Principal Researcher – Trainee Clinical Psychologist |
| Dr Sarah Watts  [Sarah.Watts@mpft.nhs.uk](mailto:Sarah.Watts@mpft.nhs.uk) | Clinical Lead and Supervisor – Improving Access to Psychological Therapies Service |
| Dr Kim Gordon  [Kim.Gordon@staffs.ac.uk](mailto:Kim.Gordon@staffs.ac.uk) | Research Supervisor – Staffordshire University |

**What if I have further questions, or if something goes wrong?**

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

Dr. Tim Horne  
Research, Innovation and Impact Services  
Cadman Building, Staffordshire University  
College Road  
Stoke-on-Trent  
ST4 2DF  
[Tim.horne@staffs.ac.uk](mailto:Tim.horne@staffs.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research.**

Version 2.0 – 27/07/2022

### Appendix 7e – Focus Group Consent Form (client and Therapist)

Logo, company name

Description automatically generated**Focus Group Consent Form**

**Title of Project:** Holding the Hope? Therapist and Client Perspectives on the Psychological Aspects of Long covid. A Q-Methodology

*Project Reference Number:* 313943 *University Reference:* WBF EJT 0190522

**Researcher:** Will Burton-Fisher

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| I have read and understood the information sheet. | Yes |  | No |  |
| I have read, understood and agree to abide by the ground rules for the focus group | Yes |  | No |  |
| I have been given the opportunity to ask questions, and I have had any questions answered satisfactorily. | Yes |  | No |  |
| I understand that my participation in this study is entirely voluntary | Yes |  | No |  |
| I understand that the focus group will be audio recorded. I understand that once these recordings have been transcribed (within two weeks of the group), recordings will be deleted. | Yes |  | No |  |
| I understand and consent to the fact that I will be visible to other people in the focus group, meaning my privacy will not be possible. | Yes |  | No |  |
| I consent that data collected could be used for publication in scientific journals, or can be used for teaching purposes, and understand that all data will be presented anonymously. | Yes |  | No |  |
| I agree that data will only be used for this Long covid research, although the data may also be audited for quality control purposes | Yes |  | No |  |
| I understand that my data will be held in accordance with the General Data Protection Regulations (GDPR) and stored safely on a password protected computer. | Yes |  | No |  |
| I understand that I can withdraw from the study without explanation, and that any data I have already shared will be kept. | Yes |  | No |  |
| I understand that personal data (e.g. email address) will be stored for one year, and research data (e.g. recordings) will be stored for three years, and that this data will be destroyed after these time periods. | Yes |  | No |  |
| I hereby give consent to take part in this study | Yes |  | No |  |

**Please Turn Over**

Please complete the following personal information. This will allow us to contact you to participate in the study:

|  |  |
| --- | --- |
| **Name:** |  |
| **Role (therapist/client):** |  |
| **Sign:** |  |
| **Date:** |  |

**Unique Identifier**

Please develop and keep a record of your unique identifying code, as outlined in the participant information sheet. This identifier will be used for any future correspondence between you and the research team and allows us to ensure your data is kept confidential.

To develop your unique identifier, please use any random mix of numbers and letters and make a note of this (e.g. EL1622G).

**Code: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Contact**

Please return your completed form via email to Will Burton-Fisher at [Will.BurtonFisher@mpft.nhs.uk](mailto:Will.BurtonFisher@mpft.nhs.uk). We will contact you via the email address you used to send this form to arrange a suitable focus group time.

**Many thanks for your willingness to take part in this research.**

Version 3.0 – 27/07/22

### Logo, company name Description automatically generatedAppendix 8a – Q Sort Participant Information Form (client)

**Q-SORT INFORMATION SHEET FOR PARTICIPANTS (**client **Version)**

*Project Reference Number:* 313943 *University Reference:* WBF EJT 0190522

**Title of study**

Holding the Hope? Exploring Therapist and Client Perspectives on the Psychological Aspects of Long covid: A Q-Methodology

**Invitation Paragraph**

Thank you for your interest in being part of this research, and for completing the consent to contact form. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

Long covid is a relatively new condition which has a potentially significant impact on someone’s physical and mental health. Shropshire, Telford, Wrekin and South Staffordshire’s Improving Access to Psychological Therapies services are currently offering therapy to those affected by Long covid. However, research into its psychological components, and what treatments are best for people, remain limited. Guidelines for therapists are also currently under review, meaning there is an opportunity to explore therapists’ perspectives and the patients they support.

**Why have I been invited to take part?**

You have been invited to take part because you have or have had Long covid, and have received psychological treatment for this through one of the named Improving Access to Psychological Therapies programmes.

**Who cannot take part?**

You cannot take part if you are still receiving therapy from IAPT for your Long covid. This is to ensure we only get opinions from people who have finished their course of treatment and that we are not adding to that burden. When you do finish your therapy, you are welcome to take part. You will also be unable to take part if you are under sixteen or do not live within Shropshire, Telford, Wrekin or South Staffordshire. You will also require access to a desktop computer or laptop to complete the activity (smart devices will not work).

**What will happen if I take part?**

Your participation would involve completing an online ‘Q-sort’. This involves using computer software to sort a number of statements, based on how much you agree with these. There are forty statements to sort, which you will be asked to rank from least-agreed to most-agreed. We expect this sorting process will take no longer than forty minutes to complete.

**Do I have to take part?**

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

**What are the possible risks of taking part?**

As you have or have had Long covid, there is a risk that the activity could contribute to tiredness, screen fatigue or ‘brain fog’. To manage this risk, the activity will solely be conducted online without time limits. This allows you to take regular breaks and to complete the activity in a timeframe comfortable for you. As the activity involves thinking about Long covid and its treatment, it is possible that you might feel some distress when recalling your experiences. To help manage any potential distress, a list of local and national support organisations will be provided. You are also welcome to stop the activity at any time.

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

You may find benefit from recollecting and reflecting on the treatment you received for Long covid. It is also hoped that your experiences can help inform treatment approaches for others suffering from Long covid.

**How will we use information about you?**

We will need to use information from you for this research project. This information will include your name and email address. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

You can stop being part of the research at any time and withdraw your research data up to one month after completing the task. 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.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

* at [www.hra.nhs.uk/information-about-patients/](https://www.hra.nhs.uk/information-about-patients/)
* our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
* by asking one of the research team
* by sending an email to [William.burtonfisher@mpft.nhs.uk](mailto:William.burtonfisher@mpft.nhs.uk)

**What if I change my mind about taking part?**

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You will be able to withdraw your data up to one month after completing the Q-Sort. If you agree to participate, you will be asked to develop a unique identifier code consisting of numbers and letters (e.g. EM198976) which will be used for all correspondence and record keeping of your data. To withdraw, please contact the researcher on the details below quoting this identifier.

**What will happen to the results of the study?**

The results of the study will be used to contribute to research into Long covid. This will primarily take the form of a written doctoral thesis, however may also be published in a peer reviewed journal. Other forms of dissemination, such as presentations, training and conferences, may be used to share the results. The results may also be used as part of a report which is publicly available. Your personal information and any identifying characteristics will be anonymised and your participant data will be kept as confidential at all times.

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact me using the following contact details:

|  |  |
| --- | --- |
| **Name and Contact** | **Role** |
| Will Burton-Fisher  [William.BurtonFisher@mpft.nhs.uk](mailto:William.BurtonFisher@mpft.nhs.uk) | Principal Researcher – Trainee Clinical Psychologist |
| Dr Sarah Watts  [Sarah.Watts@mpft.nhs.uk](mailto:Sarah.Watts@mpft.nhs.uk) | Clinical Lead and Supervisor – Improving Access to Psychological Therapies Service |
| Dr Kim Gordon  [Kim.Gordon@staffs.ac.uk](mailto:Kim.Gordon@staffs.ac.uk) | Research Supervisor – Staffordshire University |

**What if I have further questions, or if something goes wrong?**

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

Dr. Tim Horne  
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College Road  
Stoke-on-Trent  
ST4 2DF  
[Tim.horne@staffs.ac.uk](mailto:Tim.horne@staffs.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research.**

Version 2.0 – 29/07/2022

### Logo, company name Description automatically generatedAppendix 8b – Q Sort Participant Information Form (Therapist)

**Q-SORT INFORMATION SHEET FOR PARTICIPANTS (Therapist Version)**

*Project Reference Number:* 313943 *University Reference:* WBF EJT 0190522

**Title of study**

Holding the Hope: Exploring Therapist and Client Perspectives on the Psychological Aspects of Long covid: A Q-Methodology

**Invitation Paragraph**

Thank you for your interest in being part of this research, and for completing the consent to contact form. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

Long covid is a relatively new condition which has a potentially significant impact on someone’s physical and mental health. Shropshire, Telford, Wrekin and South Staffordshire’s Improving Access to Psychological Therapies services are currently offering therapy to those affected by Long covid. However, research into its psychological components, and what treatments are best for people, remain limited. Guidelines for therapists are also currently under review, meaning there is an opportunity to explore therapists’ perspectives and the patients they support.

