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Doctoral Thesis

Living with Cognitive Difficulties: Experiences of Individuals with Long COVID and Couples Navigating Their Relationship After Traumatic Brain Injury

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Word count

Thesis Section	Main Text	Appendices (including tables, figures, and references)	Total
Thesis Abstract	299	-	299
Literature Review	7997	7398	15395
Research Paper	7990	7883	15873
Critical Appraisal	3970	864	4834
Ethics	3162	5086	8248
Total	23418	21261	44613

Abstract

The primary focus of the research is the experience of cognitive and emotional difficulties and how these are navigated both individually and as a couple. The literature review collated evidence in relation to how couples navigate romantic relationships after one partner experiences a traumatic brain injury (TBI). The empirical paper focusses on the experience of persistent cognitive difficulties in individuals following a COVID-19 infection.

Section one details the systematic literature review. This summarised and synthesised qualitative research exploring how injured persons and their partners navigate their romantic relationships following a TBI, using thematic synthesis. Five databases were searched: AMED, CINAHL, MEDLINE, PsycINFO, and Web of Science. Thirteen papers met the inclusion criteria. Descriptive themes and then analytical themes were constructed from the data. Findings showed that the rupture of identity and meaning was a key theme amongst couples as well as difficulties with communication and connectedness. Despite these challenges, couples were able to find new meaning and experience shared growth.

Section two details the empirical paper, exploring people's experiences of persistent cognitive difficulties following an infection of COVID-19. Thirteen individuals aged 18-65 who were experiencing cognitive difficulties following an infection of COVID-19 were interviewed. Transcribed data was analysed using reflexive thematic analysis. Four themes were constructed: (1) Dealing with loss: stolen identity and a sense of injustice, (2) Internal turmoil: unpredictability and emotional distress (3) Isolation and misunderstanding vs empowerment by social connection, (4) Navigating healthcare: the good, the bad and the uncertain. These findings have implications for support offered by healthcare professionals to this population. Future research exploring the experience of specific groups and the impact of cognitive rehabilitation and psychological therapy would be beneficial.

Section three appraises sections one and two critically, including further limitations, clinical implications, and some of the author's reflections through the process.

Declaration

This thesis documents research undertaken for the Doctorate in Clinical Psychology at the Division for Health Research, Lancaster University. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Ammara Haque

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Date: 1st July 2024

Acknowledgements

Bismillahir-Rahmanir-Raheem

In the name of God; the most Gracious, the most Merciful.

For my loving parents Nadeem & Rabia, without whom none of this would have been possible. A million lifetimes would not be enough for me to thank you for your unwavering support, love and guidance. Your sacrifices, no matter how big or small, have never gone unnoticed and I feel incredibly lucky to have parents who have always believed in me, encouraged me to pursue my dreams and stood by my side through it all. This is for you.

I would like to extend my deepest gratitude to the incredible participants who volunteered their time to take part in this research. I was honoured and humbled to have heard the depth and richness of your stories. Whilst the word limit here is not nearly enough to capture your narratives, I hope I have done your stories justice.

I'd also like to thank my supervisors Fiona Eccles and Will Curvis who have been an absolute delight to work with. Thank you for your guidance and expertise and constant support throughout this process over the last three years. Thank you for keeping me grounded and reminding me that things will work out. Your dedication to research and commitment to students is inspiring and I only hope I can be as knowledgeable and passionate as you one day.

I wish to extend the most heartfelt thanks to my siblings and friends (both from home and new friends on the course) who put up with hours of me talking about my thesis and encouraged me to see the light at the end of the tunnel. Whether it was moments of laughter or moments of tears, you have kept me going through it all and have been the foundations of my resilience.

Finally, I'd like to extend my thoughts to the class of 2024 in Gaza, Palestine - and those around the world living in conflict - who were unable to graduate. You are forever in our hearts, and we will not forget.

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Section One: Systematic Literature Review

Navigating Romantic Relationships after Traumatic Brain Injury: A Systematic Review and Thematic Synthesis

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Abstract

This systematic review and thematic synthesis examined couples’ experiences of their relationship after one partner sustained a traumatic brain injury (TBI). A systematic search was completed in April 2024 across five databases: PsycINFO, AMED, MEDLINE, CINAHL and Web of Science. The included articles were synthesised using thematic synthesis and appraised using the Critical Appraisal Skills Programme Qualitative Checklist. Analysis of the 13 papers which met the inclusion criteria produced three themes: (1) Ruptured meaning and identities, which described the renegotiation of relationship dynamics (2) Communication and connection, which described difficulties in communication and its impacts on feeling connected to one another, (3) Supporting shared growth, which described seeking external support and the determination of couples resulting in finding new meaning. An overarching theme was also identified: an evolving journey which demonstrated the ongoing work required to navigate their relationships. The findings provided insight into the difficulties couples experienced in navigating their relationships post TBI. Clinical implications include neuropsychological input with a relational focus to include the experience of the couple as a dyad. Future research should consider exploring the experiences of more diverse groups for a more nuanced understanding.

Keywords: traumatic brain injury, romantic relationship, couples, thematic synthesis, systematic review

Introduction

Traumatic brain injury (TBI) is the term used to describe injuries sustained to the brain as a result of an external force to the head (Menon et al., 2010). The majority of TBIs result from road traffic accidents (RTA), falls, assaults and sports injuries (Johnson & Griswold, 2017). It is the leading cause of death and disability for those under 40 years old although in recent years there has been an increase in older populations (65+) sustaining TBI (Waltzman et al. 2022). Injured individuals often experience a range of ongoing physical, cognitive, behavioural and emotional difficulties which can vary widely depending on the location and severity of the injury. TBIs are a complex phenomenon in which damage can occur not only due to immediate injury, but more severe injuries can result in secondary problems such as hypoxia or swelling etc. which can impact other areas of the brain. The long-term effects of TBI are therefore often difficult to predict as they can be different for each individual and can continue for several years or may even cause life-long disability (Stochetti & Zanier, 2016).

TBI recovery is a complex process that extends beyond the injured individual, significantly impacting family caregivers, particularly partners and parents (Chan et al., 2009; McIntyre et al. 2018). Many of these caregivers juggle multiple roles, including providing personal and physical care (Kraus et al., 1984; Turner et al. 2007) often at the expense of their own careers and personal lives (Turner et al. 2007). The psychological toll on caregivers is substantial, with around 40% experiencing significant distress (Kreutzer et al. 1992; Laratta et al., 2020), including depression, anxiety (Loh et al., 2017), and post-traumatic symptoms (Meyers et al., 2020). Crucially, this psychological strain can create a cyclical effect on the recovery process. As caregiver stress increases, their ability to provide effective support may decrease, potentially hindering the injured person's recovery.

Whiffin et al.'s (2021) meta-synthesis of families' experiences after TBI highlights the importance of drawing on subjective experiences, which can reveal more complex positions when understanding and adjusting to TBI. The review found that caregivers within the family often face emotional and psychological impacts related to identity, loss and isolation, unpredictability for the future and renegotiation of the family equilibrium.

Although it is useful to understand the impact of caregiving on the whole family, research has highlighted the importance of differentiating between the experiences of different family members (Perlesz et al., 1999; Verhaeghe et al., 2005). Grouping caregivers together can obscure the unique experiences and specific needs of individual family members. For example, couples in romantic relationships may experience unique difficulties which are different from parent carers, such as impact on intimacy and sexual functioning and marital dissatisfaction (Hibbard et al., 2000; Godwin et al., 2011; Kratz et al., 2017; Latella et al., 2018; Fraser et al., 2020).

Literature has highlighted distinct differences in the experiences of partners and parents caring for individuals with TBI. Partners often describe a loss of their 'peer-based', reciprocal relationships (Gervasio & Kreutzer, 1987; Lezak, 1988), whereas parents may view their role as a return to a familiar caregiving position. Additionally, partners frequently face unique challenges, including increased financial strain (Gervasio & Kreutzer, 1997) and reduced support in parenting their own children (Perlesz et al., 1999). Thus, some authors suggest that the caregiving experience may be more challenging for partners, potentially creating increased strain on the romantic relationship (Perlesz et al., 1999).

The impact of TBI on romantic relationships is significant and varied. A review of studies examining divorce rates and separations after one partner experienced a TBI found a range of 15-78% (Godwin et al., 2011). The severity of the brain injury played a crucial role in this variance, with more severe injuries generally leading to higher divorce rates (Kreutzer et al., 2016). Other factors influencing relationship outcomes include the age and gender of the injured person, the pre-existing length and quality of the relationship, and the presence of supportive family networks (Kreutzer et al., 2007; Godwin et al., 2011).

Interestingly, despite high levels of marital distress, some studies have indicated relatively high levels of marital stability in the earlier stages after TBI (Kreutzer et al., 2016). This suggests that couples often remain together despite difficulties within the relationship. Some authors have proposed that uninjured partners may feel guilty about leaving their struggling spouses (Lezak, 1988), which could contribute to the variability in divorce rates. The authors concluded that more research was needed to explore the experiences of couples whose marriages remained stable despite ongoing relationship distress.

In contrast, not all caregivers of people with TBI experience negative outcomes (Sullivan et al., 2016). While negative outcomes are frequently studied, positive traits like resilience can serve as protective factors against burden and psychological strain. This may explain why some caregivers face negative outcomes while others do not (King et al., 2020).

Previous reviews exploring marital adjustment following TBI have generally taken a narrative approach (Blais & Boisvert, 2005; Liss & Willer, 1990). This review will take a systematic approach to retrieving relevant literature and will focus specifically on TBIs. Although literature often groups brain injuries together, differentiating between types of acquired brain injury (ABI) is crucial due to differing pathologies and challenges, particularly since TBI is more common in younger adults.

Most research has examined the impact of TBI on either the injured individual or their uninjured partner in isolation and have not considered the couple as a unit. This fails to capture the dynamic interplay within the relationship and restricts insights to a single perspective (Godwin et al., 2011). This may be due to the complexity of data collection when exploring couples' experiences as a dyad, particularly when the injured person may have cognitive or communication impairments. Nevertheless, researchers have advocated for a more systemic approach (Blais & Boisvert, 2005); Godwin et al., 2011) that considers the dyadic nature of the shared relationship and its associated processes. This review will, therefore, triangulate information from studies which explored couples' experiences and relationship quality following TBI from all three perspectives: injured person, uninjured partner and as a dyad, to build a more systemic view of the impact on the couple.

Overall, high levels of burden and distress are reported in family caregivers of people living with TBI but there is limited understanding of uninjured partner experiences or indeed experiences of the couple as a unit. Gaining a better understanding of the current TBI evidence-base around couples’ experiences and relationships triangulated from the three perspectives may highlight the individuals’ and couples’ unique experiences and interactional processes. Qualitative research is essential in understanding meaning and complex nuances within lived experience and there is a growing body of such work in relation to couple’s experiences of TBI. Thus, this is a timely opportunity for a systematic review within the area which may offer insights into the couple's needs. This review therefore aims to examine and synthesise the available qualitative research exploring couple’s experiences of their relationship following a TBI.

Methods

Design

Thematic synthesis (Thomas and Harden, 2008) has been adopted to analyse and synthesise data from primary qualitative research. The steps outlined by Thomas and Harden (2008) for completing a thematic synthesis were followed: (1) Searching; (2) Quality assessment; (3) Extracting data from the studies (including results or findings sections of each paper); (4) Coding text; (5) Developing descriptive themes; and finally (6) Generating analytic themes. ENTREQ guidelines (Tong et al., 2012) were followed throughout.

Search Strategy

Five databases covering literature in psychology, medicine and nursing were systematically searched to identify eligible articles: PsycINFO, AMED, MEDLINE, CINAHL and Web of Science. Title and abstract searches were completed according to pre-defined search terms involving three areas:

the population (persons with TBI and their partners), the phenomenon of interest (TBI) and the design of the study (qualitative). Free text searches were conducted in the titles, abstracts and keywords of the articles and combined with the subject headings searches. The search strategy was reviewed by a specialist university librarian. Additional searches were conducted by searching for articles citing the selected papers, and then searching the reference lists of the selected papers. Date restrictions were not applied. Searches were completed in April 2024. Details of an example search strategy for one database can be found in Table 1.1.

[Table 1.1 here]

Inclusion and exclusion criteria

Inclusion criteria for papers to be selected were: (1) the sample included adults who had had a TBI and/or their partners; (2) the participants were in an ongoing relationship rather than trying to start a new one; (3) the study included data collection and analysis which used qualitative research methodology; (4) the results of the study documented key themes evidenced by participant quotes; (5) the study was published in a peer reviewed journal; and (6) the study was written in English. Grey literature was not included as papers had to be peer reviewed to ensure a basic level of quality. Additionally, there was limited time and financial resources available for the review. Studies were excluded if: (1) the sample included people with ABI where the number of participants who experienced a TBI was under 75%. (2) experiences of other caregivers/family members were reported and the results did not separate out the experiences of romantic partners, and (3) the TBI was as a result of domestic violence due to the distinct relational context and dynamics associated with such cases.

Search Results

Following the searches the 741 papers retrieved were exported into a reference manager (Rayyan). Duplicates (555) were removed through a manual review and the remaining 186 papers were screened and assessed for relevance by the author, based on their titles and abstracts. This resulted in the exclusion of 155 papers. The full texts of the remaining 31 papers were accessed; the reviewer excluded 18 as they did not meet the inclusion criteria or met the exclusion criteria. Reference sections of papers selected for inclusion were assessed for additional papers (backwards searching), and citations of the final set of papers were also searched (forwards searching). No additional papers were identified. A total of 13 papers are included in the present review. This process of screening is summarised in a PRISMA diagram (Page et al., 2020) (Figure 1.1).

[Figure 1.1 here]

Critical appraisal of the selected papers

The Critical Appraisal Skills Programme qualitative checklist (CASP) (CASP, 2018) was used as a tool to assess the quality of the selected papers. The CASP consists of 10 questions which look to assess the validity and appropriateness of the methodology, design, recruitment, data collection, ethical considerations, analysis, results, and the implications of the research. Items were assessed using a three-point scale (Duggleby et al. 2010), with three points being scored for strong evidence, two points for moderate evidence and one point for weak evidence. The majority of papers were assessed independently by the author, and 5 papers were evaluated by an independent second rater to assess agreement of scores. Disagreements were discussed, leading to minor alterations to the scoring. The scores for selected papers ranged from 14 to 27 showing variation in quality as determined by the CASP items. Although CASP scores were not used to include or exclude papers for review, papers were coded and analysed based on the CASP ratings, with high scoring papers being analysed first. The resulting themes were representative of a range of papers with differing CASP scores, with no themes relying solely on the weaker papers. Details of the CASP scores for the papers included in this review are displayed in Table 1.2.

[Table 1.2 here]

Data extraction and analysis

Papers identified for inclusion were analysed by hand. The selected papers were read several times in order to become familiar with the data and ensure that all relevant data were identified. Stage four of Thomas and Harden's (2008) procedure, coding, was then commenced. This process focused exclusively on the findings and discussion sections of each paper, ensuring that only participant data and authors' interpretations were included in the analysis. Each line of text was assigned a 'code' based on its descriptive meaning and context. The process of coding was iterative, with subsequent papers sometimes highlighting further codes within previous papers. To ensure all potential codes had been generated, papers were reviewed multiple times. In the next phase of analysis, codes were grouped together into descriptive themes based on commonality and similarities (Appendix 1-C). This iterative process involved reviewing and adjusting themes to best represent the data. The final stage involved the development of analytical themes by comparing and restructuring descriptive themes and initial codes. This can be seen in Appendix 1-D, demonstrating how the descriptive and analytical themes relate to each other.

Thematic synthesis requires the author to make interpretations to generate themes across the papers, thus the author will have an influence on this process (Toye et al. 2013). The author of the review is a female clinical psychologist with experience and interest in working with brain injuries. In order to have a clear audit trail and ensure a rigorous process the author regularly consulted with supervisors to discuss the theme development and regularly returned to the original papers to ensure the meaning remained true to the original context.

Findings

Characteristics of the selected papers

The selected papers were published between 1991 and 2021. Participants were from five countries, USA, UK, Ireland, Canada and Australia. Sample sizes ranged from 4 to 36. Ages of participants were not uniformly reported, but where they were these ranged from 24 to 87 years. Gender of participants were not always mentioned, however the majority of participants were in heterosexual relationships with the exception of two same sex couples (Gill et al., 2011; Knox et al., 2015). The majority of papers involved data collected via interviews on one single occasion. Further available details of the selected papers, including data collection and analysis are summarised in Table 1.3.

[Table 1.3 here]

Three themes were constructed from the data: (1) Ruptured meaning and identities, (2) Communication and connection, (3) Supporting shared growth. An overarching theme was also constructed: An evolving journey. This is an umbrella theme demonstrating that themes 1 to 3 are not static, but rather constantly evolve and change over time. All papers contributed to theme 1 and 2. Eight papers contribute to theme 3.

Theme 1: Ruptured Meaning and Identities

This theme captures the process of rebuilding identities within relationships impacted by TBI, emphasising the difficulties faced in adapting to new and frequently challenging circumstances. It includes re-evaluating and redefining individual identities (subtheme 1) and the renegotiation of roles and dynamics within the relationship (subtheme 2).

Subtheme 1: Personal Identity Shifts

TBI frequently caused a dramatic shift in the injured partner's identity, profoundly affecting their role within the relationship (Choum et al., 2021; Gill et al., 2011; Godwin et al., 2014; Hammond et al., 2011; Layman et al., 2015; O'Keeffe et al., 2020). Pre-injury, individuals often had a clear self-concept based on their abilities, values, and interests, which shaped the roles they played in relationships. The sudden cognitive and physical changes resulting from TBI often brought about a significant identity crisis: "Your whole body is transformed; you lose part of yourself … it's like having a split personality. So, I was grand before the accident and now I feel like two different people." (O'Keeffe et al., 2020, p. 499). This also impacted how injured persons viewed themselves in relation to those close to them.

For many injured persons, the loss of pre-injury competencies across various life domains often led to feelings of inadequacy and frustration (Godwin et al., 2014; Layman et al., 205; O'Keeffe et al., 2020). This shift challenged their self-concept and individuals struggled not only with adapting to new limitations but also with integrating these changes into a coherent sense of self and who they were within their relationships.

For some uninjured partners, these shifts in identity of the injured person led to a huge sense of loss. Caregivers described how difficult it was to mourn a person that was still physically in front of them but was so different to the person they used to know: "It's really strange because I can look at photos of him before his accident and I'll cry. It's like – it's like he's died. It's like I'm grieving. You know I'll look at a photo and I'll say, 'I really miss you." (Bodley-Scott and Riley, 2015, p. 14).

Subtheme 2: Renegotiating Relationship Dynamics

Couples found that they needed to reframe their relationship due to one partner's significant changes following TBI. This meant re-evaluating both long-term life goals and daily routines (Bodley-Scott & Riley, 2015; Chwalisz & Worblewski, 1996; Hyatt et al., 2015; Layman et al., 2015). A key change was the renegotiation of practical tasks and household responsibilities. Injured persons were often unable to resume their pre-injury roles of supporting with parenting children, contributing to practical tasks around the home such as cooking, cleaning and driving. This shift required a renegotiation of responsibilities, causing tension in the relationship. The uninjured partner, previously sharing responsibilities equally, now managed both their own and their partner's tasks, leading to a sense of sole responsibility and increased burden (Acorn & Roberts, 1992; Bodley-Scott & Riley, 2015; Gill et al., 2011; O’Keeffe et al., 2020). Further changing the dynamics was the tendency for the uninjured partner to take on a more significant role in decision-making which only added to the burden: “The biggest thing is trying to, I suppose live for two people… it’s draining. It drains you like you would not believe… trying to make all the decisions.” (Knox et al., 2015, p. 751).

Similarly, career goals were adjusted to accommodate the TBI limitations. Several studies noted changes in financial roles, resulting in increased financial strain for couples. Often, the uninjured partner had to take on more work or increase their hours, which felt overwhelming (Bodley-Scott & Riley, 2015; Chwalisz and Wroblewski, 1996; Gill et al., 2011; Godwin et al., 2014; Hammond et al., 2011; Knox et al., 2015; O’Keeffe et al., 2020). This was stressful for both individuals for different reasons. For example, uninjured partners struggled with the increased burden, as well as concern around leaving the person with the TBI alone for a significant period of time due to safety reasons. Whilst injured persons felt they were having to rely more on their partner, leading to a loss of independence: “I think before the injury we were both very independent... After the injury we—I’ve been much more dependent on her.” (Layman et al., 2005, p. 914).

Along with renegotiating tasks and responsibilities, the uninjured partner often found themselves taking on an unexpected caregiver role. This change was often sudden and required the uninjured partner to acquire new skills in managing the physical, emotional and behavioural changes of their injured partner. For some, this learning curve was often described as steep and led to a sense of sadness and despair (Acorn and Roberts, 1992; Villa & Riley, 2017). For others, the changes did not feel too drastic and individuals were able to cope well: "I don't find that things are unbearably different. Let's put it that way. They're not, you know, they're quite cope, they're manageable and I'm coping with them". (Villa and Riley, 2017, p.12).

These role shifts required significant emotional and practical adjustments from both partners. Some uninjured partners often felt burdened by the increased responsibilities, (Chuoum et al., 2021; Gill et al., 2011; Godwin et al., 2014; Layman et al., 2005) and had to balance their own needs with the demands of caregiving, often leading to feelings of burnout and resentment: "I'm a carer and a housekeeper and a babysitter and the chief cook and bottle washer but I'm not a wife anymore, that doesn't even come into it." (O'Keeffe et al., 2020, p. 500).

Uninjured partners also described their post-injury relationship to one of a parent and child (Layman et al., 2005; Chwalisz & Wroblewski 1996; Gill et al., 2011; Hammond et al., 2011; Villa & Riley, 2017), which for some created conflict within the relationship: "I felt I was taking care of him more like a mother rather than a partner. You know, it was like dealing with a child now." (Layman et al., 2005, p. 915).

Theme 2: Communication and Connection

This theme explores the challenges in communication between partners post TBI and the emotional toll of miscommunication. It captures the struggles couples faced in understanding each other as a result of anger and irritability from the injured person (subtheme 1), affecting the overall quality of the relationship. Couples also described a lack of emotional reciprocity (subtheme 2) leading to feelings of isolation and being disconnected (subtheme 3). This emotional disconnection impacted intimacy and sexual functioning within the relationship (subtheme 4).

Subtheme 1: Anger and Irritability

Behavioural and cognitive changes following a TBI had a significant impact on communication within relationships. Many uninjured partners reported significant increases in aggression and irritability from their injured partners (Bodley-Scott and Riley, 2015; Hammond et al., 2012). This change was often experienced as sudden outbursts of anger or frustration, which were previously uncharacteristic of the injured person. Injured persons also reported moments of lashing out followed by strong feelings of guilt and shame: "I've lashed out like, started shouting and then the kids are crying and she's upset and the kids are upset and I've just ruined it" (O'Keeffe et al., 2020, p. 500). These behavioural changes created a volatile environment, forcing the uninjured partner to constantly monitor and adjust their actions to avoid negative reactions, leading to anxiety and tension within the relationship: "I'm constantly stressed out when I'm in the house with him, constantly. It's like my heart's coming out of my chest, beating that fast." (Bodley-Scott and Riley., 2015, p. 210).

The unpredictability of the injured partner's reactions made communication challenging, as the uninjured partner often feared provoking an adverse response. This led to breakdowns in everyday discussions creating an increased emotional distance between partners (Hammond et al., 2012). In addition, some uninjured partners described the difficulty in displaying love as a result of these outbursts: "In between his violent outbursts and his verbal abuse, he still wants a lot of love. I can't give that. No way can you be treated like that one minute and switch your feelings off and cuddle somebody the next." (Bodley Scott and Riley, 2015).

Subtheme 2: Emotional Reciprocity

One of the main difficulties in maintaining emotional closeness was the injured partner's limited emotional responsiveness. Some studies highlighted that a lack of emotional reciprocity, where the injured partner was unable to respond to emotional cues and express affection as they did before, significantly undermined the relationship (Bodley-Scott & Riley, 2015; Gill et al., 2011;

Hammond et al., 2011; Hammond et al., 2012; Knox et al., 2015; Layman et al., 2005; O’Keeffe et al., 2020; Villa and Riley, 2017). This lack of mutual emotional exchange often led to feelings of resentment and emotional withdrawal from the uninjured partner (O’Keeffe et al., 2020). The injured partner often struggled to engage in the same level of emotional intimacy and empathy that was present before the injury: “It’s hard for me to tell her I love her. It’s very hard for me to come out and say it like… it’s not difficult to feel it. It’s just hard to say it out.” (O’Keeffe et al., 2020, p. 499).

The uninjured partner often bore the responsibility of maintaining the emotional connection, as the injured person was less able to initiate or reciprocate emotional interactions. This led to emotional exhaustion and feelings of being undervalued, with the uninjured partner feeling pressured to stay strong despite their own unmet needs.

Subtheme 3: Isolation and Disconnection

These changes to communication and lack of emotional reciprocity contributed to feelings of isolation and emotional distance for the uninjured partner. As the injured person's ability to engage in meaningful, reciprocal communication changed, the uninjured partner often felt they were losing the person they once knew. This resulted in an eroded sense of connection and leaving the uninjured partner feeling alone in their struggles (Bodley-Scott & Riley., 2015; Chwalisz & Wroblewski., 1996; Gill et al., 2011; Godwin et al., 2011).

For many couples, experiencing a disconnect in their relationship was extremely challenging. An injured person expressed that he struggled to emotionally connect with his spouse due to difficulties in developing an intimate attachment: “I just don’t have the emotional attachment—the love, I guess you’d say. I’m in a situation where I don’t even know if I CAN develop an emotional attachment with someone.” (Godwin et al., 2014, p. 6). Similarly, caregivers described seeing the person they had always known, loved and been connected to, but being unable to reach that person emotionally, which led leading to feelings of isolation and disconnection. Some uninjured partners found it difficult to share their experiences with friends or family as they could not grasp the extent of the TBI, further exacerbating their sense of solitude. This emotional distance often led to a breakdown in the relational dynamic and mutual feelings of isolation, where partners were unable to effectively support each other through the challenges posed by TBI (Godwin et al., 2014; O’Keeffe et al., 2020; Villa & Riley, 2017).

Subtheme 4: Intimacy and Sexual Functioning

Emotional disconnection often led to physical disconnection. Many couples experienced a decrease in the frequency and quality of sexual intercourse (Chwalisz & Wroblewski., 1996; Gill et al., 2011; Hammond et al., 2011; Layman et al., 2005; O’Keeffe et al., 2020). Injured persons often avoided intimacy due to cognitive and physical changes and difficulties with sexual performance (Hammond et al., 2011) whilst uninjured partners struggled with unpredictable sexual satisfaction which impacted their ability to maintain an intimate connection. This unpredictability led to shared feelings of frustration and loss (Godwin et al., 2014).

Furthermore, uninjured partners frequently reported a loss of closeness and difficulty in re-establishing emotional and physical intimacy. The changes in personality and behaviour of the injured partner created a sense of living with a different person, making sexual intimacy particularly difficult (Bodley-Scott & Riley., 2015; Gill et al., 2011; Hammond et al., 2011). One participant described the struggle of living with someone who felt different, making her reluctant to engage in sexual intimacy: “My partner has felt like a stranger to me since the injury.” (Villa and Riley, 2017, p. 3). Additionally, some uninjured partners reported an incompatibility between roles of a caregiver and a spouse (Bodley-Scott & Riley, 2015; Gill et al., 2011; Hammond et al., 2011) which further eroded the intimate bond.

In contrast, partners who experienced a continuous emotional connection were better able to maintain their relationship quality whereas those who experienced discontinuity felt more distressed and burdened (Bodley-Scott & Riley., 2015; Villa & Riley., 2017; O’Keeffe et al., 2020).

Theme 3: Supporting Shared Growth

This theme captures the growth shared between couples when navigating a life changing injury. Despite a great deal of distress and emotional suffering in renegotiating roles and communication styles (themes 1 and 2), some couples were able to find new meaning within their relationships (theme 3: subtheme 1). Additionally, couples highlighted aspects of gratitude (theme 3: subtheme 2) and touched on wider sources of support (theme 3: subtheme 3) to help them navigate through the challenges of TBI and move forward together.

Subtheme 1: Finding New Meaning

For many couples, jointly experiencing grief and emotional challenges fostered growth and often led to a deeper understanding of each other (Godwin et al., 2014; Layman et al., 2005). This difficult period was viewed as an opportunity for mutual healing and a chance to uncover new meaning and purpose in their relationships. Couples often discovered unexpected strengths and formed new interests or adapted activities to fit with their new lifestyle (O'Keeffe et al., 2020; Godwin et al., 2014). They developed a revised sense of their shared identity, different from their pre-injury relationship, which led to the establishment of new life goals that better reflected their current abilities and circumstances.

Couples found that spending time together played a vital role in finding new meaning post-TBI. They actively sought ways to express their affection and dedication through joint activities and acts of service (Gill et al., 2011; O'Keeffe et al., 2020; Villa & Riley., 2017). This helped to deepen their emotional connection leading to the emergence of new meaning within the relationship. Couples who managed to integrate the new dynamics with aspects of their old relationship often felt a greater sense of normalcy and continuity (Bodley-Scott & Riley., 2015).

Subtheme 2: Gratitude and Determination

Gratitude was a key coping mechanism for both TBI survivors and their partners (Chuoum et al., 2021; Bodley-Scott & Riley., 2015; Gill et al., 2011; Godwin et al., 2014; Knox et al., 2015; Layman et al., 2005; O’Keeffe., 2020), reflecting their resilience during recovery Many injured individuals expressed relief that their injuries were not more severe: "I was very lucky to not have become severely hurt." (Chuoum et al., 2021, p. 59). Uninjured partners noticed their injured loved ones' increased appreciation for life and each other, which often strengthened their bond and intimacy during recovery: “It brought us closer together...knowing that he could have been taken away from me within an instant. So, it just brings more intimacy into the relationship, me caring for him, letting him know, okay, you know you survived this accident and we’re going to make it through this period of our lives.” (Gill et al., 2011, p. 64).

Many couples were determined to stay together, despite the challenges they had been through since the TBI: “It’s been the greatest challenge of my life. It’s taken almost everything I had to give, but it’s been worth it. The bond between us is made of steel and will never break.” (Acorn and Roberts, 1992, p. 326).

Some couples found comfort and strength in their shared spiritual beliefs (Chuoum et al., 2021; Gill et al., 2011) which provided a framework for accepting their new circumstances and reinforced their commitment to each other. The conviction that they were destined to be together or that their relationship was part of a higher plan often helped alleviate relationship stress and uncertainty following the injury. One participant expressed: "I believe that I was meant for X and was born to marry her...I think the factor is God." (Gill et al., 2011, p. 64).

Additionally, couples who had previously faced significant life challenges, such as serious illnesses or other traumatic events, felt that this had better equipped them to cope with the challenges of TBI (Gill et al., 2011). These past experiences helped to build resilience and a sense of overcoming adversity together which meant that these couples could approach their current situation with a greater sense of strength and unity.

Subtheme 3: Systemic Support

Broader social support was vital for couples coping with TBI (Acorn & Roberts., 1992; Chuoum et al., 2021; Chwalisz and Wroblewski., 1996; Gill et al., 2011; Hyatt et al., 2015; Layman et al., 2005; O’Keeffe et al., 2020). Families who were already significant to some partners before the injury, became invaluable sources of support following the injury. However, this support had its limitations. While many uninjured partners were grateful for the assistance from family members, they also felt frustrated when the expected support was inconsistent: “Families can be just wonderful, they can also be stinky, so it's better to have them be in a crisis time I think is when it shows up, their true character. And in the between time they're just busy that's why they don't come...” (Chhuom et al., 2021, p. 60).

Support networks extended beyond immediate family to include friends, colleagues and religious communities. In the early stages post-injury, the collective efforts of family and friends were particularly valuable in reducing stress, alleviating fatigue, and managing anxiety. Many participants emphasized how this broader support system was key to maintaining their intimate relationships (Gill et al., 2011; Layman et al., 2005). Furthermore, for couples with children, their shared commitment to parenting often served as motivation to sustain their relationship: “We both are totally committed to each other very much...we have a child and one on the way and that’s even more of a reason to make sure it stays that way.” (Gill et al., 2011, p. 64).

Although professional support was not universally successful (Chuoum et al., 2021; Knox et al., 2015), for some couples it emerged as a vital component in supporting them through the challenges discussed in themes 1 and 2 (O’Keeffe et al., 2020). Engaging with neurorehabilitation professionals was particularly beneficial in understanding the behavioural and interactional impacts of TBI, which was crucial for coping: ‘It’s helped me to understand what’s been going on for me and then (June) can understand now too. I’ve had to accept that I’m like this now. But they’ve helped me to do that yeah.’ (O’Keeffe et al., 2020, p. 501).

Overarching Theme: An Evolving Journey

The three themes – ruptured meaning and identities, communication and connection, and supporting shared growth - were dynamic and ever-changing over time or indeed even at any one time, mirroring the dynamic and fluid nature of relationships impacted by TBI. These themes were characterised by a general sense of fluidity, highlighting the fact that these were processes that required constant work. There were often days and weeks where couples oscillated between the themes. This could occur both concurrently and consecutively. Couples discovered that in order to adapt to changing needs and circumstances, their strategies for intimacy, connection, and communication had to be continuously evaluated and changed (Gill et al., 2011; Godwin et al., 2014; Hyatt et al., 2015; Knox et al., 2015). A key theme that ran across all of their experiences was this ongoing progression, which demonstrated how these parts of their relationships were never static. Rather, their relationships and the environment in which they interacted changed throughout time, necessitating constant work and flexibility to preserve unity or indeed where unresolved, leading to unfulfilled relationships.

