Do illness perceptions predict health outcomes

in adults with Long COVID?

Sarah Charlotte Caroline Keith

Department of Psychology, Faculty of Natural Sciences

University of Stirling

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Abstract

Background: The cognitive and emotional responses to an illness, known as illness perceptions, can contribute to psychological distress and impact self-management of health conditions. This research looks at the illness perceptions associated with Long COVID, the name given to symptoms which persist for more than 12 weeks after a COVID-19 infection.

Objectives: This study aims to identify the psychological characteristics of adults with Long COVID, investigate associations between illness perceptions and mental health, and explore whether illness perceptions and mental health are predictors of quality of life and functioning in adults with Long COVID.

Methods: 253 participants were recruited from a Long COVID assessment clinic within the National Health Service in England and completed outcome measures evaluating mental health, quality of life, functioning, and illness perceptions. These were completed face-to-face at baseline in the clinic. 61 participants completed quality of life and functioning outcome measurements again via post and online at least three months later at follow-up between November 2020 and March 2022. Hierarchical regression was used to investigate whether baseline measures of illness perceptions and mental health were significant predictors of health outcomes at follow-up.

Results: At baseline 59% reported clinically significant depression, 42% reported clinically significant anxiety, and 37% reported comorbid anxiety and depression. There was no difference in anxiety and depression scores between individuals who were hospitalised with acute COVID-19 and those who were not. The total Brief Illness Perception score was associated with poorer mental health at baseline. Mental health at baseline was a significant predictor of quality of life and functioning at follow-up, but illness perceptions were not.

Conclusion: Individuals with Long COVID presented with higher levels of anxiety and depression than the general population which had a negative impact on health outcomes.

Chapter 1

Introduction

Long COVID, Illness perceptions and the role of health psychology

Do illness perceptions predict health outcomes in adults with Long COVID?

1.1 The COVID pandemic

In December 2019 a new virus was identified in Wuhan, China and by March 2020 a pandemic was declared by the World Health Organisation (WHO). This new virus was caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and was commonly known as COVID-19. The severity of the illness varied, with some people experiencing little to no symptoms and others experiencing severe respiratory illness that was fatal, particularly for those with underlying medical conditions. Common symptoms were a cough, fatigue, and a loss of taste and smell (WHO, 2022). COVID-19 is an airborne illness, and as such a range of preventative measures were implemented to try and prevent the spread of the virus. In England measures such as physical distancing, the use of face masks, and self-isolation were implemented with everyone's lives impacted (COVID-19 Policy Tracker, 2020). As people began to recover from the initial infection, a new condition, named Long COVID, was emerging as people reported ongoing symptoms several months after their initial infection.

1.2 Long COVID

The World Health Organisation (WHO) recognised Long COVID in 2021 and named it 'Post COVID-19 Condition' (PCC) (Soriano et al., 2022). WHO describes the condition as ongoing symptoms from a COVID-19 infection for at least two months that cannot be explained by an alternative diagnosis (Clinical Services and Systems, 2021). Other terms used to refer to the condition are Post-Acute COVID-19 syndrome (PACS) and Post-Acute Sequelae of COVID-19 (PASC). Although a recognised medical term, post-COVID-19 syndrome is more familiar to patients and many health professionals as 'Long COVID' (Callard & Perego, 2021).

As of September 2022, it is estimated that two million people are living with Long COVID in the U.K (ONS, September 2022), and 4,837 people have been referred to Long COVID clinics in England (NHS England, September 2022). WHO

(2022) estimates that 17 million people in Europe have experienced Long COVID, with over 145 million globally. NHS England (2020) defines Long COVID as

> "signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis" (para 3).

As the following research is based on data collected in an NHS England clinic, this definition has been adopted in this research.

During the earlier stages of the pandemic, the focus had been on preventing the spread of the virus, treating the acute infection, and minimising the number of deaths. As such, this new illness, Long COVID, appeared to take some people by surprise; however, Oxford (2022) argues that Long COVID was in fact predictable. Previous pandemics (such as the Spanish Flu in 1918 and SARS in 2003) have resulted in long-term health difficulties, with symptoms similar to Long COVID, such as fatigue, body pains and cognitive difficulties. Furthermore, post-viral fatigue syndrome is a well-recognised condition and as the name suggests, develops as a result of a virus. Literature suggests that nearly two-thirds of patients with myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS) report experiencing a virus prior to developing the condition (Oxford, 2022).

It has been frequently observed in the literature that COVID-19 symptoms can persist beyond twelve weeks after the initial infection. A cohort study of 1,733 patients treated in Wuhan at the outset of the pandemic reported that 63% of patients still experienced fatigue or muscle weakness, 26% reported sleep difficulties, and 23% reported anxiety or depression six months post-infection (Huang et al., 2021). Similar findings have emerged in patients who were more recently discharged from hospitals in the UK. Patients who were seven weeks post-discharge reported fatigue, breathlessness, and psychological distress as their most common symptoms (Halpin et al., 2021). A higher prevalence of symptoms was observed in patients treated in critical care units. A systematic review incorporating 250,351 patients who met the criteria for Long COVID, found that alongside some physical symptoms, 29.6% were experiencing anxiety, and 23.8% reported difficulties with their concentration (Groff et al., 2021). These studies highlight the significant psychological impact of the COVID-19 infection.

The UK Office for National Statistics (ONS) listed fatigue, breathlessness, a cough and muscle aches as the most prevalent symptoms of Long COVID (ONS, 2022). In two-thirds, these symptoms negatively affected their ability to undertake daily activities. The ONS also highlights that within the United Kingdom, the experience of Long COVID has disproportionately affected women aged between 35-69, particularly those working in health or social care and living in deprived areas. The current study focuses on Middlesbrough and surrounding areas which are among the most deprived in England with 25% of the population considered as 'income-deprived' (McLennan et al., 2019).

Researchers are still trying to establish the effect that age has on both the acute COVID-19 infection and Long COVID. An analysis of longitudinal studies and health records in the United Kingdom found that incidents of Long COVID increased with age until the age of 70 at which point there was a decline in rates of Long COVID (Thompson et al., 2022). The authors highlight that this may be due to several factors such as lower symptom reporting in older adults, and a misattribution of Long COVID to other conditions. The following research will investigate whether there is an association between age and Long COVID in this sample.