**Why have I been invited to take part?**

You have been invited to take part because you work for one of the named Improving Access to Psychological Therapies services and have delivered therapy to people suffering with Long covid.

**Who cannot take part?**

You cannot take part if you have not delivered therapy for Long covid through IAPT. You will also be unable to take part if you do not work within Shropshire, Telford, Wrekin or South Staffordshire. You will also require access to a desktop computer or laptop to complete the activity (smart devices will not work).

**What will happen if I take part?**

Your participation would involve completing an online ‘Q-sort’. This involves using computer software to sort a number of statements, based on how much you agree with these. There are forty statements to sort, which you will be asked to rank from least-agreed to most-agreed. We expect this sorting process will take no longer than forty minutes to complete.

**Do I have to take part?**

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

**What are the possible risks of taking part?**

No significant risks are anticipated from engaging in this study. However, there is a possibility that engaging in this research will have a negative impact on staff workload. Participants are encouraged to discuss the task with their clinical supervisor, so that appropriate time can be allocated to the activity during working hours. Participants are welcome to complete the task in their own time (e.g. evenings and weekends) however this is considered a personal choice. Participation is voluntary and therapists can decide if they have the capacity to complete the task. As the task is online, the most feasible time can be chosen by participants to complete the task.

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

It is hoped that your experiences can help inform treatment approaches for people suffering from Long covid and to help shape guidance and policy for IAPT services.

**How will we use information about you?**

We will need to use information from you for this research project. This information will include your name and email address. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

You can stop being part of the research at any time and withdraw your research data up to one month after completing the task. 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.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

* at [www.hra.nhs.uk/information-about-patients/](https://www.hra.nhs.uk/information-about-patients/)
* our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
* by asking one of the research team
* by sending an email to [William.burtonfisher@mpft.nhs.uk](mailto:William.burtonfisher@mpft.nhs.uk)

**What if I change my mind about taking part?**

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You will be able to withdraw your data up to one month after completing the Q-Sort. If you agree to participate, you will be asked to develop a unique identifier code consisting of numbers and letters (e.g. EM198976) which will be used for all correspondence and record keeping of your data. To withdraw, please contact the researcher on the details below quoting this identifier.

**What will happen to the results of the study?**

The results of the study will be used to contribute to research into Long covid. This will primarily take the form of a written doctoral thesis, however may also be published in a peer reviewed journal. Other forms of dissemination, such as presentations, training and conferences, may be used to share the results. The results may also be used as part of a report which is publicly available. All personal identifying information will be anonymised and confidentiality of your data will be maintained.

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact me using the following contact details:

|  |  |
| --- | --- |
| **Name and Contact** | **Role** |
| Will Burton-Fisher  [William.BurtonFisher@mpft.nhs.uk](mailto:William.BurtonFisher@mpft.nhs.uk) | Principal Researcher – Trainee Clinical Psychologist |
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**What if I have further questions, or if something goes wrong?**

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

Dr. Tim Horne  
Research, Innovation and Impact Services  
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**Thank you for reading this information sheet and for considering taking part in this research.**

Version 2.0 – 29/07/2022

### Logo, company name Description automatically generatedAppendix 8c – Q Sort Consent Form (client and Therapist)

**Q-Sort Consent Form**

**Title of Project:** Holding the Hope? Therapist and Client Perspectives on the Psychological Aspects of Long covid. A Q-Methodology

*Project Reference Number:* 313943 *University Reference:* WBF EJT 0190522

**Researcher:** Will Burton-Fisher

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| I have read and understood the ‘information sheet for participants’ | Yes |  | No |  |
| I have been given the opportunity to ask questions, and I have had any questions answered satisfactorily. | Yes |  | No |  |
| I understand that my participation in this study is entirely voluntary | Yes |  | No |  |
| I consent that data collected could be used for publication in scientific journals, or can be used for teaching purposes, and understand that all data will be presented anonymously. | Yes |  | No |  |
| I agree that data will only be used for this Long covid research, although the data may also be audited for quality control purposes | Yes |  | No |  |
| I understand that my data will be held in accordance with the General Data Protection Regulations (GDPR) and stored safely on a password protected computer. | Yes |  | No |  |
| I understand that I can withdraw from the study without explanation, and that I can withdraw this data up to one month after completing the Q-Sort. | Yes |  | No |  |
| I understand that personal data (e.g. email address) will be stored for three months after the end of the study, and research data (e.g. Q-Sort responses) will be stored for three years, and that this data will be destroyed after these time periods. | Yes |  | No |  |
| I hereby give consent to take part in this study | Yes |  | No |  |

**Please Turn Over**

Please complete the following personal information. This will allow us to contact you to participate in the study:

|  |  |
| --- | --- |
| **Name:** |  |
| **Role (therapist/client):** |  |
| **Sign:** |  |
| **Date:** |  |

(Email request removed)

**Unique Identifier**

Please develop and keep a record of your unique identifying code, as outlined in the participant information sheet. This identifier will be used for any future correspondence between you and the research team and allows us to ensure your data is kept confidential.

To develop your unique identifier, please use any random mix of numbers and letters and make a note of this (e.g. EL1622G).

**Code: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Contact**

Please return your completed form via email to Will Burton-Fisher at [Will.BurtonFisher@mpft.nhs.uk](mailto:Will.BurtonFisher@mpft.nhs.uk). We will contact you via the email address you used to send you the Q-Sort link.

**Many thanks for your willingness to take part in this research.**

Version 3.0 – 27/07/2022

### Logo, company name Description automatically generatedAppendix 9 – Debrief Sheet

**Debrief Sheet**

*Project Reference Number:* 313943 *University Reference:* WBF EJT 0190522

Thank you for participating in this study. Please retain your participant information sheet for details on the study, including your right to withdraw and the process for this. Please find below a list of further support organisations you can contact should you wish.

**Long covid Support**

Long covid Support is a peer support and advocacy group for people living with Long covid. It provides comprehensive details and advice, including symptom management, practical support details (e.g. disability applications), support groups and more.

[www.longcovid.org](http://www.longcovid.org)

**Improving Access to Psychological Therapies Service**

The NHS talking therapies services, accepting self referrals either via telephone or online. Therapy can be delivered in a number of ways, including online workshops, video call, telephone or face to face. For full details of what is provided in your area (Staffordshire only), contact on the details below.

[www.staffsandstokewellbeing.nhs.uk](http://www.staffsandstokewellbeing.nhs.uk)

**Samaritans**

A free listening service, 24 hours a day, 365 days a year. Whatever you’re going through, Samaritans will listen. Either freephone them or chat with them online.