[Figure 1.2 here]

Discussion

The aim of this thematic synthesis was to summarise the existing qualitative evidence for navigating romantic relationships after one partner experiences a TBI. Three themes were constructed: (1) ruptured meaning and identities, (2) communication and connection, (3) supporting shared growth, which sat under an umbrella theme: an evolving journey, reflecting the evolving nature of these aspects and the constant work put in by the couples to achieve favourable outcomes.

The synthesis identified that injured persons experienced identity changes following their TBI and that this has a profound impact on the relationship (theme 1). A substantial body of literature has documented the identity changes that occur in individuals following TBI (Yeates et al., 2008; Norup & Mortensen, 2015; Beadle et al., 2016). These identity changes in the injured person disrupted the established dynamics within the relationship (theme 1). Previous work has suggested this leads to altered expectations and emotional strain (Ownsworth, 2014) and in this review uninjured partners struggled to adjust to the new reality (theme 1).

Many uninjured partners reported a sense of loss arising from changes to their partner post TBI (theme 1), commonly referred to as 'ambiguous loss' in the literature (Boss, 1999). This type of loss oftens leads to unresolved grief and stress, as the individual may be physically present and very much recognisable but cognitively or emotionally changed. This was evident in theme 1 where uninjured partners described difficulty in mourning their partner despite still being around them. This sense of loss was further highlighted by the spouse's need to fill the role in the relationship previously taken on by the injured person. Some participants found that this shift away from an equal partnership made daily challenges more difficult to navigate. Existing literature has highlighted these changing roles in terms of increased financial responsibility, transition toward a dual parenting role and reduced emotional support (Maitz & Sachs, 1995; Kreutzer et al., 1994). As participants devoted more of their time taking on extra roles and responsibilities (theme 1), they had fewer resources left for their own self-care and emotional regulation. This supports Kreutzer et al.'s (1994) hypothesis that losing a 'peer-based reciprocal relationship' may increase emotional distress in couples more so than in a parent-child relationship (Kreutzer et al., 1994).

Anger and irritability exhibited by the injured person had a significant impact on communication (theme 2). Emotion dysregulation and behavioural difficulties in individuals with TBI have been associated with low mood (Gillen et al., 1998) anxiety and depression (Perlesz et al., 2000), and increased strain or burden (Brooks et al., 1987) for the uninjured partner. Additionally, communication difficulties arose as a result of a lack of emotional reciprocity (theme 2). Social

Cognitive Theory (Bandura, 1986) emphasizes the role of cognitive processes in understanding and predicting human behaviour. The ability to recognise, interpret and respond to others' emotional cues can be significantly impaired in injured persons, leading to difficulties in maintaining emotional reciprocity within relationships. Furthermore, Theory of Mind (Baren-Cohen et al., 1985) involves the capacity to attribute mental states to oneself and others – an ability which can be significantly impaired following TBI (Bibby & McDonald, 2005). This impairment was evident in theme 2, where injured persons described a decreased ability to engage in emotionally reciprocal interactions which led to difficulties for the uninjured partner in engaging with emotional intimacy.

Both injured persons and uninjured partners reported that sexual difficulties often became a challenging aspect of the relationship (theme 2). Sexual difficulties following TBI are associated with reduced sex drive, loss of confidence and a decrease in self-esteem (Ponsford, 2003). Unpredictable behaviour from the injured person can threaten intimacy (Bannon et al., 2020) and the conflict between caregiving and romantic roles for the uninjured partner can make it difficult to resume an equal, physically intimate relationship (Gosling & Oddy, 199). This was shown in theme 2, where uninjured partners described losing the intimate element of their relationship due to increased caregiver burden. TBI specific factors including attention deficits, communication difficulties, aggressive behaviours and misinterpretation of social cues can also have a negative impact on the intimate relationship (Moreno et al. 2013). In theme 2, these cognitive, emotional and behavioural changes led to a sense of living with a different person, making it difficult for the uninjured partner to seek sexual intimacy.

Despite the challenges of navigating relationships, some studies touched on aspects of shared growth (theme 3). Participants described developing adaptive coping strategies and seeking external support to enable them to find new meaning within their relationships. This process of adjustment is in line with Moss-Morris' (2013) working model of adjustment which proposes reaching a 'return to equilibrium' where individuals achieve a balance in their emotional, cognitive, and behavioural responses to their chronic illness. The findings in this review highlight couples' acceptance of a new reality where both partners recognised the challenges but were determined to work collaboratively to maintain their relationship, thus reaching a state of relationship equilibrium (theme 3).

The overarching theme, an ongoing journey, demonstrates that these changes are an ongoing process of adjustment which couples are constantly working on to help navigate their romantic relationships following a TBI. The process is dynamic and often does not occur in a linear fashion but rather oscillates between various stages of negotiation and renegotiation, often through trial and error while couples determine the most effective strategies for their unique situation. Most of the information in themes 1 and 2 reflected concepts similar to Verhaeghe et al.’s, (2005) narrative review who described the ongoing process and ‘never-ending cycle’ of living with a TBI, however some literature also captures a sense of hope and the potential for couples to adapt and find new meaning (see theme 3) as in Whiffin et al.’s, (2021) interpretation.

Clinical Implications

This review highlights the importance of providing targeted support for the couple as a dyad. Excluding the uninjured partner from the recovery process leads to a limited understanding of the impact of TBI on the couple dynamic. Given the complexity and heterogeneity of couples, a ‘one-size fits all’ approach is not appropriate (Cameron, 2021), thus a specific tailored approach would be most beneficial. Clinical psychologists working with this population could adapt their approach to ensure the relationship is also a focus, across all stages of their work together: assessment, formulation, intervention and evaluation (see Table 1.4).

The review also highlights the need for specialist neuropsychological input with a relational focus. Coetzer (2007) highlights the risk of the therapist personalising or dismissing certain types of behaviour and cognitive impairments due to a lack of understanding of the complex effects of TBI. This could also be applied to the uninjured partner, where a lack of true understanding could lead to misinterpretations of behaviour and have a negative impact on the relationship. It is therefore crucial that support comes from clinical psychologists with specialist neuropsychological understanding of the complexities and challenges of TBI. Further understanding could be facilitated through specialised TBI training for staff working within primary and secondary psychological services.

This specialised understanding and rehabilitation approach can help couples re-establish a coherent identity. The Y-shaped model of rehabilitation after brain injury (Gracey et al. 2009), describes a process of how an individual with TBI adapts and adjusts during rehabilitation. Discrepancy between the current context and the person they aspire to be contributes to psychological distress or ‘self under threat’. Bowen et al., (2010) extend this model to consider partners in a system navigating their ‘relationship under threat’. The model considers both partners’ discrepancies and brings them together to form the Y-shaped cone. In a romantic relationship, each partner has their own concerns or issues (discrepancies) they are trying to manage to feel secure and happy. When one partner tries to address their own issues, it might unintentionally create new problems for the other. As the couple incorporates different perspectives and work together, the discrepancies become smaller, and the relationship becomes more cohesive, allowing for a more coherent relational identity.

Another model, the Family Experience Model (FEM) (Klonoff, 2010), emphasizes the importance of ongoing support and follow up care to address evolving needs and challenges overtime. This model may be effective as it reflects the ‘journey’ and ‘ongoing process’ highlighted in this synthesis. The FEM (Klonoff, 2010) addresses the complex needs of individuals recovering from brain injuries, along with the needs of their families at different stages of rehabilitation. The model emphasizes the importance of family involvement in the rehabilitation process and recognizes the impact of brain injury on both the individual and their family system through different phases of recovery. This model could be adapted to support couples by including the uninjured partner as central to the recovery process and taking into account specific changes relevant to a romantic relationship.

Limitations and Future Research

A key limitation was the reliance on a single individual, the author, for the screening process, with only a portion of the quality assessment verified by a second person. Additionally, the review did not incorporate grey literature in its analysis which may have resulted in missing valuable insights from unpublished studies, potentially limiting the comprehensiveness of the review.

The findings of this meta-synthesis are limited by the papers reviewed. Most participants interviewed across all 13 papers were couples that remained together thus the review is biased to a slightly more positive outcome. Future research should include couples that separated or divorced to provide a more comprehensive understanding of relationship challenges following TBI.

Existing research on post-TBI relationships is largely focussed on predominantly white, middle-class couples despite evidence of varied coping strategies among different families (Yeates et al., 2007). In addition, only 5 Western countries were represented throughout the selected papers, leaving a significant gap in understanding the impact of ethnicity and culture on romantic narratives. Future research should prioritise exploring the narratives of couples from diverse racial and cultural backgrounds including more traditional collectivist cultures. Furthermore, only two of the 13 studies included same-sex couples, with most focusing on heterosexual relationships. Future research should consider exploring the experiences of same-sex couples as they may encounter distinct problems and dynamics in relation to cultural and societal attitudes, legal considerations, and support networks.

Future research should differentiate between different TBI severities to better understand its impact on couples' relationships. Typically, more severe TBIs can lead to greater impairment and a greater loss of independence for the injured individual (Wells et al., 2005), while milder TBIs may present unique challenges such as poor understanding of mild cognitive problems and the impact of fatigue on spontaneity. Both are likely to affect the relationship dynamic in different ways.

Of the 13 studies collated in this review, seven reported on issues with intimacy and sexual functioning. There is a scarcity of research exploring sexual functioning particularly from the perspective of the uninjured partner and as a dyad. More research is needed to ensure that all aspects of a couple's connection are considered and nurtured through intervention.

While both genders were represented within this review, there was inevitably a bias towards men as the injured partner. There has been limited research regarding the effect of TBI on feminine or masculine identity and how this has impacted roles within the relationship. More research is needed to reveal gender nuances.

Systemic and narrative approaches in working with ABI have been described in the literature (Elbaum, 2019) as well as case studies using emotion focussed therapy with couples after ABI (Yeates et al., 2013). Further research on the efficacy of neuropsychologically informed systemic work on TBI rehabilitation would be valuable. Such research could explore the benefits and challenges of involving both partners in the rehabilitation process and examining how neuropsychologically informed work impacts their relationship dynamics and emotional well-being.

Two of the selected papers conducted interviews at different time points (Chouum et al., 2021; Knox et al., 2015). Longitudinal studies are crucial for understanding how couples adapt over different recovery stages, identifying evolving coping strategies, and assessing long-term relationship impacts. Such research could inform stage-specific interventions and identify how the needs of couples change over time.

Conclusion

This thematic synthesis sought to understand how couples navigate their relationship after one partner experiences a TBI. Findings from the current review suggest that couples may

experience ruptured identities as well as difficulties with communication and connectedness. Despite the significant challenges experienced, some couples were able to find new meaning and purpose. A narrative running throughout these themes was the idea of 'an evolving journey', whereby couples had to work consistently to adjust to new dynamics within the relationship. Implications for therapeutic work and other interventions are considered such as a systemic approach with neuropsychological input to include the experience of the couple. Future research should include more diverse groups and consider the effectiveness of neuropsychological input in supporting couples after TBI.

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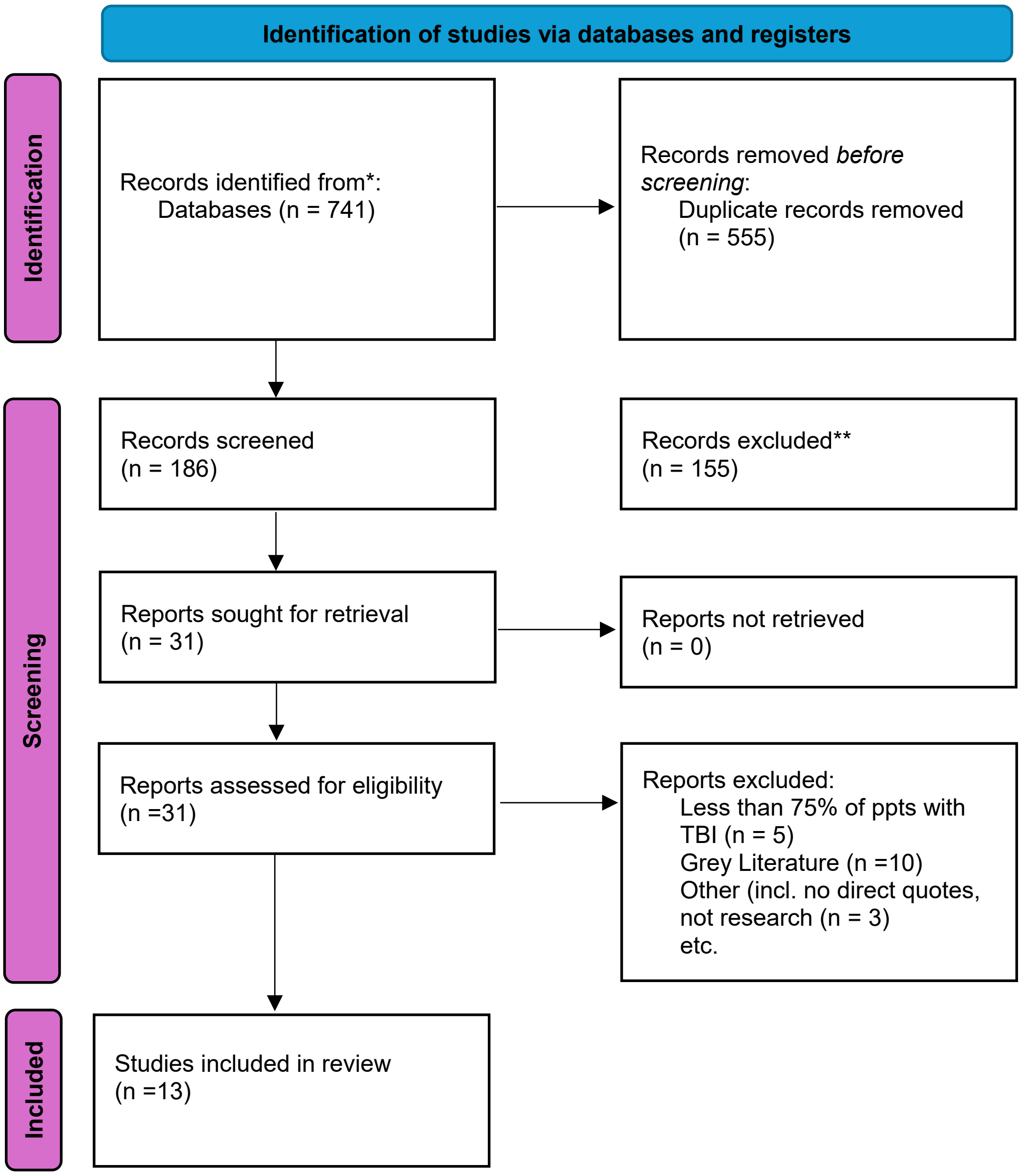
Table 1.1 Details of Search Strategy for APA PsycINFO

Item	Search Terms	Results
S1	DE "Qualitative Methods" OR TI (Qualitative OR "Focus Group*" OR "Grounded Theory" OR Phenomenolog* OR Narrat* OR Interview* OR Thematic OR ethnography OR "lived experience" OR “content analysis” OR “discourse analysis” OR “constant compar*) OR AB (Qualitative OR "Focus Group*" OR "Grounded Theory" OR Phenomenolog* OR Narrat* OR Interview* OR Thematic OR ethnography OR "lived experience" or “content analysis” or “discourse analysis” OR “constant compar*)	676,557
S2	DE "Traumatic Brain Injury" OR TI ("brain injur*" or tbi or ABI or concussion or “head injur*” or “craniocerebral trauma”) OR AB ("brain injur*" or tbi or ABI or concussion or “head injur*” or “craniocerebral trauma”)	41,300
S3	DE "Couples" OR TI ("romantic relationship" or couple* or partner* or spouse or husband or wife or "significant other") OR AB ("romantic relationship" or couple* or partner* or spouse or husband or wife or "significant other")	213,597
S4	S1 AND S2 AND S3	248

Figure 1.1 PRISMA flow diagram depicting the study selection process



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

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

Table 1.2 Quality appraisal – CASP Checklist

Author, Year	Clear Aim	Appropriate Methodology	Research Design	Sampling	Data Collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Research Value	Total
Acorn and Roberts (1992)	2	2	2	1	1	1	1	1	1	2	14
Bodley-Scott and Riley (2015)	3	3	3	2	2	2	2	3	3	2	25
Chhuoum et al. (2021)	3	3	3	2	3	2	2	3	3	3	27
Chwalisz & Wroblewsk (1996)	3	3	3	1	2	1	1	2	2	3	21
Gill et al. (2011)	3	3	2	2	2	1	1	3	2	3	22
Godwin et al. (2014)	3	3	2	2	2	1	1	2	3	2	21
Hammond et al. (2011)	3	3	3	2	2	1	1	2	2	3	23
Hammond et al. (2012)	3	3	3	2	2	1	1	2	2	3	23
Hyatt et al. (2015)	3	3	2	2	2	1	1	3	3	3	25
Knox et al. (2015)	3	3	2	1	2	1	1	2	3	3	21

Layman et al. (2005)	3	2	3	2	3	2	1	1	3	2	22
O’Keeffe et al. (2020)	3	3	3	2	3	1	1	3	3	3	26
Villa & Riley (2017)	3	3	3	3	3	1	2	3	3	3	27

1 = weak evidence or justification; 2 = moderate evidence or justification but not fully explained; 3 = strong evidence or justification

Table 1.3 Characteristics of included studies in chronological order

Author, Year, Country	Research Aim	Methodology	Data Collection	Study Participants	Sex of Injured Person	TBI Severity	Sex of uninjured partner	Time since injury	Sexual orientation of couples	Findings
Acorn and Roberts (1992) CANADA	To provide insight into the impact of head injury on the wife of the survivor	Latent content analysis	Open ended responses within a questionnaire	Uninjured wives caring for a husband (n = 12)	12 male	Not stated	12 female	1-17 years	Heterosexual	Role change, emotional impact of the injury, the concept of hope and the need for support.
Bodley-Scott and Riley (2015) UK	Explore social, behavioural and emotional changes experienced by partners of persons with TBI. Explore emotional and relationship impact	Interpretive Phenomenological Analysis	Two flexible interviews one-three weeks apart	5 uninjured cohabiting partners (n=5)	5 male	Moderate /severe	5 female	9 months – 7 years	5 heterosexual couples	Emotional Impact (Direct emotional impact; Identity change; Managing the changes) Impact on the relationship (Feeling Love; Receiving Love)
Chhuoum et al. (2021) USA	Older Spousal Dyads and the Experience of Recovery in the Year After Traumatic Brain Injury	Multiple-case study using data from a larger parent study. Qualitative content analysis	Interviews conducted at 1, 3, 6, and 12 months post injury	3 injured persons and their uninjured partners (n=6)	3 male	Mild	3 female	1 year	3 heterosexual couples	Lack of social support was a stressor, creating a barrier to recovery. Significant others tended to focus on others versus self-care needs.
Chwalisz & Wroblewsk (1996) USA	To identify some of the issues most salient for caregivers of persons with brain injuries	An inductive, typological content-analysis approach	Essay data collected as part of a larger, quantitative study	27 uninjured spouses (n=27)	Not specified	Not stated	26 female, 1 male	Not specified	Not specified	My situation is different and/or easier than others, sources of support and assistance, changes in the spouse with the injury, changes in the marital relationship as a result of

										the injury, changes in the caregiver and his/her life, miscellaneous stressors ancillary to the injury, problems with/advice for medical professionals, others don't understand and may be unsupportive, coping strategies used by the caregiver, personal resources helpful for the caregiver role, descriptions of experienced burden.
Gill et al. (2011) USA	Lived experiences of couples regarding TBI and intimate relationships	Grounded theory	One individual open ended in-depth semi-structured interview	18 couples, injured person and intimate partner (n = 36)	12 male, 6 female	No severity data	13 female; 5 male	0.55–25 years	17 heterosexual couples 1 same sex couple	Barriers to intimate relationships; Factors related to relationship strength
Godwin et al. (2014) USA	Framework for conceptualizing and assessing couples after TBI	Grounded theory	Existing personal narratives written by survivors of TBI and/or their romantic partners and clinician authored literature.	Consumer authored documents (29 blogs, 5 reported narratives, 6 memoirs) 35 by injured/uninjured 5 clinician authored (n = 40)	Not reported	No severity data	Not reported	Not specified	Not specified	Five primary themes: Ambiguous Losses, Identity Reformations, Tenuous Stability, Non Omnes Moriar and The New Us. Two grounded theories: Relational Coring and Relational Recycling.
Hammond et al. (2011) USA	Experiences spouses residing	Qualitative	Focus groups (two groups)	Uninjured spouses (n=10)	Not reported	Mild-severe	5 female, 5 male	6-12 years	Not specified	Staying married; temporality; spatiality; trust; communication'

	with individual living with TBI									emotional attachment; caregiver responsibilities; financial responsibilities; reactions to added responsibilities. (Fondness/affection; glorifying the struggle; marital disappointment/disillusionment; negativity toward spouse; We-ness versus separateness; Chaotic relationships; Volatility of the relationship; Gender role stereotypes)
Hammond et al. (2012) USA	Experience of irritability in family system perspective of people with TBI and spouses	Participatory research	Focus groups (5 different groups met 10 times each)	10 Uninjured, 16 injured persons (n = 26)	12 male, 4 female	Mild-severe	7 female, 3 male	2-16 years	Not specified	Irritability breeds further irritability; spousal reactions can trigger irritability amongst persons with TBI; Difficulties making emotional connections may incite irritability and negative spousal interactions; communication breakdowns may exist that provoke irritability; Expectations of others (real or perceived and spoke or unspoken) may contribute to irritable behaviours.
Hyatt et al., (2015) USA	Family reintegration experiences, as	Grounded theory	Nine soldiers and their spouses	Soldiers (n=9) and their	8 male, 1 female	Mild traumatic	Not stated	6 - 18 months,	Not specified	The overarching theme of “finding a new normal” emerged from the

	described by married dyads, following a combat-related mTBI		participated in a total of 27 semi-structured interviews, both joint and individual	spouses and as a dyad (n=27)		brain injuries		mean time 12 months		conjoint interviews, with the following core categories: facing up to the soldier’s unexpected homecoming, managing unexpected changes in the family routine, experiencing mismatched expectations, and adjusting to new expectations for the family.
Knox et al. (2015) AUSTRALIA	Perspective spouses severe TBI and initial model, support partners with decision-making	Constructivist grounded theory	Two in-depth interviews	Uninjured cohabiting spouses (three heterosexual, one same sex) relationship length at least four years. Three couples commenced relationship after TBI was sustained (n = 4)	2 male, 2 female	Severe	1 female, 3 male	8-19 years	Three heterosexual, one same sex couple	Features of the spousal relationship in decision making: Understanding the functional implications of the brain injury on their partner; Seeing the person in a positive light; being committed to the relationship; Finding a way to communicate; Learning from experience. The process of decision making: Stage 1. Remaining vigilant to decision-making opportunities; Stage 2. Recognising and initiating a decision point; Stage 3. Evaluating involvement; Taking action; Stage 4. Living with the outcome; Stage 5. Reflecting on the process.

Layman et al. (2005) USA	'Insider' perspectives of older couples impacted by TBI,	Participatory Action Research	One individual semi-structured interview	7 uninjured partners, 8 injured persons, 6 control individuals (n = 21)	3 male, 5 female	Mild-severe	2 female, 5 male	3-21 years	Heterosexual	Relatedness (interpersonal communication, dependence, role changes, sexual intimacy and inter-personal support); Relationship persistence (critical incidents, reasons given for staying in the relationship and references to love).
O'Keeffe et al. (2020) IRELAND	To explore the impact of TBI on the couple relationship. The analysis focused primarily on the shared dyadic perspectives of couples concerning the same relational phenomenon (living as a couple with TBI) by interviewing both members of each couple	Interpretative Phenomenological Analysis	One semi-structured interview with both parties in the couple	6 partners and 5 injured persons (n=11)	5 male	Moderate-severe	6 female	4-8 years	Heterosexual	Three themes: Broken Bonds: "those special things just between the two of us"; New Dynamics: "like oil and water" and Moving Forward Together: "we figure it out".
Villa & Riley (2017) UK	To explore whether the conceptual framework of relationship continuity may	Template Analysis	Two interviews, approximately a week apart. First interview	5 injured persons and 5 partners	4 male, 1 female	Moderate to severe	4 female, 1 male	1-10 years	Heterosexual	Three themes with subthemes: (1) Is relationship continuity an appropriate framework for conceptualising participants' experience?

	also be applicable to understanding the experience of spousal carers in acquired brain injury		focused on pre-injury relationship, second interview focused on post-injury relationship							(a) Same/different person (b) Relationship redefined (c) Same/different feelings (d) Couplehood (e) Loss (f) Were the two criteria for establishing applicability met? (2) Potential implications of continuity/discontinuity for the response to the care-giving role (a) Making sense of and managing the changes (b) The burden of care-giving (c) Thoughts about remaining within the relationship (3) A potential precursor of discontinuity (a) Lack of emotional reciprocity

Figure 1.2 Conceptual model of themes

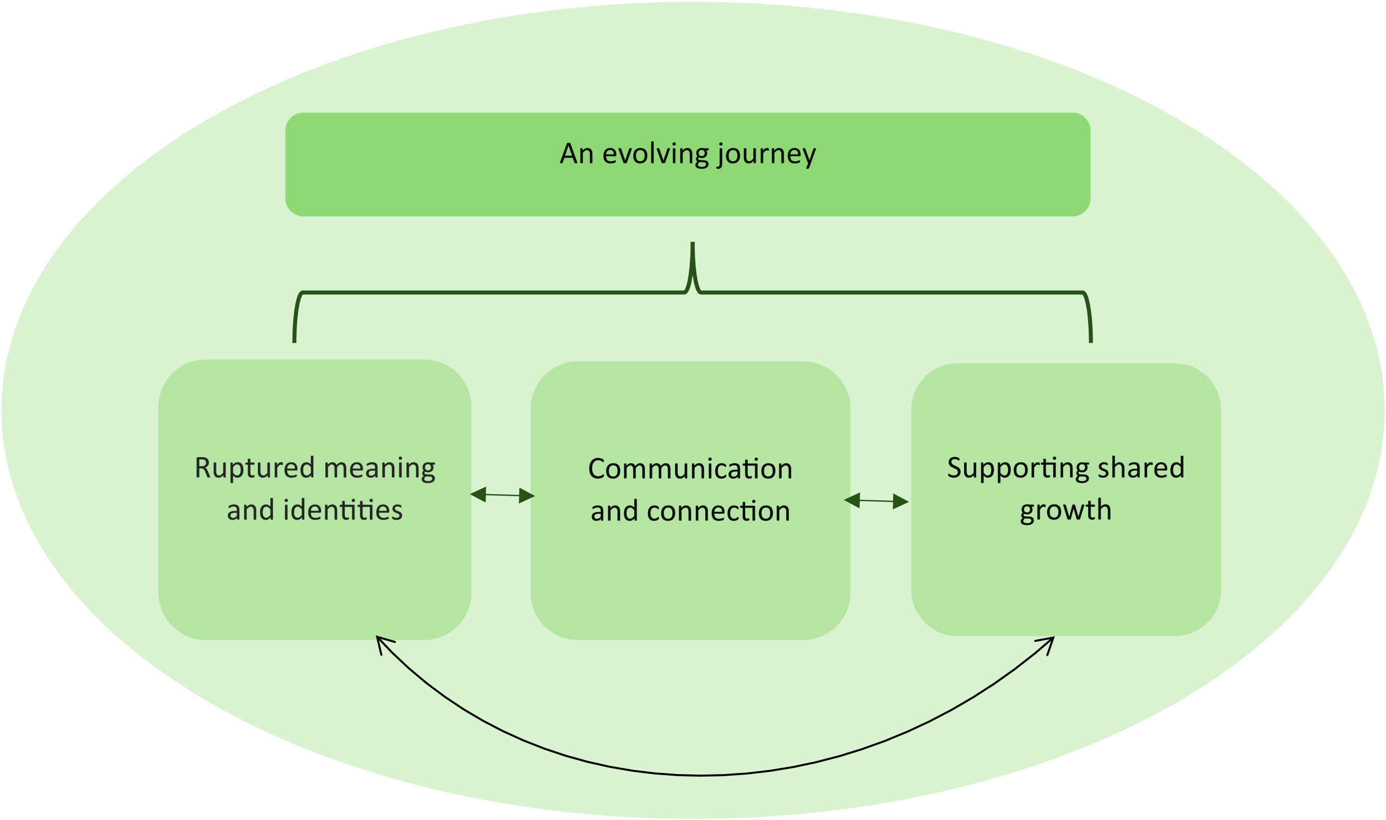


Table 1.4 Example assessment adapted for couples

The below table shows the general principles of clinical psychological practice (Marzillier & Marzillier, 2013). These recommendations are supplementary considerations for the couple relationship and not an exhaustive list of necessary factors.

Psychological Principle	**Recommendation**
Assessment and formulation	A comprehensive assessment of the patient’s brain injury, cognitive, emotional and behavioural functioning as well as family dynamics – with particular emphasis on the relationship dynamic between injured person and uninjured partner.
Goal Setting	Collaborative goal setting with the injured person and uninjured partner to ensure that rehabilitation goals are realistic and meaningful and take into account impact on the romantic relationship. The stage of brain injury recovery will also need to be taken into account.
Intervention	Implementation of individualised intervention plan that include therapy sessions, psychoeducational workshops for the couple and practical exercises using real life examples that would occur in different aspects of a romantic relationship dyad.
Evaluation	Continuous monitoring of progress and adjustment of intervention strategies as needed, regarding relationship satisfaction as an important outcome.

Appendix 1-A Submission Guidelines: Neuropsychological Rehabilitation

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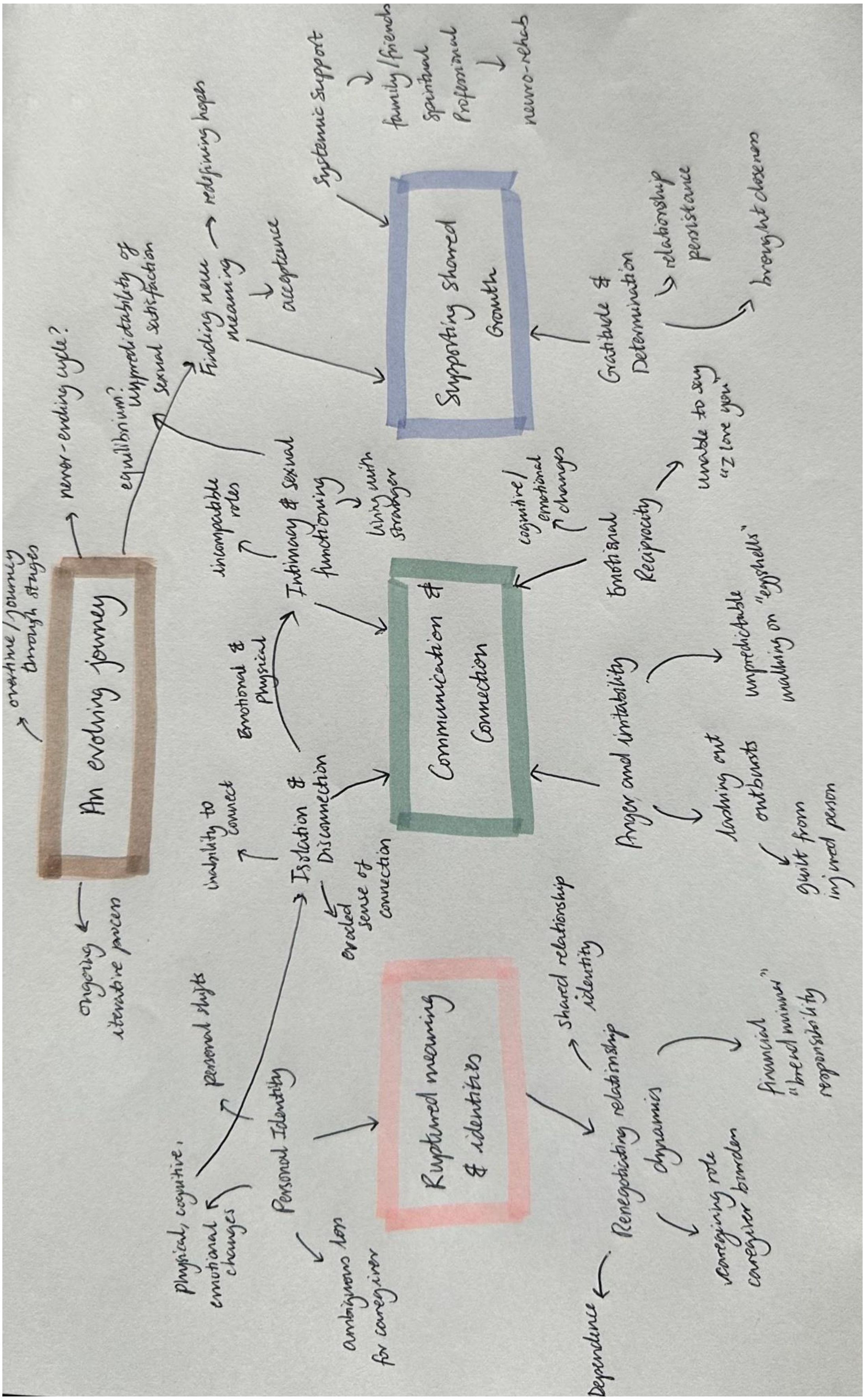
Appendix 1-B Example of transformation of line-by-line coding to descriptive and analytical themes

Theme 2: Communication and Connection

Line by Line Codes	Descriptive Themes	Analytical Themes
Impact on marital relationships Angry outbursts/lashing out Guilt from injured person	Anger and irritability	Communication and connection

Unpredictable nature of anger or violence Walking on ‘eggshells’ around injured person Fear of provoking adverse response Difficulties communicating with injured partner due to displays of aggression Emotional volatility Putting strain on the relationship		
Cognitive/emotional challenges from injured person Injured person unable to express affection/emotion Lack of flirting/emotional affection	Emotional Reciprocity	
Uninjured partner feeling alone despite being in a relationship Feeling disconnected from injured partner Eroded sense of connection Injured partner feeling disconnected Inability to connect Emotional disconnection	Isolation and disconnection	
Physical disconnection Incompatibility of carer and lover roles Unpredictability of sexual satisfaction Injured person unable to perform in the way they would like Lack of physical affection	Intimacy and sexual functioning	

Appendix 1-C Development of analytical themes



Appendix 1-D Matrix of Included Studies and Identified Theme

Study	Theme 1: Ruptured meaning and identities		Theme 2: Communication and connection				Theme 3: Supporting shared growth		
	Personal Identity	Renegotiating Relationship Dynamics	Anger and Irritability	Emotional Reciprocity	Isolation and Disconnection	Intimacy and Sexual Functioning	Finding New Meaning	Gratitude and determination	Systemic Support
1	-	Y	-	-	-	-	-	Y	Y
2	-	Y	Y	Y	Y	Y	-	Y	-
3	Y	Y	Y	-	-	-	-	-	Y
4	-	Y	Y	-	Y	Y	Y	-	Y
5	Y	Y	Y	Y	Y	Y	Y	Y	Y
6	Y	Y	Y	Y	Y	Y	Y	Y	-
7	Y	Y	Y	Y	Y	-	-	-	-
8	-	Y	Y	Y	Y	-	-	-	-
9	-	Y	Y	-	-	Y	Y	Y	Y
10	-	Y	-	Y	Y	-	-	Y	-
11	Y	Y	Y	Y	Y	Y	-	Y	Y
12	Y	Y	Y	Y	Y	Y	Y	Y	Y
13	-	Y	Y	Y	Y	-	-	Y	

Section Two: Research Paper

The experience of persistent cognitive difficulties after being infected with COVID-19.