1.3 The psychological impact of Long COVID

As with any long-term condition, it is important to understand the prevalence of psychological comorbidities for those with Long COVID (Katon, 2011). Katon highlights the bidirectional relationship between chronic physical illness and depression. The psychobiological changes associated with depression can increase the risk of chronic illness, and vice versa. Katon highlights that comorbid depression is associated with higher levels of functional impairment, symptom burden, and poorer treatment adherence. Furthermore, Strine et al. (2004) highlighted the impact that both depression and anxiety can have on our physical health. They found that individuals with anxiety and/or depression and a physical health condition reported poorer quality of life and had poorer health outcomes than individuals with physical health conditions who did not have mental health difficulties. Depression has also been linked to poorer health outcomes in those with chronic illness due to the impact

on proinflammatory factors, the autonomic nervous system (ANS) as well as the association with poorer health behaviours (Carney & Freeland, 2008). Long COVID has been identified as a condition which affects multiple organs in the body, impacts inflammation in the body and has an impact on the ANS (Raveendran et al., 2021). It is therefore beneficial for health psychologists to be involved in the care of patients with Long COVID to help manage this bidirectional link. In the context of Long COVID there is the need for therapeutic support for those with comorbid anxiety and depression which psychological professions can provide. In addition, there is the specific need for Health Psychologists to provide support in relation to self-management such as pacing activity as well as exploring the individual's understanding of their illness. This research investigates the impact that illness perceptions may have on health outcomes, thus understanding the cognitions and beliefs that individuals have of Long COVID may also help to manage the bidirectional link between mental and physical health.

Not only can depression and anxiety increase the risk of chronic illness, but so too can stress (Thoits et al., 2003; O'Connor et al., 2021). O'Connor et al. reviewed psychobiological processes to stress and health and highlight impact that stress can have on multiple biological systems. Thoits et al., (2003) highlights how exposure to stressors such as chronic pressures and traumas can widen health inequalities. Thoits et al., (2003) highlights how minority groups are often harmed by discrimination stress and that stressors can proliferate across the lifespan and generations, widening health inequalities. Thoits et al., (2003) emphasises that in order to address health inequalities, targeted interventions should be designed and delivered to those at most risk in poverty and stressful family circumstances. It's important to take this into account in the context of Long COVID in the UK as the COVID-19 pandemic widened many inequalities (Blundell et al., 2022) in society and caused many stressors for families in terms of financial pressures, bereavement, and social isolation (Singh & Singh, 2020). These stressors may then impact the health outcomes of Long COVID.

O'Connor et al., (2009) conducted a review which highlighted several key factors which can affect the immune system's response to illness, in particular the inflammatory response, including age, gender, social status and health behaviours,

including exercise, sleep, diet, caffeine, alcohol, and smoking. In relation to recovery from viral illnesses such as COVID-19, it is important to consider these factors which may contribute to the development of Long COVID and a longer recovery period from the initial COVID-19 infection.

Segerstorm and O'Connor (2012) emphasise that the same event does not have the same consequences for individuals who experience it. The context in which events occur significantly impact the consequences, such as the personality and life stage of the individuals. They highlight that there is not just a link between the individual and the event which needs to be looked at, but also the link between the event and other aspects of the person's life, such as their work, relationships and hobbies which all contribute to the levels of stress that an individual is experiencing which relate to the coping and health of the individual. Thus, in the context of Long COVID, it is important to look holistically at the individual and their context. By looking at illness perceptions, it is hoped that more information can be gathered to account for some of the different responses and health outcomes to COVID-19 and Long COVID recovery.

1.4 Illness perceptions

Leventhal's Common-Sense Model of self-regulation suggests that the way we think about illness and interpret symptoms can be related to health outcomes via the effect on emotions, cognitions and behaviour, known as 'illness perceptions' (CSM; Leventhal et al, 1980, 1984). This model suggests that how individuals perceive their illness may explain how they self-regulate and manage their illness. The common-sense assumptions that people have regarding their illnesses are known as their illness perceptions (Leventhal, Meyer & Nerenz, 1980, Diefenbach & Leventhal, 1996).

The term "illness perception" refers to people's cognitive representations of their illnesses, which according to Leventhal can be broken down into five main categories: identity (symptoms and labels associated with the illness), cause (perceived cause of their illness), consequences (beliefs about the impact and

consequences), control/cure (beliefs about their recovery and control over the illness), and timeline (duration and course) (Leventhal, 2003).

According to the model, people process their emotional (mental health) and cognitive (illness perceptions) reactions to illness largely separately. People are motivated to engage in particular behaviours to regulate their emotions and improve their health as a result of these cognitive and emotional responses. The dynamic model suggests that people constantly evaluate their behaviours and coping mechanisms and adjust their views of illness as a result. Understanding illness perceptions is crucial because they influence coping mechanisms and illness outcomes which in turn impact medical, psychological and behavioural outcomes (Petrie et al., 2007). If it is possible to gain a better understanding of these perceptions, it can provide insight into beliefs which may be contributing to psychological distress and health behaviours and understand what is limiting someone's self-management of their condition. This can then help inform a person-centred, tailored approach to their support.

The Common-Sense Model of self-regulation (CSM) suggests that the emotional and cognitive representations run in parallel but do influence one another. As such, interventions based on the CSM tend to focus on changing the illness perceptions with an assumption that emotional distress will reduce consequently (O'Carroll, 2020). O'Carroll argues that it is important also to look at the relationship the other way and consider the role that emotions play in regulating illness perceptions and behaviour. This research will look at the bidirectional relationship between illness perceptions and mental health and the impact of these on quality of life (EQ-5D and EQ-VAS), and functioning (WSAS).

There have been a range of studies in adults, which have provided support for the CSM and illness perceptions, for example inflammatory bowel disease (Dorrian et al., 2008), COPD (Tiemensma et al., 2007), and epilepsy (Goldstein, et al., 2005). In relation to Long COVID, it could be particularly useful to look at studies into CFS/ME as researchers have noted the similarities between the conditions (Komaroff & Bateman, 2021; Wong & Weitzer, 2021; Hunt et al., 2022). Haines et al., (2019) suggested that psychological therapies focusing on perceptions of perceived

control, comprehension, and identity would be most helpful for those with CFS. This study therefore wishes to investigate if the illness perceptions held by adults with Long COVID predict their perceived quality of life and functioning at short-term follow-up.

Based on research by Bierbaur et al., (2022) it is hypothesised that people with Long COVID who have higher perceived consequences and higher emotional representations of their illness on the BIPQ at timepoint one, will have poorer health outcomes at follow-up, especially a lower perceived quality of life and functioning. Greater protective perceptions such as illness control and coherence will result in better health outcomes.

Attribution Theory (Weiner, 1985) also takes into account how people's views of their illnesses may affect their cognition, emotion, and behaviour. In relation to illness perceptions, this theory proposes that there are three aspects of causal beliefs that are associated with coping and emotional adjustment; locus of causality (internal/external), stability (whether it can change) and controllability (can the cause be altered or controlled). According to Roesch and Weiner (2001), stable and uncontrolled beliefs were linked to more frequent use of avoidant coping mechanisms and, thus, worse psychological adjustment. In addition, Martin et al. (2005) observed that heart attack patients who believed the reason was lifestyle-related thus controllable, were more likely to engage in healthy lifestyle changes three months later. Additionally, they discovered that males were more inclined than women to attribute the cause to lifestyle modifications and, as a result, were more willing to adopt those changes. Therefore, if we can understand an individual's perception of their Long COVID illness, we may be able to provide more person-centred, specific support. For example, if someone does not perceive that they have much control over their illness, they may be less likely to engage in lifestyle changes, such as fatigue management, and so we may need to anticipate this and offer these individuals more support targeting these perceptions.