[www.samaritans.org](http://www.samaritans.org)

Freephone: 116 123

**NHS Patient Advice and Liaison Service (PALS)**

Provides people with extra support and advice when using health services. This includes information on further health services and organisations, help with problems that couldn’t be addressed with a service and information on how to make complaints

**Midlands Partnership PALS**

Tel: 08007832865

Email: [palsandexperience@mpft.nhs.uk](mailto:palsandexperience@mpft.nhs.uk)

Website: <https://www.mpft.nhs.uk/service-users-carers/complaints-concerns-and-compliments>

Version 1.1 – 19/05/2022

### Appendix 10a – Study Advert (clients)

**A picture containing timeline

Description automatically generated**

### Appendix 10b – Study Advert (IAPT Therapists)

**A picture containing text

Description automatically generated**

### Appendix 11 – Full Q Set Including Statement Number

1. Can be achieved through psychological therapy

2. Is easier if you meet other people with long covid

3. Is helped by sharing self-management tips with other sufferers

4. Includes feeling less lonely

5. Involves learning to manage anxiety

6. Is more likely if your therapist has had it

7. Is less likely if your therapist has had it

8. Include gettings back into work

9. Includes finding a new identity

10. Is hampered by increasing physical movement

11. Includes learning to pace yourself (boom and bust)

12. Is harder if you meet other people with Long covid

13. Happens naturally with time

14. Involves learning to accept how you feel

15. Cannot involve accepting how you feel, as this is like giving up

16. Is different for everyone

17. Includes getting back to your old self

18. Involves addressing underlying trauma

19. Involves addressing the core beliefs people have about themselves

20. Involves overcoming the fear of moving your body

21. Requires your friends and family to believe you

22. Requires professionals to believe you

23. Involves feeling close to people again

24. Includes finding a new meaning in life

25. Includes building your self esteem

26. Can make you feel stronger than you were before the illness

27. Involves becoming more independent

28. Is negatively influenced by a therapist’s personal experience of Covid-19

29. Means having better mental health

30. Means having less pain

31. Means having less fatigue

32. Means having less brain fog

33. Means doing things that are important to you in spite of the illness

34. Is achieved through doing yoga

35. Means finding meaning in having the illness

36. Is not possible

37. Is possible

38. Is made harder due to society’s stigma towards it

39. Involves taking medication for your physical health

40. Is positively influenced by a therapist’s personal experience of Covid-19

41. Involves learning breathing techniques

42. Involves overcoming guilt you have for contracting it

43. Requires you to advocate for yourself

44. Involves focussing on what you are grateful for

45. Involves learning to live with pain

46. Involves taking medication for your mental health

47. Treatments are shaped by a therapist’s own experiences of Covid-19

48. Means managing unhelpful thoughts caused by the illness

49. Means managing unhelpful thoughts which existed before the illness

50. Requires you to gradually increase your movement

51. Means taking responsibility for your own health

52. Is not a psychological issue

53. Practitioners know how to support people

54. Requires practitioners to be experts

### Appendix 12a – Correlation Matrix

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Participant** | **U1** | **U2** | **U3** | **U4** | **U5** | **U6** | **U7** | **U8** | **U9** | **U10** | **U11** | **U12** | **U13** | **U14** | **U15** | **U16** |
| **U1** | 100 | 48 | -11 | 46 | 20 | 20 | 67 | 32 | 49 | 18 | 42 | -9 | 25 | 18 | 22 | 9 |
| **U2** | 48 | 100 | 6 | 32 | 38 | 35 | 56 | 35 | 59 | 6 | 39 | 13 | 39 | 41 | 33 | 38 |
| **U3** | -11 | 6 | 100 | 11 | 11 | 5 | -8 | -14 | 9 | 15 | 7 | 17 | 35 | 32 | 46 | 43 |
| **U4** | 46 | 32 | 11 | 100 | 19 | 30 | 57 | 23 | 26 | 13 | 36 | -15 | 41 | 23 | 21 | 13 |
| **U5** | 20 | 38 | 11 | 19 | 100 | 27 | 33 | 29 | 27 | 23 | 34 | 26 | 36 | 36 | 23 | 21 |
| **U6** | 20 | 35 | 5 | 30 | 27 | 100 | 28 | 27 | 33 | 31 | 7 | 21 | 39 | 44 | 34 | 49 |
| **U7** | 67 | 56 | -8 | 57 | 33 | 28 | 100 | 43 | 55 | 29 | 48 | -13 | 36 | 20 | 22 | 15 |
| **U8** | 32 | 35 | -14 | 23 | 29 | 27 | 43 | 100 | 42 | 28 | 26 | 31 | 18 | 30 | 10 | 22 |
| **U9** | 49 | 59 | 9 | 26 | 27 | 33 | 55 | 42 | 100 | 11 | 48 | 8 | 48 | 42 | 44 | 35 |
| **U10** | 18 | 6 | 15 | 13 | 23 | 31 | 29 | 28 | 11 | 100 | 24 | 8 | 35 | 25 | 21 | 31 |
| **U11** | 42 | 39 | 7 | 36 | 34 | 7 | 48 | 26 | 48 | 24 | 100 | 10 | 41 | 16 | 20 | 25 |
| **U12** | -9 | 13 | 17 | -15 | 26 | 21 | -13 | 31 | 8 | 8 | 10 | 100 | 3 | 38 | 7 | 53 |
| **U13** | 25 | 39 | 35 | 41 | 36 | 39 | 36 | 18 | 48 | 35 | 41 | 3 | 100 | 58 | 49 | 38 |
| **U14** | 18 | 41 | 32 | 23 | 36 | 44 | 20 | 30 | 42 | 25 | 16 | 38 | 58 | 100 | 48 | 57 |
| **U15** | 22 | 33 | 46 | 21 | 23 | 34 | 22 | 10 | 44 | 21 | 20 | 7 | 49 | 48 | 100 | 38 |
| **U16** | 9 | 38 | 43 | 13 | 21 | 49 | 15 | 22 | 35 | 31 | 25 | 53 | 38 | 57 | 38 | 100 |

### Appendix 12b – Varimax Rotated Factor Loadings

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Q sort** | **Factor 1** | **Factor 2** | **Factor 3** | **Factor 4** |
| **U3** | **0.7997\*** | -0.0433 | -0.0319 | 0.0895 |
| **U4** | **0.7119\*** | 0.2118 | 0.3461 | -0.1561 |
| **U5** | -0.1549 | **0.8121\*** | 0.0377 | 0.0275 |
| **U6** | **0.6085\*** | 0.2057 | -0.2039 | 0.297 |
| **U7** | 0.3446 | 0.1287 | **0.3931\*** | 0.226 |
| **U9** | 0.2424 | 0.257 | 0.3926 | **0.4223\*** |
| **U10** | **0.8545\*** | -0.0225 | -0.0089 | 0.2597 |
| **U11** | 0.456 | -0.2542 | **0.5449\*** | 0.2661 |
| **U12** | **0.7207\*** | 0.282 | 0.2905 | -0.1205 |
| **U13** | 0.0803 | 0.1171 | 0.1331 | **0.8736\*** |
| **U14** | **0.6178\*** | 0.1223 | 0.1083 | 0.108 |
| **U15** | -0.164 | 0.0538 | **0.8643\*** | -0.0251 |
| **U16** | 0.4115 | **0.6288\*** | 0.08 | 0.3332 |
| **U17** | 0.2226 | 0.553 | **0.5232\*** | 0.1647 |
| **u18** | 0.2698 | **0.7344\*** | 0.103 | 0.0481 |
| **U19** | 0.0851 | 0.5065 | **0.6344\*** | 0.169 |

### Appendix 12c – Consensus Statements

Those That Do Not Distinguish Between ANY Pair of Factors

All Listed Statements are Non-Significant at P>0.01, and Those Flagged with an \* are also Non-Significant at P>0.05

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Statement Number** | **Significance** | **Statement** | **Statement Number** | **factor1 Q-SV** | **factor1 Z-score** | **factor2 Q-SV** | **factor2 Z-score** | **factor3 Q-SV** | **factor3 Z-score** | **factor4 Q-SV** | **factor4 Z-score** |
| 2 | \* | Is easier if you meet other people with long covid | 2 | 0 | 0.137 | 1 | 0.441 | 0 | 0.178 | 0 | 0.098 |
| 6 | \* | Is more likely if your therapist has had it | 6 | 0 | -0.337 | 0 | -0.136 | 0 | -0.445 | 0 | -0.098 |
| 26 |  | Can make you feel stronger than you were before the illness | 26 | 0 | 0.34 | 0 | -0.34 | 0 | -0.108 | 0 | -0.295 |
| 29 |  | Means having better mental health | 29 | 1 | 0.47 | 0 | -0.25 | 0 | 0.131 | 1 | 0.71 |
| 47 | \* | Treatments are shaped by a therapist’s own experiences of Covid-19 | 47 | 0 | 0.066 | 0 | 0 | 0 | -0.139 | 0 | -0.197 |
| 53 | \* | Practitioners know how to support people | 53 | -1 | -0.605 | 0 | -0.384 | 0 | -0.108 | 0 | 0 |