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Abstract

COVID-19 is an acute respiratory disease caused by the SARS-CoV-2 virus which has caused widespread health issues. Many individuals experience persistent symptoms long after recovery from the initial acute infection. These persistent symptoms are more commonly known as long COVID. There is growing evidence that individuals with long COVID experience persistent cognitive difficulties. This study aimed to explore the lived experience of persistent cognitive difficulties following a COVID-19 infection. Thirteen participants were recruited through social media and interviewed. The interviews were transcribed verbatim and analysed using reflexive thematic analysis. Four main themes were constructed from the data: (1) Dealing with loss: stolen identity and a sense of injustice, (2) Internal turmoil: unpredictability and emotional distress, (3) Isolation and misunderstanding vs empowerment by social connection, (4) Navigating healthcare: the good, the bad and the uncertain. Cognitive difficulties had far-reaching impacts on individuals' daily lives. Access to appropriate neuropsychological assessment and intervention is crucial in supporting those with ongoing cognitive difficulties following COVID-19. Psychological therapy such as Acceptance and Commitment Therapy (ACT) could be useful in managing the emotional difficulties and impact on mental health.

Key Words: Qualitative, Reflexive Thematic Analysis, COVID-19, Long COVID, Cognitive Impairment.

Introduction

COVID-19, caused by the SARS-CoV-2 virus, was first detected in 2019 and led the World Health Organisation (WHO) to declare a pandemic in early 2020. Typical acute symptoms of this respiratory based illness include loss of taste and smell, difficulty breathing, and a high temperature (WHO, 2023). However, symptoms can persist, or indeed new symptoms can develop beyond the four weeks of the acute illness period with some symptoms having been found to persist even longer, beyond 12 weeks of initial infection. These persistent symptoms are more commonly known as ‘long COVID’ (WHO, 2023) or referred to as post-acute sequelae of COVID-19 (PASC) throughout the literature. It is estimated that at least 65 million people globally are currently living with long COVID, with 1.9 million in UK alone (Office for National Statistics (ONS), 2023). 1.1 million of these individuals have experienced symptoms for over 12 months and 20% report significant impacts on their daily activity. Current evidence suggests that long COVID can be experienced by individuals of all ages regardless of initial disease severity (Notarte et al., 2022). There are currently limited pathways in health and social care for support and no official treatments.

Long COVID has been shown to impact multiple bodily systems with the respiratory system being the most commonly affected. In a systematic review, Zeng et al. (2023) found that around half of the individuals diagnosed with acute COVID-19 exhibited long-term respiratory difficulties for up to 12 months after initial infection, with impaired pulmonary function being the most prevalent symptom. Research has also suggested COVID-19 can lead to other complications, impacting the gastrointestinal tract (Choudhury et al., 2022), cardiovascular system, central nervous system and immune functioning (Moslehi et al., 2022).

A substantial psychological impact on individuals with long COVID has been documented in the literature. Research has shown a positive correlation between COVID-19 severity and anxiety and depression symptoms (Gramaglia et al., 2022; Rahmati et al., 2023; Premraj et al., 2022). While depression rates decreased over time, some patients experienced persistent symptoms beyond one year (Ettman et al., 2022). Out of a sample of 655 participants, long-term post-traumatic stress disorder was shown to affect over 20% of individuals (Goodman et al., 2023). The data for long-term psychosis, though limited, suggests paranoid ideation and hallucinations can occur up to 6 (Ahmed et al., 2021) and 9 months post-infection (Damianio et al., 2022), particularly in individuals with severe initial infection.

Long COVID symptoms have been shown to have a significant impact on individuals' quality of life (QoL). Malik et al. (2022) found a pooled prevalence of 59% for poor QoL, with patients with intensive care unit (ICU) admission and fatigue experiencing significantly poorer QoL. Analysis of responses to an online survey showed that long COVID impacted individuals across various domains including significant changes to their lifestyle, severely limiting their daily activities, impacts on social and family connections as well as employment and mental health (Owen et al., 2023). Similar themes were found in a study by Thomas et al. (2023) in which participants described changes in functional and physical ability, the emotional impact of long COVID on personal identity and the fluctuating nature of symptoms making recovery extremely challenging - all of which negatively impacted on QoL.

Persistent cognitive difficulties in people experiencing long COVID has been suggested by recent evidence (Li et al., 2023; Rahmati et al., 2023, Mar Ariza et al., 2023) and neuropsychological deficits have been demonstrated in 20-80% of long COVID patients (Miskowiak et al., 2023; Ceban et al., 2022). These include difficulties with visuospatial and executive function, processing speed, reduced memory and attention, language expression, and word finding difficulties (Fanshawe et al., 2024; Cummings, 2023). In addition, a recent study has found generalised cognitive slowing in patients with long COVID compared with age matched healthy individuals (Zhao et al., 2024). As current evidence has suggested, the COVID-19 virus can enter the central nervous system with a possibility that it may be able to directly damage the structure and function of the brain. This has been linked to disruptions in brain homeostasis and neuroinflammatory responses triggered by the virus, resulting in cognitive impairment in individuals (Li et al., 2023).

Many individuals have displayed persisting cognitive difficulties for up to 12 months of initial infection and beyond (Han et al., 2022) with some evidence suggesting they can persist for up to two years post infection (Rahmati et al., 2023). It is unclear if symptoms may improve over time. Ferucci et al. (2022) noted improvement in tests of attention, processing speed and verbal memory at one year after infection compared to five months post infection however there was no significant change in the visuospatial domain. In contrast, a recent systematic review has suggested no significant change in neuropsychological assessment scores at two years compared with one year post infection (Rahmati et al., 2023).

Studies have investigated possible predictors of the development of cognitive impairment. Those examining disease severity have found inconsistent results, with some finding severity does predict impairment (Piloto et al., 2021; Garcia-Sanchez et al., 2022; Cecchetti et al., 2022; Hampshire et al., 2022; Becker et al., 2023; Mar Ariza et al., 2023; Taquet et al., 2023) whilst other studies do not (Hadad et al., 2022; Miskowiak et al., 2021; Premraj et al., 2022). More recently, Wahlgren et al. (2023) conducted a two year follow up of hospitalised patients with COVID-19 in Sweden comparing cognitive symptoms of those who required ICU and those who did not. There did not appear to be any significant difference between the two groups, though there was a significant improvement seen with attention difficulties from 4 months to 24 months post infection in the non-ICU group. Similarly, no difference in cognitive performance has been found between hospitalised and non-hospitalised groups when compared with healthy controls and their expected performance on a number of cognitive tests (Miskowiak et al., 2023). Interestingly, hospitalised and non-hospitalised patients also showed no significant differences in subjective cognitive difficulties.

Evidence therefore suggests a wide range of persisting cognitive difficulties, which do not always relate to disease severity, and which alongside other long COVID symptoms, can significantly impact QoL. Despite global policy and clinical guidelines emphasising a multidisciplinary approach, including physical, psychiatric and psychological aspects in managing long COVID (National Institute for Health and Care Excellence (NICE), 2020), this is often implemented inconsistently across different regions and practices. It is essential to gain a deeper understanding of the underlying mechanisms of long COVID as well as lived experiences of those affected to develop appropriate treatment pathways.

Thus far, few studies have investigated the experience of cognitive difficulties, how people make sense of these difficulties and their impact on daily life. While this paper was in preparation, Callan et al. (2022) published a paper exploring the experience of “brain fog” after COVID-19. They recruited 50 participants and used focus groups to further understand their lived experience of brain fog. Key findings included common impairments in executive function, attention, memory, and language, often emerging weeks to months after the acute illness with gradual improvements over the course of several months. Participants also described an impact on personal and professional roles in their daily lives and challenges in navigating the healthcare system. Recruitment was largely through online support groups for those experiencing persistent cognitive symptoms (Callan et al., 2022), thus suggesting that participants were likely to be more severely affected and may have experienced higher levels of distress. They also had a large sample size of 50, meaning it was not possible to understand each individual’s experience in depth. The aim of the present study was also to explore participants’ experiences of living with cognitive difficulties persisting beyond at least 12 weeks of initial COVID-19 infection. However, the current study explored the experiences of a smaller group of participants to gain an in-depth understanding of their experiences. It recruited participants primarily through social media platforms and online support groups via Facebook.

The present study aimed to better understand the longevity of symptoms and how they had a functional impact on people’s lives. It also sought to understand individuals’ views on healthcare regarding long COVID and what demonstrated usefulness or lack thereof during recovery. An improved understanding of the experience and impact of cognitive difficulties will be valuable to clinical psychologists and neuropsychologists and may have implications for supporting this population and improving clinical care. The main research question was: "What is the experience of living with persistent cognitive difficulties due to COVID-19?”

Methods

Design

A qualitative design was adopted for this study, with data collected by semi-structured interview. Braun and Clarke's (2019) reflexive thematic analysis (RTA) was used to explore experiences of people affected by cognitive difficulties and identify patterns across the data. RTA is used within a range of theoretical frameworks to generate themes across a dataset addressing a specific research question. RTA emphasizes the role of reflexivity in the process in which the researchers' subjective interpretations of the data are at the core of data analysis (Braun & Clarke, 2019).

RTA is not grounded in a particular philosophy; rather it is up to the researcher to consider which ontological and epistemological assumptions best align with their research (Braun & Clarke, 2021). RTA recognises that meaning is actively constructed across the data through process of analysis (Braun & Clarke, 2017). The researcher has drawn on elements of critical realism, which views knowledge as socially influenced but maintains that it reflects an independent reality that can only be partially accessed. The ontological position in this study occupies a critical realist stance, seeking to understand complex phenomena through a contextualist epistemological approach.

Two experts by experience who identified as having long COVID were consulted regarding the recruitment and design to ensure relevance and that relevant ethical and practical issues were adequately addressed.

Ethical Approval

Ethical approval for the study was granted by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University (see Section 4).

Participants

Potential participants self-reported that they had been infected with COVID-19 and were subsequently experiencing cognitive difficulties persisting beyond 12 weeks from the initial infection. The cognitive difficulties must have been ongoing at the time of interview and had some sort of functional impact on their lives (ascertained by self-report). People who had co-morbid conditions or cognitive difficulties prior to contracting COVID-19 were excluded to reduce the likelihood of other issues accounting for their cognitive symptoms. Eligible participants were between the ages of 18 and 65.

The study was advertised on three social media platforms: Twitter, Facebook and Instagram. 18 people expressed their interest in the study and contacted the researcher via Direct Message or email. Two people did not meet the eligibility criteria as they had long term health conditions prior to contracting COVID-19. Three people did not follow up after the initial response. Thirteen people decided to proceed with the study of whom one was recruited via Twitter, one via word of mouth, two via Facebook and nine via Instagram. All participants were given pseudonyms to protect their anonymity.

The ideal sample size for TA has been debated in the literature. Braun and Clarke (2013) argue the focus should be on adequately addressing the research question emphasizing quality over quantity. A sample size of 12-15 was used in this study considering the in-depth approach for analysis, focused research question and sample specificity (Malterud et al., 2016).

The sample consisted of nine women and four men, aged between 25 and 64 years old. Time since infection varied between 8 months and 34 months with the majority of participants experiencing cognitive difficulties for 6 months to 2 years. Two people were working full-time, 1 part-time, 1 was a student, 1 was self-employed and 2 were on long-term sick leave. The remaining six participants were unemployed as a result of long COVID symptoms. All participants experienced various cognitive difficulties which included brain fog, language difficulties, memory and concentration problems. Four participants were hospitalised with COVID-19 whilst the remaining 9 participants experienced COVID-19 in the community. Physical symptoms during the acute stage varied amongst the participants with many of them reporting shortness of breath, fever, and a persistent cough. Details are given in table 2.2.

[Insert Table 2.2 here]

Procedure

The study was advertised on social media and prospective participants expressed interest by contacting the researcher via email or direct message on Instagram. They were then emailed a participant information sheet and consent form (see ethics section) and a date and time was arranged for interview. Participants were informed that they did not need to sign the consent form as audio consent would be obtained on the day of the interview. Participants were asked to ensure they were in a private, safe and comfortable space for the duration of their interview.

Data collection

Twelve semi-structured video interviews were conducted over Microsoft Teams and one via telephone. The interviews ranged in length from 47 to 98 minutes. The semi structured nature of the interviews allowed for questions based on the participants' responses thereby focusing on important areas which arose for them. Demographic information such as age, gender, ethnicity, living situation, partnership status, occupation status, time since infection and duration of and type of cognitive difficulties were also gathered.

Data analysis

The interviews were transcribed verbatim by the researcher (Braun & Clarke, 2013). The six-step process outlined by Braun & Clarke (2019) was used as a guide for data analysis. Due to the recursive process of RTA, there was movement back and forth between different phases to facilitate a robust analysis. Each transcript was read and re-read to become further familiar with its contents. During this phase, notes were taken to capture initial insights and impressions in relation to individual transcripts and the overall research question. All transcripts were then coded to highlight important features of the data and were often revisited and changed if appropriate to capture more nuanced ideas (Appendix 2-B). Semantic and latent codes were constructed to capture both surface and implicit meanings in the data. Once rich and complex codes of the data were generated, they were then collated and further examined to develop broader patterns of meaning and generate initial themes (Appendix 2-C). Further analysis involved refining the themes against the codes and dataset as a whole, ensuring they captured meaningful stories relevant to the research question, and constructing an analytic narrative.

Reflexivity

A reflexive stance was maintained throughout the process of this project, recognising researcher subjectivity as an asset and a crucial and ongoing part of RTA (Braun & Clarke, 2023). The researcher is a female trainee clinical psychologist with a keen interest in cognitive neuroscience and health conditions which has significantly shaped her perspective. Previous experience in a neuropsychology placement where the researcher supported adults with cognitive difficulties following acquired brain injuries such as stroke and mild traumatic brain injury (TBI) has influenced her approach and heightened her research interests in understanding cognitive functioning within different health contexts.

Findings

Four main themes were constructed from the data: 1) Dealing with loss: stolen identity and a sense of injustice, 2) Internal turmoil: unpredictability and emotional distress, 3) Isolation and misunderstanding vs empowerment by social connection, 4) Navigating healthcare: the good, the bad and the uncertain.

Theme 1 - Dealing with loss: stolen identity and a sense of injustice

All 13 participants discussed a loss of identity whereby both the physical and cognitive symptoms of long COVID meant that they no longer felt like themselves. Participants described how different roles in their life were affected, both personal (subtheme 1) and professional (subtheme 2) and they grieved the loss of their former selves (subtheme 3). This removal of their identities by something they did not choose created a profound sense of injustice. Participants also highlighted the panic to gain control over what was happening, however, their normal coping strategies were ineffective.

Subtheme 1: Personal Identity

When describing their lives living with the cognitive difficulties of long COVID, participants expressed a profound sense of loss and injustice regarding the 'taking away' of their former identity: *'I had a perfectly enriched, happy life with everything we ever could have wanted. I was healthy and happy. And now sometimes I can barely string a sentence together and I can't look after myself. It's all just been taken away.'* (Megan). Many described feeling as though their identity was forcibly taken, leaving them with no control over the matter. This loss was further intensified by the feeling of injustice; despite not being at fault for their circumstances, participants had to grapple with the consequences: *'Why me? So many people recovered so why am I struggling?'* (Josie). Some participants spoke about the difficulty in going through this transition of losing their identity and having to form a new one: *'I was having such a difficult time letting go of my identity and I was getting really depressed by everything, it was devastating.'* (Luana).

Participants described that their usual strategies of dealing with illness such as 'pushing through' did not necessarily work. This resulted in a significant change to their sense of self: *'As a boxer, you know you've got to perform under pressure. And I've always been able to do that. And then when you can't, that was like the beginning of the deconstruction of my identity.'* (Michael). The desire to control symptoms was evident among participants, but their efforts often inadvertently exacerbated their struggles, adding to their feelings of frustration and powerlessness: *'I wanted to just push through it. In the past when I've been sick, I've continued to go about my normal routine* *and eventually it goes away. But this just got worse and worse. I couldn't understand what I was doing wrong. I felt helpless.'* (Michael).

Subtheme 2: Professional Identity

The loss of identity also extended into professional roles. Participants described an inability to remember things and navigate cognitive challenges, leaving them feeling overwhelmed when trying to meet the demands of their workplace. Participants described struggles to keep up with multiple tasks and suffered from "mind blanks" and "brain fog" causing confusion and distress: *'I stopped working completely in January […], I was sitting in quite a big meeting with a lot of people, [...]. There was a heated discussion and all of a sudden my brain just shut down. I couldn't understand what anyone was saying to me, it's like they were speaking a different language.'* (Josie)

The lack of awareness and understanding of cognitive difficulties by employers further exacerbated feelings of isolation as individuals came to terms with the fact that their jobs no longer felt feasible. Many were forced to make the difficult decision to either stop working altogether or seek alternative employment. One participant discussed how she had been in her line of work for many years but felt unable to continue. She described that her identity was attached to her job and leaving her employment meant leaving behind her identity: *'I needed to find myself a new identity because my identity got taken away when I couldn't do the work that I've been doing. I've been doing my work for close to 10 years and I worked very hard. I really liked it. But I needed to redefine myself.'* (Josie).

Subtheme 3: Grieving a former self

Central to the experiences shared by participants was a deep sense of grief for their pre-illness selves. The process of adapting to a new identity, one marked by limitations and adjustments, was likened to a mourning process. The grief was not just for the loss of abilities but also for the loss of a sense of self that was intimately tied to those capabilities: *'I've been through a massive grieving* *experience because I had to. They say you have to grieve for the life you had and the person you used to be.'* (Catherine). However, amidst the narratives of loss and struggle, there were also stories of resilience and adaptation. For some participants, while they acknowledged the sense of having their former identity taken away, the impact was mitigated by their ability to cope and adapt. Despite facing challenges, these individuals were able to engage in meaningful activities and maintain a sense of agency over their lives, though it took a long time to reach this stage: *'There was a point where I was grieving my old self but I'm at peace with it now. I'm at a place where I want to help other people'.* (Michael).

Theme 2: Internal turmoil – unpredictability and emotional distress

This theme captures the internal turmoil arising from the unpredictable nature of long COVID. It encompasses experiences of unpredictability across three levels. Subtheme 1 describes unpredictability with the broader nature of the condition. Subtheme 2 highlights inconsistencies in the symptoms experienced by participants day to day as well as the impact of physical health on cognitive function (and vice versa). Subtheme 3 discusses the unpredictability of cognitive difficulties presenting moment to moment. At all levels, this unpredictability was associated with emotional distress.

Subtheme 1: "Russian Roulette" – the unpredictable nature of long COVID

Participants spoke about differences in symptoms across individuals, and the difficulties of not being able to foresee that they would develop long COVID. Participants described the unpredictability regarding who would be affected and to what extent. They described a lack of control given the sudden onset of both physical and cognitive symptoms. Three participants spoke about the sudden onset of worsening symptoms without warning or predictability, which only added to the confusion and distress surrounding long COVID: *'I worked at a [school] as a teacher, so everyone had it. It was doing the rounds. But I was one of the first employees that got it and nobody* *else got it the way I did. It felt very much like a Russian roulette kind of thing. Who's getting it bad and who's not, you know?'* (Josie). Moreover, the lack of knowledge about how to prevent or mitigate the worsening symptoms left individuals feeling powerless and at the mercy of the illness: *'My dad had COVID three times and he was fine, but I got it once and have struggled ever since. You just don't know who is going to get it and there's no knowledge of how to prevent it.' (Samir)*

This sense of helplessness was exacerbated by the realisation that the condition is unpredictable – something that is bestowed upon them, with no control or agency over its onset or progression. One participant described that they felt it was their fault that they had experienced symptoms of long COVID which left them feeling helpless and distressed.

Subtheme 2: Day to day unpredictability

The unpredictable nature of symptoms was also evident in day-to-day life. Participants described the variability of physical symptoms, making it difficult to plan their schedules as symptoms were different on different days. As well as this, participants described how having to constantly monitor their well-being became a necessity as they were forced to plan their activities in a way that wouldn't leave them exhausted, due to the impact of fatigue. Some participants talked about the importance of pacing to manage fatigue however this need for self-regulation added another layer of distress to another already burdensome situation: *'You're constantly pacing your activities, weighing things up. Is that worth it? It's exhausting. I know going out for lunch isn't just going out for an hour or so. It's actually going out for an hour and being in bed for the next three days.' (Luana)*

Participants also described the unpredictable nature of the cognitive difficulties, with some days being worse than others, further challenging their ability to navigate daily life with consistency and confidence. Some participants described that when they were more fatigued or stressed, this exacerbated the cognitive difficulties and made it harder to think clearly. Others explained that it felt quite random – some weeks they would feel fatigued and others they would notice more of the cognitive symptoms: *'It fluctuates. The symptoms shift a little bit from day to day or week to week. One week I'm fatigued and the next my brain keeps on forgetting things. It's very unpredictable.' (Josie).*

The fluctuation of physical and cognitive symptoms and the unpredictability of not knowing what symptoms they would experience when, impacted emotional wellbeing. Participants described juggling a multitude of emotions ranging from frustration and despair to hope and determination – yet another thing participants had to learn to manage: *'There's a huge kind of emotional dysregulation that comes with it. Trying to get your point across makes you exhausted, tearful and tired. The emotional energy is absolutely exhausting.' (Ashleigh).*

Some participants described the unpredictability of their future and how this led to deep emotional distress: '*I think that I have gone through the darkest period of my life after my illness. I'm not sure whether this is because of an unpredictable future or not having a clear perspective of recovery.'* (Samir).

Subtheme 3: Moment to moment unpredictability

Participants described a sense of unpredictability in their daily interactions. Many participants discussed the lack of consistency in terms of how they were presenting cognitively and described often catching themselves off guard when noticing these difficulties in interactions: *'I could feel myself struggling to find the right words. I thought to myself you know what you want to say so why can't you just say it?'* (Josie). Another participant described noticing herself struggling to speak coherently and trying to find ways to manage it in the moment. This led to emotional distress and a deep sense of shame which impacted on her self-esteem and confidence: *'I'm tripping over myself whilst I'm speaking... it just comes out of nowhere …I'll sort of try to shake myself out of it and just say, like, OK, speak slowly. But it's so embarrassing that you feel you don't want to talk.'* (Diana).

This unpredictability of their cognitive symptoms left them feeling vulnerable and anxious about how they may behave in future interactions. This ongoing uncertainty eroded confidence in their abilities and undermined self-esteem, as individuals struggled to trust their own abilities: *‘When I’m reading my notes back there's words in there and I'm thinking I didn't put that word in there. It’s really quite scary. It's actually a combination of scary and embarrassing.’* (Diana).

Theme 3 - Isolation and misunderstanding vs empowerment by social connection

This theme describes the contrasting experiences of social support. Individuals felt isolated as a result of misunderstandings about long COVID (subtheme 1). Where connection was lacking in their immediate social network, people felt empowered through connections via social media with others that were going through similar difficulties (subtheme 2).

Subtheme 1: Struggle for recognition and validation

Participants struggled to name the difficulties and found it particularly challenging trying to explain it to others. They often resorted to metaphors to try to explain the nature of their cognitive difficulties: *‘It's just that my brain is not working as fast as it used to. It feels like we're stuck in 3rd gear when we've got 6. That’s how I explain it to other people - that my brain is nowhere near at full performance'.* (Michael).

Despite these attempts to explain their difficulties, some people still struggled to understand. The inability of others to perceive the cognitive struggles added a layer of isolation to an already isolating experience, exacerbating feelings of frustration, alienation, and invalidation: *'It was the lack of understanding and the community feeling because you are so alone with it all and then you don't get that understanding. It really affects your mental health.'* (Megan).

Many participants were met with disbelief from family and friends, many of whom did not understand or acknowledge the cognitive difficulties associated with long COVID, leading to further frustration: *‘They think I’m faking it. Because, I mean, I can go out one day and be fine, but nobody* *sees the preparation before and after and how I really am after. Nobody sees that I can't do anything for the next few days.'* (Maria). This led to further frustration as the cognitive difficulties were not readily apparent to others, leaving room for suspicion and judgement around whether they truly exist or not: *'It's the judgments of other people when you are saying you have long COVID and brain fog because they have had COVID multiple times and they were fine. It's invisible. After all, if you see me in the street you will think I'm normal, right?'* (Josie).

Some individuals described difficulties in their personal relationships with friends and family or romantic partners as a result of their long COVID symptoms. They felt that people in their social network did not always understand the challenges they were dealing with. Many participants noticed changes within their social relationship dynamics particularly due to their cognitive difficulties. Michael described how his friends noticed that he was no longer engaging in friendly banter and struggled to understand why: *'I've noticed a few times when I've been with friends that it's not been as easy to get involved in those conversations that we used to have. I just, I haven't got it in me anymore. If I'm with my mates and it's like lads like banter, I just haven't got comebacks anymore and I just haven't got the mental fortitude to be involved in that sort of back and forth all the time and they just didn't understand that.'* (Michael). Megan described how her friends stopped inviting her to social gatherings because they assumed she wouldn't be able to keep up: *'After a while they stopped inviting me. I don't get invited to things anymore.' (Megan)*.

Participants also found that others often made comparisons and assumptions based on their own experiences of COVID-19. As the long-term complications varied greatly from person to person, the idea that an acute illness like COVID-19 could turn into a long-term condition was difficult to grasp - because for many it was a short-term illness: *'She was just like, 'well, you look fine. You've recovered from COVID'. We had both been ill at the same time. She got better. And I got progressively worse. And she just didn't get it.' (Luana)*

Subtheme 2: The importance of social connection

Despite strained relationships in real life, many individuals found support from online groups through linking with like-minded individuals on various social media platforms. It allowed them to find strength, support and understanding through new online communities that they had formed. Connecting with others who shared similar experiences or offered empathy and validation provided individuals facing challenges from long COVID with a sense of belonging and empowerment: *'Speaking to other people in long COVID community really helped, that's a huge one, both to get fellow support, but also hear what worked for them and what did not work for them.'* (Nathan).

One participant described finding solace in these communities, knowing they were not alone in their struggles, and together, they created spaces where everyone's experiences were valued and validated: *'It had a huge impact on me and also one of them has become one of my closest friend even though we live in different ends of the world. We speak almost every day and support each other through it because even though we don't have long COVID the same way, we still have similar symptoms.'* (Luana).

Theme 4 - Navigating healthcare: the good, the bad and the uncertain

This theme relates to participants' experiences of navigating the healthcare system including feelings of uncertainty and conversely more positive experiences (subtheme 1). It also captures the need to become their own experts when healthcare staff were unable to support (subtheme 2).

Subtheme 1: Seeking Support

Alongside the cognitive difficulties, participants described an overwhelming challenge in trying to obtain support for their symptoms from their healthcare providers. The strong sense of uncertainty surrounding their condition left participants with a lack of clarity and direction. Participants described feeling adrift in uncharted territory, with healthcare staff often unable to provide guidance due to limited understanding of the novel condition: *'The GPs have been rubbish and the follow up has been rubbish because nobody just no one knows what to do and what's going* *on.'* (Megan). At times, cognitive difficulties were mistaken for psychological symptoms. Samir described that when he sought support for brain fog, healthcare providers attributed it to depression: *'Unfortunately, even the specialist suspected [the cognitive difficulties] may be depression. They think it's a psychological issue, but it isn't.'* (Samir).

Absence of clear guidance on long COVID management, particularly cognitive symptoms, led to conflicting advice and treatments. This inconsistency, coupled with a lack of professional consensus, eroded trust between participants and healthcare staff and complicated recovery. Patients struggled with physical and cognitive challenges as well as having to navigate an ambiguous healthcare landscape, affecting their understanding, treatment decisions, and outlook on the future.

Conversely, participants had a positive experience if they found a healthcare practitioner who a) acknowledged long COVID, b) had an understanding of cognitive difficulties and c) were willing to listen in an open and curious way. It often started with GPs as they were the first port of call for many participants. A GP that understood long COVID and its cognitive difficulties, and believed participants' experiences, contributed to increased access to resources and a better experience overall, though this was rare.

Three participants reported seeing a psychological therapist to help them with their difficulties which was overall a positive experience though did not support the cognitive difficulties per se. One participant, when asked whether the cognitive difficulties had become better or worse in response to therapy reported: *'I think what's gotten better is my acceptance and how I treat myself. I'm a lot nicer to myself now.'* (Tara).

Subtheme 2: Becoming their own expert

Having felt isolated in navigating their recovery and left to battle uncertainty, many participants found that they had no choice but to become their own experts: *'You've got to do it all yourself, you know, there was really no help for anything.' (Nathan)*. This developed from the frustration of not being taken seriously or not having their experiences validated by those in positions of authority or support. In the absence of understanding and support from traditional sources, individuals were left with no choice but to educate themselves about their condition, research potential coping strategies, and advocate for their own needs within the healthcare system. Some participants described feeling betrayed and abandoned by the very institutions that were meant to provide care and support: *'I feel let down by the world I feel let down by governments. By doctors, friends and family and everyone around me, basically.'* (Catherine).

Furthermore, some participants discussed the failings of the government to address systemic issues within the healthcare system which again left individuals to navigate their health journeys alone. Two participants mentioned the need for systemic change and greater empathy within healthcare and support networks.

Discussion

This project aimed to understand the experience of persistent cognitive difficulties following an infection of COVID-19. Participants described a loss of identity, internal turmoil, isolation and misunderstanding and difficulties navigating healthcare.

In the first theme, participants discussed the loss of their identity. They referred to their pre-COVID selves as a 'former self' in relation to both physical and cognitive difficulties. Charmaz (1999) described how suffering caused by chronic illness often results in a changed self. A large part of suffering is the erosion of self-identity without the emergence of a new one, resulting in a constrained lifestyle, feelings of social isolation and societal marginalisation. This is evident in this study as participants described the breakdown of their former identities and the disruption that long COVID created in their lives, with many experiencing social isolation and marginalisation. This type of identity disruption is also seen in individuals with traumatic brain injury (TBI). Although vastly different in many ways, long COVID and TBI can both cause persistent cognitive impairment, chronic fatigue, and emotional disturbances, significantly impacting an individual's QoL. Nochi (1998) identified a key discourse in survivors of TBI around 'loss of self' through memory loss, comparison of pre and post injury selves and how others perceive them. Gracey and Ownsworth (2012) suggest that the onset of a brain injury and the ongoing functional impacts, can lead to significant changes in daily routines, roles and plans for the future. This was evident amongst the participants who described making difficult decisions to leave their long-term careers as they felt unable to keep up with the requirements of the role.

Research has suggested that cognitive, emotional and social changes following a brain injury can also lead to the ‘unmaking and remaking’ of identity (Kim et al., 2019). Similarly, Charmaz’s (1995) adaptation theory describes how chronic illness requires ongoing adaptation to manage its physical, emotional, and social consequences. While chronic illness often leads to acceptance of non-recovery, long COVID's uncertain prognosis complicates this process. Nevertheless, this study found that many participants began adapting to a new self, incorporating their persistent symptoms as a permanent aspect of their identities (theme 1).

The unpredictability of long COVID symptoms emerged as a significant theme, aligning with Mishel's (1988; 1990) Uncertainty in Illness Theory (UIT). UIT posits that uncertainty stems from the inability to determine the meaning of illness-related events, impacting an individuals’ ability to adapt to the illness. Participants' experiences of unpredictable symptoms, corresponded to UIT's 'stimuli frame' concept, disrupting daily life and future planning, thus increasing distress (theme 2). The mismatch between expected acute COVID-19 recovery and persistent long COVID symptoms described in theme 2 ('event incongruence') further amplified uncertainty. Moreover, Mishel emphasised cognitive capacity as crucial in appraising uncertainty. This aspect is particularly relevant for individuals with long COVID, as ongoing cognitive difficulties and distress may impair their ability to make sense of the illness, potentially exacerbating uncertainty and emotional distress.