1.5 The impact of hospitalisation

Post-intensive care syndrome (PICS) is a well-recognised health consequence of inpatient critical care with persistent cognitive impairment, a recognised complication after any critical illness (Sakusic & Rabinstein, 2018). However, many patients who did not require hospitalisation and subsequently developed Long COVID syndrome report cognitive symptoms which PICS cannot explain. Colloquially, 'brain fog' has become a popular umbrella term for the Long COVID experience of difficulties with concentration, memory, receptive language, word retrieval and/or executive functioning (Nalnamdiam et al., 2021, Del Brutto et al., 2021).

Evans and colleagues (2021) conducted a multi-centre follow-up study of adults in the UK treated in hospital for COVID-19 and have identified female gender, middle age, the presence of two or more comorbidities and more acute severe illness requiring hospitalisation as risk factors for the development of Long COVID syndrome. Furthermore, Jones et al. (2021) found frailty to be a predictor of Long COVID and highlight the importance of clinicians having awareness of this when patients present with new and prolonged symptoms, that are typical of Long COVID.

A sub question that will be looked at in this research is whether hospitalisation with acute COVID-19 has any impact on health outcomes at timepoint one or two.

1.6 NHS Service Provision for Long Covid

In October 2020, NHS England and NHS Improvement launched a five-point plan to support individuals with Long COVID (Fernández-de-Las-Peñas et al., 2021). A key part of this plan was to establish Long COVID assessment clinics to provide patients access to multi-disciplinary teams (MDT) to ensure that they had the best clinical advice to manage optimally their symptoms. In response, a local Long COVID MDT service was established in South Tees in November 2020 comprised of Respiratory Medicine, Physiotherapy and Medical Psychology.

1.7 The role of health psychology

Long COVID is primarily experienced as physical symptoms, and psychological comorbidities may present alongside. Health Psychologists can play an important role, and one which is different from clinical psychologists who may focus more on severe mental health difficulties. Health Psychologists can not only support patients with psychological comorbidities but can also provide support in relation to the management of physical symptoms, treatment adherence, and adjustment, focusing on models of behaviour change. For example, fatigue is the most common physical symptom, but can be managed by behaviour change techniques such as pacing. For many people, this can be difficult as it may mean doing less than they are used to and may require them to reassess their expectations and goals.

Health care is typically delivered based upon the biomedical model whereby patients are diagnosed and treated for an illness, with little acknowledgement of the other multi-factorial difficulties that contribute to our health (Was & Halligan, 2017). Psychologists working in healthcare, often find that they are in services that treat either physical or mental health conditions and focus on service-led pre-determined outcomes rather than patient-determined outcomes (Hamilton, 2021). Instead, a biopsychosocial model proposed by Engel (1981), is a more holistic and effective approach taking into account the biological, psychological and social elements to illness. In relation to Long COVID, this approach can provide valuable information to the clinical team and aid in appropriate support and treatment. For example, a medical doctor can assess for any physiological difficulties, such as lung damage. Health Psychologists can play an important role in these clinics, assessing for any psychological difficulties, such as low mood or anxiety, considering coping strategies used, and look at any social difficulties, such as the impact of not being able to work or do day to day tasks on health outcomes. This joined up, holistic approach can provide patients with more effective and timely treatment specific to their need.

A health psychology approach can also contribute to the psychological adjustment that is required with long term health conditions. This can involve learning to cope with major loss, an altered sense of self and the management of personal and interpersonal reactions (Gracey et al., 2009). It has also been highlighted that within long-term health conditions, it is important to be aware of

automatic attempts to avoid suffering which can hinder self-management and adjustment such as supressing emotion and denial (de Ridder et al., 2008). In relation to Long COVID, patients are often required to implement fatigue management strategies, such as pacing, which involve reducing their physical and mental activities and managing their expectations. Other behavioural changes include implementing sleep hygiene strategies, changing breathing patterns such as not breathing through their mouths, and pain management strategies.

As this is a relatively new illness there is still much we can learn. One way to gain a better understanding is to consider how patients respond to their symptoms and how their understanding of the illness relates to health outcomes. An effective way to do this is to assess people's illness perceptions and mental health.

1.8 Role of health psychology in the Long COVID clinic

This research was conducted in collaboration with the Long COVID assessment clinic in South Tees NHS Foundation Trust. The service assesses patients' mental and physical health in relation to Long COVID diagnostic status. Over 300 patients were seen between November 2020 and March 2022 with referrals ongoing. Patients were referred to the service via their GP or Occupational Health (if they were a member of staff within the Trust). Six patients per week were seen by the multidisciplinary team. Patients were seen by a Respiratory Consultant who could assess for any physical difficulties. A respiratory physiotherapist then assessed patients for any difficulties which they can support with, such as dysfunctional breathing. Finally, the psychology team assessed the patient's mood as well as assessing for any trauma or neurological symptoms. If treatment is required, patients were referred onward for specialist support. Currently, this clinic can only assess patients, provide brief advice, and then refer them on for treatment. By gathering further data at least three months after they have attended the clinic, the MDT aimed to predict more effectively who will need further support and contribute to the design of a more effective service.

As a trainee health psychologist, the author supported the establishment of the long COVID service in South Tees as part of their training. This began in in the

summer of 2020, when a literature review was conducted and other psychologists working in similar areas were contacted to establish which outcome measures should be used. With input from the service lead and neuropsychologist, as well as a clinical psychologist with expertise in trauma, the initial protocol and ideas for this research was designed.

The author continued to attend the clinic weekly and built up a working relationship with the wider MDT. They were joined by a rotation of three clinical psychologists. It was important to remain up to date on current literature, guidance, and research and the author became the co-chair of the British Psychological Society specialist interest group in Long COVID. As part of their role they provided guidance to the MDT in relation to language use around mental health, breaking bad news to patients, and working in a psychologically minded way. As the clinic progressed and they received additional funding for treatment they went on to develop a group programme with a session on sleep and mood, as well as an Acceptance and Commitment Therapy (ACT) based adjustment session.

1.9 The current study

The current study has been broken down into three key questions which share the same overarching aim of identifying whether illness perceptions are predictors of health outcomes in adults with Long COVID. Specifically, the study looks at functioning and quality of life when referring to health outcomes. In order to answer this question, data were gathered by the author from a newly established Long COVID assessment clinic. Treatment was not available in this clinic at the time of the study. It is hoped that the data gathered will help us to gain a better understanding of the links between illness perceptions, mental health, and health outcomes at two time points; attendance at the assessment clinic and at follow-up at least three months after attendance.

The data used in this study is part of routine data collected from the Long COVID clinic. The clinic collects data on overall perceived health, fatigue, anxiety, depression, adjustment, trauma, and cognitive function. This research will focus on health-related data, excluding data collected on fatigue, trauma or cognitive function.

1.10 Research Questions

The overarching question that this research and longitudinal prospective study investigates is whether illness perceptions are useful additional predictors of health outcomes in adults with Long COVID. In order to answer this, the question has been broken down into three sub-questions which have been investigated over three separate areas of work described below and in figure 1.