### Appendix 12d – Factor Arrays For all Factors

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Statements | Factor 1 | Factor 2 | Factor 3 | Factor 4 |
| 1 | Can be achieved through psychological therapy | 2 | -1 | -1 | -2 |
| 2 | Is easier if you meet other people with long covid | 0 | 1 | 0 | 0 |
| 3 | Is helped by sharing self-management tips with other sufferers | 0 | 1 | 0 | -2 |
| 4 | Includes feeling less lonely | 0 | 1 | -1 | 1 |
| 5 | Involves learning to manage anxiety | 1 | 0 | -1 | 1 |
| 6 | Is more likely if your therapist has had it | 0 | 0 | 0 | 0 |
| 7 | Is less likely if your therapist has had it | -1 | -1 | 0 | -3 |
| 8 | Includes getting back into work | -1 | 1 | 1 | -1 |
| 9 | Includes finding a new identity | 0 | 0 | -3 | 0 |
| 10 | Is hampered by increasing physical movement | -1 | 0 | 2 | 1 |
| 11 | Includes learning to pace yourself (boom and bust) | 3 | 3 | 0 | -1 |
| 12 | Is harder if you meet other people with Long covid | -2 | -3 | -1 | 0 |
| 13 | Happens naturally with time | -1 | -1 | -1 | 0 |
| 14 | Involves learning to accept how you feel | 2 | 0 | 0 | 0 |
| 15 | Cannot involve accepting how you feel, as this is like giving up | -3 | -2 | 2 | -2 |
| 16 | Is different for everyone | 2 | 2 | 1 | 0 |
| 17 | Includes getting back to your old self | -2 | 0 | 1 | 0 |
| 18 | Involves addressing underlying trauma | 0 | -1 | 2 | -1 |
| 19 | Involves addressing the core beliefs people have about themselves | 1 | -2 | -1 | -1 |
| 20 | Involves overcoming the fear of moving your body | 1 | 0 | -1 | 0 |
| 21 | Requires your friends and family to believe you | 0 | 3 | -1 | 0 |
| 22 | Requires professionals to believe you | 0 | 2 | 1 | 2 |
| 23 | Involves feeling close to people again | 0 | 1 | -1 | -1 |
| 24 | Includes finding a new meaning in life | 1 | 0 | -2 | 2 |
| 25 | Includes building your self esteem | 0 | 0 | 0 | 1 |
| 26 | Can make you feel stronger than you were before the illness | 0 | -1 | 0 | 0 |
| 27 | Involves becoming more independent | -1 | -1 | 0 | 0 |
| 28 | Is negatively influenced by a therapist’s personal experience of Covid-19 | -2 | 0 | 0 | 0 |
| 29 | Means having better mental health | 1 | 0 | 0 | 1 |
| 30 | Means having less pain | -1 | 0 | 2 | 1 |
| 31 | Means having less fatigue | 0 | 2 | 3 | 2 |
| 32 | Means having less brain fog | 0 | 2 | 2 | 1 |
| 33 | Means doing things that are important to you in spite of the illness | 2 | 1 | 1 | 3 |
| 34 | Is achieved through doing yoga | -2 | 0 | -2 | -3 |
| 35 | Means finding meaning in having the illness | 1 | -1 | -2 | 2 |
| 36 | Is not possible | -3 | -1 | -3 | -2 |
| 37 | Is possible | 3 | 0 | 3 | 1 |
| 38 | Is made harder due to society’s stigma towards it | 0 | 1 | 1 | -1 |
| 39 | Involves taking medication for your physical health | -1 | -1 | 1 | -1 |
| 40 | Is positively influenced by a therapist’s personal experience of Covid-19 | 0 | 0 | 0 | -2 |
| 41 | Involves learning breathing techniques | 0 | 2 | 0 | 3 |
| 42 | Involves overcoming guilt you have for contracting it | 0 | -2 | -1 | -1 |
| 43 | Requires you to advocate for yourself | 1 | 1 | 0 | -1 |
| 44 | Involves focussing on what you are grateful for | 0 | 0 | -2 | 0 |
| 45 | Involves learning to live with pain | 0 | 0 | -2 | 1 |
| 46 | Involves taking medication for your mental health | -1 | -2 | 0 | 2 |
| 47 | Treatments are shaped by a therapist’s own experiences of Covid-19 | 0 | 0 | 0 | 0 |
| 48 | Means managing unhelpful thoughts caused by the illness | 1 | -2 | 0 | 0 |
| 49 | Means managing unhelpful thoughts which existed before the illness | 1 | -3 | 0 | -1 |
| 50 | Requires you to gradually increase your movement | 1 | 0 | 0 | 0 |
| 51 | Means taking responsibility for your own health | 2 | 0 | 1 | 1 |
| 52 | Is not a psychological issue | -2 | 1 | 1 | 0 |
| 53 | Practitioners know how to support people | -1 | -1 | 0 | 0 |
| 54 | Requires practitioners to be experts | -1 | 1 | 1 | 0 |

### Appendix 13a – Factor 1 Factor Array Distribution Grid

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **-3** | **-2** | **-1** | **0** | **+1** | **+2** | **+3** |
| 15 | 34 | 30 | 22 | 5 | 16 | 37 |
| 36 | 12 | 39 | 26 | 20 | 1 | 11 |
|  | 28 | 27 | 3 | 48 | 51 |  |
|  | 17 | 53 | 25 | 19 | 14 |  |
|  | 52 | 54 | 2 | 49 | 33 |  |
|  |  | 8 | 21 | 43 |  |  |
|  |  | 10 | 47 | 24 |  |  |
|  |  | 13 | 44 | 35 |  |  |
|  |  | 46 | 42 | 50 |  |  |
|  |  | 7 | 4 | 29 |  |  |
|  |  |  | 23 |  |  |  |
|  |  |  | 38 |  |  |  |
|  |  |  | 40 |  |  |  |
|  |  |  | 31 |  |  |  |
|  |  |  | 32 |  |  |  |
|  |  |  | 18 |  |  |  |
|  |  |  | 45 |  |  |  |
|  |  |  | 9 |  |  |  |
|  |  |  | 41 |  |  |  |
|  |  |  | 6 |  |  |  |

**Factor 1 Array** All statements start with “Long covid recovery…”

Given below are the highest and lowest ranking statements in this factor array compared to all other factor arrays, as outlined in Watts and Stenner (2012).

**Highest Ranked Statements**

|  |  |
| --- | --- |
| 37. is possible | 3 |
| 11. includes learning to pace yourself (boom and bust) | 3 |

**Positive Statements ranked higher in Factor 2 array than in other factor arrays**

|  |  |
| --- | --- |
| 16. Is different for everyone | 2 |
| 1. Can be achieved through psychological therapy | 2 |
| 51. Means taking responsibility for your own health | 2 |
| 14. Involves learning to accept how you feel | 2 |
| 5. Involves learning to manage anxiety | 1 |
| 20. Involves overcoming the fear of moving your body | 1 |
| 48. Means managing unhelpful thoughts caused by the illness | 1 |
| 19. Involves addressing the core beliefs people have about themselves | 1 |
| 49. Means managing unhelpful thoughts which existed before the illness | 1 |
| 43. Requires you to advocate for yourself | 1 |
| 50. Requires you to gradually increase your movement | 1 |
| 29. Means having better mental health | 1 |
| 26. Can make you feel stronger than you were before the illness | 0 |
| 47. Treatments are shaped by a therapist’s own experiences of Covid-19 | 0 |
| 44. Involves focussing on what you are grateful for | 0 |
| 42. Involves overcoming guilt you have for contracting it | 0 |
| 23. Involves feeling close to people again | 0 |
| 40. Is positively influenced by a therapist’s personal experience of Covid-19 | 0 |
| 9. Includes finding a new identity | 0 |
| 6. Is more likely if your therapist has had it | 0 |