Stigma was evident in theme 3 when participants struggled to socialise with friends as they did not understand or acknowledge the cognitive difficulties. Goffman's (1968) concept of spoiled identity effectively describes the social stigma and discrimination that individuals may experience due to certain characteristics that are different from societal norms or expectations. Scambler and Hopkins (1986) introduced a distinction between enacted and felt stigma. Enacted stigma refers to the discrimination or marginalisation placed on individuals by others. For many participants, this was experienced at work. Michael felt that he could no longer stay in his corporate job due to the emphasis on high productivity, leading him to consider resigning. For others, this was experienced in their friendships. Megan described how her friends no longer invited her to social gathering as they assumed she would not be able to keep up. As the difficulties cannot be seen, the symptoms that individuals describe can be ignored, belittled or dismissed (Charmaz, 2016). Individuals with invisible disabilities may therefore be hesitant in disclosing their difficulties, through fear of being invalidated or discredited (Charmaz, 2016).

Felt stigma on the other hand refers to the internalised feelings of shame or self-blame associated with a condition often leading to negative self-concepts and low self-esteem. Diana described how she felt embarrassed because she was unable to hold complex conversations with her coworkers despite having previously been able to do this as second nature, resulting in feelings of embarrassment and shame (theme 2). The findings of the present study were consistent with Callan et al., (2022) in experiences of shame and stigma, however the current study revealed distinct nuances such as participants' heightened feelings of embarrassment and humiliation during interactions due to their cognitive difficulties.

Link and Phelan (2001) emphasised the role of stigma in shaping social determinants of health and argued that stigma influences access to healthcare, resources and social support. This was evident in this study (theme 4) as Charlotte described that she had to make multiple complaints to her healthcare provider before she was referred to a long COVID clinic as the initial descriptions of cognitive difficulties were minimised. This aspect of this stigma within healthcare professionals is commonly known as 'medical gaslighting'. Medical gaslighting refers to the dismissal or downplaying of patient symptoms without thorough evaluation and can often contribute to delays in diagnosis and access to treatment. The lack of understanding and validation of the COVID-related cognitive difficulties from healthcare staff left participants feeling unsupported in their journey when seeking medical treatment (theme 4). The novel nature of long COVID has led to limited understanding of its causes and long-term effects. Although new research is continuously emerging (Li et al., 2023), in the height of the pandemic the pathology and long-term effects of the virus remained unclear, leading to scepticism or dismissal of symptoms that did not appear to have a biological marker. This is commonly seen in other conditions such as functional neurological disorder (FND) and myalgic encephalomyelitis (ME) for which research and biological understanding have more recently emerged highlighting new physical understandings (Mavroudis et al., 2024; Sweetman et al., 2019).

Social connection played a crucial role in managing the impact of cognitive difficulties as many participants felt understood and supported by their new online networks (theme 3). The buffering hypothesis of social support (Cohen and Will, 1985) suggests that social support is a crucial factor in alleviating the adverse effects of stress on health and wellbeing by acting as a buffer against the negative impact of stressful life events. Supportive relationships such as friends and family or broader community relationships, can influence individuals’ perceptions of stress and their ability to cope effectively. Schafer (1992) described social support as being a resource for individuals to help them cope with a stressful issue. This is evident in the present study as participants described how important it was to make connections with other people with long COVID - even if their symptoms were entirely different.

Clinical Implications

Findings of the current study suggest cognitive difficulties in long COVID are important for health professionals to consider across a range of clinical settings. Given the general lack of understanding by healthcare providers, education for health professionals about the nature of cognitive impairments and their impact on individuals' lives is crucial in challenging misconceptions and reducing stigma, particularly as cognitive difficulties are ‘invisible’ and can be easily missed.

Clinical psychologists, particularly specialist neuropsychologists, are well positioned to implement this in services and drive systemic changes. Additionally, participants had specific suggestions about educational resources that could be helpful for both those with long COVID and family and friends (see table 1.3).

Neuropsychologically informed assessment and intervention in managing the cognitive difficulties is also needed. Neuropsychological tests are currently used in the assessment of cognitive difficulties in acquired brain injury (ABI) and other neurological conditions to provide information and guide intervention (Lezak, 2004). In addition to this, there has been evidence to suggest the effectiveness of cognitive rehabilitation including cognitive training and compensatory strategies in adults with mild traumatic brain injury and stroke (Johnson & Weinberg, 2023) and evidence to suggest that managing cognitive difficulties can help to reduce levels of distress (Tiersky et al., 2005). This is a useful consideration for individuals with long COVID as many participants identified the sudden onset and persistent nature of cognitive difficulties as one cause of distress. Specialist knowledge of neuropsychological rehabilitation is crucial to promote a holistic understanding of the role that cognitive rehabilitation strategies can play in psychological intervention; an understanding which may be missing in statutory mental health services. Moreover, adopting a neuropsychologically informed perspective can help to combat stigma and misunderstanding associated with invisible difficulties.

Part of a holistic approach to recovery also involves considering the emotional difficulties that individuals endure. Whilst there were practical impacts of the cognitive difficulties, participants also discussed impacts on their identity which for some was likened to a grieving process. In addition to this, long COVID was described as a complex phenomenon completely outside of people's control, which for some participants lead to a strong sense of chaos and confusion. Acceptance and commitment therapy (ACT) may be a useful approach in supporting individuals struggling with emotional and identity changes (Harris, 2006) and coping with unpredictability (Hayes et al., 2022). ACT is a mindfulness-based therapy which emphasises identifying one's own values and pursuing committed behavioural change in line with these values. It has become an increasingly popular approach in supporting people adjusting to long term conditions or disabilities, encouraging 'psychological flexibility' and enabling individuals to accept difficult thoughts and feelings while living in a meaningful way that aligns with their values. (Curvis & Methley, 2021).

Limitations and future research

As recruitment of participants was primarily through social media, it relied on participants being able to access the internet and indeed social media. This automatically excluded people that did not have access and that did not engage with social media and therefore missed those perspectives. Furthermore, the requirement for participants to be cognitively able to engage in interviews meant that the study will not have captured the experiences of individuals with more severe cognitive impairments as a result of long COVID.

Due to the small sample size, certain demographic factors such as ethnicity and geographic location (including those living in other countries) were not adequately represented. This limitation highlights the need for future research to deliberately target underrepresented groups to gain a more comprehensive understanding of their experiences. Although the study identified consistent experiences among participants, there were also unique narratives that could be explored further.

Intersectional theories highlight how medical gaslighting can intersect with gender, race, ethnicity, and other social identities (Berenstain, 2018; Crenshaw, 2019; Sebring, 2021). It is also useful to note that stigmatised identities can intersect (Link and Phelan, 2021), leading to unique experiences of stigma for individuals with multiple marginalised identities. Although there were hints of this throughout the data, further research is needed to truly understand the impact of stigma on different groups and the effects it has on health outcomes.

Moreover, it is widely understood that particular demographics were disproportionately impacted by COVID-19 (Rubini, 2023). Future research endeavours should prioritise investigating the experiences of these communities to ensure their perspectives are heard to gain a more nuanced understanding of their needs, ultimately leading to more inclusive and effective interventions and policies. Finally, a crucial direction for future research is to investigate the impact of cognitive rehabilitation and indeed psychological therapy with people with cognitive difficulties as a result of COVID-19.

Conclusion

This study explored 13 participants' experiences of persistent cognitive difficulties following COVID-19. Participants described a significant impact on their identities, battling unpredictability and emotional distress, difficulties navigating the healthcare system as well as empowerment by social connection. These findings have implications for support offered by healthcare professionals to people living with these difficulties. Future research exploring the experience of specific groups and the impact of cognitive rehabilitation and psychological therapy would be beneficial to understand how to better tailor support for individuals living with cognitive difficulties after COVID-19.

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Table 1.1 Participants' Demographic Details

Pseudonym	Gender	Age	Time Since Initial Infection	Duration of Cognitive Symptoms	Location	Ethnic Group	Relationship Status	Employment Status
Diana	Female	52	32 months	30 months	UK	Black Caribbean	Married	Employed
Maria	Female	25	11 months	10 months	UK	White other	Married	Student
Chris	Male	45	23 months	22 months	Ireland	White other	Married	Unemployed
Violet	Female	37	10 months	6 months	UK	White other	Co-habiting	Employed
Luana	Female	38	8 months	7 months	UK	White British	Single	Employed
Tara	Female	38	24 months	23 months	UK	Kurdish	Married	Unemployed
Michael	Male	35	27 months	26 months	UK	White British	Single	Employed
Megan	Female	31	27 months	26 months	UK	White British	Co-habiting	Unemployed
Charlotte	Female	56	25 months	23 months	UK	Mixed heritage	Single	Unemployed
Nathan	Male	64	34 months	33 months	UK	White British	Married	Self-employed
Ashleigh	Female	34	24 months	21 months	UK	White British	Single	Unemployed
Josie	Female	37	8 months	6 months	Netherlands	White other	Single	Long term sick
Samir	Male	43	27 months	26 months	Iran	Persian	Married	Unemployed

Table 1.2 Participants' Acute Physical and Ongoing Cognitive Symptoms

Pseudonym	Acute Physical Symptoms	Ongoing Cognitive Symptoms
Diana	High temperature, low blood pressure, low oxygen, difficulty breathing, loss of appetite, taste and smell	Mixing words when speaking, difficulties with short-term memory, forgetting driving routes, word finding difficulties
Maria	High temperature, shortness of breath, vomiting, headaches, body aches, persistent cough, fatigue	Short term memory loss, language and speaking difficulties in mother tongue, forgetfulness
Chris	Fatigue, high temperature, headache, breathing difficulty	Difficulties driving, concentration difficulties, difficulty with basic sums, spelling difficulties, mind blanks, brain fog, word finding difficulties
Violet	Loss sense of taste and smell, persistent cough, cold, mild fever, muscle weakness, brain fog, headaches, ear infection	Difficulties with short term memory, difficulty concentrating, word finding difficulties, problems with decision making
Luana	Flu like symptoms, high temperature, cough, cold, fatigue, sore throat, body aches, migraines	Brain fog, difficulty concentrating, difficulties with long term memory
Tara	High temperature, breathing difficulties, body aches, fatigue, chest pains	Difficulty concentrating, difficulty organising thoughts and planning day, short term memory loss, problems with decision making
Michael	Flu, gastrointestinal symptoms, numbness in fingers, headaches	Brain fog, forgetfulness, difficulty concentrating, difficulties with hand eye co-ordination, language difficulties, word finding difficulties, difficulty organising thoughts, mind blanks, decision making problems
Megan	High temperature, cough, breathlessness, low blood pressure	Attention difficulties, memory difficulties, brain fog, difficulties with attention/concentration, word finding difficulties, forgotten how to read music and play chords
Charlotte	High temperature, cough, shortness of breath	Brain fog, word finding difficulties, problems with decision making
Nathan	Mild flu, headaches, body cramps	Difficulties with short term memory, word finding difficulties, difficulties with attention/concentration, difficulty organising/planning
Ashleigh	Loss of taste and smell, lack of energy, fatigue, cough, temperature	Short term memory difficulties, word finding difficulties, mind blank, losing train of thought, attributing wrong words to objects
Josie	High temperature, sore throat, cold, bodily pain, shortness of breath, tight chest	Short term memory loss, brain fog, difficulties with attention and concentration, difficulty planning day, difficulty understanding instructions
Samir	High temperature, cough, aches and pains, shivers, tight chest, nausea	Difficulties with attention/concentration, decision making problems, short term memory loss, confusion, brain fog

Table 1.3 Participant Recommendations

Participants made a number of practical recommendations for education resources which they thought would be helpful for people struggling with long COVID and their friends and families. The recommendations are detailed in the table below.

Recommendations
Readily available information regarding neurocognitive symptoms to raise awareness
Brochures describing the types of neurocognitive difficulties that could be expected
Stories from patients of different genders, ages and ethnicities on NHS websites describing lived experience of cognitive difficulties following COVID-19
Guidance towards relevant literature
One page easy to read summary that could be given to friends and family to increase awareness and understanding
Resources detailing the link between sleep stress and anxiety and cognitive difficulties

Appendix 2-A: Submission guidelines: Neuropsychological Rehabilitation

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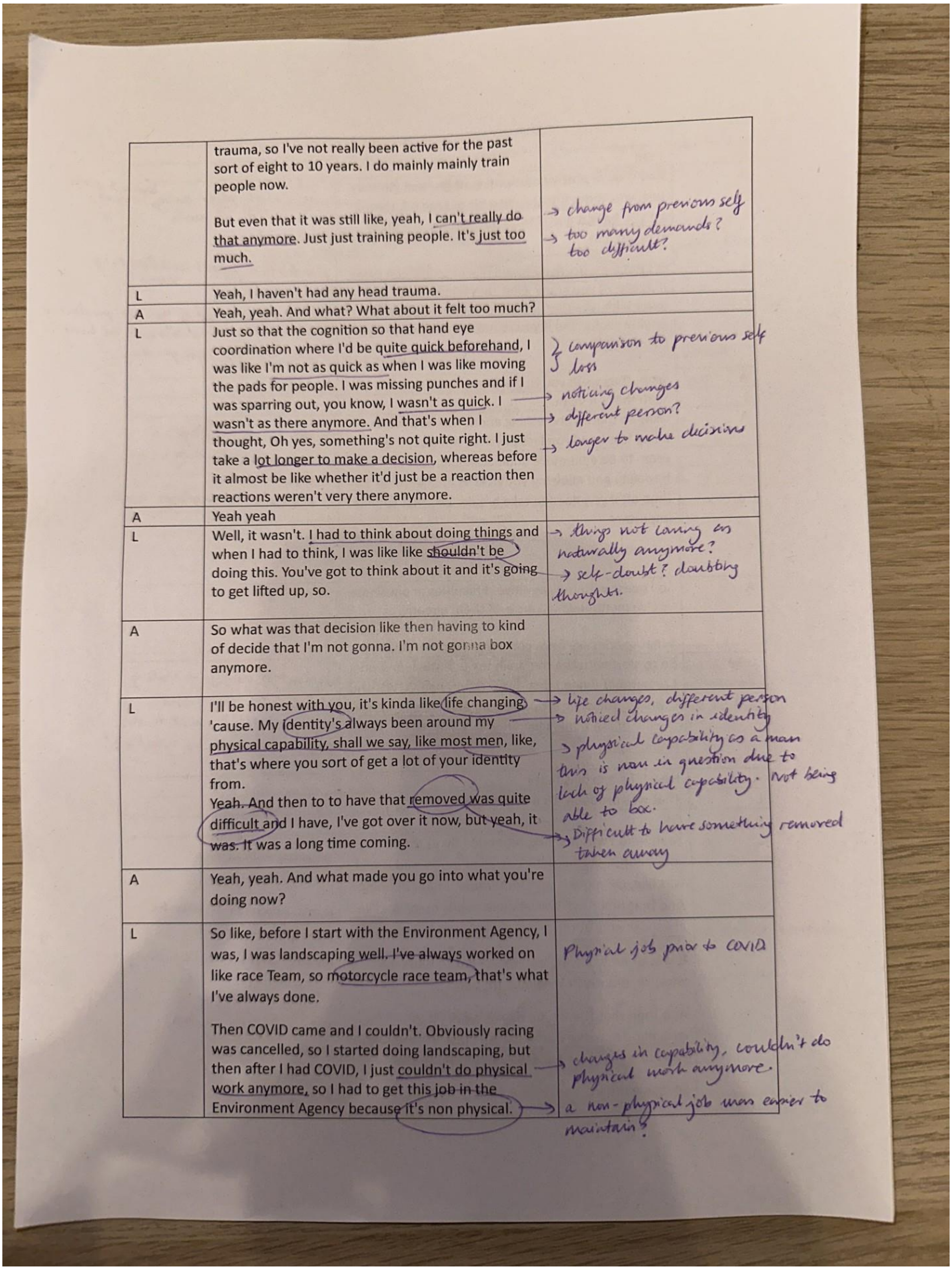
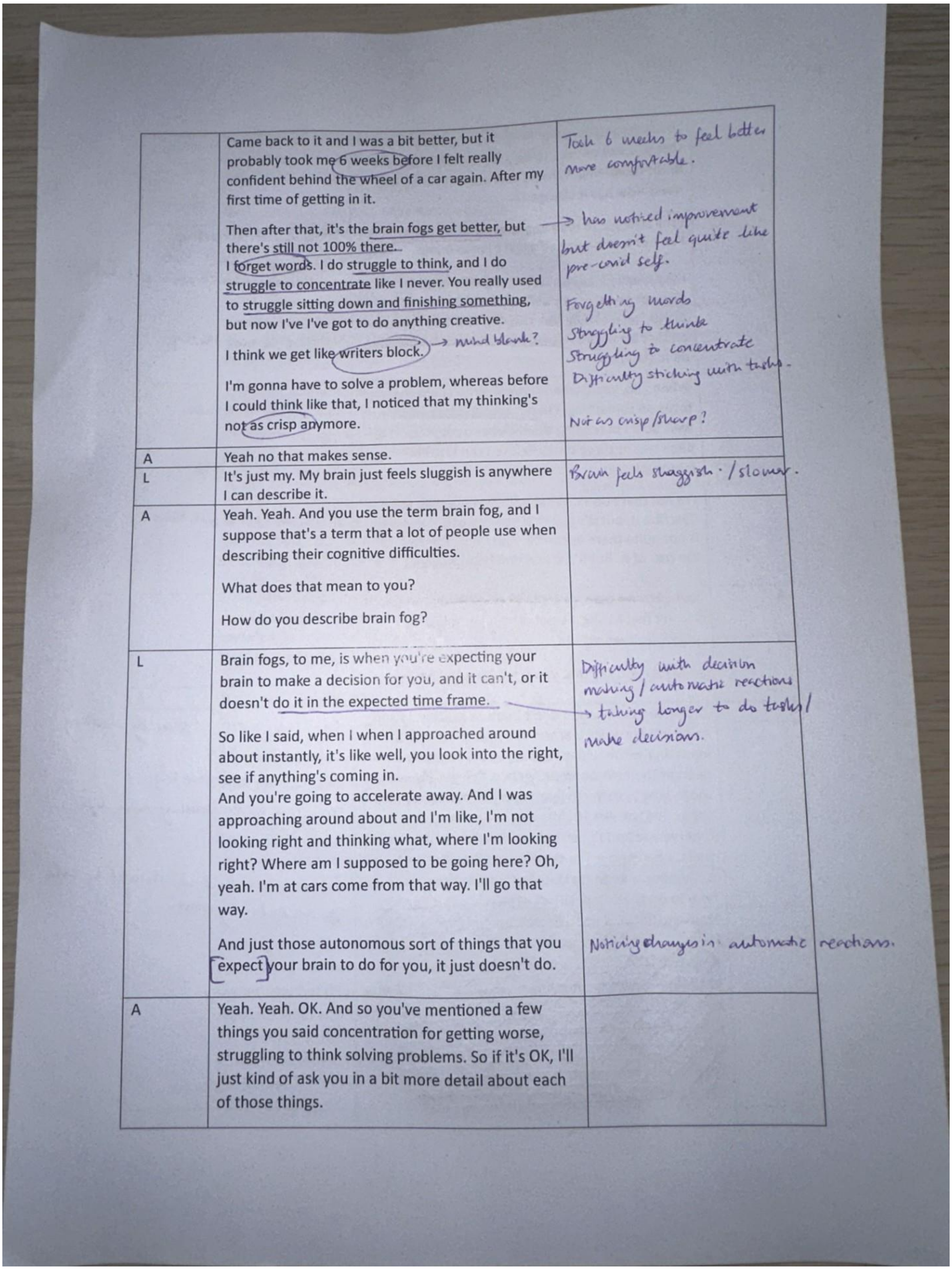
Appendix 2-B: Examples of coded extract for one participant



	trauma, so I've not really been active for the past sort of eight to 10 years. I do mainly mainly train people now. But even that it was still like, yeah, I can't really do that anymore. Just just training people. It's just too much.	→ change from previous self → too many demands? too difficult?
L	Yeah, I haven't had any head trauma.	
A	Yeah, yeah. And what? What about it felt too much?	
L	Just so that the cognition so that hand eye coordination where I'd be quite quick beforehand, I was like I'm not as quick as when I was like moving the pads for people. I was missing punches and if I was sparring out, you know, I wasn't as quick. I wasn't as there anymore. And that's when I thought, Oh yes, something's not quite right. I just take a lot longer to make a decision, whereas before it almost be like whether it'd just be a reaction then reactions weren't very there anymore.	} comparison to previous self loss → noticing changes → different person? → longer to make decisions
A	Yeah yeah	
L	Well, it wasn't. I had to think about doing things and when I had to think, I was like like shouldn't be doing this. You've got to think about it and it's going to get lifted up, so.	→ things not coming as naturally anymore? → self-doubt? doubting thoughts.
A	So what was that decision like then having to kind of decide that I'm not gonna. I'm not gonna box anymore.	
L	I'll be honest with you, it's kinda like life changing 'cause. My identity's always been around my physical capability, shall we say, like most men, like, that's where you sort of get a lot of your identity from. Yeah. And then to to have that removed was quite difficult and I have, I've got over it now, but yeah, it was. It was a long time coming.	→ life changes, different person → noticed changes in identity → physical capability as a man this is now in question due to lack of physical capability. Not being able to box. → Difficult to have something removed taken away
A	Yeah, yeah. And what made you go into what you're doing now?	
L	So like, before I start with the Environment Agency, I was, I was landscaping well. I've always worked on like race Team, so motorcycle race team, that's what I've always done. Then COVID came and I couldn't. Obviously racing was cancelled, so I started doing landscaping, but then after I had COVID, I just couldn't do physical work anymore, so I had to get this job in the Environment Agency because it's non physical.	Physical job prior to COVID → changes in capability, couldn't do physical work anymore. → a non-physical job was easier to maintain?



	Came back to it and I was a bit better, but it probably took me 6 weeks before I felt really confident behind the wheel of a car again. After my first time of getting in it. Then after that, it's the brain fogs get better, but there's still not 100% there. I forget words. I do struggle to think, and I do struggle to concentrate like I never. You really used to struggle sitting down and finishing something, but now I've I've got to do anything creative. I think we get like writers block. → mind blank? I'm gonna have to solve a problem, whereas before I could think like that, I noticed that my thinking's not as crisp anymore.	Took 6 weeks to feel better more comfortable. → has noticed improvement but doesn't feel quite like pre-covid self. Forgetting words Struggling to think Struggling to concentrate Difficulty sticking with tasks. Not as crisp/sharp?
A	Yeah no that makes sense.	
L	It's just my. My brain just feels sluggish is anywhere I can describe it.	Brain feels sluggish. / slower.
A	Yeah. Yeah. And you use the term brain fog, and I suppose that's a term that a lot of people use when describing their cognitive difficulties. What does that mean to you? How do you describe brain fog?	
L	Brain fogs, to me, is when you're expecting your brain to make a decision for you, and it can't, or it doesn't do it in the expected time frame. So like I said, when I when I approached around about instantly, it's like well, you look into the right, see if anything's coming in. And you're going to accelerate away. And I was approaching around about and I'm like, I'm not looking right and thinking what, where I'm looking right? Where am I supposed to be going here? Oh, yeah. I'm at cars come from that way. I'll go that way. And just those autonomous sort of things that you expect your brain to do for you, it just doesn't do.	Difficulty with decision making / automatic reactions → taking longer to do tasks / make decisions. Noticing changes in automatic reactions.
A	Yeah. Yeah. OK. And so you've mentioned a few things you said concentration for getting worse, struggling to think solving problems. So if it's OK, I'll just kind of ask you in a bit more detail about each of those things.	

Appendix 2-C: Example of code clustering and emergent themes

This table shows how codes were clustered together and how these linked to the corresponding themes.

Codes	Subthemes	Themes
Identity taken away Noticing changes in identity Sense of unfairness and injustice Grief of losing old identity Comparison to former self Deconstruction of identity Changes in cognition Altered self-perception Emotional impact of identity loss Sense of injustice Impacting on work/employment Loss of professional role or capability	(1) Personal Identity (2) Professional identity (3) Grieving a former self	Dealing with loss: stolen identity and a sense of injustice
Can't plan for the future Lack of control Who will get long COVID? Impact on self esteem Uncertainty for the future Fluctuating systems Emotional turbulence Impact on self-esteem and confidence – feeling embarrassed Noticing challenges in day-to-day life How will my symptoms be from one day to the next? Symptom fluctuation Emotional rollercoaster Fear of not being believed Impact on mental health Difficulty planning for future Physical and emotional exhaustion Uncertainty about recovery	(1) "Russian Roulette" (2) Day to day unpredictability (3) Moment to moment unpredictability	Internal turmoil: unpredictability and emotional distress
People don't understand brain fog Other people think it's not real Strained relationships Relating to people I've met online Support from online communities Feeling misunderstood by others Social withdrawal Stigma from others Loneliness and isolation Difficulty maintaining social connections Experiences of empathy and support	(1) Struggle for recognition and validation (2) The importance of social connection	Isolation and misunderstanding vs empowerment by social connection

Feelings of relatability Value of peer support groups		
Finding it difficult to get help Frustration with healthcare providers Difficulty accessing appropriate care Feeling dismissed by medical professionals Navigating multiple specialists Importance of patient advocacy Healthcare staff not understanding long COVID Ambiguity in how to gain support Lack of clear treatment protocols Experiences of positive healthcare interactions Finding information online Learning from online resources Gathering information	(1) Seeking support (2) Becoming their own expert	Navigating healthcare: the good, the bad and the uncertain

Appendix 2-D: Table of final themes, subthemes and corresponding quotes

This table illustrates quotes that were linked to particular subthemes and corresponding themes.

Theme	Subtheme	Quotes
Dealing with loss: stolen identity and a sense of injustice	(1) Personal Identity	'I had a perfectly enriched, happy life with everything we ever could have wanted. I was healthy, I was happy. I was fit. And now sometimes I can barely string a sentence together and I can't look after myself.' 'I'm just not the same person, I can't do the same things. It's infuriating. It's all just been taken away.' 'I was having such a difficult time letting go of my identity and I was getting really depressed by everything, it was devastating.' (Luana). 'As a boxer, you know you've got to perform under pressure. And I've always been able to do that. And then when you can't, that was like the beginning of the deconstruction of my identity.' (Michael) 'I wanted to just push through it. In the past when I've been sick, I've continued to go about my normal routine and eventually it goes away. But this didn't go away it got worse and worse. I couldn't understand why or what I was doing wrong. I felt helpless.' (Michael).
	(2) Professional Identity	'I stopped working completely in January because[…], I was sitting in a quite big meeting with a lot of people, […] There was a heated discussion and all of a sudden my brain just shut down. I couldn't understand what anyone was saying to me, it's like they were speaking a different language.' (Josie) 'I needed to find myself a new identity because my identity got taken away when I couldn't do the work that I've been doing. I've been doing my work for close to 10 years and I worked very hard. I really liked it. But I needed to redefine myself.' (Josie).
	(3) Grieving a former self	'I've been through a massive grieving experience because I had to. They say you have to grieve for

		your able body, grieve for the life you had and the person you used to be.' (Catherine) 'There was a point where I was grieving my old self but I'm at peace with it now. I'm at a place where I want to help other people'. (Michael).
Internal Turmoil: Unpredictability and emotional distress	(1) "Russian Roulette" – the unpredictable nature of long COVID	'I worked at a [school] as a teacher, so everyone had it. It was doing the rounds. But I was one of the first one of the employees that got it and nobody else got it the way I got. It felt very much like a Russian roulette kind of thing. Who's getting it bad and who's not, you know?' (Josie). 'My dad had COVID three times and he was fine, but I got it once and have struggled ever since. You just don't know who is going to get it and there's no knowledge of how to prevent it.' (Samir) 'It's just something that gets given to you and you have to deal with it'. (Diana) 'I started to blame myself a lot for getting sick. I couldn't understand why I was struggling so much but others were fine'. I worked with like 25 people and no one got it as bad as me. I felt like it was my fault.'
	(2) Day to day	'It fluctuates. The symptoms shift a little bit from day to day or week to week. One week I'm fatigued and the next my brain keeps on forgetting things. It's very unpredictable.' 'You're constantly pacing your activities, weighing things up. Is that worth it? It's exhausting. I know going out for lunch isn't just going out for an hour or so. It's actually going out for an hour and being in bed for the next three days.' (Luana) 'I think that I have gone through the darkest period of my life after my illness. I'm not sure whether this is because of an unpredictable future or not having a clear perspective of recovery.' (Samir). 'There's a huge kind of emotional dysregulation that comes with not being able to remember things and not being able to get your words out. Trying to get your point across makes you

		exhausted, tearful and tired. The emotional energy is absolutely exhausting.’ (Ashleigh)
	(3) Moment to moment	‘I could feel myself struggling to find the right words. I thought to myself you know what you want to say so why can’t you just say it?’ (Josie). ‘I'm tripping over myself whilst I'm speaking... it just comes out of nowhere …I'll sort of try to shake myself out of it and just say, like, OK, speak slowly. But it’s so embarrassing. It’s so embarrassing that you feel you don’t want to talk.’ (Diana). ‘When I’m reading my notes back there's words in there and I'm thinking I didn't put that word in there. It’s really quite scary. It's actually a combination of scary and embarrassing.’ (Diana).
Isolation and misunderstanding vs empowerment by social connection	(1) Struggle for recognition and validation	‘It's just that my brain is not working as fast as it used to. It feels like we're stuck in 3rd gear when we've got 6. That’s how I explain it to other people - that my brain is nowhere near at full performance'. (Michael). 'It was the lack of understanding and the community feeling because you are so alone with it all and then you don't get that understanding. It really affects your mental health.' (Megan). ‘They think I’m faking it. Because, I mean, I can go out one day and be fine, but nobody sees the preparation before and after and how I really am after. Nobody sees that I can’t do anything for the next three days. They just think I’m fine.’ (Maria). 'It's the judgments of other people when you are saying you have long COVID and brain fog because they have had COVID multiple times and they were fine. It is invisible. After all, I mean, if you see me in the street you will think I’m normal, right?’ (Josie). ‘I've noticed a few times when I've been with friends that it's not been as easy to get involved in those conversations that we used to have. I just, I haven't got it in me anymore. If I'm with my mates and it's like lads like banter, I just haven't got comebacks anymore and I just

		haven't got the mental fortitude to be involved in that sort of back and forth all the time and they just didn’t understand that.’ (Michael) ‘She was just like, ‘well, you look fine. You've recovered from COVID’. We had both been ill at the same time. She got better. And I got progressively worse. And she just didn’t get it.’ (Luana) ‘Speaking to other people in long COVID community really helped, that's a huge one, both to get fellow support, but also hear what worked for them and what did not work for them.’ (Nathan).
	(2) The importance of social connection	‘It had a huge impact on me and also one of them has become one of my closest friend even though we live in different ends of the world. So we speak together almost every day and support each other through it because even though we don't have long COVID the same way, we still have similar symptoms.’ (Luana).
Navigating healthcare: the good the bad and the uncertain	(1) Seeking Support	'The GPs have been rubbish and the follow up has been rubbish because nobody just no one knows what to do and what's going on.' (Megan). ‘Unfortunately, even the specialist suspected [the cognitive difficulties] may be depression. They think it’s a psychological issue, but it isn’t.’ (Samir). ‘I think what's gotten better is my acceptance and how I treat myself. I'm a lot nicer to myself now.' (Tara).
	(2) Becoming their own expert	‘You’ve gotta do it all yourself, you don’t get anything from the NHS [UK National Health Service].’ (Catherine). "I feel let down by the world I feel let down by governments. By doctors, friends and family and everyone around me, basically." (Catherine)

Section Three: Critical Appraisal

Word Count (excluding references): 3970

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Introduction

The overall aim of this project was to explore the impact of cognitive difficulties on various aspects of an individual's life. This paper aims to summarise the findings from the systematic literature review and empirical paper as well as reflect on various aspects of the research process including methodological issues, clinical implications and future research. There will also be some personal reflections.

Section One: Systematic Review

The systematic review explored the impact of a traumatic brain injury (TBI) on romantic relationships integrating information from three different perspectives: the injured person, the caregiver, and a dyadic perspective. The review found that couples may experience ruptured identities through role changes and shifts in the relationship dynamic as well as difficulties with communication and connectedness. Despite the significant challenges experienced, some couples were able to find new meaning and experience shared growth. A narrative running throughout these themes was the idea of 'an evolving journey', whereby couples had to work consistently to adjust to new dynamics within the relationship.

Clinical Implications

In the clinical implications of the systematic review, I discussed the use of the Y-shaped model (Gracey et al., 2009) and how this could be adapted for work with couples. The Family Experiential Model (FEM) (Klonoff, 2010) was also mentioned briefly, but here I expand further on this to give more detail about its potential use with couples.

The varied experiences reported by couples at different stages of rehabilitation demonstrates the importance of understanding each couple's unique journey and timeline following TBI, recognising that that needs may differ significantly between early and later stages of rehabilitation.

The FEM, originally designed to address the complex needs of individuals recovering from brain injuries and their families, emphasises family involvement in the rehabilitation process. It outlines seven phases, from pre-injury life (Phase 0) to post-rehabilitation (Phase 7), with phases 4-6 focusing on improving the family's awareness, acceptance, and realistic understanding of their loved one's injury. Adapting this model for couples affected by TBI could involve centring the uninjured partner in the recovery process and addressing specific changes relevant to romantic relationships such as, the shift to a parent-child dynamic, impact on intimacy and sexual functioning and relationship dissatisfaction. Furthermore, pre-injury narratives about how couples relate, communicate, and adjust to challenges could prove valuable when developing support strategies. The model's emphasis on ongoing support and follow-up care aligns well with the need to address evolving challenges over time in couples affected by TBI.