Research Question 1. *What is the psychological impact of Long COVID at baseline for people attending a Long-COVID assessment clinic?*

Research question one reports on cross-sectional data gathered over the first year of the clinic running from November 2020 to November 2021. We aimed to identify the impact of Long COVID on mental health for clinic attenders at referral (timepoint one). In order to achieve this, we analysed data which was routinely collected as part of the Long COVID clinic assessment including, anxiety and depression measures, as well as measures of quality of life and functioning. The author hypothesised that those with Long COVID will report poorer mental health than the general population at time point one. The primary purpose of this question was to gather baseline data and see how patients were presenting with Long COVID. This information was then used to inform the subsequent research questions.

Research Question 2. *What is the relationship between illness perceptions and mental health for people attending a long COVID clinic?*

Research question two is a cross-sectional design, which investigates illness perceptions and mental health collected at the patients' initial assessment in the Long COVID clinic, timepoint one (T1). This could be any point between January 2021 and March 2022. We could not include data from 19 patients who were seen between November and December 2020 as we did not start measuring illness perceptions until January 2021. The period for data collection was kept open as long

as possible to increase sample size. The author hypothesises that those who reported more negative illness perceptions would also report poorer mental health outcomes.

Research Question 3. *a) What is the longitudinal impact of Long COVID on quality of life and functioning*
b) To what extent do baseline illness perceptions and mental health predict quality of life and functioning at follow-up for people attending a long-COVID assessment clinic?

Research question three was split into two sub questions with the aim of investigating whether there are any changes in quality of life and functioning at follow-up for attenders at a Long COVID assessment clinic. Furthermore, the question investigated whether illness perceptions and mental health at baseline predicted quality of life and functioning at follow-up. The author hypothesises that individuals who reported more negative illness perceptions and poorer mental health at timepoint one, would report poorer quality of life and functioning at timepoint two.

With this information the author hopes to gain a better understanding of the impact of Long COVID on health outcomes, and how illness perceptions influence health outcomes of patients at follow-up. The author hopes to be able to use this information to design effective interventions for patients with Long COVID, addressing illness perceptions in order to improve mental health and support their recovery.

Overall, it is hypothesised that those with more negative illness perceptions are likely to report poorer quality of life and functioning. This is based on Leventhal's common-sense model of self-regulation (CSM; Leventhal et al., 1980, 1984) which proposes that the way people perceive their illness affects how they self-regulate and manage their illness. Thus, those who have more negative illness perceptions may be less likely to engage in the most appropriate self-management of their Long COVID, for example pacing for fatigue management.

Similarly, it is expected that anxiety and depression at baseline would be related to poorer quality of life and functioning at follow-up, however it is not known how illness perceptions and mental health will jointly predict these health outcomes. It could be anticipated that mental health might mediate the relationship between illness perceptions and quality of life. For example, negative illness perceptions may lead to poorer mental health and result in a poorer quality of life.

Figure 1

A diagram demonstrating the hypothesis that negative illness perceptions and mental health at timepoint one will have a negative impact on health outcomes at timepoint two.
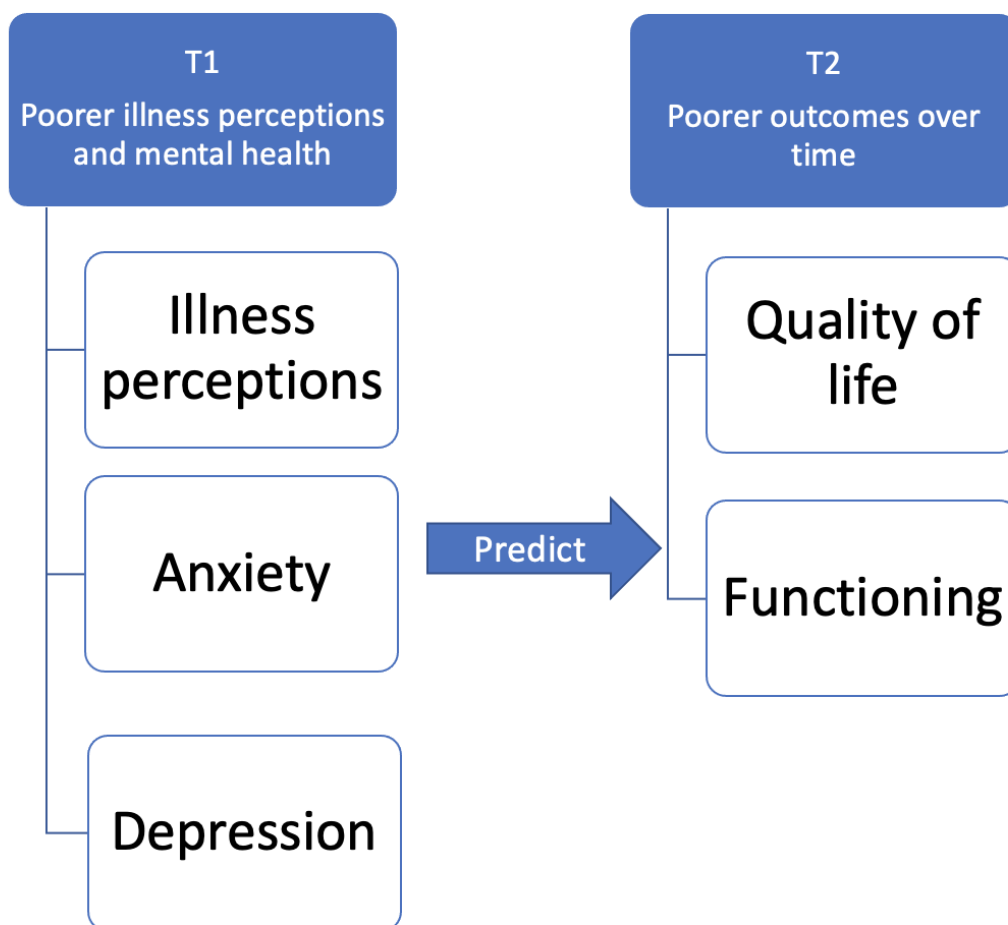
1.11 Measuring the predictors of health outcomes

The research looks at the effect that illness perceptions and mental health had on health outcomes, in particular quality of life and functioning. The author specifically chose to look at anxiety with the GAD -7 (Generalised Anxiety Disorder assessment; Spitzer et al., 2006) and depression with the PHQ-9 (Patient Health Questionnaire; Kroenke at al., 2011). Previous research has shown poorer mental health to be related to more negative illness perceptions and hence poorer coping (Costa et al., (2016); Hepgul et al., (2016); Pavon-Blanco et al., (2019)).