**Negative Statements ranked lower in factor 2 array than in other factor arrays**

|  |  |
| --- | --- |
| 22. Requires professionals to believe you | 0 |
| 26. Can make you feel stronger than you were before the illness | 0 |
| 2. Is easier if you meet other people with Long covid | 0 |
| 47. Treatments are shaped by a therapist’s own experience of Covid-19 | 0 |
| 4. Includes feeling less lonely | 0 |
| 31. Means having less fatigue | 0 |
| 32. Means having less brain fog | 0 |
| 41. Involves learning breathing techniques | 0 |
| 6. Is more likely if your therapist has had it | 0 |
| 30. Means having less pain | -1 |
| 39. Involves taking medication for your physical health | -1 |
| 53. Practitioners know how to support people | -1 |
| 54. Requires practitioners to be experts | -1 |
| 8. Includes getting back into work | -1 |
| 10. Is hampered by increasing physical movement | -1 |
| 13. Happens naturally with time | -1 |
| 28. Is negatively influenced by a therapist’s personal experience of Covid-19 | -2 |
| 17. Includes getting back to your old self | -2 |
| 52. Is not a psychological issue | -2 |

**Lowest Ranked Statements**

|  |  |
| --- | --- |
| 15. Cannot involve accepting how you feel, as this is like giving up | -3 |
| 36. Is not possible | -3 |

### Appendix 13b - Factor 2 Factor Array Distribution Grid

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **-3** | **-2** | **-1** | **0** | **+1** | **+2** | **+3** |
| 49 | 15 | 39 | 30 | 38 | 22 | 21 |
| 12 | 42 | 26 | 51 | 43 | 41 | 11 |
|  | 48 | 53 | 34 | 33 | 31 |  |
|  | 19 | 1 | 14 | 52 | 32 |  |
|  | 46 | 18 | 45 | 3 | 16 |  |
|  |  | 35 | 17 | 54 |  |  |
|  |  | 13 | 37 | 2 |  |  |
|  |  | 36 | 5 | 8 |  |  |
|  |  | 7 | 25 | 4 |  |  |
|  |  | 27 | 20 | 23 |  |  |
|  |  |  | 44 |  |  |  |
|  |  |  | 47 |  |  |  |
|  |  |  | 29 |  |  |  |
|  |  |  | 10 |  |  |  |
|  |  |  | 50 |  |  |  |
|  |  |  | 24 |  |  |  |
|  |  |  | 6 |  |  |  |
|  |  |  | 28 |  |  |  |
|  |  |  | 40 |  |  |  |
|  |  |  | 9 |  |  |  |

**Factor 2 Array** All statements start with “Long covid recovery….”

Given below are the highest and lowest ranking statements in this factor array compared to all other factor arrays, as outlined in Watts and Stenner (2012).

**Highest Ranked Statements**

|  |  |
| --- | --- |
| 21. Requires your friends and family to believe you | 3 |
| 11. Includes learning to pace yourself (boom and bust) | 3 |

**Positive Statements ranked higher in Factor 2 array than in other factor arrays**

|  |  |
| --- | --- |
| 22. Requires professionals to believe you | 2 |
| 16. Is different for everyone | 2 |
| 32. Means having less brain fog | 2 |
| 38. Is made harder due to society’s stigma towards it | 1 |
| 3. Is helped by sharing self-management tips with other sufferers | 1 |
| 43. Requires you to advocate for yourself | 1 |
| 52. Is not a psychological issue | 1 |
| 54. Requires practitioners to be experts | 1 |
| 4. Includes feeling less lonely | 1 |
| 2. Is easier if you meet other people with long covid | 1 |
| 5. Involves learning to manage anxiety | 1 |
| 8. Includes getting back into work | 1 |
| 23. Involves feeling close to people again | 0 |
| 34. Is achieved through doing yoga | 0 |
| 9. Includes finding a new identity | 0 |
| 44. Involves focussing on what you are grateful for | 0 |
| 47. Treatments are shaped by a therapist’s own experiences of Covid-19 | 0 |
| 6. Is more likely if your therapist has had it | 0 |
| 26. Can make you feel stronger than you were before the illness | 0 |
| 53. Practitioners know how to support people | 0 |

**Negative Statements ranked lower in factor 2 array than in other factor arrays**

|  |  |
| --- | --- |
| 51. Means taking responsibility for your own health | 0 |
| 37. Is possible | 0 |
| 47. Treatments are shaped by a therapist’s own experiences of Covid-19 | 0 |
| 6. Is more likely if your therapist has had it | 0 |
| 29. Means having better mental health | 0 |
| 26. Can make you feel stronger than you were before the illness | 0 |
| 39. Involves taking medication for your physical health | -1 |
| 18. Involves addressing underlying trauma | -1 |
| 13. Happens naturally with time | -1 |
| 42. Involves overcoming guilt you have for contracting it | -2 |
| 19. Involves addressing the core beliefs people have about themselves | -2 |
| 27. Involves becoming more independent | -2 |
| 46. Involves taking medication for your mental health | -2 |
| 49. Means managing unhelpful thoughts which existed before the illness | -2 |

**Lowest Ranked Statements**

|  |  |
| --- | --- |
| 48. Means managing unhelpful thoughts caused by the illness | -3 |
| 12. Is harder if you meet other people with Long covid | -3 |

### Appendix 13c – Factor 3 Factor Array Distribution Grid

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **-3** | **-2** | **-1** | **0** | **+1** | **+2** | **+3** |
| 9 | 44 | 42 | 11 | 51 | 10 | 37 |
| 36 | 45 | 12 | 41 | 16 | 32 | 31 |
|  | 34 | 5 | 48 | 22 | 15 |  |
|  | 24 | 1 | 13 | 17 | 18 |  |
|  | 35 | 4 | 43 | 8 | 30 |  |
|  |  | 23 | 40 | 39 |  |  |
|  |  | 14 | 2 | 33 |  |  |
|  |  | 19 | 29 | 38 |  |  |
|  |  | 20 | 26 | 54 |  |  |
|  |  | 21 | 53 | 52 |  |  |
|  |  |  | 3 |  |  |  |
|  |  |  | 49 |  |  |  |
|  |  |  | 47 |  |  |  |
|  |  |  | 6 |  |  |  |
|  |  |  | 28 |  |  |  |
|  |  |  | 46 |  |  |  |
|  |  |  | 50 |  |  |  |
|  |  |  | 27 |  |  |  |
|  |  |  | 25 |  |  |  |
|  |  |  | 7 |  |  |  |

**Factor 3 Array** All statements start with “Long covid recovery….”

Given below are the highest and lowest ranking statements in this factor array compared to all other factor arrays, as outlined in Watts and Stenner (2012).

**Highest Ranked Statements**

|  |  |
| --- | --- |
| 37. Is possible | 3 |
| 31. Means having less fatigue | 3 |

**Positive Statements ranked higher in Factor 3 array than in other factor arrays**

|  |  |
| --- | --- |
| 32. Means having less brain fog | 2 |
| 10. Is hampered by increasing physical movement | 2 |
| 18. Involves addressing underlying trauma | 2 |
| 15. Cannot involve accepting how you feel, as this is like giving up | 2 |
| 30. Means having less pain | 1 |
| 8. Include gettings back into work | 1 |
| 39. Involves taking medication for your physical health | 1 |
| 38. Is made harder due to society’s stigma towards it | 1 |
| 52. Is not a psychological issue | 1 |
| 54. Requires practitioners to be experts | 1 |
| 17. Includes getting back to your old self | 0 |
| 13. Happens naturally with time | 0 |
| 40. Is positively influenced by a therapist’s personal experience of Covid-19 | 0 |
| 26. Can make you feel stronger than you were before the illness | 0 |
| 53. Practitioners know how to support people | 0 |
| 47. Treatments are shaped by a therapist’s own experiences of Covid-19 | 0 |
| 28. Is negatively influenced by a therapist’s personal experience of Covid-19 | 0 |
| 27. Involves becoming more independent | 0 |
| 6. Is more likely if your therapist has had it | 0 |
| 7. Is less likely if your therapist has had it | 0 |

**Negative Statements ranked lower in factor 3 array than in other factor arrays**

|  |  |
| --- | --- |
| 41. Involves learning breathing techniques | 0 |
| 2. Is easier if you meet other people with long covid | 0 |
| 29. Means having better mental health | 0 |
| 26. Can make you feel stronger than you were before the illness | 0 |
| 47. Treatments are shaped by a therapist’s own experiences of Covid-19 | 0 |
| 50. Requires you to gradually increase your movement | 0 |
| 6. Is more likely if your therapist has had it | 0 |
| 25. Includes building your self esteem | -1 |
| 14. Involves learning to accept how you feel | -1 |
| 21. Requires your friends and family to believe you | -1 |
| 23. Involves feeling close to people again | -1 |
| 5. Involves learning to manage anxiety | -1 |
| 4. Includes feeling less lonely | -1 |
| 20. Involves overcoming the fear of moving your body | -2 |
| 44. Involves focussing on what you are grateful for | -2 |
| 19. Involves addressing the core beliefs people have about themselves | -2 |
| 45. Involves learning to live with pain | -2 |
| 35. Means finding meaning in having the illness | -2 |