Deciding on the Focus for the Review

One of the challenges of the literature review process was deciding and defining the focus of the review. A lot of the existing research is on acquired brain injury (ABI) but a decision was made, based on prioritising the homogeneity of the studies, just to include TBI. The literature has extensively addressed the broader category ABI, offering valuable insights into its impact on identity, relationships, work etc. While this broader focus has been beneficial and has identified common themes across both ABI and TBI, it often overlooks the specific nuances associated with TBI which are typically more prevalent among younger adults. For instance, the experiences of an older couple dealing with the aftermath of a stroke will differ markedly from those of a younger couple navigating the challenges of one partner having a TBI. Whilst both experiences are important to understand, they will involve distinct challenges and experiences. By examining ABI and TBI together, there is a risk of missing these specific nuances and informing the tailored interventions that can better address the distinct needs of each group. Thus, future research should prioritise separating out distinct populations. In addition, research has investigated the efficacy of neuropsychologically informed intervention with couples navigating ABI (e.g. Yeates et al., 2013) but given the potential differences it may be useful for future research to focus specifically on developing interventions for couples navigating TBI for a better understanding of this population.

Section Two: Empirical Paper

The empirical paper explored the persistent cognitive difficulties in individuals after being infected with the SARS-CoV-2 virus. After 13 interviews and in-depth analysis of the data, four themes were constructed: (1) Dealing with loss: stolen identity and a sense of injustice, (2) Internal turmoil: unpredictability and emotional distress, (3) Isolation and misunderstanding vs empowerment by social connection and (4) Navigating healthcare: the good, the bad and the uncertain. In the empirical paper these findings were discussed with respect to theories of chronic illness (Charmaz, 1995), stigma (Goffman, 1968; Scambler and Hopkins, 1986) and social connection (Cohen and Will, 1985).

Systemic Issues

The initial focus of the COVID-19 pandemic was on saving lives due to its high mortality rate, which strained healthcare systems globally (Filip et al, 2020). As the acute impacts of the virus have subsided somewhat, many individuals with long COVID believe they have been abandoned as their ongoing functional difficulties have not received the same level of concern as the previously high death toll.

Despite the end of the global public health emergency, it is clear that the fallout from COVID may well be with us for some time. However, many individuals are struggling to get the appropriate help and support they need to help understand and manage the symptoms of long COVID.

There are many different symptoms of long COVID (Rochmawati et al., 2024) and each person will have a very individual profile and require thorough investigation and treatment tailored specifically to them. It has therefore been difficult to diagnose and find appropriate treatments for long COVID which in part is the frustration amongst the long COVID community. Lack of appropriate assessment and treatment has meant that many individuals are left to their own devices in figuring out how to manage these symptoms and changes which has often led to poorer quality of life (Owen et al., 2024).

It is also interesting to note that this is the first global pandemic to happen in the internet/social media age, offering both benefits and challenges. While these platforms facilitated connection and information sharing, they also highlighted inconsistencies in global approaches and enabled the spread of misinformation. Not everyone has equal access to or engages with these technologies, potentially leading to disparities in support and representation. Participants in this study found empowerment through social media connections, but those without such access may have experienced greater isolation and their perspectives would not have been captured throughout this study.

Methodological Issues

One possible limitation in the methodology was the reliance of self-report of the cognitive issues experienced by participants. The study relied on participants' knowledge of where they thought the cognitive issues stemmed from. I attempted to account for this by ensuring participants had no previous long term health conditions and no previous experience of cognitive difficulties.

Another issue I had to address was how the study was perceived. Once the recruitment poster was advertised on Facebook, group members had some concerns. Perhaps the predominant concern from members of the online COVID support group was that of 'psychologising' the cognitive difficulties, particularly as medical research has begun to highlight possible brain inflammation and other theories which suggest a biological marker (Li et al., 2023). Members stated that a psychological study would cause 'more harm than good' as the long COVID community had been fighting to get their symptoms recognised medically. One user commented 'we want blood tests, not

CBT'. Upon reading these comments I had a number of thoughts. I initially felt quite shocked and apprehensive. At the time of starting this project long COVID, and particularly the cognitive difficulties related to it, was an underrepresented area with little knowledge in the evidence base. My aim was to create more understanding of the experience of cognitive difficulties following COVID-19 and amplify lived experiences. Often understanding lived experience can foster empathy and compassion surrounding the condition and lead to further helpful discourse around supporting people whose quality of life had been impacted (Gair, 2012). The thought of doing more harm than good further exacerbated feelings of anxiousness as it was the exact opposite of why I set out to do this project. The main aim for the project was to raise awareness and amplify lived experiences of long COVID. The thought of not doing so, conflicted with my values not only as a researcher but also as a trainee clinical psychologist.

Upon reflection, I understood the anger and sense of injustice from the members of the long COVID community. I also believe there is a wider reputation of psychology which is suggestive of illnesses being 'all in your head'. Although we are moving away from this, it is important to highlight that more work needs to be done to dispel some of these myths.

Another decision I faced when designing the study was identifying an appropriate sample size for the empirical paper. The study aimed to recruit 12-15 participants in order to conduct reflexive thematic analysis (RTA). 15 participants were booked in for interview but 2 cancelled and were not able to rearrange. Having recruited 13 participants, many of whose interviews were rich and in depth, I decided to stop recruitment as I needed to give myself enough time to analyse the data. There is no definitive sample size for RTA (Braun & Clarke, 2012). While some researchers advocate for data saturation (the point in the data where no new themes emerge) (Constantinou et al., 2017; Vasileiou et al., 2018), Braun & Clarke (2021), the original authors of RTA, argue against this concept. They emphasize the quality of data over quantity and the importance of in-depth analysis to achieve theoretical saturation - the point where the research question can be adequately answered.

This study aimed for theoretical saturation, balancing in-depth analysis with the practical constraints of doctoral research i.e., limited time and resources.

Additionally, I drew on principles of information power to guide adequate sample size for this study (Malterud et al., 2016). The authors discussed that the size of a sample with sufficient information power depends on several factors. As a novice researcher, I acknowledged my limited experience, but recognized that the training received during my doctoral course has equipped me with strong interviewing skills (quality of dialogue). The study's aim was neither particularly broad nor narrow in scope, which didn't significantly influence the sample size in either direction. The specific focus on individuals experiencing cognitive difficulties following COVID-19 infection (sample specificity) allowed for a more targeted recruitment, potentially reducing the number of participants required. Weighing these various factors, a sample size of 12-15 participants was decided, which seemed appropriate to achieve the study's objectives while being manageable within the constraints of the research project.

Clinical Implications

Working in an acquired brain injury service exposed to me to the multiple different psychological interventions used to support people with cognitive impairment, many of which could be relevant when considering the support offered to people with cognitive problems long COVID. I supported individuals with complex physical and mental health co-morbidities using a variety of different evidence-based models (e.g, acceptance and commitment therapy (ACT), compassion focussed therapy (CFT) and cognitive behavioural therapy (CBT). More frequently, this included the use of cognitive rehabilitation, ACT with a particular focus on values-based work (Harris, 2006) and elements of CFT (Gilbert, 2009). I saw firsthand how these various therapies helped support individuals through their recovery.

I have reflected on the parallels between traumatic brain injury (TBI), the focus of my systematic review and long COVID, the focus of my empirical paper. Although there are obvious differences in underlying mechanisms e.g., through trauma to the head versus through a viral infection, there are key themes which draw the two together. One similarity is the sudden onset of cognitive difficulties.

People with TBI receive more medical care during the acute phase and patients with long term difficulties in the community are often left to their own devices to understand and learn more about recovery. They are often left to seek other resources as there are limited treatment pathways supporting people with longer term difficulties from a TBI. This is similar to long COVID where a large focus of support was placed on the acute phase of infection with limited treatment for longer term impacts. The chronic nature of these conditions draws similarities between them. In addition to this, there are often profound emotional and psychological impacts of a chronic health condition. Brain injuries and other chronic health conditions have been shown to have a severe impact on peoples' identities (Charmaz, 2009; Ownsworth, 2014). This was also one of the major themes constructed from the data set in the empirical paper. Further similarities between TBI and long COVID include experiences of fatigue and weakness with impacts on daily functioning and quality of life. Perhaps the biggest similarity between the two, pertaining particularly to the cognitive difficulties, is the varying trajectory of recovery. Cognitive impairment from both brain injuries and long COVID is variable in its trajectory with some individuals experiencing no cognitive difficulties at all, some experiencing gradual improvement over time, and others experiencing persisting cognitive difficulties lasting for months or years.

It stands to reason then that neuropsychological interventions used to support individuals with TBI may be useful for those struggling with persistent cognitive difficulties as a result of COVID-19. Hence, the clinical implication section of the empirical paper discusses the potential use of cognitive rehabilitation and psychological therapies such as ACT to help people cope with this life changing condition. Here, I offer further discussion in regard to therapeutic interventions.

Cognitive rehabilitation has been well documented in the literature for supporting individuals with brain injuries. It aims to improve cognitive functioning by providing compensatory strategies such as memory aids and mnemonic techniques to help individuals work around their cognitive difficulties and support cognitive function. It also uses restorative approaches such as specific cognitive exercises aiming to promote neuroplasticity in the brain, though the efficacy of such approaches has been questioned (Cicerone et al., 2019). Given the emerging evidence of potential damage to the brain due to SARS-CoV-2 (Zeng et al., 2023), cognitive rehabilitation may be a useful direction in supporting people with cognitive difficulties from long COVID. However, it is important to note that in the UK specialized interventions are generally only available through neurorehabilitation or acquired brain injury (ABI) services. Standard mental health teams operating within the statutory system do not typically offer or implement such interventions, meaning there is limited access to such support.

Another avenue for support is the use of psychological therapies. ACT is a values-based approach helping individuals to identify their core values which are meaningful to them and encouraging individuals to take committed action that align with these values (Harris, 2006). A key component of ACT is mindfulness which could be a useful tool in facilitating acceptance and supporting steps towards valued activity. Mindfulness encourages individuals to be engaged with the present moment helping them disengage from worries about the future (Baer and Krietemeyer, 2006). It can often help individuals manage uncertainty regarding their prognosis (Crowe et al., 2016). Participants from the present study explained how high levels of stress and over exertion had an impact on their cognitive function. It has been evidenced that stress can have an impact on cognitive function and that managing stress can help relieve some of these difficulties. This could be applied to individuals with long COVID where uncertainty is a huge factor as there is little understanding of why someone may experience cognitive difficulties and how long they will last for or whether they will ever resolve completely. Given the number of long COVID cases, many of these individuals will present to services that have little neuropsychological knowledge e.g., mental health and physical health pathways. It is important to consider how services can adapt their approach to be inclusive and support individuals with cognitive needs.

The experiences of the majority of participants in the present study highlighted the difficulties in navigating the healthcare system and in finding practitioners that did not dismiss and were compassionate towards the cognitive difficulties they were experiencing. Although data has been emerging over the past couple of years regarding persistent cognitive difficulties after COVID-19, this understanding seems to have trickled down into very few healthcare services. The current NICE guidelines for post-COVID-19 syndrome or long COVID recommend a comprehensive examination that involves ‘assessing physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities’ (NICE, 2020, p. 50). Despite the recognition of neurocognitive symptoms in national guidelines, participants in the present study experienced challenges with their healthcare providers with some feeling dismissed or silenced. There is therefore a need to increase awareness and understanding of neurocognitive symptoms amongst healthcare providers. Increasing awareness helps to reduce stigma and helps dispel myths surrounding the condition. Many participants spoke about the difficulty of not being believed about the cognitive difficulties and other symptoms of long COVID in general. Increased awareness also contributes to improved access to resources and appropriate treatments in a timely fashion. Given that clinical psychologists play a key role in working with long term health conditions, they are well placed to provide training for allied health professionals within their respective teams.

General Reflections

The topic for the empirical paper was chosen for a number of reasons. Firstly, the COVID-19 pandemic was the first time during my lifetime where modern medicine appeared to be unprepared. I wanted to understand more about the psychological impact of COVID as it is an event that is cemented in our history. The COVID pandemic was a time like no other due to social isolation and government-imposed lockdowns in an attempt to slow down the spread of the virus, as well as a challenging time for our NHS services and society as a whole (Willan et al., 2020; Zoumpourlis et al., 2020). The pandemic was experienced as chaotic and there was a growing fear about catching the virus (Lin, 2020). In addition to this, there was a huge degree of uncertainty about how the virus would impact individuals. My personal COVID experience was that of a flu with an additional loss of taste and smell. However, this was an extremely different experience to my uncle who tragically passed away due to the virus. This stark difference in experiences led me reflect on differences in how people in wider society might have experienced COVID-19.

Secondly, during my undergraduate degree I developed specific interests in neuropsychology. This was further developed throughout DClinPsy training. To pursue these interests, I requested a placement in an acquired brain injury (ABI) service in which I was exposed to the impact of TBI as well as stroke. I saw firsthand how illness can have an impact on cognitive functioning and thus how cognitive impairment can impact people’s lives. I worked with patients with complex presentations who had experienced difficulties with memory, language, executive functioning and formulated these difficulties in a holistic way along with physical health comorbidities. I became interested in how pathophysiology can impact cognitive functioning. At the time of picking out a thesis topic, new research was emerging looking into the long-term cognitive effects of COVID-19. There appeared to be a number of studies exploring cognitive difficulties at various time points after COVID. However, there were no studies which looked into the experiences of cognitive impairment. It became clear that hearing from individuals with lived experience of cognitive impairments following COVID and a better understanding of these experiences was crucial in order for our services to provide the best quality of care.

After difficulties with the initial recruitment, I was very mindful about not ‘psychologising’ long COVID. I wanted to ensure that I was supporting this community and not making things more difficult. It felt like there was more of a pressure to present the biological side of COVID-19 before discussing any of the psychological impact. I first noticed this when I was explaining the study to prospective participants. I introduced myself as a researcher studying clinical psychology and felt a pull to explain that this is one angle of research alongside more biomedical focussed work. It was interesting to acknowledge this switch in my approach most likely due to the previous comments I had received. Furthermore, I was very aware that I did not have any experience of cognitive difficulties or long-term health conditions which further added to my feelings of apprehension. It was an interesting experience studying a topic without lived experience of it. This highlighted two main themes for me; the weight of wanting to do the topic justice and confronting issues of health equity and social justice. Both of these were difficult paths for me to steer. On the one hand I felt the need to almost suppress the psychological approach as I didn't want to cause further harm, but on the other as a trainee clinical psychologist I recognised the importance of a holistic biopsychosocial approach in understanding long COVID and the need for research from a multi-disciplinary perspective.

I was honoured and humbled to hear the depth of my participants' stories. Their narratives highlighted some incredibly difficult challenges, particularly issues of stigma and social justice. Many reported dismissal of their symptoms, which echoed my family's experience with my uncle's COVID related death in 2021. This resonance evoked emotions and thoughts about mistrust in healthcare services. While constructing themes, I found myself drawn to negative healthcare experiences, perhaps influenced by my own feelings of anger and disappointment. However, using a reflective journal helped me acknowledge these biases and ensure an accurate representation, including both negative and positive participant experiences. This process was crucial in crafting a comprehensive narrative that did justice to the participants' stories.

Furthermore, my supervisor is part of the myalgic encephalomyelitis (ME) community and as someone who has spent many years advocating for the medical acknowledgement of ME, there were aspects that she battled with when approaching this topic. There have been many links drawn between the symptoms of long COVID and ME (e.g., Wong et al., 2021). I was mindful about not offending my supervisor but equally wanted to create a space where we could have open and transparent discussions about some of the challenges faced by both communities. We were able to create a safe space during supervision to talk openly about this which was incredibly useful for my reflective process. I had an additional supervisor who worked with brain injuries and was able to look at the material from another perspective ensuring that any potential bias or excessive focus on particular themes was identified and addressed. They also facilitated some useful discussions regarding clinical implications.

Future Directions

When constructing the themes for the empirical study, there were elements of nuance that were not captured within this study. Although the analysis identified consistent experiences among participants, there were also unique narratives that could be explored further. For example, there were hints of intersectionality at play and further work is needed to understand these better.

Furthermore, it is widely known that global south communities were disproportionately impacted by COVID-19 (Katikireddi et al., 2021), and were 5-88% times more likely to contract the virus (Frederic, 2023). The large variance suggests that there are differences even within different global south communities. Black and Asian populations had a 23% increased risk of excess deaths (Frederic, 2023) and also faced limited access to sick pay, inadequate support, and unequal vaccination coverage. Thus, experiences from people in these communities are likely to be significantly different from global North communities. In this study, participants from Kurdish and Black Caribbean backgrounds reported experiences of dismissal and lack of support, highlighting potential disparities. Due to the limited sample size of this study, it was not possible to say that these were collective experiences, however further research into the experiences of marginalised communities could reveal important nuances inform evidence-based policies prioritising the needs of global South communities.

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Section Four: Ethics

Ethics Application for Research Paper: The Experience of Persistent Cognitive Difficulties Following an Infection of COVID-19

Ammara Haque

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

July 2024

Word Count: (Excluding References)

All correspondence should be sent to:
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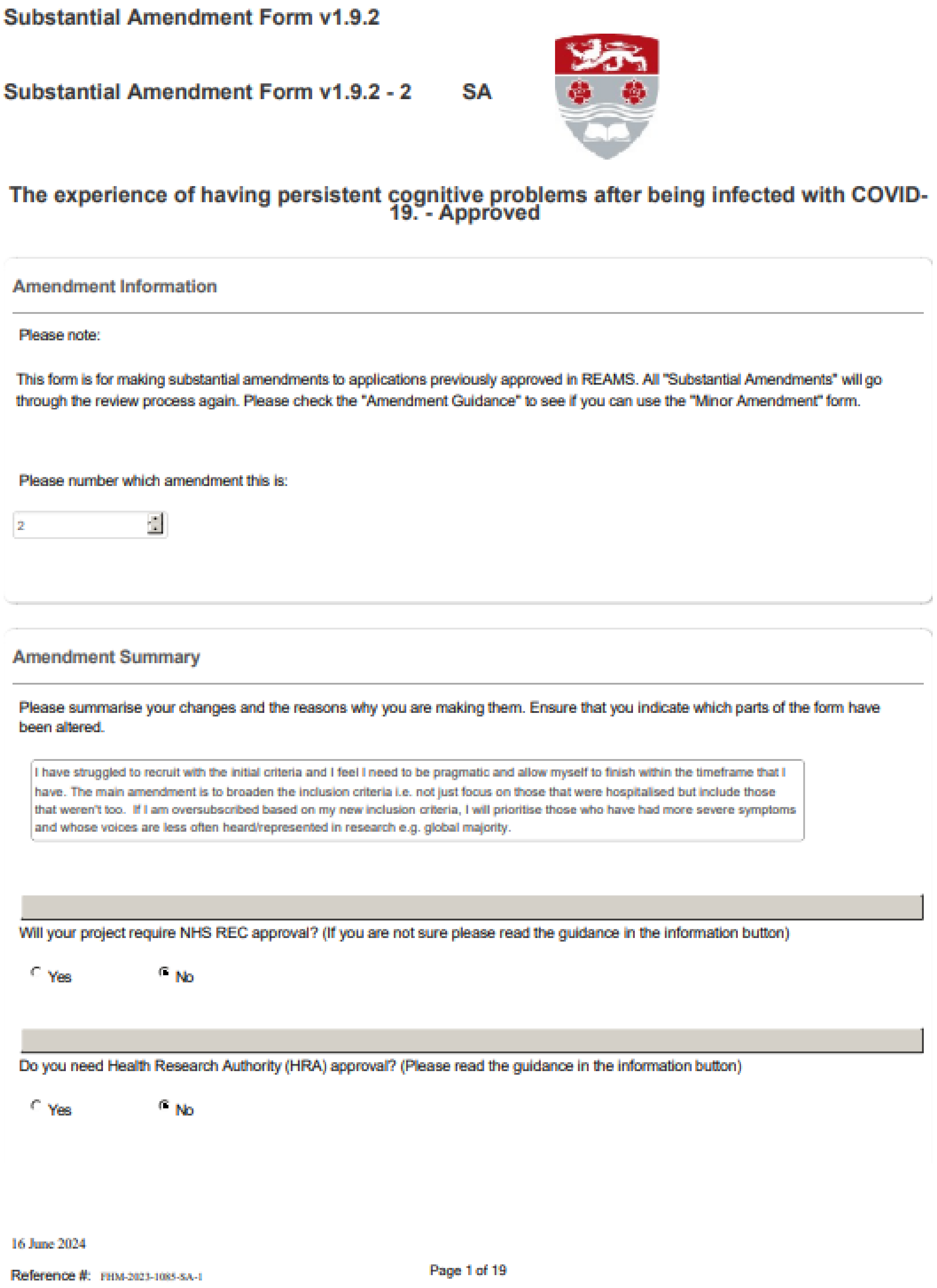


Substantial Amendment Form v1.9.2

Substantial Amendment Form v1.9.2 - 2 SA

The experience of having persistent cognitive problems after being infected with COVID-19. - Approved

Amendment Information

Please note:

This form is for making substantial amendments to applications previously approved in REAMS. All "Substantial Amendments" will go through the review process again. Please check the "Amendment Guidance" to see if you can use the "Minor Amendment" form.

Please number which amendment this is:

2

Amendment Summary

Please summarise your changes and the reasons why you are making them. Ensure that you indicate which parts of the form have been altered.

I have struggled to recruit with the initial criteria and I feel I need to be pragmatic and allow myself to finish within the timeframe that I have. The main amendment is to broaden the inclusion criteria i.e. not just focus on those that were hospitalised but include those that weren't too. If I am oversubscribed based on my new inclusion criteria, I will prioritise those who have had more severe symptoms and whose voices are less often heard/represented in research e.g. global majority.

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

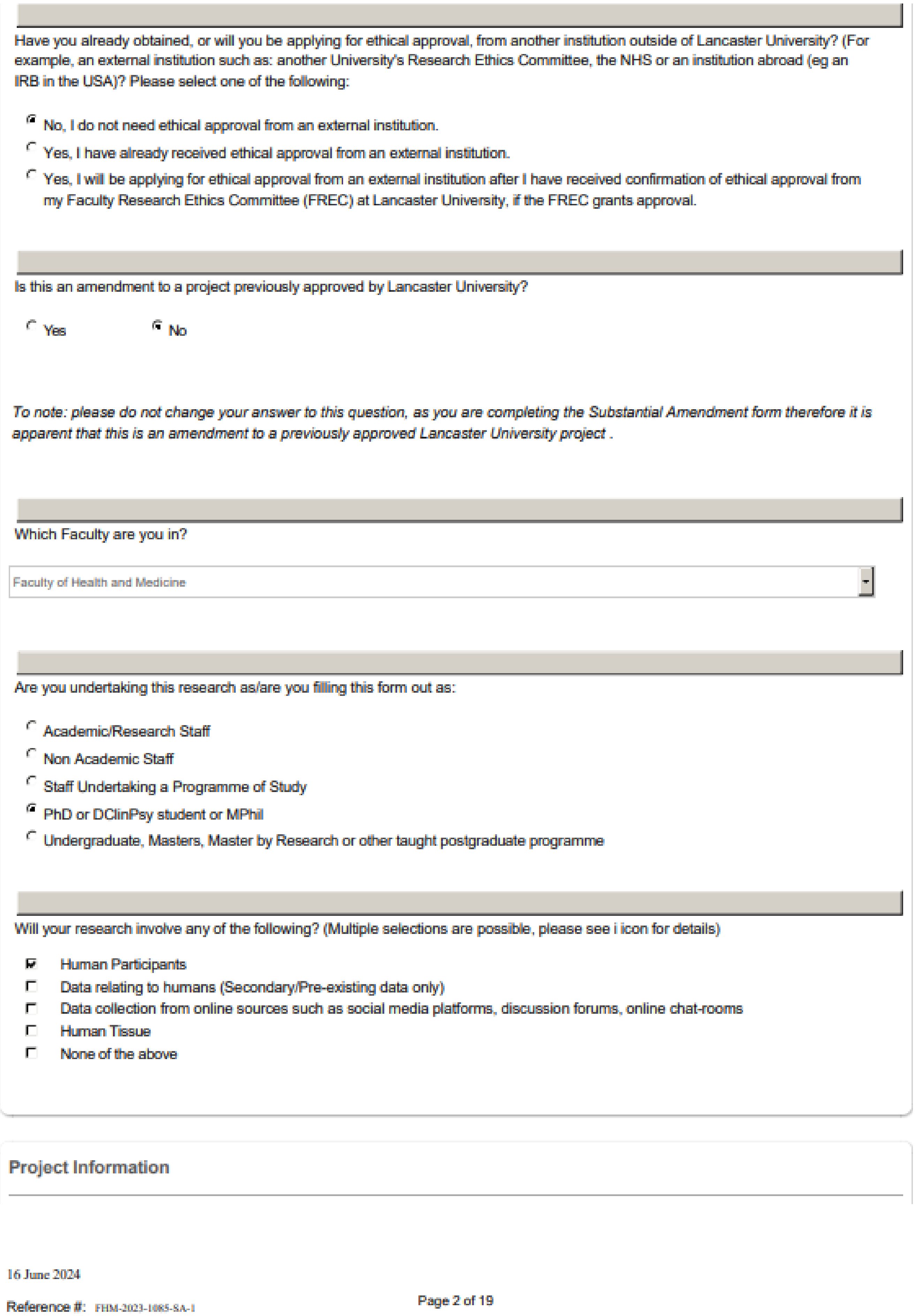
○ Yes ● No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

○ Yes ● No

16 June 2024

Reference #: FHM-2023-1085-SA-1



Have you already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (For example, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

- ● No, I do not need ethical approval from an external institution.
- ○ Yes, I have already received ethical approval from an external institution.
- ○ Yes, I will be applying for ethical approval from an external institution after I have received confirmation of ethical approval from my Faculty Research Ethics Committee (FREC) at Lancaster University, if the FREC grants approval.

Is this an amendment to a project previously approved by Lancaster University?

○ Yes ● No

To note: please do not change your answer to this question, as you are completing the Substantial Amendment form therefore it is apparent that this is an amendment to a previously approved Lancaster University project .

Which Faculty are you in?

Faculty of Health and Medicine

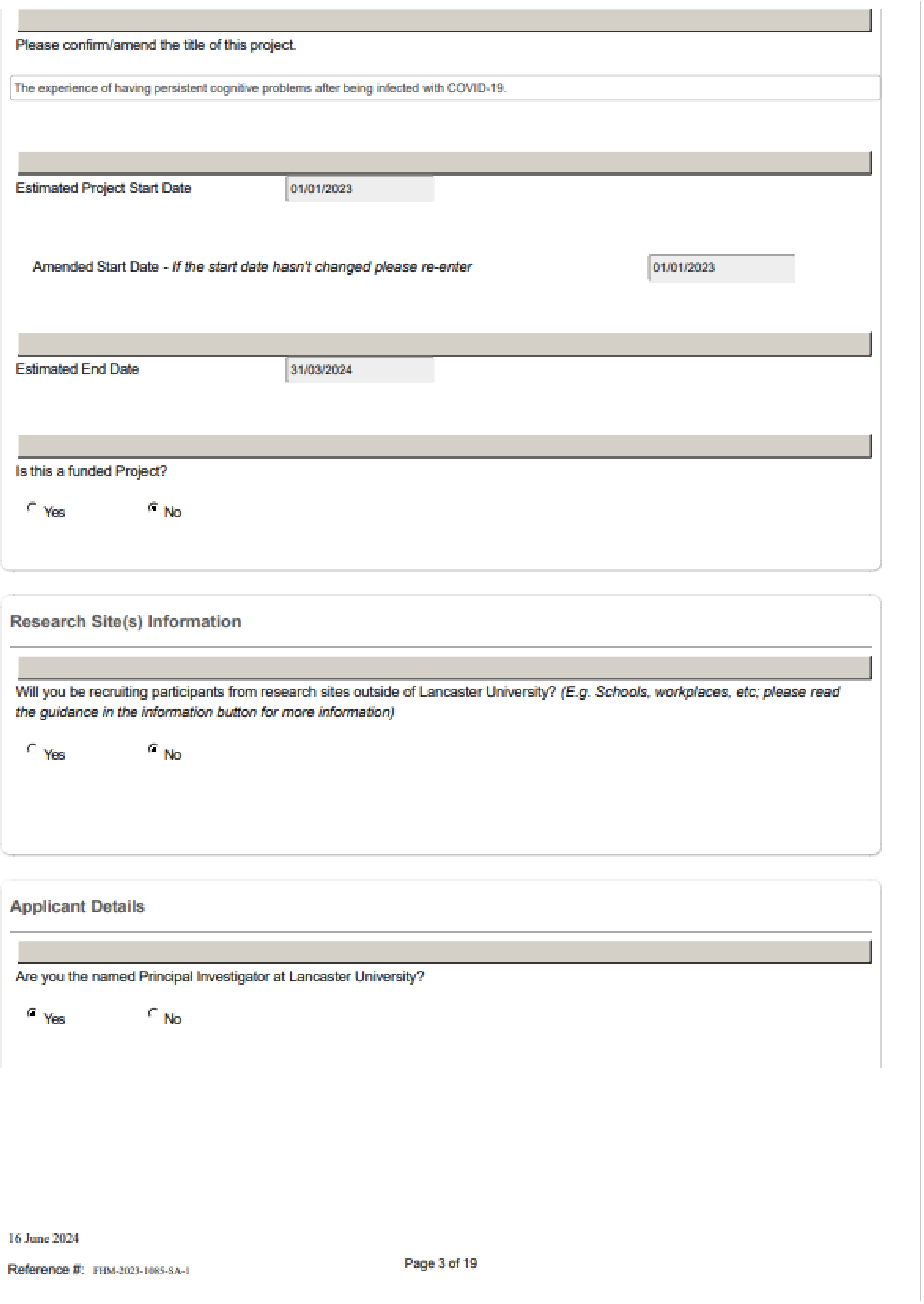
Are you undertaking this research as/are you filling this form out as:

- ○ Academic/Research Staff
- ○ Non Academic Staff
- ○ Staff Undertaking a Programme of Study
- ● PhD or DClinPsy student or MPhil
- ○ Undergraduate, Masters, Master by Research or other taught postgraduate programme

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

- ☑ Human Participants
- ☐ Data relating to humans (Secondary/Pre-existing data only)
- ☐ Data collection from online sources such as social media platforms, discussion forums, online chat-rooms
- ☐ Human Tissue
- ☐ None of the above

Project Information



Please confirm/amend the title of this project.

The experience of having persistent cognitive problems after being infected with COVID-19.

Estimated Project Start Date 01/01/2023

Amended Start Date - *If the start date hasn't changed please re-enter* 01/01/2023

Estimated End Date 31/03/2024

Is this a funded Project?

○ Yes ● No

Research Site(s) Information

Will you be recruiting participants from research sites outside of Lancaster University? *(E.g. Schools, workplaces, etc; please read the guidance in the information button for more information)*

○ Yes ● No

Applicant Details

Are you the named Principal Investigator at Lancaster University?

● Yes ○ No

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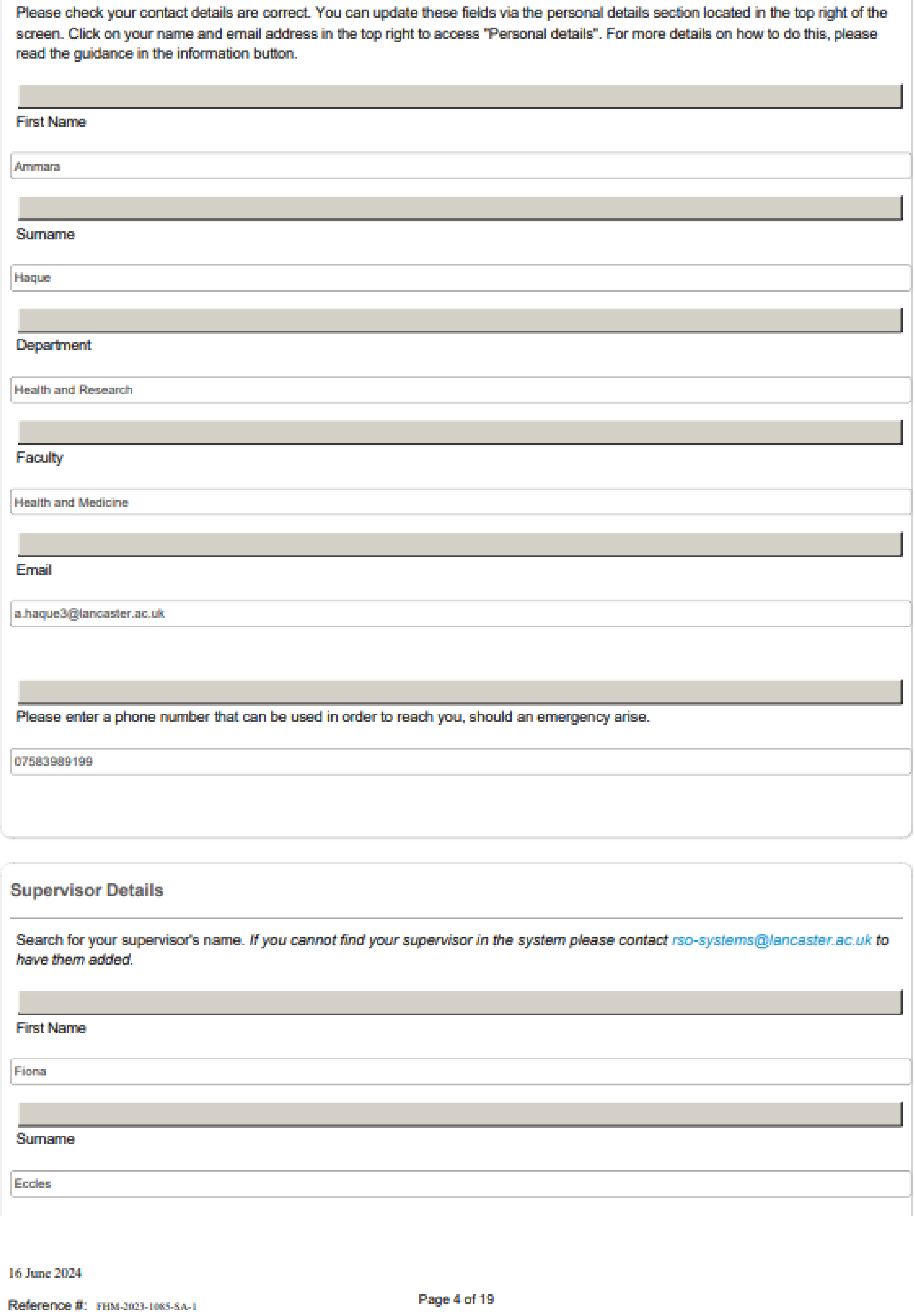

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, please read the guidance in the information button.