There are currently three main questionnaires used to assess illness perceptions which are based upon the Illness Perceptions Questionnaire (IPQ) (Weinman et al, 1996). These are the full (50 item) Illness Perception Questionnaire (IPQ), the revised (38 item) Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002), and the (nine item) Brief Illness Perceptions Questionnaire (B-IPQ) (Broadbent et al., 2006). The current study uses the Brief Illness Perception Questionnaire (BIPQ), which was designed for time efficient assessment. The components utilised in the questionnaire, sample items, and the implications of higher scores on each component are included in Appendix A. Higher scores on the 'consequence', 'identity', 'timeline', and 'emotional representations' elements of these questionnaires typically suggest more negative beliefs, whereas higher scores on the 'coherence' and 'control' dimensions generally reflect more positive beliefs. Research has shown the BIPQ to have good criterion validity (Broadbent et al., 2016), however questions have been raised over the content validity with participants misinterpreting, particularly in relation to personal control and cause (Van Oort et al., 2011). Despite this limitation, the BIPQ has been shown to have good concurrent validity and correlates well with other illness perception questionnaires and is consistent with theory and literature (Broadbent et al., 2016).

Research has found that for some conditions such as heart attacks, greater positive illness perceptions in the early stages of the illness can result in shorter periods of time off work (Petrie et al., 1996). It is, therefore, important, particularly in

the early stages of an illness, to understand illness perceptions in order to develop targeted interventions to improve health outcomes and support people's return to health and optimal functioning. Other research has shown how negative views of illness can hasten the development of conditions like chronic renal disease (Meuleman et al., 2015). If it is possible to identify illness perceptions early, related to an individual's diagnosis, and develop interventions to target negative perceptions, then there is the potential to slow down disease progression or positively influence other health outcomes.

A recently published cross-sectional study investigating illness perceptions in adults with Long COVID found that a greater number of reported symptoms, higher perceived consequences, and higher emotional representation were related to poorer health outcomes (Bierbauer et al. 2022). They also found that individuals had poor coherence of their condition and perceived it to be difficult to control. The current study looks to build on these findings by looking at their cross-sectional relationship with mental health and whether illness perceptions are a predictor of health outcomes over time, using longitudinal survey methods.

1.12 Measuring health outcomes

It was important to consider broad health outcomes in relation to peoples' experience of Long-COVID. To do this the EuroQol Visual Analogue Scale (EQ-VAS) and EQ-5D (Herdman et al., 2011) were chosen which measure quality of life. These are recommended by NHS England to be used in Long COVID clinics and this data was already routinely gathered for the clinic (NHS England, July 2022). The Work and Social Adjustment Scale (WSAS) (Mundt et al., 2002) was also used to assess functioning. This measurement has been shown to measure a distinct social functioning component and is of particular benefit when used alongside the PHQ-9 and GAD-7 (Zahra et al., 2014). In addition, it has been found to be a reliable and valid tool measuring functioning in adults with CFS (Cella et al., 2011).

Figure 2 below presents an overview of the work presented in the research together with the timeline.

Figure 2

A diagram of the sequence of studies conducted

Question 1: *Research Question 1: What is the psychological impact of Long COVID at baseline for people attending a Long-COVID assessment clinic?*

November 2020 - November 2021
Timepoint 1, n=253

Question 2: *What is the relationship between illness perceptions and mental health for people attending a long COVID clinic?*

January 2021 - March 2022
Timepoint 1, n=61

Question 3: *a) What is the longitudinal impact of Long COVID on quality of life and functioning b) To what extent do baseline illness perceptions and mental health predict quality of life and functioning at follow-up for people attending a long-COVID assessment clinic?*

January 2021 - July 2022
Timepoints 1 & 2, n=61

Chapter 2

Methods used in the research

2.1 Research design for research question one

2.1a Participants and research design

To answer this question, data collected over twelve months from a Long COVID MDT assessment clinic was examined. The research question investigated the psychological impact of Long COVID on patients who attended the assessment clinic between November 2020 and November 2021. We looked at routinely collected outcome measures detailed in Table 1 which looked at mental health, quality of life and functioning. This research question aims to characterise the psychological profile and intervention needs of patients with Long COVID.

Table 1

Outcome measures and predictors taken at each timepoint

Measure		Timepoint 1	Timepoint 2
Outcomes			
	EuroQoL EQ-5D-5L	X	X
	EuroQoL EQ-VAS	X	X
	WSAS	X	X
Predictors			
	GAD-7	X	
	PHQ-9	X	
	BIPQ	X	
	Demographics	X	X

Note. EQ-5D-5L Euroqol-5 dimensions-5 level, *EQ-VAS* Euroqol visual analogue scale, *WSAS* Work and Social Adjustment Scale, *GAD-7* Generalised Anxiety Disorder scale, *PHQ-9* Patient Health Questionnaire-9, *BIPQ* Brief Illness Perception Questionnaire.

2.1b Stakeholder involvement

When designing the research it was important that the research would truly be of benefit to the clinic and MDT. As a result, the MDT was consulted when designing the research and their feedback was taken into account. For example, we discussed the range of outcome measures used and data collected and agreed which measures to include in the research. The use of the EQ-5D was of particular importance to the team given the requirements from NHS England to use this measure. It was important to utilise this data and analyse what was routinely collected.

2.1c Ethics

Research and evaluation approval was granted from South Tees NHS Foundation Trust (ID: 7301 04.05.22) (see Appendix B) and ethical approval was granted from The University of Stirling for baseline and follow-up data, (ID: 7301, 16.05.22) (see Appendix C).

2.1d Participants

Inclusion Criteria

The study was conducted in an acute Trust in Teesside, North East England. Participants were referred by their GP. For members of staff within the Trust, Occupational Health could also refer. The service accepted referrals for adults over the age of 18 who lived within the South Tees CCG area, or worked within the Trust. Patients were accepted if they were experiencing ongoing symptoms from a COVID-19 infection for at least 12 weeks, and other possible causes had been ruled out. The Respiratory Medicine Service triaged all referrals. Data for this study was collected by the author, a trainee health psychologist, between November 2020 to November 2021. Participants completed outcome measures during the appointment.

Descriptive statistics revealed that 253 patients were seen during the study period of whom 104 (41%) had been hospitalised due to COVID-19 infection. 161 (64%) of all patients were female and 175 (70%) of participants were aged between 40 and 70 years (mean age= 51, SD=21.21) (see figure 3). Just under a third of the patients were NHS employees (n=77, 30%).

Figure 3

Age distribution of patients at baseline (T1)
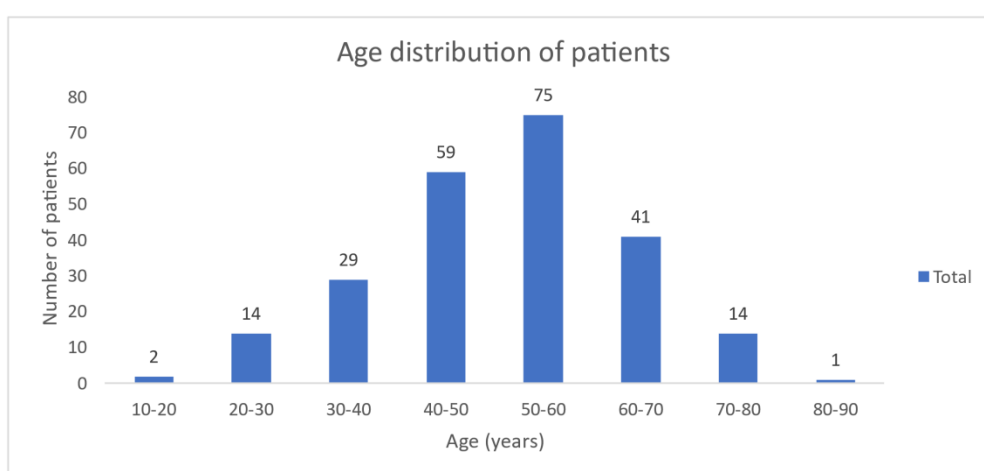
2.1e Measures