**Lowest Ranked Statements**

|  |  |
| --- | --- |
| 9. Includes finding a new identity | -3 |
| 36. Is not possible | -3 |

### Appendix 13d - Factor 4 Factor Array Distribution Grid

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **-3** | **-2** | **-1** | **0** | **+1** | **+2** | **+3** |
| 7 | 3 | 8 | 16 | 32 | 31 | 33 |
| 34 | 1 | 11 | 27 | 10 | 24 | 41 |
|  | 36 | 42 | 14 | 37 | 35 |  |
|  | 40 | 18 | 19 | 51 | 46 |  |
|  | 15 | 23 | 48 | 25 | 22 |  |
|  |  | 38 | 2 | 30 |  |  |
|  |  | 39 | 54 | 45 |  |  |
|  |  | 43 | 9 | 29 |  |  |
|  |  | 49 | 44 | 4 |  |  |
|  |  | 20 | 50 | 5 |  |  |
|  |  |  | 53 |  |  |  |
|  |  |  | 6 |  |  |  |
|  |  |  | 13 |  |  |  |
|  |  |  | 17 |  |  |  |
|  |  |  | 21 |  |  |  |
|  |  |  | 52 |  |  |  |
|  |  |  | 47 |  |  |  |
|  |  |  | 12 |  |  |  |
|  |  |  | 28 |  |  |  |
|  |  |  | 26 |  |  |  |

**Factor 4 Array** All statements start with “Long covid recovery….”

Given below are the highest and lowest ranking statements in this factor array compared to all other factor arrays, as outlined in Watts and Stenner (2012).

**Highest Ranked Statements**

|  |  |
| --- | --- |
| 33. Means doing things that are important to you in spite of the illness | 3 |
| 41. Involves learning breathing techniques | 3 |

**Positive statements ranked higher in Factor 4 array than in other factor arrays**

|  |  |
| --- | --- |
| 24. Includes finding a new meaning in life | 2 |
| 35. Means finding meaning in having the illness | 2 |
| 46. Involves taking medication for your mental health | 2 |
| 22. Requires professionals to believe you | 2 |
| 25. Includes building your self esteem | 1 |
| 29. Means having better mental health | 1 |
| 45. Involves learning to live with pain | 1 |
| 4. Includes feeling less lonely | 1 |
| 5. Involves learning to manage anxiety | 1 |
| 27. Involves becoming more independent | 0 |
| 9. Includes finding a new identity | 0 |
| 44. Involves focussing on what you are grateful for | 0 |
| 53. Practitioners know how to support people | 0 |
| 6. Is more likely if your therapist has had it | 0 |
| 13. Happens naturally with time | 0 |
| 12. Is harder if you meet other people with Long covid | 0 |
| 28. Is negatively influenced by a therapist’s personal experience of Covid-19 | 0 |
| 47. Treatments are shaped by a therapist’s own experiences of Covid-19 | 0 |
| 26. Can make you feel stronger than you were before the illness | 0 |

**Negative statements ranked lower in factor 4 array than in other factor arrays**

|  |  |
| --- | --- |
| 16. Is different for everyone | 0 |
| 2. Is easier if you meet other people with long covid | 0 |
| 50. Requires you to gradually increase your movement | 0 |
| 6. Is more likely if your therapist has had it | 0 |
| 47. Treatments are shaped by a therapist’s own experiences of Covid-19 | 0 |
| 26. Can make you feel stronger than you were before the illness | -1 |
| 8. Includes getting back into work | -1 |
| 11. Includes learning to pace yourself (boom and bust) | -1 |
| 18. Involves addressing underlying trauma | -1 |
| 23. Involves feeling close to people again | -1 |
| 38. Is made harder due to society’s stigma towards it | -1 |
| 39. Involves taking medication for your physical health | -1 |
| 43. Requires you to advocate for yourself | -1 |
| 20. Involves overcoming the fear of moving your body | -2 |
| 3. Is helped by sharing self-management tips with other sufferers | -2 |
| 1. Can be achieved through psychological therapy | -2 |

**Lowest Ranked Statements**

|  |  |
| --- | --- |
| 7. Is less likely if your therapist has had it | -3 |
| 34. Is achieved through doing yoga | -3 |

### Appendix 14 – Qualitative Responses

U number = Participant number

**U1:** I have found that underlying core beliefs/ rules (often linked to perfectionism) play a definite role in how well people adapt to having Long covid.

**U2:** n.a

**U3:** Some of the statements I feel need expanding on. For example Long covid is not a psychological issue – however it is extremely psychologically challenging and these two ideas are easily and frequently mixed up. Psychological help is often needed because of the extreme challenges that people with Long covid face not because it is a psychological illness but because it takes away so much of what is important to someone which often includes supportive relationships and previous expectations that a medical professional you consult will be able to help or even believe your symptoms in the first place. Long covid destabilises life as you know it. and this is why meeting other people with Long covid including professionals can make such a difference in recovery.

**U4:** Depends on the relationship with the practitioner

**U5:** we need more groups talking about it . not just mental health issues.

**U6:** It is difficulty. There are good days and bad days. Set backs are very frustrating and lead me to low times. Deciding to get on and live life anyway is helpful but hard.

**U7:** It's multi-disciplinary

**U8:** Will be useful to receive the outcome of the research it did me me think hard about which column to put each statement

**U9:** I found the individual category limits unhelpful as they hence effectively restricted the accuracy of my answers as I was being guided into categorising them this way as a result.

**U10:** no

**U11:** it would be better if doctors pay more attention to the patients with long covid

**U12:** Covid infected our bodies. Long covid is the result of the original infection which remains in our bodies not yet 100% removed. We did not cure Covid. The remaining infection impacts our lives our mobility & abilities and our breathing. The side effects of having to handle this infection over the years has impacted some peoples mental health. Cure the route cause kill the infection 100% and allow for use to recover with support and assistance if required.