First Name

Ammara

Surname

Haque

Department

Health and Research

Faculty

Health and Medicine

Email

a.haque3@lancaster.ac.uk

Please enter a phone number that can be used in order to reach you, should an emergency arise.

07583989199

Supervisor Details

Search for your supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.*

First Name

Fiona

Surname

Eccles

16 June 2024

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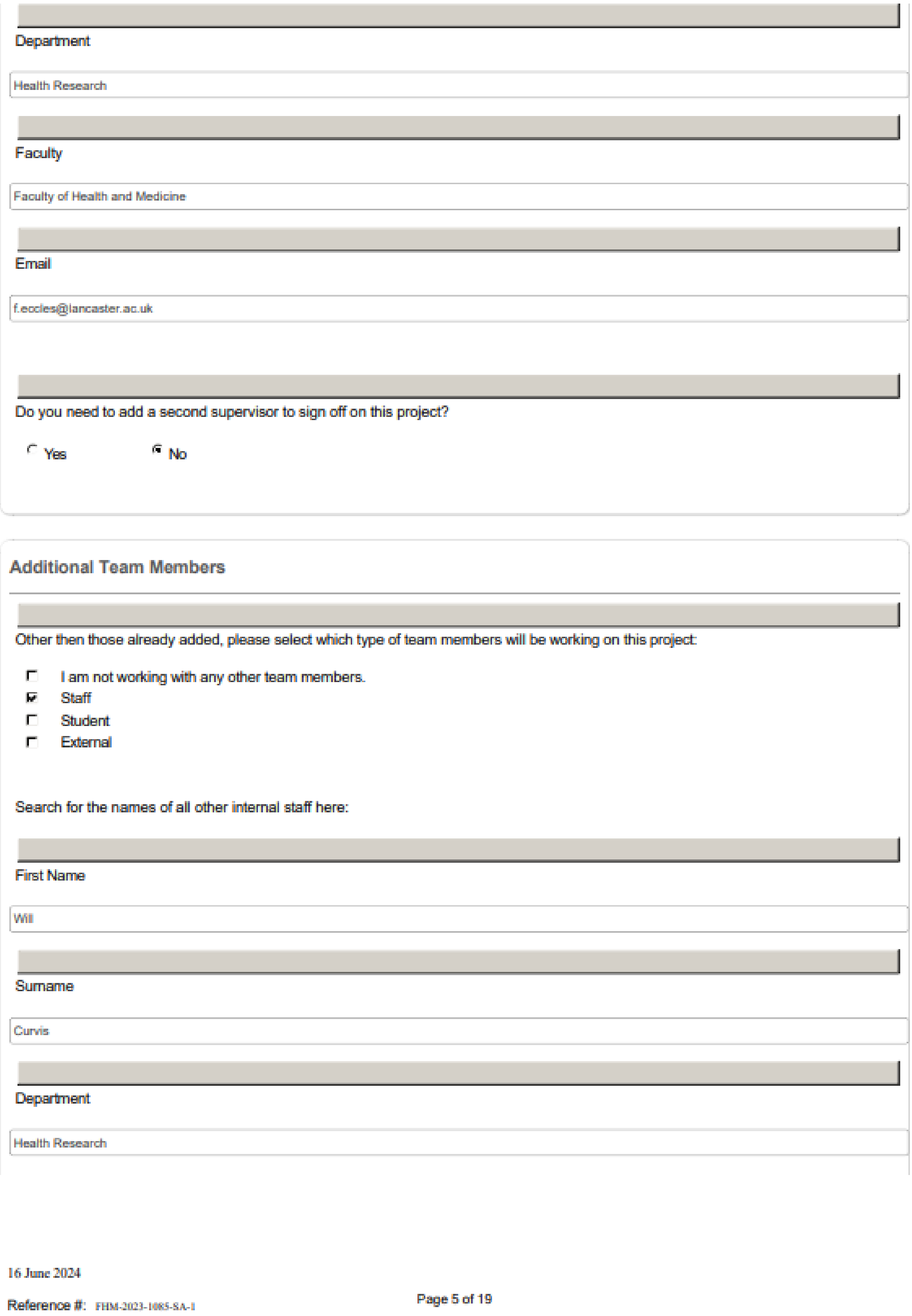

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

f.eccles@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

○ Yes ● No

Additional Team Members

Other then those already added, please select which type of team members will be working on this project:

☐ I am not working with any other team members.
☑ Staff
☐ Student
☐ External

Search for the names of all other internal staff here:

First Name

Will

Surname

Curvis

Department

Health Research

16 June 2024

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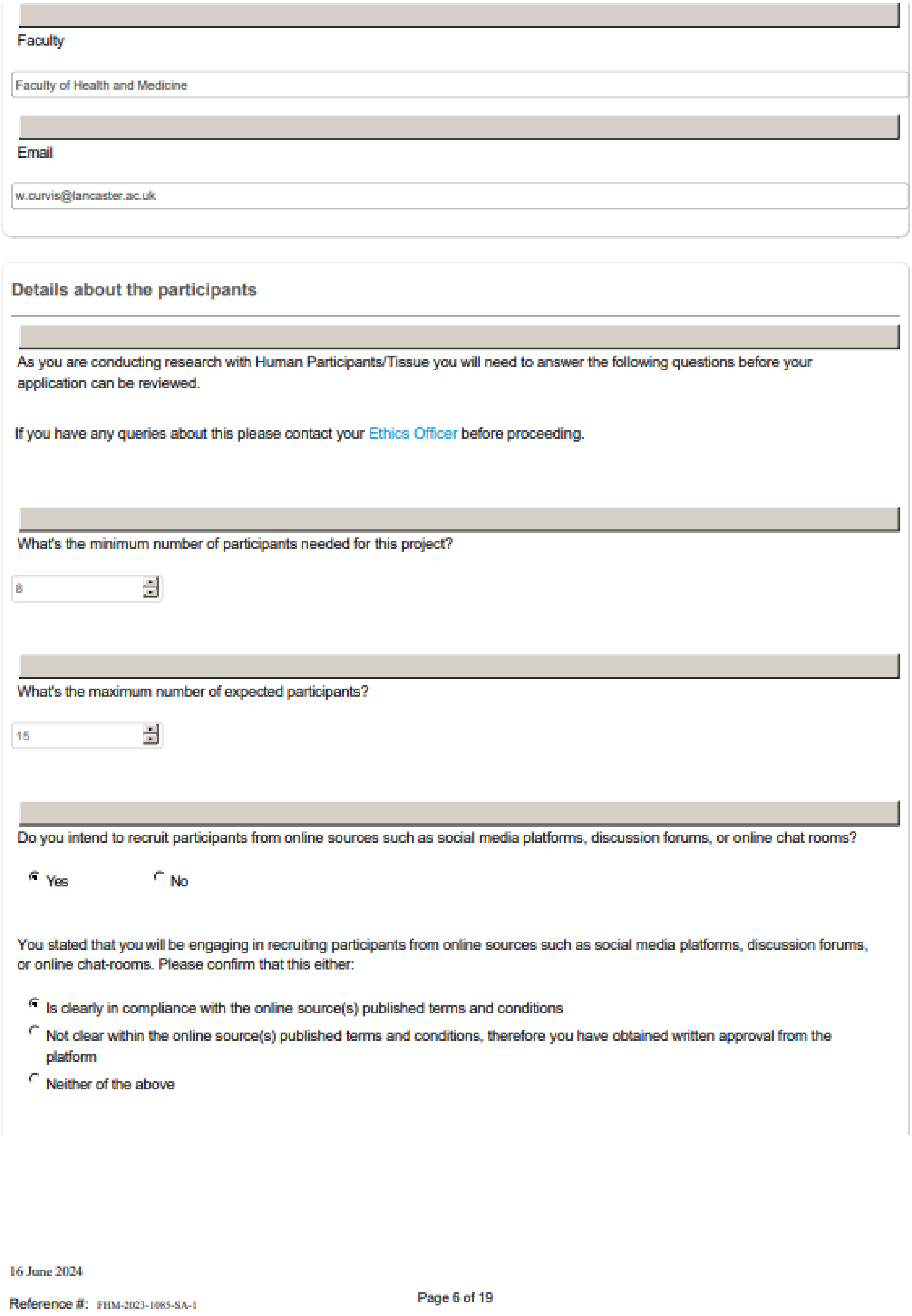

Faculty

Faculty of Health and Medicine

Email

w.curvis@lancaster.ac.uk

Details about the participants

As you are conducting research with Human Participants/Tissue you will need to answer the following questions before your application can be reviewed.

If you have any queries about this please contact your Ethics Officer before proceeding.

What's the minimum number of participants needed for this project?

8

What's the maximum number of expected participants?

15

Do you intend to recruit participants from online sources such as social media platforms, discussion forums, or online chat rooms?

● Yes ○ No

You stated that you will be engaging in recruiting participants from online sources such as social media platforms, discussion forums, or online chat-rooms. Please confirm that this either:

- ● Is clearly in compliance with the online source(s) published terms and conditions
- ○ Not clear within the online source(s) published terms and conditions, therefore you have obtained written approval from the platform
- ○ Neither of the above

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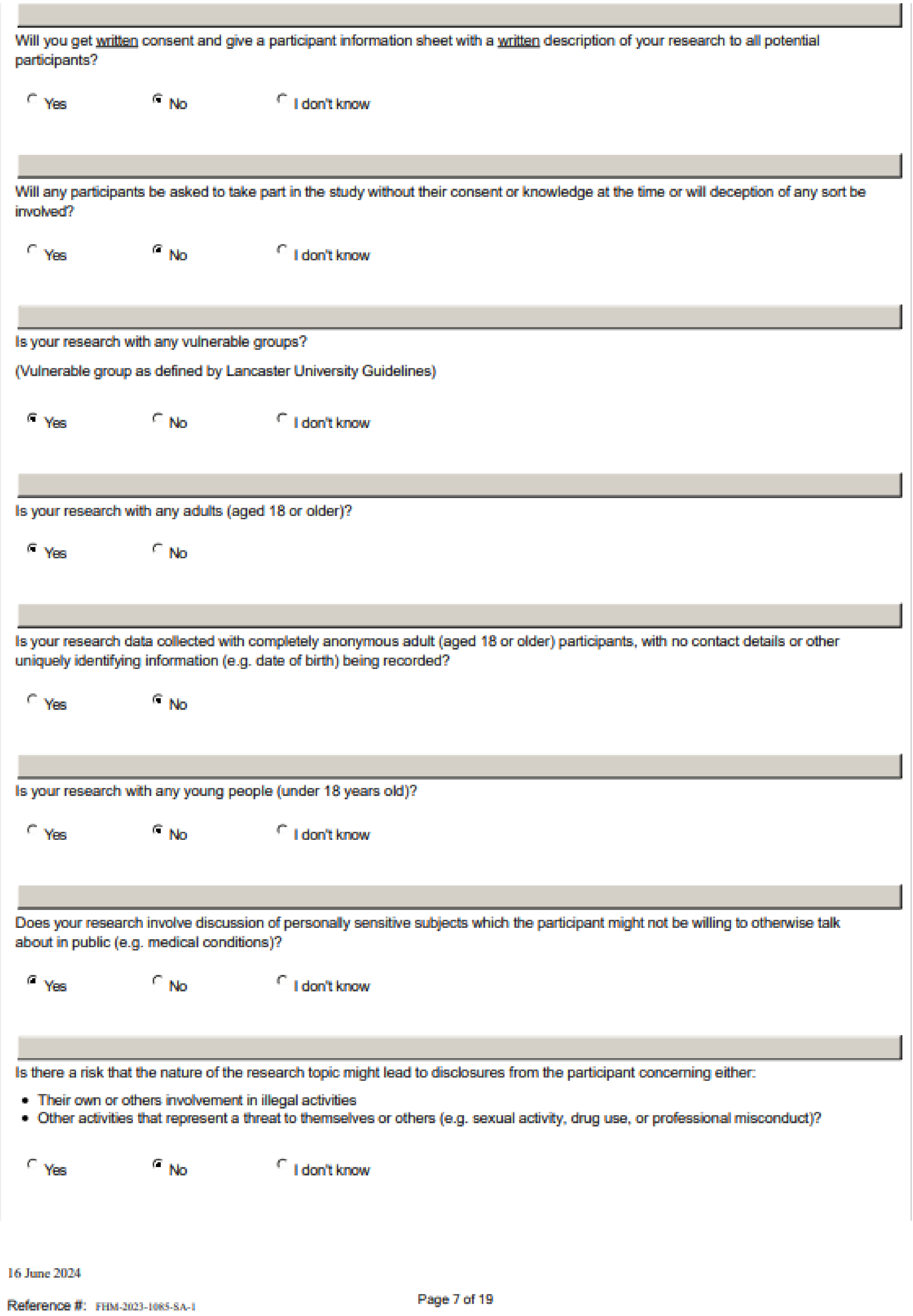

Will you get written consent and give a participant information sheet with a written description of your research to all potential participants?

○ Yes ● No ○ I don't know

Will any participants be asked to take part in the study without their consent or knowledge at the time or will deception of any sort be involved?

○ Yes ● No ○ I don't know

Is your research with any vulnerable groups?

(Vulnerable group as defined by Lancaster University Guidelines)

● Yes ○ No ○ I don't know

Is your research with any adults (aged 18 or older)?

● Yes ○ No

Is your research data collected with completely anonymous adult (aged 18 or older) participants, with no contact details or other uniquely identifying information (e.g. date of birth) being recorded?

○ Yes ● No

Is your research with any young people (under 18 years old)?

○ Yes ● No ○ I don't know

Does your research involve discussion of personally sensitive subjects which the participant might not be willing to otherwise talk about in public (e.g. medical conditions)?

● Yes ○ No ○ I don't know

Is there a risk that the nature of the research topic might lead to disclosures from the participant concerning either:

- Their own or others involvement in illegal activities
- Other activities that represent a threat to themselves or others (e.g. sexual activity, drug use, or professional misconduct)?

○ Yes ● No ○ I don't know

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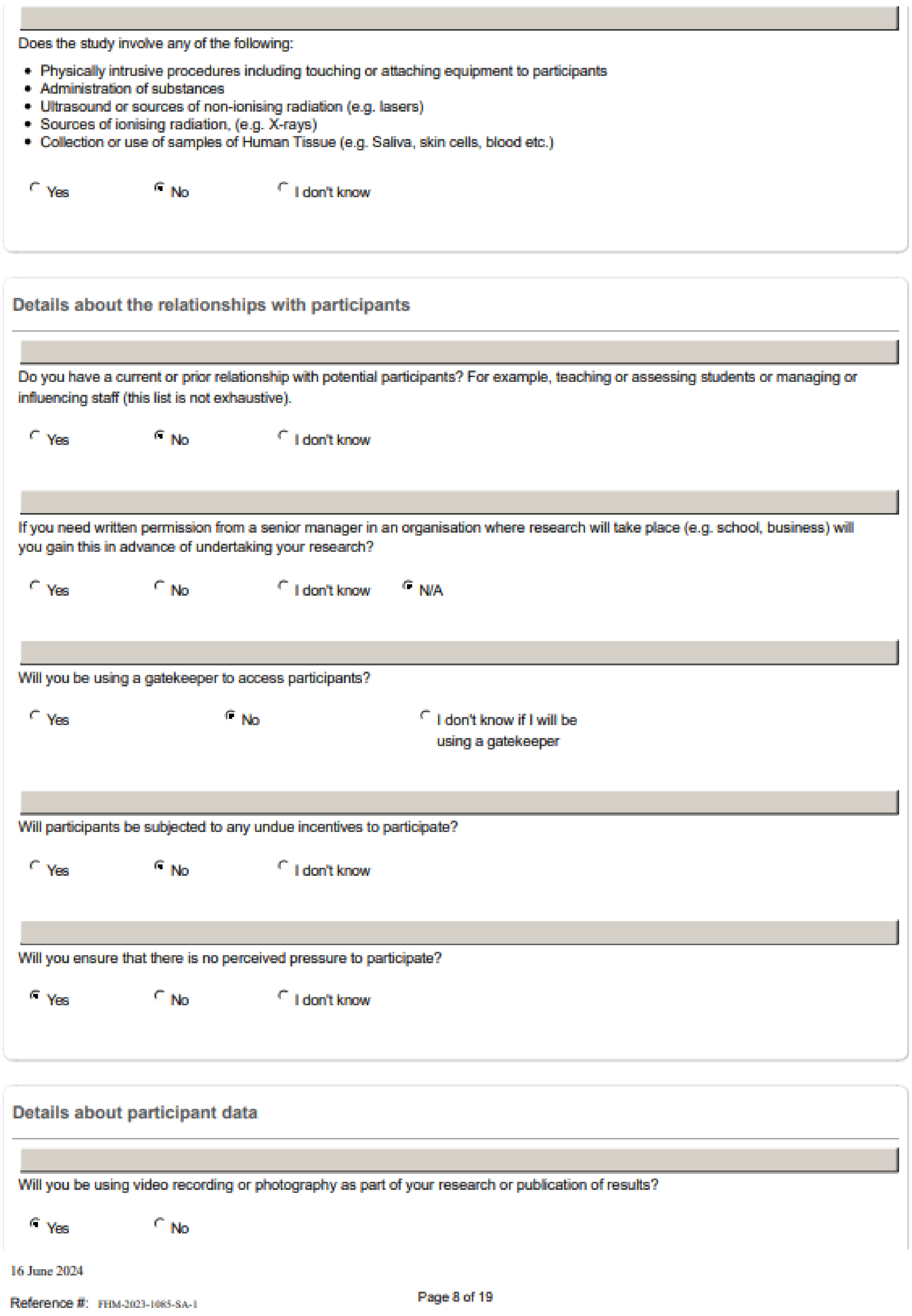

Does the study involve any of the following:

- Physically intrusive procedures including touching or attaching equipment to participants
- Administration of substances
- Ultrasound or sources of non-ionising radiation (e.g. lasers)
- Sources of ionising radiation, (e.g. X-rays)
- Collection or use of samples of Human Tissue (e.g. Saliva, skin cells, blood etc.)

○ Yes ● No ○ I don't know

Details about the relationships with participants

Do you have a current or prior relationship with potential participants? For example, teaching or assessing students or managing or influencing staff (this list is not exhaustive).

○ Yes ● No ○ I don't know

If you need written permission from a senior manager in an organisation where research will take place (e.g. school, business) will you gain this in advance of undertaking your research?

○ Yes ○ No ○ I don't know ● N/A

Will you be using a gatekeeper to access participants?

○ Yes ● No ○ I don't know if I will be using a gatekeeper

Will participants be subjected to any undue incentives to participate?

○ Yes ● No ○ I don't know

Will you ensure that there is no perceived pressure to participate?

● Yes ○ No ○ I don't know

Details about participant data

Will you be using video recording or photography as part of your research or publication of results?

● Yes ○ No

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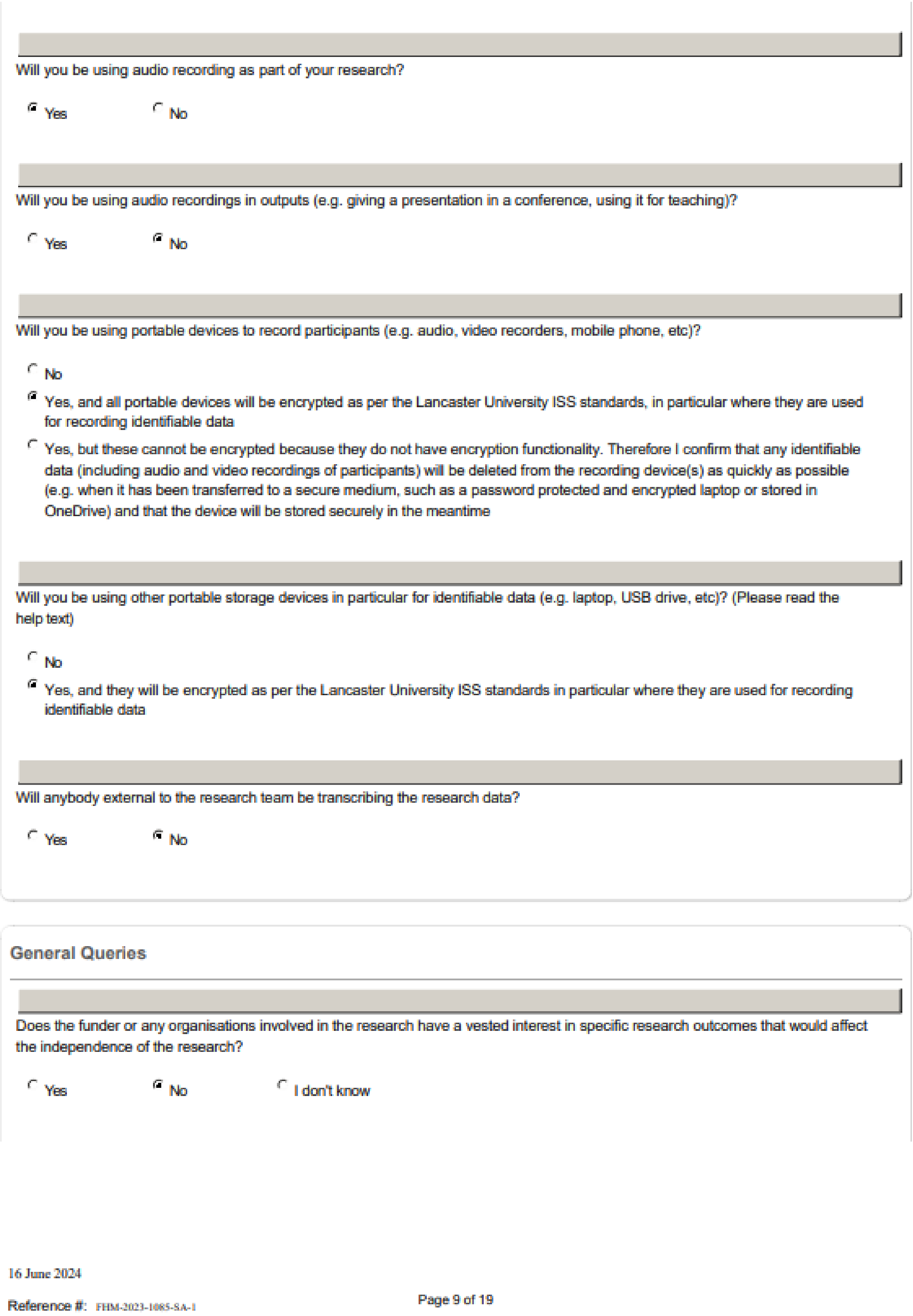

Will you be using audio recording as part of your research?

● Yes ○ No

Will you be using audio recordings in outputs (e.g. giving a presentation in a conference, using it for teaching)?

○ Yes ● No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

- ○ No
- ● Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data
- ○ Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

- ○ No
- ● Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

○ Yes ● No

General Queries

Does the funder or any organisations involved in the research have a vested interest in specific research outcomes that would affect the independence of the research?

○ Yes ● No ○ I don't know

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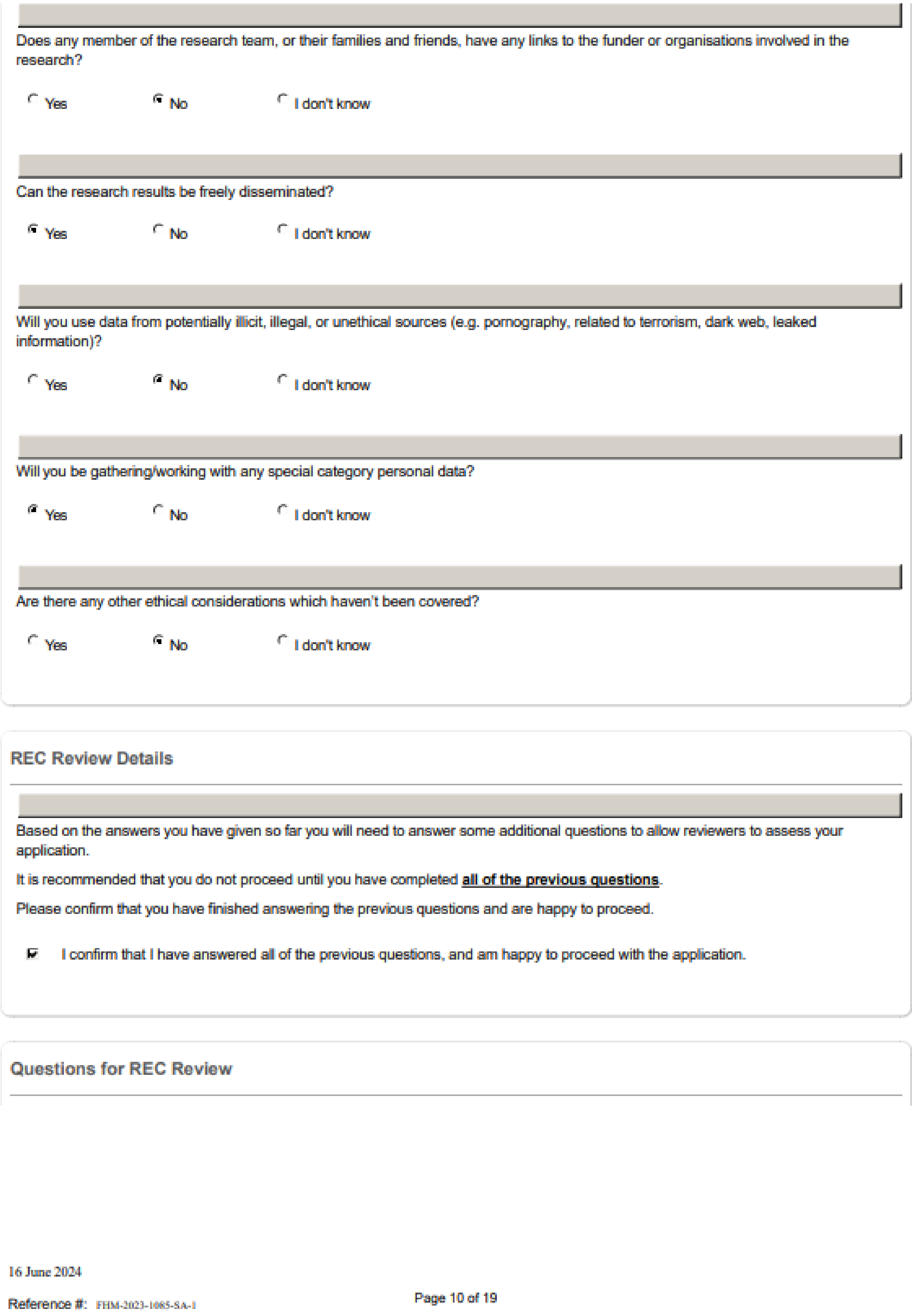


Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in the research?

○ Yes ● No ○ I don't know

Can the research results be freely disseminated?

● Yes ○ No ○ I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

○ Yes ● No ○ I don't know

Will you be gathering/working with any special category personal data?

● Yes ○ No ○ I don't know

Are there any other ethical considerations which haven't been covered?

○ Yes ● No ○ I don't know

REC Review Details

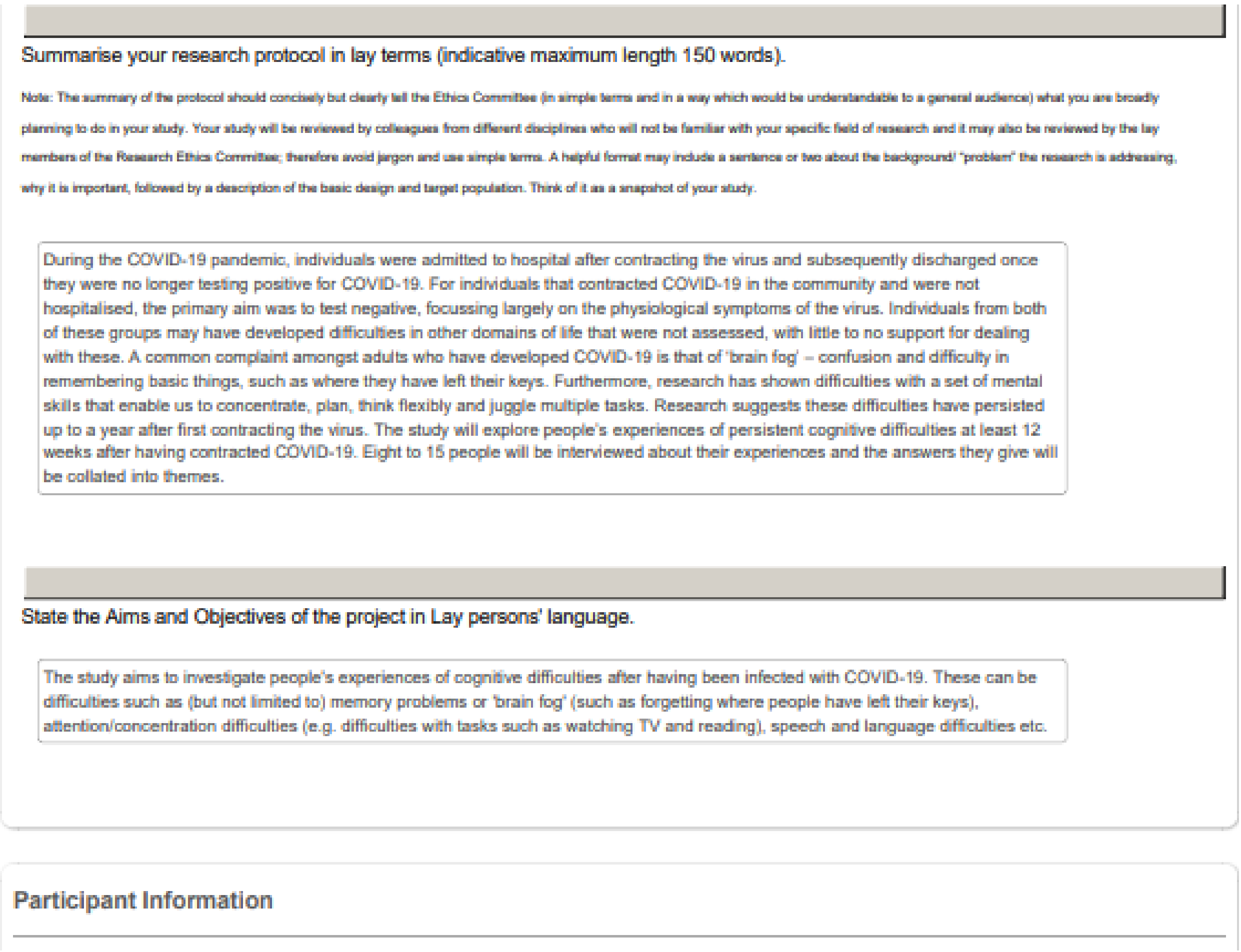
Based on the answers you have given so far you will need to answer some additional questions to allow reviewers to assess your application.

It is recommended that you do not proceed until you have completed **all of the previous questions**.

Please confirm that you have finished answering the previous questions and are happy to proceed.

☑ I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

Questions for REC Review



Summarise your research protocol in lay terms (indicative maximum length 150 words).