Overall perceived quality of life was measured with the EuroQol Visual Analogue Scale (EQ-VAS) and the EQ-5D (Herdman et al., 2011). The EQ-5D asks individuals to rate five 'domains' on a five-point scale of difficulty (mobility, self-care, usual activities, pain/discomfort, anxiety/depression). The visual analogue scale (EQ-VAS) then asks participants to rate their global, or overall health, out of 100. The study specifically used version 5L which has two additional levels for participants to choose (non, mild, moderate, severe, extreme) compared to the previous version (EQ-5D-3L) (non, moderate, extreme) which increases its sensitivity. This is also the recommended version for Long COVID clinics by NHS England (July, 2022). The Cronbach's alpha value for the EQ-5D-5L in the current sample was 0.72 which suggests an acceptable level of internal consistency. Although the EQ5D measures different dimensions, the use of Cronbach's alpha to evaluate the EQ-5D-5L's reliability have been reported in previous studies (Pickard et al., 2007; King et al., 2009).

Functional Impairment was measured with the Work and Social Adjustment Scale (WSAS) (Mundt et al., 2002). This is a five-item questionnaire where statements are rated on an eight-point likert scale and a sum score is calculated (possible range 0-40). Scores between 10 and 20 indicate significant functional impairment and scores over 20 indicate moderately severe impairment (Mundt et al., 2002). The Cronbach's alpha value for the WSAS in the current sample was 0.96.

Anxiety was measured with the GAD-7 (Generalised Anxiety Disorder assessment; Spitzer et al., 2006). This is a seven-item questionnaire where participants rate their mood over the last 14 days on a four-point likert scale. Their responses are then summed together to generate a total out of 21. A score over ten indicates moderate anxiety levels, and a score over 15 suggests severe anxiety (Spitzer et al., 2006). The Cronbach's alpha value for the GAD-7 in the current sample was 0.9.

Depressive symptoms were assessed with the PHQ-9 (Patient Health Questionnaire; Kroenke at al., 2011). This comprises nine questions on a four-point likert scale. Participants are asked to rate their mood over the last 14 days and their responses are summed together out of 27. A score over 15 suggests moderately severe low mood, and a score over 20 suggests severe low mood (Kroenke et al., 2011). The Cronbach's alpha value for the PHQ-9 in the current sample was 0.87.

Table 2

BIPQ component and the implication of a higher score

BIPQ component	Implication of a higher score
Consequences	Greater impact on life
Timeline	Chronic
Personal control	More control
Treatment control	More control
Identity	More severe symptoms
Concern	Greater concern
Understanding	Greater understanding
Emotional response	Greater emotional response

Note. BIPQ Brief Illness Perception Questionnaire.

The patient remained in the same clinic room and was assessed by a rotation of a respiratory consultant, physiotherapist, and a member of the Psychology team in 20-minute consultations. Advice and information was provided and patients were either signposted to other specialist services (e.g. mental health, cardiology, neurology) or discharged from the clinic.

The service was initially set up with the expectation that critically ill survivors of COVID-19 would require the greatest support and most of the early referrals were from critical care, respiratory medicine and infectious disease units. However, after three months, most referrals originated from primary care and the hospital's occupational health department.

2.2 Research design for research question two

2.2a Participants and research design

Health outcomes (EQ-5D, EQ-VAS, and WSAS) were collected at timepoint one when participants first attended the Long COVID assessment clinic. All patients were asked to complete all outcome measures. Of the initial 253 patients who had attended the Long COVID clinic, 188 patients who had been seen in the Long COVID clinic in South Tees Hospitals NHS foundation Trust between January 2021 and March 2022 had completed the BIPQ, and were contacted via post between March and June 2022 to complete the WSAS, EQ-5D and EQ-VAS again at timepoint two (see figure 4).

Participants were over 18 years of age and lived within the Teesside and North Yorkshire area of Northeast England, or worked within South Tees NHS Hospitals Foundation Trust. All participants had been seen in the Long COVID assessment clinic at South Tees.

Participants were contacted via post between March and June 2022, at least three months after their assessment and sent an information sheet and consent

form. Follow-up letters were also sent in July 2022 to increase participation. We received 61 (32%) responses, 51 (84%) of which were via postal responses.

Figure 4

A diagram highlighting the recruitment process.

November 2020 – March 2022 T1
- 188 patients completed all outcome measures including BIPQ face to face in assessment clinic

March 2022 – June 2022 T2
- 188 patients contacted by post to complete follow up measures (EQ-5D, EQ-VAS, WSAS)

July 2022
- Reminder letters sent via post

2.2b Procedure

Participants were asked to complete the outcome measures at timepoint one, during their initial appointment in the Long COVID clinic. Demographic information was taken as part of the clinic's routinely gathered data including, age, gender, and occupation.

2.2c Consent

Written consent was obtained from the participants when they returned their consent form which detailed what the study involved. For those who completed the survey online, consent was obtained via ticking a box to provide their consent after they had read the participant information sheet. All data were anonymised.

2.1e Measures

Illness perceptions were measured with the Brief Illness Perception Questionnaire which has been shown to be appropriate for use with health conditions (BIPQ) (Broadbent et al., 2006). This is a shorter version of the Illness Perception Questionnaire and provides a quantitative measurement of illness representations. Participants rate their views in relation to a list of statements on a zero to ten scale. An overall illness perception score can be calculated by reverse scoring items three, four and seven and then adding these to the remaining items. A higher score indicates a more negative view of their illness. The Cronbach's alpha value for the BIPQ in the current sample was 0.73. Table 2 explains what a higher score in each perception indicates.