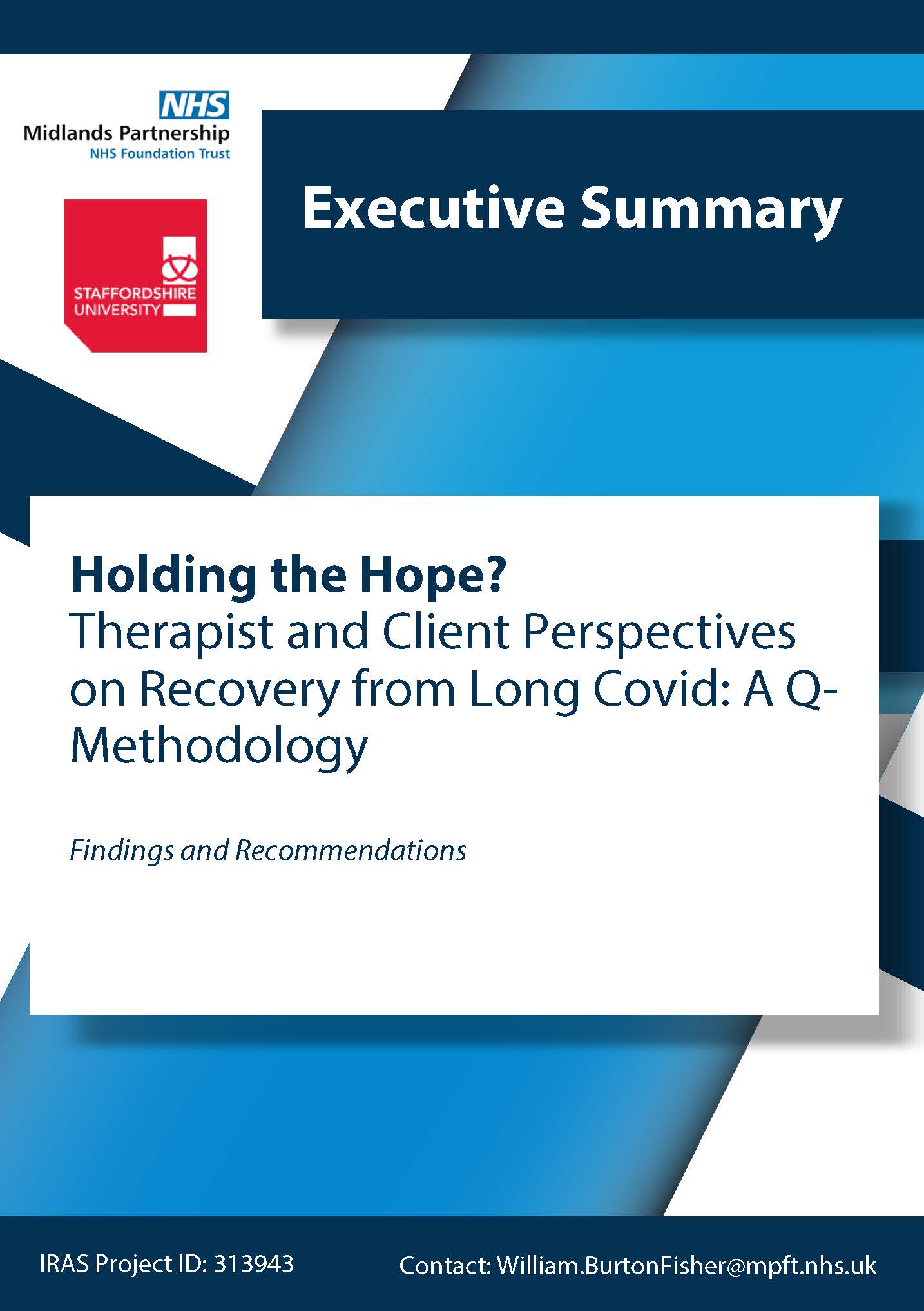
**U13:** I feel very let down by the medical profession as I was not believed and made to feel stupid. I had Covid back in April 2020 and nearly three years later I am still suffering with Long covid. I work had to manage my symptoms through yoga breathing techniques meditation walking my dog and good nutrition. I own and run my own business so I had no choice but to go back to work but every day is a struggle and although my family are incredibly supportive non of them fully appreciate just how hard it is living with Long covid.

**U14:** there appears to me to a potential overlap between long covid and anaemia

**U15:** One size does not fit all it is my belief that the meaning of recovery and how to achieve it is different for everyone.

**U16:** No

# Paper Three – Executive Summary



## A picture containing text, businesscard Description automatically generatedStatement of Purpose

This executive summary details a research project exploring people’s beliefs of recovery from Long covid, with particular attention given to its psychological aspects. This summary is designed to be shared with people with lived experience of Long covid, alongside professionals working in the field.

## Background

The covid-19 pandemic has had wide-reaching impacts across the globe. Many lives were lost to the virus and healthcare services struggled, at times, to keep up with demand. Whilst the acute stages of the virus have now subsided, the pandemic has had a lasting effect in many other areas of every day life, including employment, education and mental health. This executive summary summarises research in to just one of these lasting effects; namely, long covid.

Long covid is a chronic illness which is estimated to have affected over 2 million people in the United Kingdom alone (Office of National Statistics, 2022). Currently, there are over two hundred recognised symptoms of the illness, including tachycardia (high heart rate), chronic fatigue and muscle pains, which have left many people debilitated and unable to live their lives as they normally would (University College London, 2021). Considered an ‘invisible illness’ (Vink & Vink-Neese, 2020; Gahan, 2023), most long covid symptoms cannot be seen by others, and more research is needed to understand how best to support people with the illness.

Similar to other invisible illnesses such as Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME), people with long covid have often struggled to access healthcare and support (Rehmeyer, 2016; Gahan, 2023). Reports of being disbelieved by healthcare professionals are common, which have left people feeling ignored and invalidated (ibid). Others have been told that their symptoms are due to anxiety, rather than being a physical health problem, which has left people feeling blamed or belittled (Thompson et al., 2022).

Long covid hubs have been set up in NHS services across the country with the aim of recognising the reality of people’s symptoms and offering them appropriate support. Along with physical health interventions, this includes psychological therapies (also called ‘talking therapies’), where people can speak to a mental health professional and learn skills to manage their mental health. Locally, this mental health support is mostly provided by local Improving Access to Psychological Therapies (IAPT) services.

However, there is currently limited official guidance on how to offer psychological support to people with long covid. Guidance that did exist for illnesses with similar symptoms (CFS/ME) has also been withdrawn, due to the potential harm they might have on people with chronic fatigue (Turner-Stokes & Wade, 2020). In addition, whilst symptoms may be similar between long covid and CFS/ME, these illnesses are different and care must be taken not to conflate them, or to assume what support might work best. 

People living with Long covid have therefore found themselves facing a multitude of challenges, including being disbelieved, having their access to healthcare denied, and living with an illness without a strong evidence base for intervention. These challenges, which are all additional to the debilitating and unpredictable nature of the illness itself, have caused some to feel hopeless and even experience suicidal thoughts and urges (Sher, 2021).

In other arenas of psychotherapy, a therapist’s role may be that of *“holding hope”* (Bartholomew et al., 2019, p. 501) for their clients. Research suggests that hope, which can arise when a person has a goal in mind and knows how to achieve it, improves people’s wellbeing by encouraging them to persevere in the face of adversity (Snyder, 2002; Leite et al., 2019).In contrast, hopelessness can stir feelings of suicide and worsen one’s mental health, as beliefs arise that things might never improve (Beck et al., 2006). A therapist holding hope for their clients might therefore support their recovery, by offering tools and suggestions that can help people believe things can improve (Coppock et al., 2010). Questions therefore remain unanswered, in terms of if and how people with long covid, and the therapists who support them, are hopeful that recovery can be achieved.

## Purpose and Aims of the Study

This research wanted to understand how therapists and clients might define recovery from long covid, if they thought recovery was possible, and what tools or techniques they thought could help. It aimed to compare the perspectives of therapists and clients, to see if there was consensus around these ideas or if groups had different expectations. In the absence of clear guidance, and on the background of physical and social barriers to recovery, our research question asked: *Can (and if so, how can) therapists and clients hold hope for Long covid recovery?*

It is hoped that this research can help inform future therapeutic guidance, alongside shining a light on the lived experience of long covid and ensuring people’s voices are heard.

## What We Did

This was an online-only study, aimed at reducing the physical burden it might put on people with long covid. It was hoped that this process would also help with therapist recruitment, on the basis that it would place fewer demands on clinical work. Therapists and clients were recruited from within a local NHS Trust long covid pathway. All client participants had received and completed psychological therapies from a local IAPT service, with most therapists having worked there.

Q-methodology was the adopted approach, which involved participants arranging a set of statements (54 in total) on a grid based on how much they agreed with them (see figure 1). Where the statements were placed dictated the score they were given, from -3 to +3. The statements were written based on a number of activities, including:

* Conducting a literature review of people’s lived experiences
* Attending training and workshops delivered by people with long covid
* Reading news articles
* Meeting with professionals working in the field
* Discussing statements in focus groups

After all participants completed the activity, all sorting grids and scores were combined and statistically analysed to find underlying factors. Written feedback from participants was used to give context to and interpret factors

.

A diagram of a diagram

Description automatically generated**Figure 1: Example statements being scored on a sorting grid**

## A blue and white squares Description automatically generatedWhat We Found

Sixteen participants completed the study, including five therapists and eleven client living with long covid. Therapists were included if they had delivered therapy for long covid, whereas clients were included if they had received therapy for long covid through a local IAPT service. People under eighteen could not participate in the study.

The results found four overall viewpoints on the concept of long covid recovery. These four viewpoints were: 1) psychological pathways to recovery; 2) social context (of Long covid) and agency; 3) physiological recovery goals, and; 4) personal meaning making. Given below is an overview of each of these viewpoints.

### Viewpoint One: Psychological Pathways to Recovery

**Who this viewpoint represents:**

Four IAPT Therapists and Two clients

**Representative Quote:**

*“I have found that underlying core beliefs/ rules (often linked to perfectionism) play a definite role in how well people adapt to living with Long covid”*

Viewpoint one presented recovery from long covid as a psychological task, including learning therapeutic techniques such as challenging unhelpful thoughts, worries and beliefs.