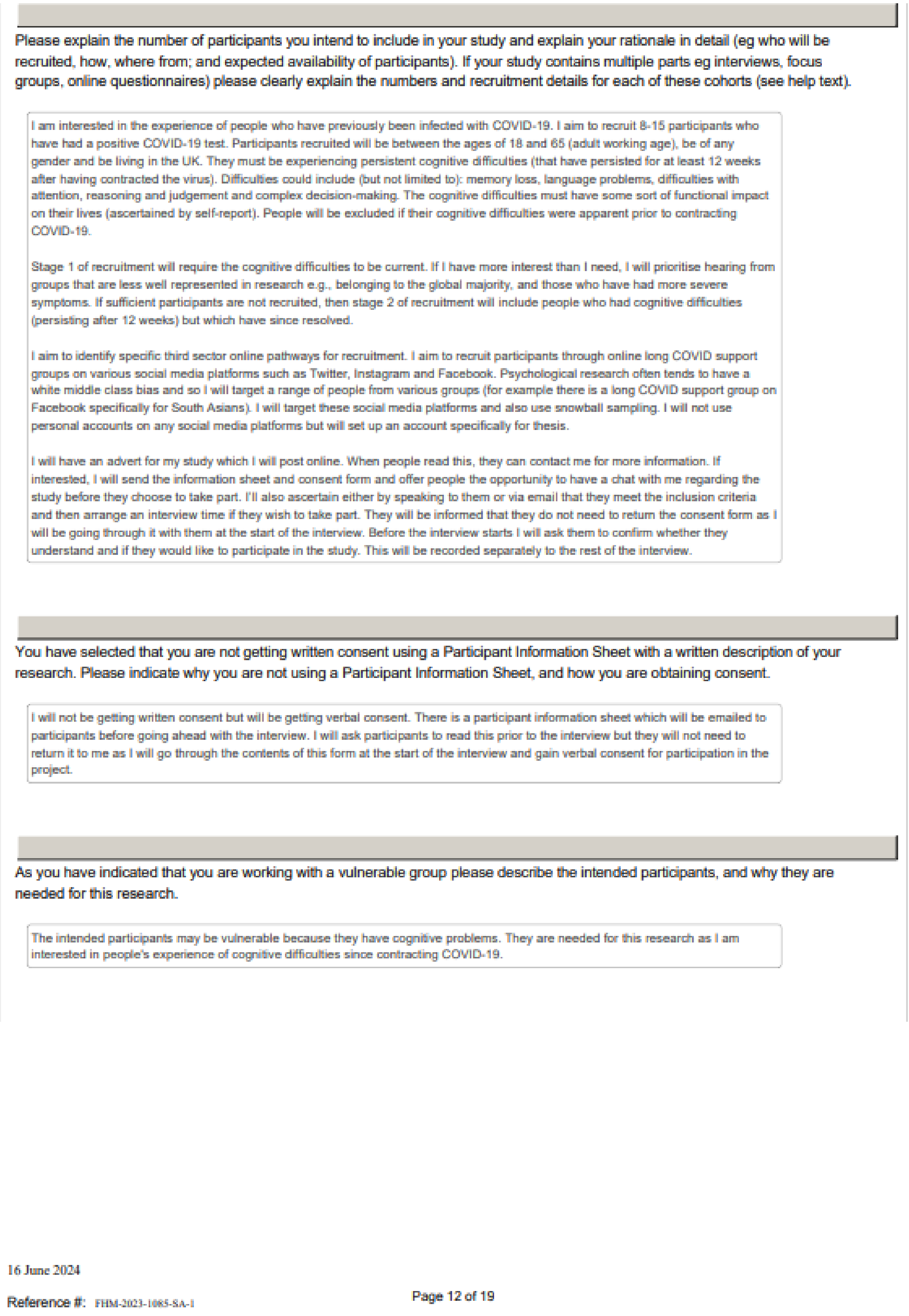
Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/ "problem" the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

During the COVID-19 pandemic, individuals were admitted to hospital after contracting the virus and subsequently discharged once they were no longer testing positive for COVID-19. For individuals that contracted COVID-19 in the community and were not hospitalised, the primary aim was to test negative, focussing largely on the physiological symptoms of the virus. Individuals from both of these groups may have developed difficulties in other domains of life that were not assessed, with little to no support for dealing with these. A common complaint amongst adults who have developed COVID-19 is that of 'brain fog' – confusion and difficulty in remembering basic things, such as where they have left their keys. Furthermore, research has shown difficulties with a set of mental skills that enable us to concentrate, plan, think flexibly and juggle multiple tasks. Research suggests these difficulties have persisted up to a year after first contracting the virus. The study will explore people's experiences of persistent cognitive difficulties at least 12 weeks after having contracted COVID-19. Eight to 15 people will be interviewed about their experiences and the answers they give will be collated into themes.

State the Aims and Objectives of the project in Lay persons' language.

The study aims to investigate people's experiences of cognitive difficulties after having been infected with COVID-19. These can be difficulties such as (but not limited to) memory problems or 'brain fog' (such as forgetting where people have left their keys), attention/concentration difficulties (e.g. difficulties with tasks such as watching TV and reading), speech and language difficulties etc.

Participant Information



Please explain the number of participants you intend to include in your study and explain your rationale in detail (eg who will be recruited, how, where from; and expected availability of participants). If your study contains multiple parts eg interviews, focus groups, online questionnaires) please clearly explain the numbers and recruitment details for each of these cohorts (see help text).

I am interested in the experience of people who have previously been infected with COVID-19. I aim to recruit 8-15 participants who have had a positive COVID-19 test. Participants recruited will be between the ages of 18 and 65 (adult working age), be of any gender and be living in the UK. They must be experiencing persistent cognitive difficulties (that have persisted for at least 12 weeks after having contracted the virus). Difficulties could include (but not limited to): memory loss, language problems, difficulties with attention, reasoning and judgement and complex decision-making. The cognitive difficulties must have some sort of functional impact on their lives (ascertained by self-report). People will be excluded if their cognitive difficulties were apparent prior to contracting COVID-19.

Stage 1 of recruitment will require the cognitive difficulties to be current. If I have more interest than I need, I will prioritise hearing from groups that are less well represented in research e.g., belonging to the global majority, and those who have had more severe symptoms. If sufficient participants are not recruited, then stage 2 of recruitment will include people who had cognitive difficulties (persisting after 12 weeks) but which have since resolved.

I aim to identify specific third sector online pathways for recruitment. I aim to recruit participants through online long COVID support groups on various social media platforms such as Twitter, Instagram and Facebook. Psychological research often tends to have a white middle class bias and so I will target a range of people from various groups (for example there is a long COVID support group on Facebook specifically for South Asians). I will target these social media platforms and also use snowball sampling. I will not use personal accounts on any social media platforms but will set up an account specifically for thesis.

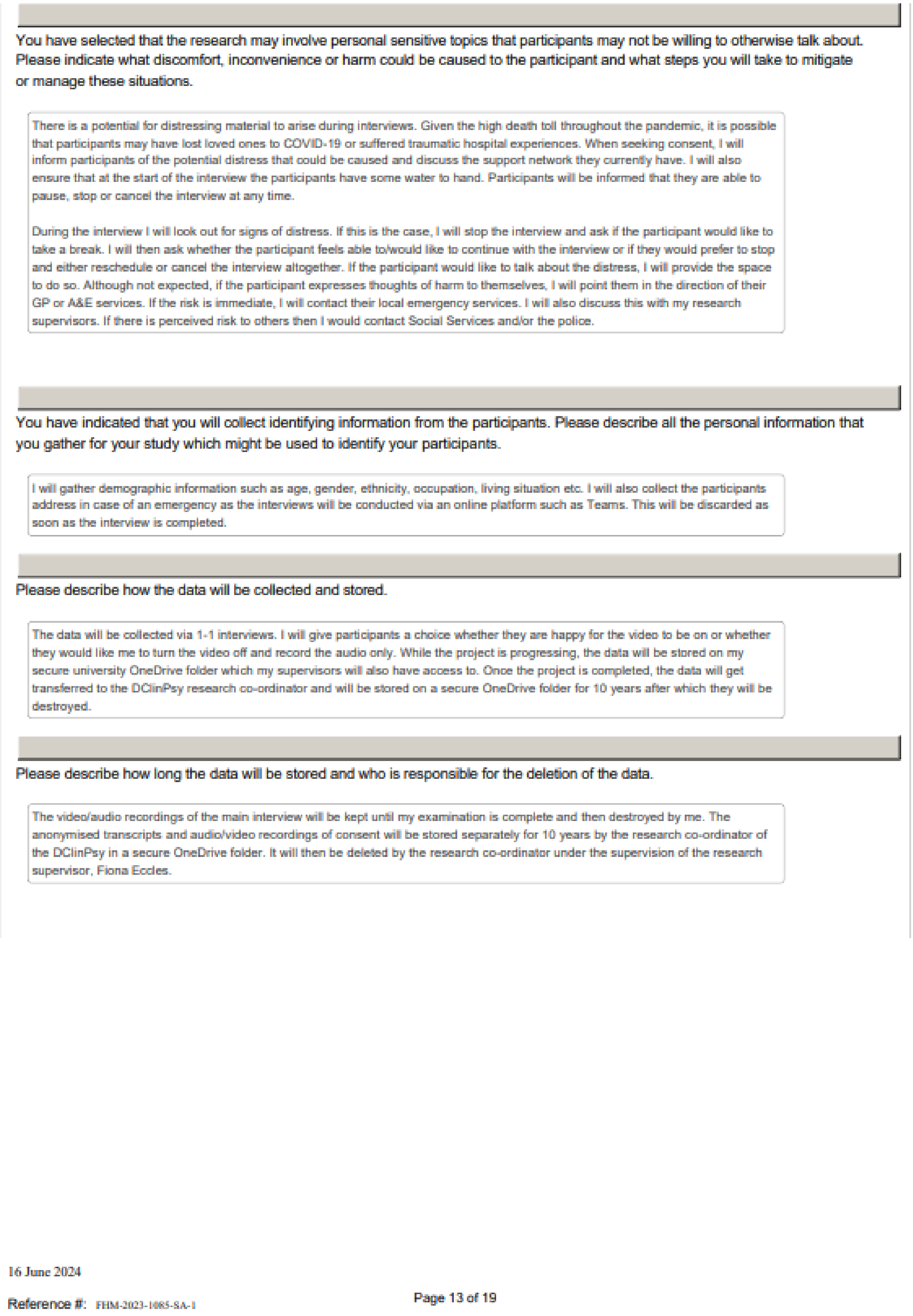
I will have an advert for my study which I will post online. When people read this, they can contact me for more information. If interested, I will send the information sheet and consent form and offer people the opportunity to have a chat with me regarding the study before they choose to take part. I'll also ascertain either by speaking to them or via email that they meet the inclusion criteria and then arrange an interview time if they wish to take part. They will be informed that they do not need to return the consent form as I will be going through it with them at the start of the interview. Before the interview starts I will ask them to confirm whether they understand and if they would like to participate in the study. This will be recorded separately to the rest of the interview.

You have selected that you are not getting written consent using a Participant Information Sheet with a written description of your research. Please indicate why you are not using a Participant Information Sheet, and how you are obtaining consent.

I will not be getting written consent but will be getting verbal consent. There is a participant information sheet which will be emailed to participants before going ahead with the interview. I will ask participants to read this prior to the interview but they will not need to return it to me as I will go through the contents of this form at the start of the interview and gain verbal consent for participation in the project.

As you have indicated that you are working with a vulnerable group please describe the intended participants, and why they are needed for this research.

The intended participants may be vulnerable because they have cognitive problems. They are needed for this research as I am interested in people's experience of cognitive difficulties since contracting COVID-19.



You have selected that the research may involve personal sensitive topics that participants may not be willing to otherwise talk about. Please indicate what discomfort, inconvenience or harm could be caused to the participant and what steps you will take to mitigate or manage these situations.

There is a potential for distressing material to arise during interviews. Given the high death toll throughout the pandemic, it is possible that participants may have lost loved ones to COVID-19 or suffered traumatic hospital experiences. When seeking consent, I will inform participants of the potential distress that could be caused and discuss the support network they currently have. I will also ensure that at the start of the interview the participants have some water to hand. Participants will be informed that they are able to pause, stop or cancel the interview at any time.

During the interview I will look out for signs of distress. If this is the case, I will stop the interview and ask if the participant would like to take a break. I will then ask whether the participant feels able to/would like to continue with the interview or if they would prefer to stop and either reschedule or cancel the interview altogether. If the participant would like to talk about the distress, I will provide the space to do so. Although not expected, if the participant expresses thoughts of harm to themselves, I will point them in the direction of their GP or A&E services. If the risk is immediate, I will contact their local emergency services. I will also discuss this with my research supervisors. If there is perceived risk to others then I would contact Social Services and/or the police.

You have indicated that you will collect identifying information from the participants. Please describe all the personal information that you gather for your study which might be used to identify your participants.

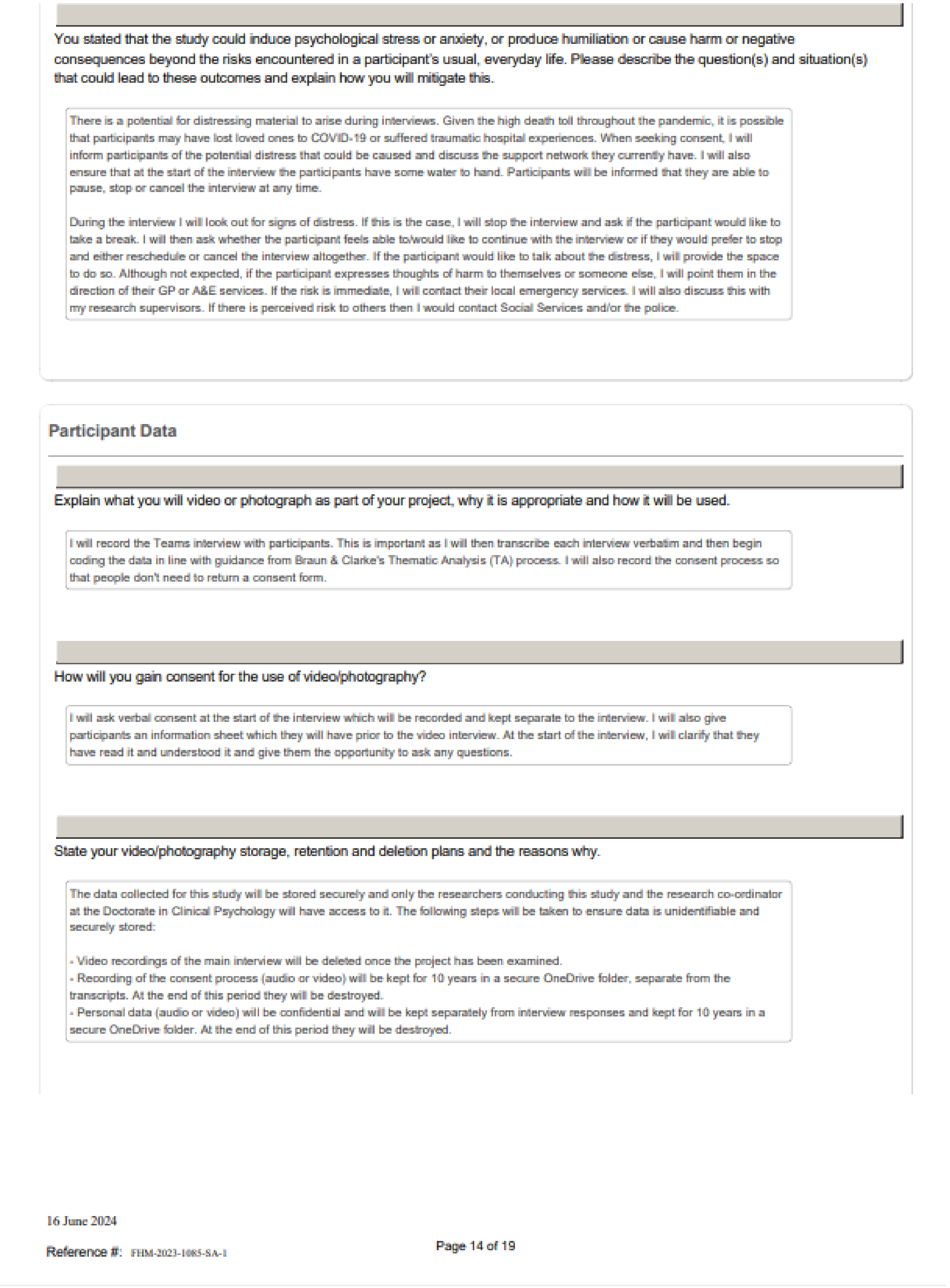
I will gather demographic information such as age, gender, ethnicity, occupation, living situation etc. I will also collect the participants address in case of an emergency as the interviews will be conducted via an online platform such as Teams. This will be discarded as soon as the interview is completed.

Please describe how the data will be collected and stored.

The data will be collected via 1-1 interviews. I will give participants a choice whether they are happy for the video to be on or whether they would like me to turn the video off and record the audio only. While the project is progressing, the data will be stored on my secure university OneDrive folder which my supervisors will also have access to. Once the project is completed, the data will get transferred to the DClinPsy research co-ordinator and will be stored on a secure OneDrive folder for 10 years after which they will be destroyed.

Please describe how long the data will be stored and who is responsible for the deletion of the data.

The video/audio recordings of the main interview will be kept until my examination is complete and then destroyed by me. The anonymised transcripts and audio/video recordings of consent will be stored separately for 10 years by the research co-ordinator of the DClinPsy in a secure OneDrive folder. It will then be deleted by the research co-ordinator under the supervision of the research supervisor, Fiona Eccles.



You stated that the study could induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual, everyday life. Please describe the question(s) and situation(s) that could lead to these outcomes and explain how you will mitigate this.

There is a potential for distressing material to arise during interviews. Given the high death toll throughout the pandemic, it is possible that participants may have lost loved ones to COVID-19 or suffered traumatic hospital experiences. When seeking consent, I will inform participants of the potential distress that could be caused and discuss the support network they currently have. I will also ensure that at the start of the interview the participants have some water to hand. Participants will be informed that they are able to pause, stop or cancel the interview at any time.

During the interview I will look out for signs of distress. If this is the case, I will stop the interview and ask if the participant would like to take a break. I will then ask whether the participant feels able to/would like to continue with the interview or if they would prefer to stop and either reschedule or cancel the interview altogether. If the participant would like to talk about the distress, I will provide the space to do so. Although not expected, if the participant expresses thoughts of harm to themselves or someone else, I will point them in the direction of their GP or A&E services. If the risk is immediate, I will contact their local emergency services. I will also discuss this with my research supervisors. If there is perceived risk to others then I would contact Social Services and/or the police.

Participant Data

Explain what you will video or photograph as part of your project, why it is appropriate and how it will be used.

I will record the Teams interview with participants. This is important as I will then transcribe each interview verbatim and then begin coding the data in line with guidance from Braun & Clarke's Thematic Analysis (TA) process. I will also record the consent process so that people don't need to return a consent form.

How will you gain consent for the use of video/photography?

I will ask verbal consent at the start of the interview which will be recorded and kept separate to the interview. I will also give participants an information sheet which they will have prior to the video interview. At the start of the interview, I will clarify that they have read it and understood it and give them the opportunity to ask any questions.

State your video/photography storage, retention and deletion plans and the reasons why.

The data collected for this study will be stored securely and only the researchers conducting this study and the research co-ordinator at the Doctorate in Clinical Psychology will have access to it. The following steps will be taken to ensure data is unidentifiable and securely stored:

- Video recordings of the main interview will be deleted once the project has been examined.
- Recording of the consent process (audio or video) will be kept for 10 years in a secure OneDrive folder, separate from the transcripts. At the end of this period they will be destroyed.
- Personal data (audio or video) will be confidential and will be kept separately from interview responses and kept for 10 years in a secure OneDrive folder. At the end of this period they will be destroyed.

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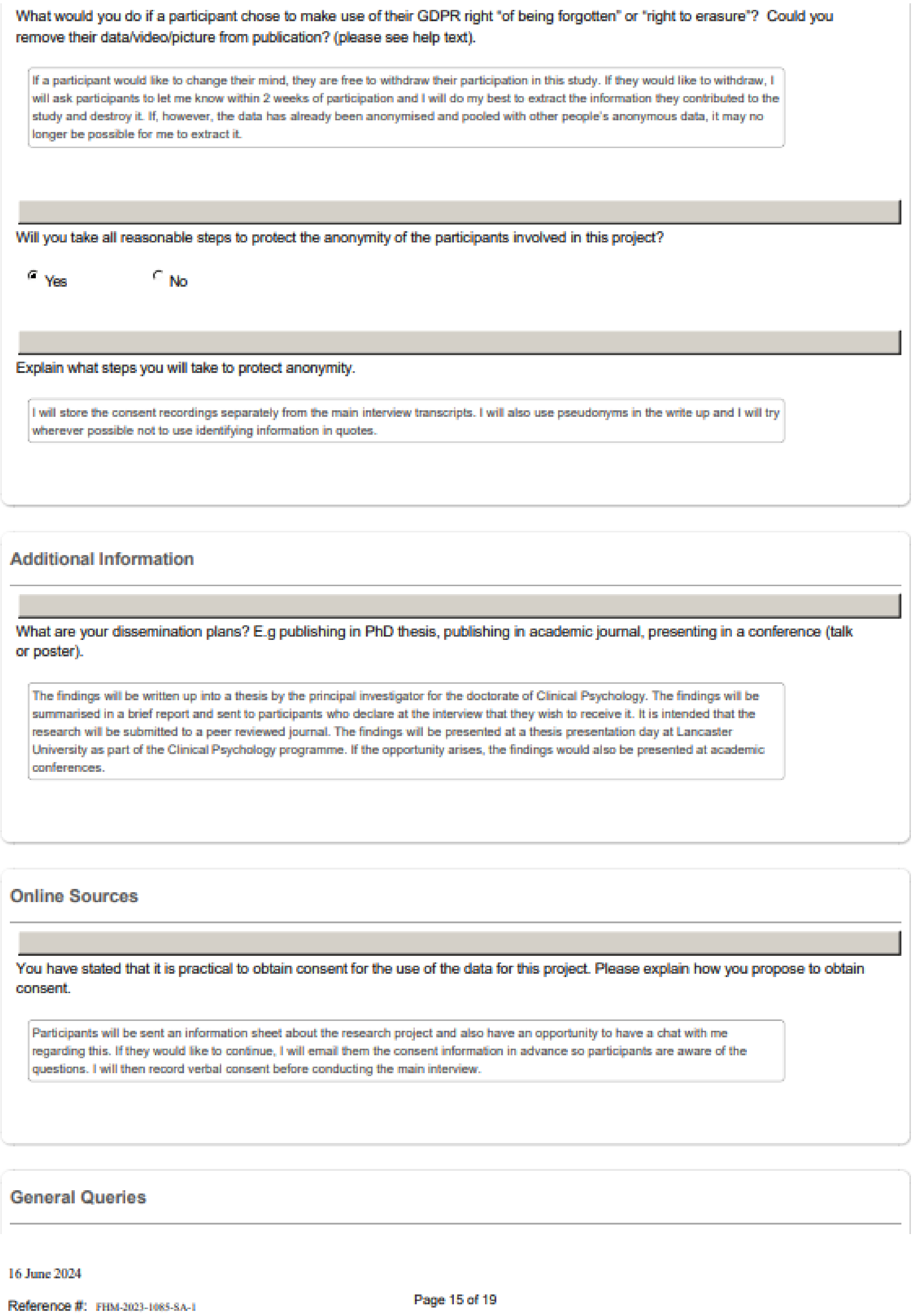

What would you do if a participant chose to make use of their GDPR right "of being forgotten" or "right to erasure"? Could you remove their data/video/picture from publication? (please see help text).

If a participant would like to change their mind, they are free to withdraw their participation in this study. If they would like to withdraw, I will ask participants to let me know within 2 weeks of participation and I will do my best to extract the information they contributed to the study and destroy it. If, however, the data has already been anonymised and pooled with other people's anonymous data, it may no longer be possible for me to extract it.

Will you take all reasonable steps to protect the anonymity of the participants involved in this project?

● Yes ○ No

Explain what steps you will take to protect anonymity.

I will store the consent recordings separately from the main interview transcripts. I will also use pseudonyms in the write up and I will try wherever possible not to use identifying information in quotes.

Additional Information

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

The findings will be written up into a thesis by the principal investigator for the doctorate of Clinical Psychology. The findings will be summarised in a brief report and sent to participants who declare at the interview that they wish to receive it. It is intended that the research will be submitted to a peer reviewed journal. The findings will be presented at a thesis presentation day at Lancaster University as part of the Clinical Psychology programme. If the opportunity arises, the findings would also be presented at academic conferences.

Online Sources

You have stated that it is practical to obtain consent for the use of the data for this project. Please explain how you propose to obtain consent.

Participants will be sent an information sheet about the research project and also have an opportunity to have a chat with me regarding this. If they would like to continue, I will email them the consent information in advance so participants are aware of the questions. I will then record verbal consent before conducting the main interview.

General Queries

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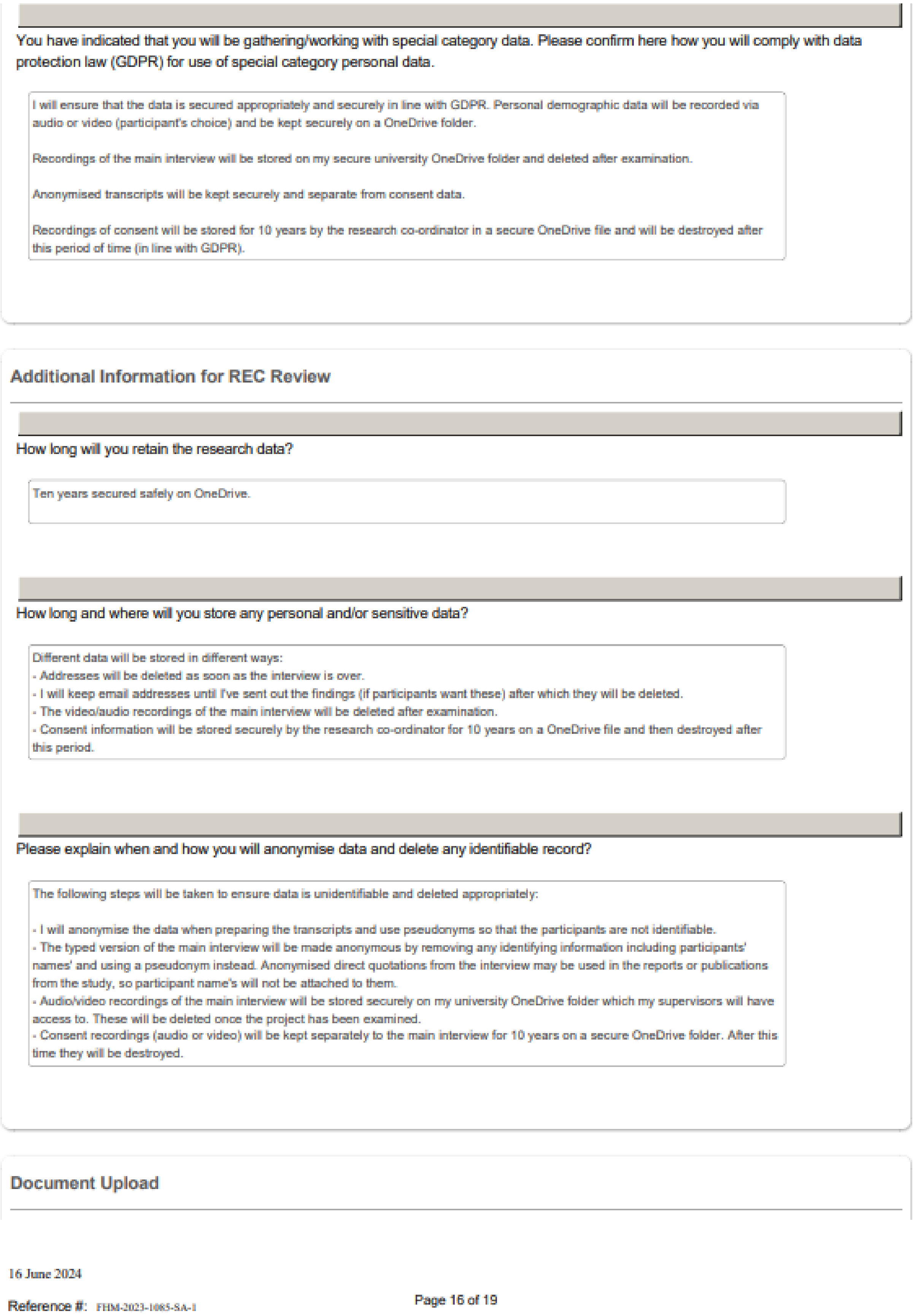

You have indicated that you will be gathering/working with special category data. Please confirm here how you will comply with data protection law (GDPR) for use of special category personal data.

I will ensure that the data is secured appropriately and securely in line with GDPR. Personal demographic data will be recorded via audio or video (participant's choice) and be kept securely on a OneDrive folder.

Recordings of the main interview will be stored on my secure university OneDrive folder and deleted after examination.

Anonymised transcripts will be kept securely and separate from consent data.

Recordings of consent will be stored for 10 years by the research co-ordinator in a secure OneDrive file and will be destroyed after this period of time (in line with GDPR).

Additional Information for REC Review

How long will you retain the research data?

Ten years secured safely on OneDrive.

How long and where will you store any personal and/or sensitive data?

Different data will be stored in different ways:
- Addresses will be deleted as soon as the interview is over.
- I will keep email addresses until I've sent out the findings (if participants want these) after which they will be deleted.
- The video/audio recordings of the main interview will be deleted after examination.
- Consent information will be stored securely by the research co-ordinator for 10 years on a OneDrive file and then destroyed after this period.

Please explain when and how you will anonymise data and delete any identifiable record?

The following steps will be taken to ensure data is unidentifiable and deleted appropriately:

- I will anonymise the data when preparing the transcripts and use pseudonyms so that the participants are not identifiable.
- The typed version of the main interview will be made anonymous by removing any identifying information including participants' names' and using a pseudonym instead. Anonymised direct quotations from the interview may be used in the reports or publications from the study, so participant name's will not be attached to them.
- Audio/video recordings of the main interview will be stored securely on my university OneDrive folder which my supervisors will have access to. These will be deleted once the project has been examined.
- Consent recordings (audio or video) will be kept separately to the main interview for 10 years on a secure OneDrive folder. After this time they will be destroyed.

Document Upload

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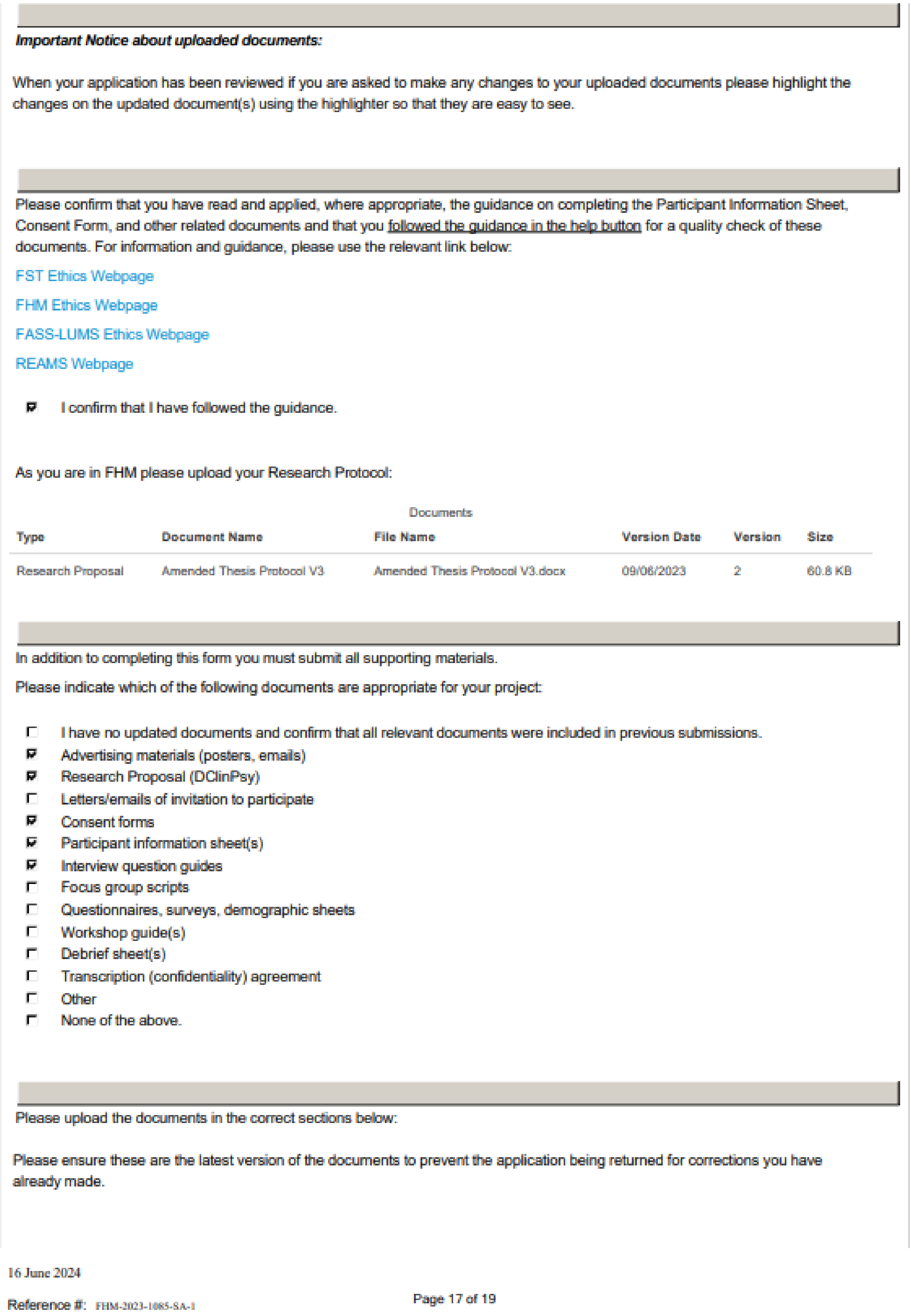

Important Notice about uploaded documents:

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight the changes on the updated document(s) using the highlighter so that they are easy to see.

Please confirm that you have read and applied, where appropriate, the guidance on completing the Participant Information Sheet, Consent Form, and other related documents and that you followed the guidance in the help button for a quality check of these documents. For information and guidance, please use the relevant link below:

FST Ethics Webpage

FHM Ethics Webpage

FASS-LUMS Ethics Webpage

REAMS Webpage

☑ I confirm that I have followed the guidance.