2.3 Participants and design for research question three

2.3a Participants and research design

A longitudinal cohort follow-up was conducted using quantitative survey methods. Of the initial 253 patients who had attended the Long COVID clinic, 188 patients had completed the BIPQ. They were contacted via post at least three months after clinic attendance and asked to complete the EQ-VAS, EQ-5D, and the WSAS.
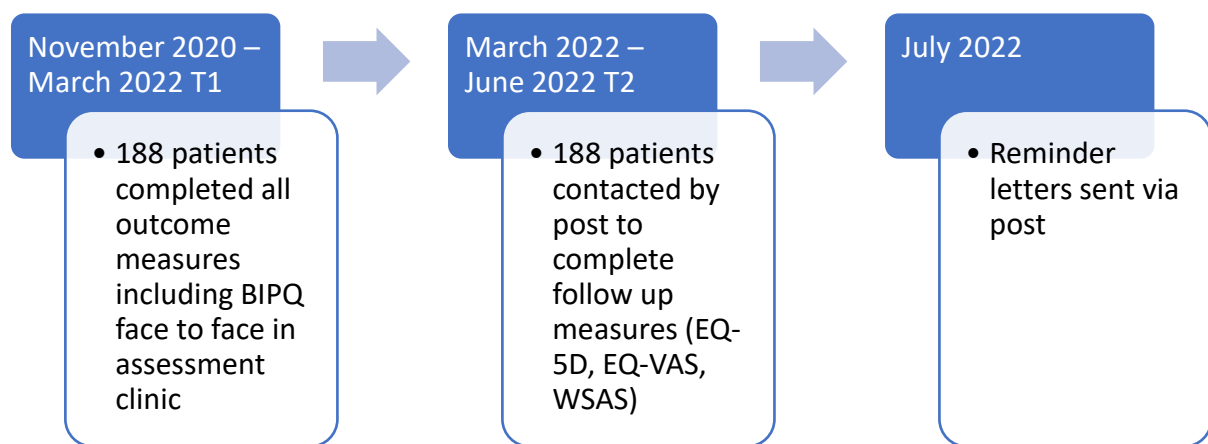
Participants were over 18 years of age and lived within the Teesside and North Yorkshire area of Northeast England, or worked within South Tees NHS Hospitals Foundation Trust.

2.3b Materials

See table 1

2.3c Procedure

Participants were contacted via post and provided with an information sheet and letter (see Appendix E and D) and invited to complete the WSAS, EQ-5D, and EQ-VAS at timepoint two, at least three months after their initial assessment at timepoint one. A weblink and QR code were also provided in the letter so that participants had the choice to complete the questionnaires online via Qualtrics. Follow-up letters were also sent to increase participation (see Appendix G). We received 61 (32%) responses, 51 (84%) of which were via postal responses.

Chapter 3

Results of research question one:

Identifying the psychological impact of Long COVID at timepoint one

3.1 Research Question 1. What is the psychological impact of Long COVID at baseline for people attending a Long-COVID assessment clinic?

The first research question that was investigated, (RQ1) aimed to identify the psychological impact of Long COVID on mental health at timepoint one. As part of this a sub-question was also considered (RQ1a); 'What is the impact of hospitalisation on mental health for people with Long COVID?'.

3.2 Data used

The data used to answer this question was gathered at timepoint one at participant's attendance at the Long COVID assessment clinic. Data from 253 patients was used who attended clinic between November 2020 and November 2021. To answer this question, responses from GAD-7 and PHQ-9 were analysed, alongside demographic data routinely collected in clinic such as gender, age, and whether participants were hospitalised with their acute COVID-19 infection.

3.3 Analysis

An a priori G*Power (Faul et al., 2007) calculation was conducted for a sample size estimation based on published effect sizes in chronic fatigue and depression (McAndrew et al., 2019). Power calculation based on an independent means t-test specified a minimum sample size of 216. This would allow detection of a medium effect size (0.4) with a power of 0.9, with alpha set at 0.05.

Data was analysed in Microsoft Office Excel and SPSS 28 (IBM Corp, 2020) statistical software. Chi-square analyses were conducted to determine if there was an association between GAD-7 and PHQ-9 scores and whether patients were treated in hospital or not for COVID-19. There were 48 participants with missing data for these measures, so these patients were omitted from the analysis.

For RQ 1, descriptive analysis was conducted and all questionnaires were scored and grouped into clinical cut-off points, and then the percentage in each category was calculated and compared with normative data for each measure. For

RQ1a, chi-square tests were conducted to compare data between patients who had been treated in the hospital for their acute COVID-19 illness against those who had not been hospitalised.

3.4 Results

Table three presents demographic and descriptive data. The assessment clinic saw 18% more patients who had not been hospitalised with COVID-19 than had been hospitalised, and of these 64% were female and 30% were employed by the NHS. In relation to mental health, 42% presented with clinically significant levels of anxiety, and over half of patients (59%) presented with significant levels of depression.

Table 3

Demographic information and descriptive data for anxiety and depression for hospitalised and non-hospitalised patients.

	Hospitalised N (percentage)	Not hospitalised N (percentage)	Combined total of hospitalised and non-hospitalised patients N (percentage)
Total number of patients	104 (41%)	149 (59%)	253
Gender	Male: 19% Female: 81%	Male: 17% Female: 83%	Male: 36% Female: 64%
NHS staff	20 (8%)	57 (23%)	77 (30%)
Moderate to severe anxiety (Scoring over 10 on the GAD-7)	44 (17%)	64 (25%)	108 (42%)

Moderate to severe	62 (25%)	87 (34%)	149 (59%)
depression (Scoring over 10			
on the PHQ-9)			

Note. NHS National Health Service, *GAD-7* Generalised Anxiety and Disorder, *PHQ-9* Patient Health Questionnaire

The GAD-7 scores demonstrated that 44% (n=108) of the sample reported clinically significant anxiety, (M=9.1, SD=6). This is defined as those who scored 10 or more out of 21 and indicates treatment for anxiety is needed, with scores of 15 or more suggesting severe anxiety (Spitzer et al., 2006). There was no statistically significant difference between those who were hospitalised and those who were not hospitalised in relation to GAD-7 scores when split into two groups, those who score over 10 and those who score below 10 χ^2(2, *N*=232) = .02, *p* = .89. However, there was a statistically significant difference between gender, with females more likely to report symptoms of anxiety χ^2(2, *N*=247) = 7.37, *p* =.007. Overall, 32% of females reported clinically significant anxiety compared to 11% of males.

There was a significant difference in the mean GAD-7 scores for individuals with Long COVID and the general population t(60) = 7.1, *p*<.001. The mean GAD-7 score for those with Long COVID is 9, whereas the mean GAD-7 score for the general population is 2.97 (Löwe et al., 2008).

Figure 5

Percentage of Hospitalised and Non-hospitalised patients reporting clinically significant levels of anxiety on the GAD-7.