All IAPT therapists broadly shared this perspective, along with two clients (people who had received talking therapies through IAPT). People sharing this viewpoint were hopeful that recovery was possible, with therapeutic techniques seen as being a method of achieving it.

**Viewpoint One  
Highly Supported Statements**

Long covid Recovery is possible

It is different for everyone

It can be achieved through psychological therapy

It involves accepting how you feel

It involves adapting and pacing yourself

It can be helped by managing unhelpful thoughts and beliefs

Rather than regarding recovery as a removal of physical symptoms, factor one participants believed that recovery involves adapting to the illness and accepting how you feel.

However, this group did emphasise that recovery is different for everyone, rather than being a ‘one size fits all’.

### Head with gears with solid fillViewpoint Two: Social Context and Agency

**Who this viewpoint represents:**

One Therapist (non-IAPT) and Two clients

**Representative Quote:**

*“I feel very let down by the medical profession as I was not believed and made to feel stupid”*

Viewpoint two represented the social context surrounding long covid recovery, including the importance of being believed by friends, family and professionals.

One non-IAPT therapist and two clients loaded shared this perspective. Hopefulness for recovery was less present here, with emphasis being given to the barriers to recovery instead. This included the stigma people with long covid face, and how being disbelieved might prevent people from accessing support.

Similarly to the fire viewpoint, people here shared a belief that recovery involved pacing oneself according to their illness. However, this viewpoint differed to the first in that it disagreed that recovery could be achieved through psychological techniques.

**ViewpointTwo  
Highly Supported Statements**

Recovery involves adapting and pacing yourself

It is different for everyone

It requires your friends and family to believe you

It requires professionals to believe you

It is made harder due to society’s stigma

It does not involve managing unhelpful thoughts and beliefs

People sharing this perspective explained that psychological explanations for long covid, such as suggesting it is an anxiety symptom, have been experienced as dismissive. These might then undermine people’s willingness to reach out for support.

### Head with gears with solid fill**Viewpoint Three: Physiological Recovery Goals**

**Who this viewpoint represents:**

Five clients

**Representative Quote:**

*Cure the root cause kill the infection 100% and allow for us* *to recover with support and assistance if required”*

Viewpoint three represented the physical health effects of long covid, and the idea that recovery involves eliminating these symptoms.

Five clients shared this perspective, with hopefulness for recovery being higher for them compared to other groups. On the premise that recovery involved reducing physical symptoms, including fatigue, pain and brain fog, participants with this outlook gave more priority to physical health medication than in other viewpoints.

People with this viewpoint also disagreed with psychological approaches to long covid. For instance, there was a rejection of accepting how one feels, and a dismissal that challenging core beliefs can help.

**Viewpoint Three  
Highly Supported Statements**

Long covid recovery is possible

It involves having less fatigue, brain fog and pain

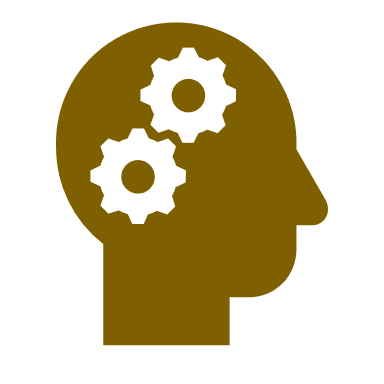
It involves taking physical health medication

It is hampered by increasing physical movement

It does not involve accepting how you feel

It does not involve addressing core beliefs

People with this perspective also felt that increasing physical movement can make recovery harder. This echoes the debate within the CFS/ME literature, with these participants suggesting graded exercise approaches could be harmful.

****

### Viewpoint Four: Personal Meaning Making

**Who this viewpoint represents:**

Two clients

**Representative Quote:**

*. “There are good days and bad days. Setbacks are very frustrating and lead me to low times. Deciding to get on and live life anyway is helpful but hard”*

The final viewpoint represented attempts to follow a meaningful life in spite of living with long covid.

The two clients sharing this perspective did not strongly suggest that recovery was possible. Instead, they emphasised the importance of finding meaning in one’s life, and making sense of having the illness. This suggested that long covid was seen as something that was ongoing and needed adapting to.

Whilst this viewpoint largely disagreed that psychological therapies could help recovery, these participants believed that breathing techniques can help with everyday symptoms.

**Viewpoint Four  
Highly Supported Statements**

Recovery means finding new meaning in life

It means finding meaning in having the illness

It involves learning breathing techniques

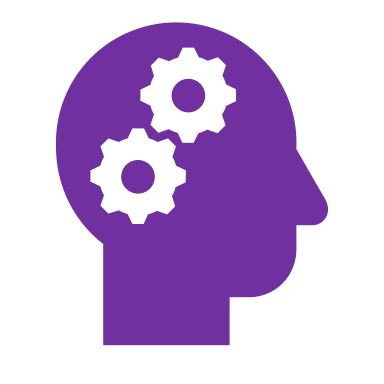
It does not involve psychological therapy

It requires professionals to believe you

It means doing things important to you in spite of the illness

This reflects other people’s experiences of living with long covid, where tools such as breathing might be used to calm the nervous system (Gahan, 2023).

Having professionals believe them scored highly, suggesting that validation and understanding from healthcare services was important for these people.



## Conclusions

Viewpoints one (psychological pathways to recovery) and three (physiological recovery goals) were the highest scoring in terms of hopefulness, which suggested that having clear ideas about recovery, and how to get there, were important for feeling hopeful. The results suggest that some people prioritise psychological interventions for long covid, including IAPT staff, but that we need to consider the broader aspects of someone’s long covid. For instance, ensuring that people feel they are believed, and recognising previous experiences which might have harmed them. For some, the prospect of finding a physical cure maintained their hopefulness for future recovery. Whilst such a cure has not yet been found, therapists might share this hope with clients, in the recognition that hopefulness itself might support their psychological wellbeing.

However, the different viewpoints also suggest that psychological therapy is not valued by everybody, and may in some cases be declined depending on a person’s previous experience. This highlights the importance of supporting individuals to define recovery on their own terms, to ensure they feel respected, listened to and supported.

## Recommendations

Based on these findings, a number of recommendations are made. These include:

1. **Validate people’s experiences**

Many people have experienced being disbelieved by health professionals and broader society. People have found it most helpful when their concerns have been taken seriously, which might encourage them to seek help when needed. We recommend validating people’s experiences and believing them as the top priority for this reason.

1. **Explore other therapeutic models**

IAPT often takes a cognitive behavioural approach to supporting people with their problems, such as by challenging their beliefs or their behaviour. Whilst many people found this helpful, the results of this study suggest support might also be inspired by other therapeutic models. In respect of viewpoint four, therapies such as Narrative Therapy and Acceptance and Commitment Therapy might help a client make sense of their experience and adapt to it, to live a meaningful and fulfilling life in spite of illness.

1. **Promote social support groups further**

Evidence suggests that support groups can be helpful for someone’s recovery, because they promote a sense of shared belonging and validation (Day, 2022). It is therefore recommended that online and in-person social support groups are advertised widely across the local trust..

1. **Consider the whole person**

Not all participants considered psychological therapies as the main driver of their recovery, with many focussing on their physical health or social experience. It is recommended that these other aspects of a person’s experience are proactively discussed, and working closely with other services (e.g. social care, physiotherapy) is encouraged where possible.

## 

## Dissemination

This executive summary will be shared with client participants, the IAPT services participating in the study, the sponsoring Trust and other interested parties on request.

# **Limitations**

The research was conducted purely online so that people could participate from the comfort of their homes. However, this also meant that some people might not have been able to participate, for instance if they did not have access to a desktop computer/laptop.

Instead of interviews, people were asked to type in their thoughts and feelings about the research and long covid more generally. Whilst this gave some further insight into how people feel about long covid recovery, interviews would have given us a richer understanding of their lived experiences.

Similarly, demographic information such as age, gender, and duration of long covid were not recorded. This meant it was not possible to explore if viewpoints changed depending on someone’s life experience. For example, it may be useful to understand if males were less likely to have a psychological viewpoint, or if people with long covid for longer times felt less hopeful. It is therefore recommended that future studies explore these demographics in more detail, to ensure support can be tailored to groups and individuals.

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