As you are in FHM please upload your Research Protocol:

Documents

Type	Document Name	File Name	Version Date	Version	Size
Research Proposal	Amended Thesis Protocol V3	Amended Thesis Protocol V3.docx	09/06/2023	2	60.8 KB

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

☐ I have no updated documents and confirm that all relevant documents were included in previous submissions.
☑ Advertising materials (posters, emails)
☑ Research Proposal (DClinPsy)
☐ Letters/emails of invitation to participate
☑ Consent forms
☑ Participant information sheet(s)
☑ Interview question guides
☐ Focus group scripts
☐ Questionnaires, surveys, demographic sheets
☐ Workshop guide(s)
☐ Debrief sheet(s)
☐ Transcription (confidentiality) agreement
☐ Other
☐ None of the above.

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you have already made.

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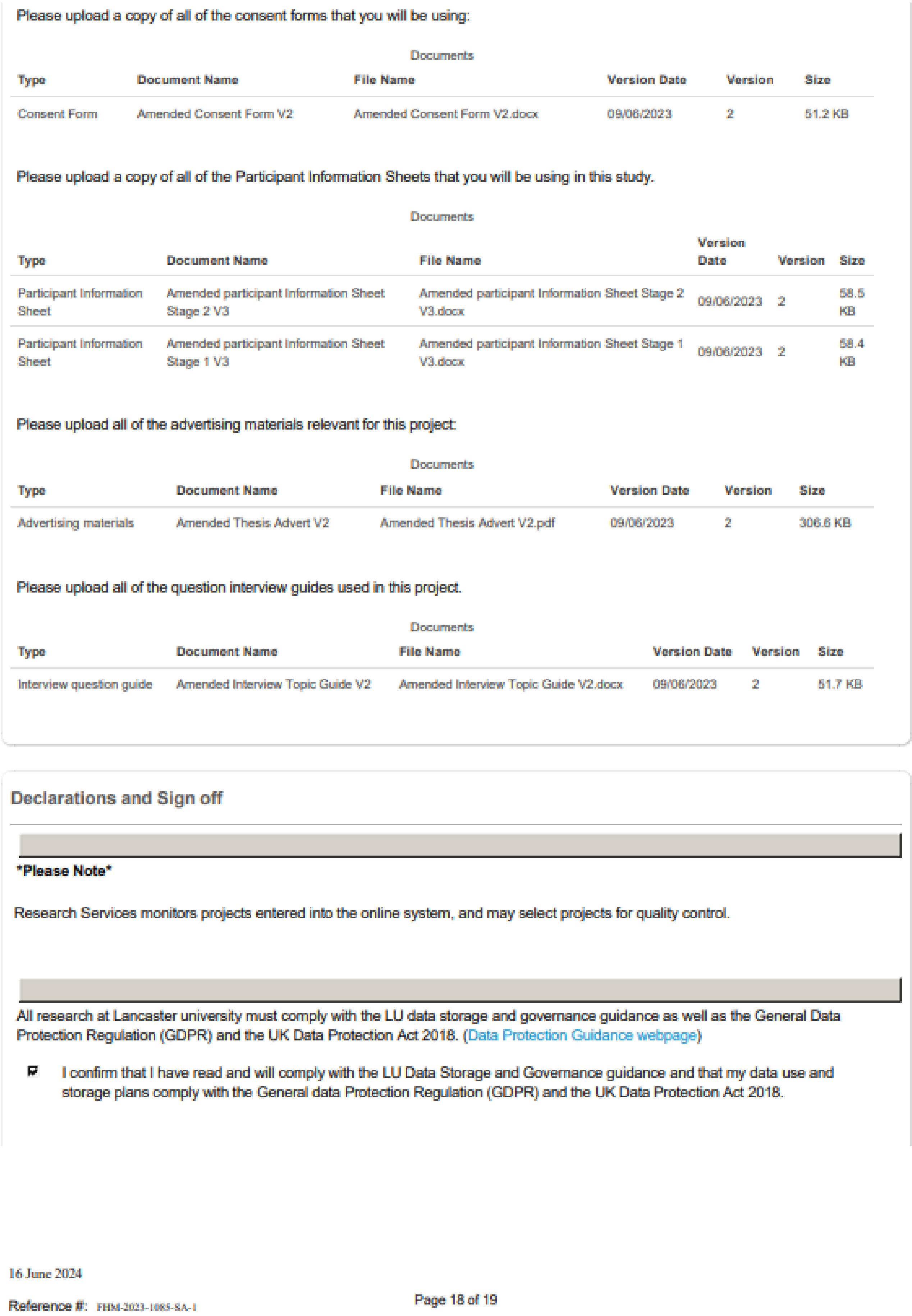

Please upload a copy of all of the consent forms that you will be using:

Documents

Type	Document Name	File Name	Version Date	Version	Size
Consent Form	Amended Consent Form V2	Amended Consent Form V2.docx	09/06/2023	2	51.2 KB

Please upload a copy of all of the Participant Information Sheets that you will be using in this study.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Participant Information Sheet	Amended participant Information Sheet Stage 2 V3	Amended participant Information Sheet Stage 2 V3.docx	09/06/2023	2	58.5 KB
Participant Information Sheet	Amended participant Information Sheet Stage 1 V3	Amended participant Information Sheet Stage 1 V3.docx	09/06/2023	2	58.4 KB

Please upload all of the advertising materials relevant for this project:

Documents

Type	Document Name	File Name	Version Date	Version	Size
Advertising materials	Amended Thesis Advert V2	Amended Thesis Advert V2.pdf	09/06/2023	2	306.6 KB

Please upload all of the question interview guides used in this project.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Interview question guide	Amended Interview Topic Guide V2	Amended Interview Topic Guide V2.docx	09/06/2023	2	51.7 KB

Declarations and Sign off

Please Note

Research Services monitors projects entered into the online system, and may select projects for quality control.

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. (Data Protection Guidance webpage)

☑ I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

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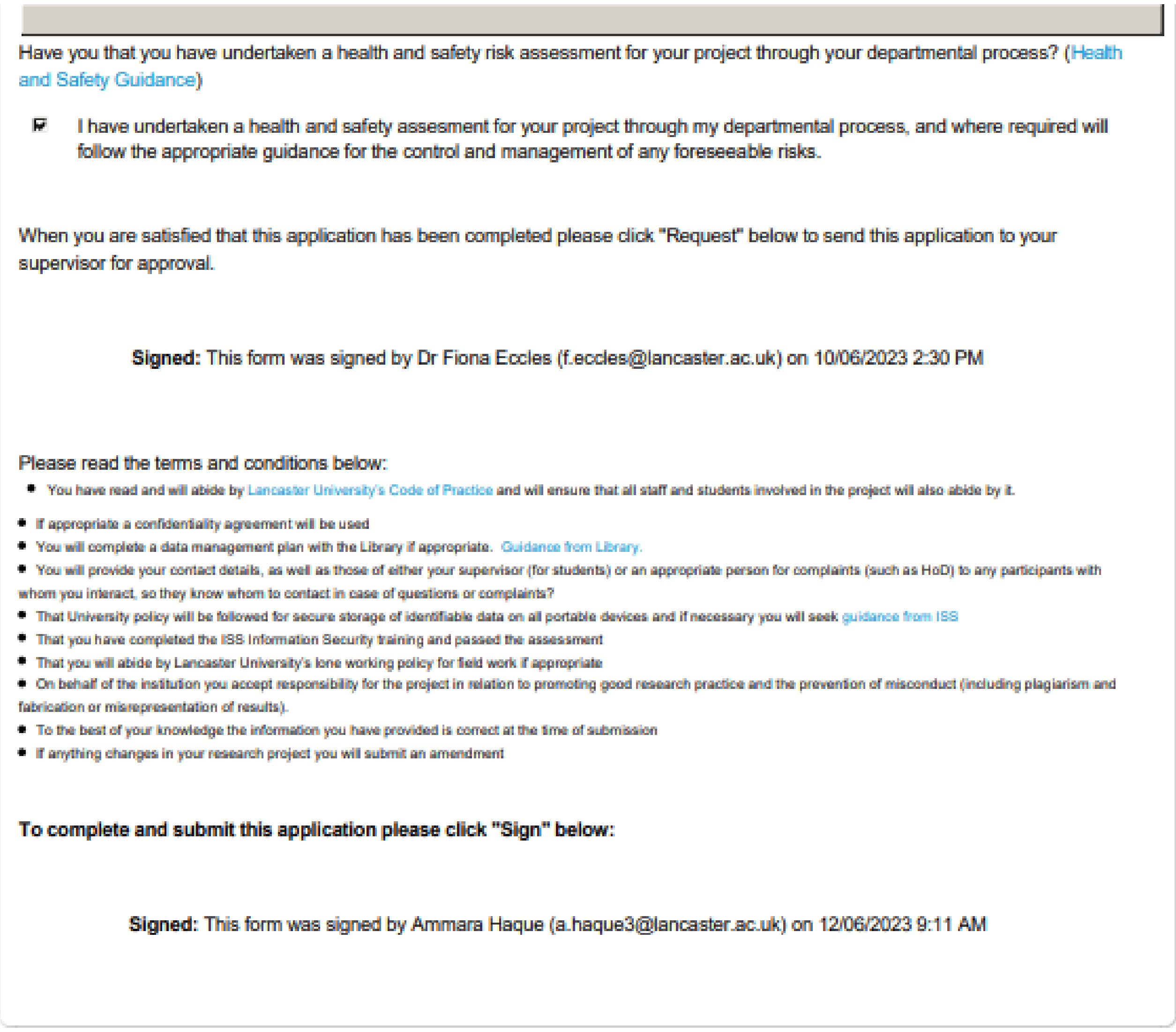

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? (Health and Safety Guidance)

☑ I have undertaken a health and safety assesment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval.

Signed: This form was signed by Dr Fiona Eccles (f.eccles@lancaster.ac.uk) on 10/06/2023 2:30 PM

Please read the terms and conditions below:

- You have read and will abide by Lancaster University's Code of Practice and will ensure that all staff and students involved in the project will also abide by it.
- If appropriate a confidentiality agreement will be used
- You will complete a data management plan with the Library if appropriate. Guidance from Library.
- You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
- That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek guidance from ISS
- That you have completed the ISS Information Security training and passed the assessment
- That you will abide by Lancaster University's lone working policy for field work if appropriate
- On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- To the best of your knowledge the information you have provided is correct at the time of submission
- If anything changes in your research project you will submit an amendment

To complete and submit this application please click "Sign" below:

Signed: This form was signed by Ammara Haque (a.haque3@lancaster.ac.uk) on 12/06/2023 9:11 AM

Appendix 4-A Research Protocol

Title

The experience of having persistent cognitive problems after being infected with COVID-19.

Name of applicant/supervisors/affiliations

Principal Investigator: Ammara Haque, Trainee Clinical Psychologist, Lancaster University

University Project Supervisor: Dr Fiona Eccles, Lecturer in Research Methods, Lancaster University

Field Supervisor: Dr Will Curvis, Clinical Tutor, DClinPsy, Lancaster University

Introduction

The SARS-CoV-2 virus which causes the disease COVID-19 was first detected in 2019 and the World Health Organisation declared a pandemic in early 2020. There are prevalent acute physical symptoms of this respiratory based illness (such as loss of taste and smell, difficulty breathing, high temperature etc.) but there are also many symptoms which for some persist beyond the four weeks of the acute illness – these are known as ongoing symptoms of COVID-19. Some symptoms have been found to persist even longer (beyond 12 weeks of initial infection). These persistent symptoms are more commonly known as 'long COVID-19' (World Health Organisation (WHO), 2022). The nature of the persistent symptoms is hugely variable and while physical symptoms are common (Huang et al., 2020; Fernández-de-Las-Peñas et al., 2021), cognitive impairment as well as psychological distress have also persisted within some individuals (Shou et al.,2021).

Shou et al., (2021) collated 27 studies in their review which investigated cognitive decline at two different time points. One study found that 78% of patients reported cognitive impairment in at least one domain at a three month follow up (Mazza et al. 2021). Similarly, Chaumont et al. (2021) found that at a six month follow up, 34% of previously hospitalised patients reported memory impairment with 68.9% of patients showing impaired cognition. A systematic review (Jennings et al., 2021) found that 35% of people reported memory impairment 12 weeks post initial COVID-19 infection. Lu et al. (2020) also found cognitive deficits at 3 months post-COVID with a specific increase in memory loss from one month to three months follow up.

A recent study conducted by Tabacof et al., (2022) with a longer follow up of 351 days, found 67% of participants reported “brain fog” (a colloquial term for cognitive difficulties) as one of the most common symptoms. Memory loss and confusion was reported by 52% and 46% of people respectively. The Neuro-Qol was used to determine cognitive impairment and 63% of patients self-reported at least mild cognitive impairment however the study’s lack of comparison to pre COVID-19 data meant it was difficult to determine whether this is due specifically to having contracted the SARS-CoV-2 virus. Lamontagne et al., (2021) found that participants were shown to have impairment in attention and executive functioning four months after initial infection. This is consistent with results from Mazza et al. (2021) who showed similar impairments at a three month follow up however, they also found cognitive impairments in other domains such as verbal fluency and information processing.

Severity of depressive symptoms has been identified as one predictor of cognitive impairment (Gennaro et al., 2021). Gouraud et al. (2021) found that 29% of participants reported cognitive complaints at one month follow up which was found to be associated with psychological distress. However, given this is a cross-sectional study, cause and effect cannot be ascertained. ICU admission was not found to be a predictor of cognitive complaints however the length of stay in ICU was associated with developing neurocognitive and psychological difficulties. This could be because patients in ICU were focussed less on the cognitive impacts and more on the immediate physical impacts at the time. This suggests that there are varied experiences of cognitive impairment and psychological distress.

Thus a large volume of literature has focussed on quantitative data showing that cognitive difficulties are present even up to a year after initial infection. However, no study has explored how people make sense of these difficulties and the impact of them in their daily lives. In addition to this, one must also consider the social context of the pandemic, where the illness the person has experienced is a topic of everyday conversation and government decision making. Furthermore, it is possible that individuals were discharged from acute care without much assessment in the early days of the pandemic and there were limited pathways for neuropsychological assessment or support post-discharge. Therefore, my study is interested in looking the experiences/perspectives of people who were infected with COVID-19 and have been left with cognitive impairments that have had a functional impact on their lives. The study aims to specifically understand cognitive difficulties that have persisted after at least 12 weeks of initial infection to better understand the longevity of symptoms and how they have had a functional impact on people's lives. With a large proportion of individuals having been infected with COVID-19, it is important to understand the cognitive difficulties they face as it can help to inform the role of clinical psychology in direct work with people with cognitive difficulties. The study can help to inform practice in supporting individuals in a way that is efficient and effective. It may also help to advocate for this population on a wider systemic level if we are to know more about how they are being affected by persistent cognitive difficulties.

Method

Design

Qualitative methodology using thematic analysis (TA) (Braun & Clarke, 2006) will be used to explore the experiences of people affected by cognitive difficulties and identify patterns across the data. As the study is concerned with how individuals make sense of their experience of cognitive difficulties after being hospitalised with COVID-19, I plan to use phenomenologically informed TA to gain a detailed interpretative account of individual experience. TA has been used widely in clinical psychology to research people's experiences of illness, psychological distress etc. and identify patterns across the data. This is particularly important as the study aims to recruit individuals from a wide range of backgrounds to counter the typical white middle class bias amongst psychological research (Roberts et al., 2020).

Participants

I am interested in the experience of people who have previously been ~~hospitalised~~ infected with COVID-19 and are experiencing persistent cognitive difficulties as a result of this. I aim to recruit 8-15 participants who have had a positive COVID-19 test. Participants recruited will be between the ages of 18 and 65 (adult working age), be of any gender and be living in the UK. They must be experiencing persistent cognitive difficulties (that have *persisted for at least 12 weeks* after having contracted the virus). Difficulties could include (but not limited to): memory loss, language problems, difficulties with attention, reasoning and judgement and complex decision-making. The cognitive difficulties must have some sort of functional impact on their lives (ascertained by self-report). People will be excluded if their cognitive difficulties were apparent prior to contracting COVID-19.

Stage 1 of recruitment will require the cognitive difficulties to be current. If I have more interest than I need, I will prioritise hearing from groups that are less well represented in research e.g., belonging to the global majority, and those who have had more severe symptoms. If sufficient participants are not recruited, then stage 2 of recruitment will include people who had cognitive difficulties (persisting after 12 weeks) but which have since resolved.

Recruitment

I aim to identify specific third sector and online pathways for recruitment. I aim to recruit participants through online long covid support groups and various social media platform such as Twitter. Psychological research often tends to have a white middle class bias and so I will target a range of people from various groups (for example there is a long covid support group specifically for South Asians).

I will have an advert for my study which I will post online. When people read this, they can contact me for more information. If interested, I will send the information sheet (Appendix 2) and consent form (Appendix 1) and offer people the opportunity to have a chat with me regarding the study before they choose to take part. I'll also ascertain either by speaking to them or via email that they meet the inclusion criteria and then arrange an interview time if they wish to take part. They will be informed that they do not need to return the consent form as I will be going through it with them at the start of the interview. Before the interview starts, I will ask them to confirm whether they understand and if they would like to participate in the study. This will be recorded separately to the rest of the interview.

Data collection

I will use 1-1 semi structured interviews to collect data (anticipated to be approximately 1 hour each), offering a remote option to make it accessible for all (telephone or online). There will also be the opportunity to conduct the interview over more than one session if participants are fatigued. Interviews will provide the richness in data as it is personal experience that the study aims to identify. The semi structured nature of the interview will allow me to ask questions based on the participants' responses thereby focusing on important areas which arise for the participant, allowing a greater flexibility of coverage. This means that the interview topic guide (Appendix 3) will act as a guide, but the interview will focus on the topics that participants feel is most important to them.

The interviews will be conducted through an online platform such as MS Teams or via the telephone if internet access is not possible to increase the geographical pool of the study. Demographical information such as age, gender, ethnicity, living situation, partnership status, occupation status, time since hospitalisation and duration of cognitive difficulties will also be gathered. At the start of the interview, the participant's address will be collected in case of any immediate risk for which I may need to contact the local emergency services. The address will be destroyed immediately once each interview is completed.

Proposed analysis

I will transcribe each interview verbatim (using the automated function from Teams and then checking by hand). I will then code all the transcripts and then collate the codes into themes following Braun and Clarke (2006).

Practical issues (e.g., costs/logistics)

There are potential recruitment difficulties as it may be difficult to identify the specific group that I am targeting however getting in touch with online long COVID support groups could help to overcome the challenges of this. As I will be using social media (twitter and online forums) for recruitment, it is possible that this could lead to a largely white, middle-class perspective. To address this, I will target specific groups for a range of people.

Ethical concerns

As the population will be experiencing cognitive difficulties, I will need to take this into account when planning interviews (i.e., finding an appropriate time of day and offering people breaks if needed).

There is also a potential for distressing material to arise during interviews. Given the high death toll throughout the pandemic, it is possible that participants may have lost loved ones to COVID-19 or suffered traumatic hospital experiences. When seeking consent, I will inform participants of the potential distress that could be caused and discuss the support network they currently have. I will also ensure that at the start of the interview the participants have some water to hand. Participants will be informed that they are able to pause, stop or cancel the interview at any time.

During the interview I will look out for signs of distress. If this is the case, I will stop the interview and ask if the participant would like to take a break. I will then ask whether the participant feels able to/would like to continue with the interview or if they would prefer to stop and either reschedule or cancel the interview altogether. If the participant would like to talk about the distress, I will provide the space to do so. Although not expected, if the participant expresses thoughts of harm to themselves, I will point them in the direction of their GP or A&E services. If the risk is immediate, I will contact their local emergency services. I will also discuss this with my research supervisors. If there is perceived risk to others, then I would contact Social Services and/or the police.

Timescale

Prepare Ethics Documentation	June – Sept 2022
Ethics Committee Review	Oct – Nov 2022
Recruitment	Jan – Aug 2023
Analysis	Aug – Oct 2023
Write up	Nov – Dec 2023

Dissemination

The findings will be written up into a thesis by the principal investigator for the Doctor of Clinical Psychology. The findings will be summarised in a brief report and sent to participants who declare at the interview that they wish to receive it. It is intended that the research will be submitted to a peer reviewed journal. The findings will be presented at a thesis presentation day at Lancaster University as part of the Clinical Psychology programme. If the opportunity arises, the findings would also be presented at academic conferences or special interest groups.

Service User Involvement

I have consulted an expert by experience (an individual who was hospitalised with COVID-19), to seek their views and advice regarding the design, recruitment, and interview schedule of the project. They have also looked over the participant information sheet and consent form and provided feedback for these which has been incorporated.

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Appendix 4-B Participant Information Sheet

Participant Information Sheet (Stage 1 recruitment)

The experience of having persistent cognitive problems after being infected with COVID-19.

My name is Ammara Haque, and I am conducting this research as a student in the Doctorate of Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom. I would like to invite you to take part in a research study about living with cognitive difficulties after contracting COVID-19.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/datae-protection

What is the study about?
Many of the population were infected with COVID-19 during the global pandemic and have found that some of their symptoms persisted. In particular in this study, I'm interested to hear from people who have continued to experience cognitive problems, i.e., problems with thinking, memory, planning etc which started after falling ill with COVID-19. I want to talk to people whose difficulties are having an impact on their daily lives, making it harder to do everyday tasks like managing their finances, cooking, planning, paid work, taking care of the family etc. I want to find out what it is like living with these difficulties.

Why have I been invited?
Thank you for your interest in taking part in my study. You have been approached because the study requires views and thoughts from people who have previously been infected with COVID-19 and have experienced problems which affect the functioning of their daily lives. I would like to hear from you if you are experiencing any form of cognitive difficulties such as (but not limited to): difficulties with speech/language, memory problems, difficulties with attention/concentration and/or decision making. **These difficulties must have persisted beyond 12 weeks after the initial infection, and you must be experiencing them currently.** If I have a lot of interest from participants, I will need to further select participants and will require some brief information from you such as your ethnicity and severity of COVID, prior to the interview. This is so we can enable a broad range of voices in research.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part. Your participation is voluntary.

What will I be asked to do if I take part?
If you decide you would like to take part, or would just like to know more about the study, please let me know by sending me an email on a.haque3@lancaster.ac.uk. If you decide you want to take part, I'll ask some questions to check you are eligible for the research and if you are happy to continue, we will agree on a suitable date and time for an online/telephone interview.

The interview will most likely be held on an online platform such as MS Teams. If you have difficulties accessing the internet, we can conduct the interview via telephone. You will be asked to read the attached consent form before the interview. You do not need to fill out the form and return it as I will read its contents to you before the interview and ask whether you understand and agree to participate in the study. I will audio record your consent in a separate file from the interview.

During the interview I will ask you a series of questions about the cognitive difficulties you have been experiencing. The interview will last up to one hour and will be audio/video recorded. The interview can be split up into smaller parts if concentrating for an hour is too difficult.

If you would like to take part in the study but there are barriers to taking part such as limited/no access to the internet, please get in contact and we can discuss other means such as a telephone interview.

What if I change my mind?
If you change your mind, you are free to withdraw your participation in this study. If you would like to withdraw, please let me know within 2 weeks of participation and I will extract the information you contributed to the study and destroy it. If you contact me after 2 weeks I may still be able to remove your data however, if your data has already been anonymised and pooled with other people's anonymous data, it may no longer be possible for me to extract it.

How will my data be stored?
The data collected for this study will be stored securely and only the researchers conducting this study and the research co-ordinator at the Doctorate in Clinical Psychology will have access to it. The following steps will be taken to ensure data is unidentifiable and securely stored:

- Audio recordings of the main interview will be deleted once the project has been examined.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, electronic copies of the transcripts and audio recordings of consent will be kept securely separately in OneDrive folders for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I must do this.

What will happen to the results?
The results will form part of my doctoral thesis for the Doctorate in Clinical Psychology programme. The findings will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal and presented at conferences and special interest groups. I am happy to provide you with a copy of the findings if you would like one.

When writing up the findings from this study, I may use direct quotes from your interview. These will always be anonymised so that they are not identifiable. Please see the heading 'How my data will be stored' for a further explanation of this.

Are there any risks?
There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?
This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the main researcher: Ammara Haque a.haque3@lancaster.ac.uk. You can also contact Fiona Eccles (f.eccles@lancaster.ac.uk) or Will Curvis (w.curvis@lancaster.ac.uk) who are supervising this project.

Complaints or Concerns
If you wish to make a complaint or raise concerns about any aspect of this study and do not wish to speak to the researcher, you can contact:

Ian Smith, Research Director of the Doctorate in Clinical Psychology
Tel: 01524 592282
Email: i.smith@lancaster.ac.uk
Division of Health Research
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Dr Laura Machin, Chair of FHM REC
Tel: +44 (0)1524 594973
Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Resources in the event of distress
Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

You are advised to talk to your GP if you are experiencing distress.

Long COVID support groups:

https://www.longcovid.org/

Mind Info line: 0300 123 3393
http://www.mind.org.uk/

The Samaritans Info line: 08457 90 90 90
http://www.samaritans.org/

Thank you for your consideration to participate in this project.

Appendix 4-C Participant Consent Form

Consent Form

Study Title: The experience of having persistent cognitive difficulties after being infected with COVID-19.

Note: You do not need to return this form – it is provided for information only.

We are asking if you would like to take part in a research project investigating the experiences of cognitive difficulties after being infected with COVID-19. Before you consent to participating in the study, we ask that you read the participant information sheet and this consent form. If you consent to take part in the study, we will review the statements below at the start of the interview and I will ask you to confirm that you agree to each of them – verbally (as interviews will be conducted via an online video platform or over the telephone if you have difficulties accessing the internet). This will be recorded either via video or audio.

If you have any questions or queries before consenting, please email the principal investigator, Ammara Haque at a.haque3@lancaster.ac.uk.

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio and video recorded and then made into an anonymized written transcript.
4. I understand that audio and video recordings will be kept until the research project has been examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
6. I understand that I have two weeks after the interview to contact the researcher if I wish to withdraw my data. I understand that it may not be possible to withdraw my data after this point if my data has been already analysed.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymized and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that the researcher will discuss data with their supervisors as needed.
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor.
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.

12. I consent to take part in the above study.

Appendix 4-D: Interview Topic Guide

Interview Topic Guide

Although these are topics that will be covered, I will be guided by what is of interest to the participants.

1) Verbal consent for taking part in the study
2) Collection of demographic data
    a. Full name
    b. Age
    c. Gender at birth
    d. Preferred Gender
    e. Ethnic group
    f. Relationship Status
    g. Do you live alone? Yes or No
    h. Occupation
3) When did you first become ill with COVID-19?
    a. Were you hospitalised?
        i. How long were you hospitalised for?
        ii. What was the hospital experience like?
    b. If you weren't hospitalised how long did you have COVID for?
        i. What was the experience like?
4) Some people have experienced long term difficulties with their thinking skills. What sorts of cognitive difficulties/thinking/memory problems have you been experiencing? (e.g., I am always forgetting where I leave my keys; I am getting my words jumbled up; I find it harder to concentrate for long periods of time etc.)
    a. How long for?
    b. Have these become better or worse over time?
        i. Attention/Concentration
            1. Can you maintain concentration for more than 20 mins
            2. Are you able to shift your attention between different things
            3. Do you get distracted easily, can you bring yourself back? What sorts of things distract you.
            4. Is there particular information you find difficult sticking? Info that you've heard or seen?
        ii. Memory – past, current, working. Have you noticed any difficulties with your memory? Noticed any differences with words compared to numbers? Can you remember phone numbers? Does your mind go blank?
        iii. Language – reading, writing, spelling, speech.
            1. How are your reading skills? Has that changed since being hospitalised with covid?
            2. Are you getting your words jumbled up? Can you find the right words to say?
            3. Are you making more spelling mistakes than you usually would?
        iv. Changes to vision?

        v. Executive functioning – planning, problem solving, decision making. Do you beat yourself up more when you can't get things right.

5) Sense making of the cognitive difficulties and the experience of having it
    a. What is it like having these difficulties? How would you describe/explain it to someone? What would you compare it with?
    b. What is your understanding of the cognitive difficulties?
    c. How do others understand it? (family, friends, health care staff)
6) What is the impact of your cognitive difficulties on your functioning and wellbeing?
    a. On work, leisure, and relationships (family life, intimate relationships, friends)
    b. On your mental health and wellbeing – how was it before you experienced the cognitive difficulties and how is it now? How is your relationship with yourself – how do you view yourself?
    c. Is there anything you think people should know about cognitive difficulties since contracting COVID-19?
7) How have you been managing these difficulties?
    a. What have you been doing to manage and continue with your activities of daily living/daily functioning?
8) What is your experience (if any) of receiving support for these difficulties so far? – from family, friends, professionals.
    a. What's been helpful? What's not been helpful? What do you think would be more helpful?
    b. Have you accessed any psychological support for these difficulties? Why/why not?
    c. If yes, how helpful has this been?
9) What do you wish health professionals knew or understood that you know now?
10) If recovered or recovering: what do you think helped the recovery the most? If not recovering – what do you think are the barriers to your recovery? What would help?
11) Is there anything else that you feel is important that I have not asked about?

Appendix 4-E: Advertising Materials

PARTICIPANTS NEEDED

Recruiting participants now, contact: a.haque3@lancaster.ac.uk

Exploring cognitive difficulties post COVID-19

Who am I?

My name is Ammara and I am a student on the Doctorate of Clinical Psychology programme at Lancaster University. I would like to invite you to take part in a study on experiences of cognitive difficulties after COVID-19.

Who is eligible?

You are invited to take part if you:

- Are **18-65** years old
- Have been infected with COVID-19
- Have experienced **brain fog or other cognitive difficulties** persisting beyond 12 weeks of initial infection

What is it about?

This study aims to explore the cognitive difficulties that people have been experiencing since being discharged from hospital with COVID-19.

Your contribution would help mental health services learn how to better support individuals suffering with cognitive difficulties since contracting COVID-19.

What will I need to do?

You will be required to take part in an hour long interview on MS Teams or over the phone (breaks included if required)!

What are cognitive difficulties?

Some examples include things like brain fog and memory loss (such as forgetting where you left your keys), difficulty concentrating, issues with communication or problem solving - but of course, is not limited to these.

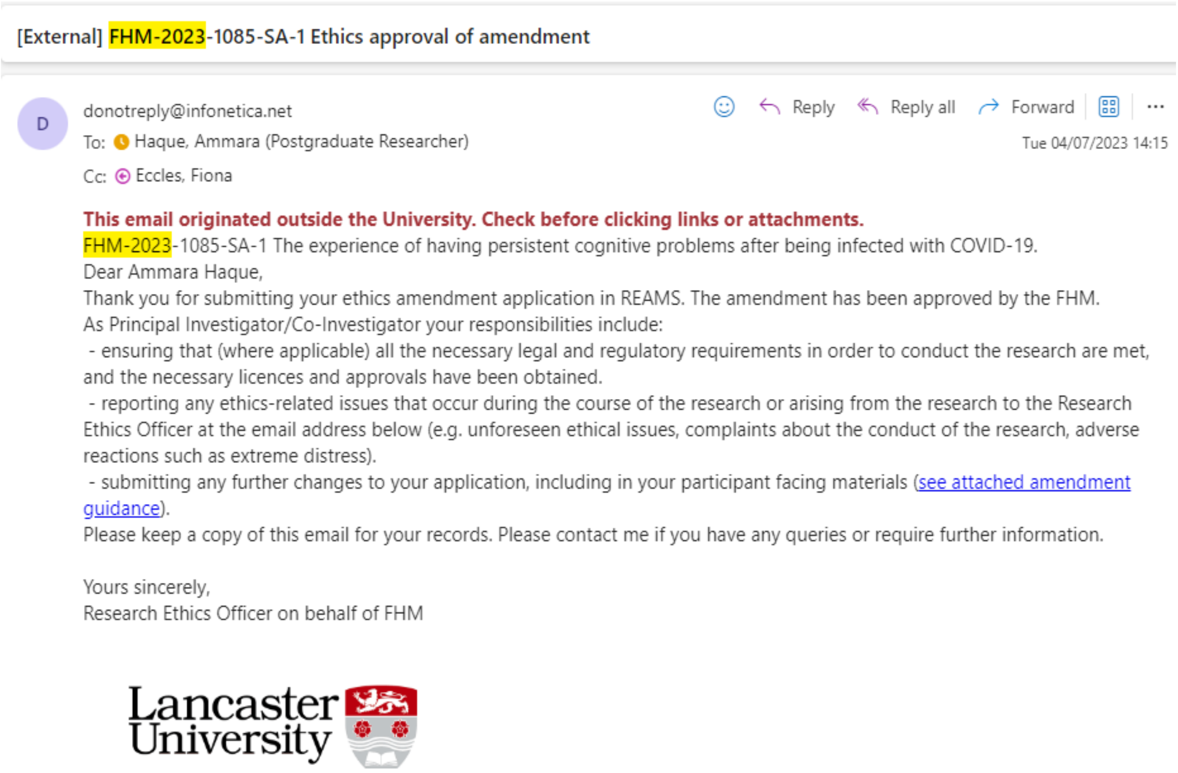
Interested?

If you are interested in participating, or would like more information, please contact:

A.HAQUE3@LANCASTER.AC.UK

We would like to hear your story!

Appendix 4-F: Ethics Approval Email



[External] FHM-2023-1085-SA-1 Ethics approval of amendment

donotreply@infonetica.net
To: Haque, Ammara (Postgraduate Researcher)
Cc: Eccles, Fiona
Tue 04/07/2023 14:15

This email originated outside the University. Check before clicking links or attachments.

FHM-2023-1085-SA-1 The experience of having persistent cognitive problems after being infected with COVID-19.

Dear Ammara Haque,

Thank you for submitting your ethics amendment application in REAMS. The amendment has been approved by the FHM.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).
- submitting any further changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,
Research Ethics Officer on behalf of FHM

Lancaster University