Anxiety scores for hospitalised and non hospitalised patients
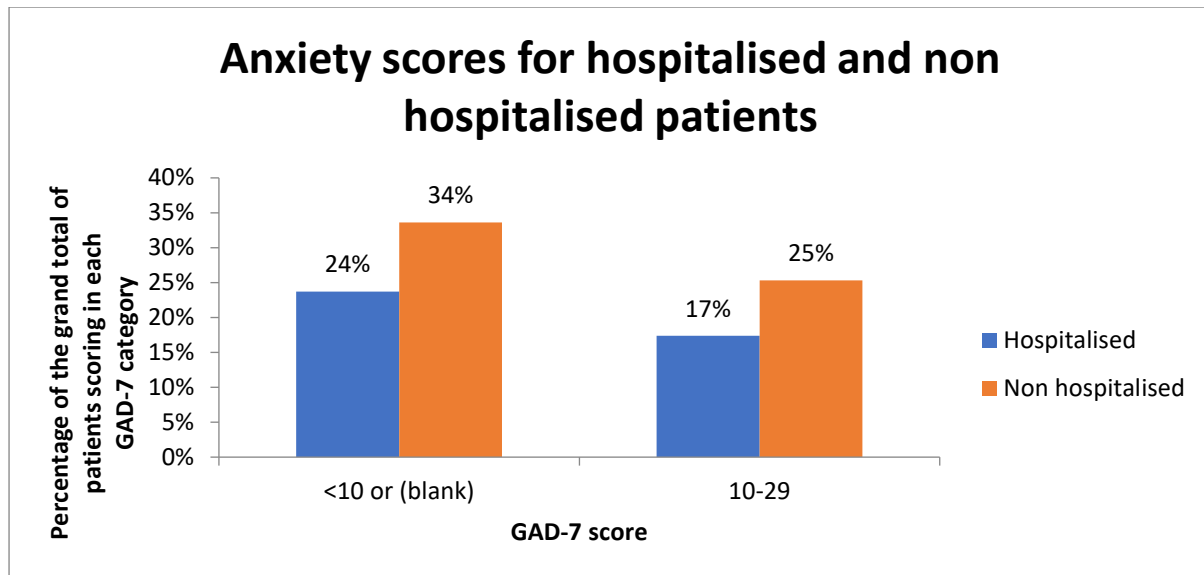
Note. GAD-7 Generalised Anxiety Disorder

The PHQ-9 scores demonstrated 59% (n=149) of the sample reported symptoms of depression (M=11.8, SD=3.2) which were in the 'moderate or above' range of severity (a score of 10 or more out of 27), suggesting treatment is indicated (Kroenke et al., 2011). Kroenke proposed that scores between 0-9 out of 27 were indicative of mild symptoms. Scores of ten and over indicated treatment was required, and scores over 20 were indicative of severe depression.

There was not a statistically significant difference between PHQ-9 scores (when grouped into those who scored above and below 10) for those who were hospitalised and those who were not hospitalised, as shown in Figure 5 χ^2(2, *N*=231) = .45, *p* =.504. However, there was a statistically significant difference between gender, with females more likely to report symptoms of depression χ^2(2, *N*=246) = 8.93, *p* =.003. Overall, 43% of females reported clinically significant levels of depression compared to 17% of males.

There was a significant difference in the mean PHQ-9 scores for individuals with Long COVID and the general population t(60) = 10.5, *p*<.001. The mean PHQ-9 score for those with Long COVID is 12.18, whereas the mean PHQ-9 score for the general population is 2.91 (Kocalevent, et al., 2013).

Figure 6

Percentage of patients in each category reporting clinically significant levels of depression on PHQ-9
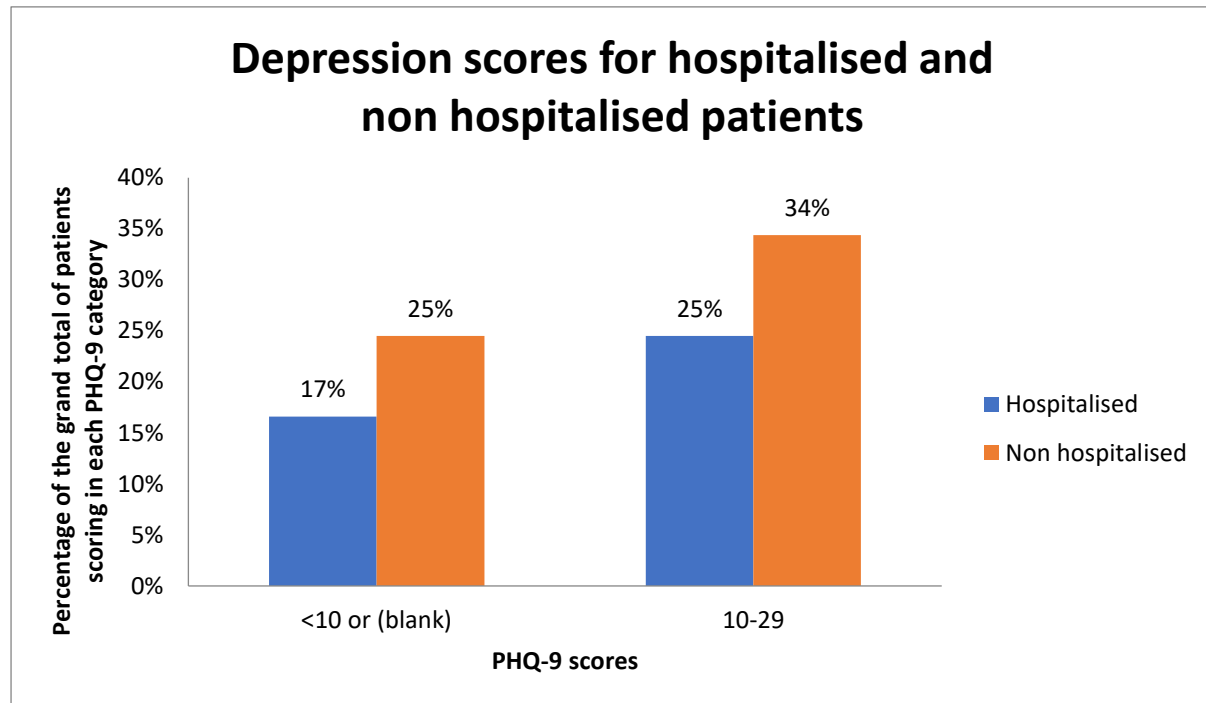
Note. PHQ-9 Patient Health Questionnaire-9

Clinicians recommended talking therapy to 58% (n=128) of patients based on clinical interviews alongside the cut-off scores from the questionnaires. For patients scoring over ten for anxiety and/or depression, a discussion was initiated into their current coping strategies and support network. If after this discussion the patient felt that they would benefit from talking therapy a referral was made. A small number were already attending therapy at the time of clinic assessment. There was not a statistically significant difference between the number of patients recommended for talking therapy for those who were hospitalised (22%) and those who were not hospitalised (36%) $\chi^2(2, N=208) = 0.17$, $p =.92$.

3.4a Hospitalisation and other demographic characteristics

A chi-square test found a statistically significant association between gender and whether participants were hospitalised with COVID-19 from our sample, χ^2

(1, N=61) = 4.57, *p*=.03. Men were more likely to have been hospitalised with COVID-19. Of the 24 male participants, 13 (54%) were treated in hospital for COVID-19, whereas ten of the 37 female participants were hospitalised (27%).

The relationship between hospitalisation and NHS employment was also investigated. A chi-square test did not find a statistically significant association between NHS employment and hospitalisation $\chi2$ (1, N=61) = 2.02, *p*=.16.

3.5 Summary

Overall, a high proportion of patients demonstrated clinically significant levels of depression (59%) and anxiety (42%) for whom further support was necessary to support their self-management, recovery, and rehabilitation towards levels of pre-infection functioning. These rates were similar between patients who had been hospitalised with COVID-19 and those who had not. Similarly, gender differences were observed with females more likely to report clinically significant levels of anxiety and depression.

There was a statistically significant association between gender and hospitalisation rates, with men more likely to have been hospitalised with COVID-19. However, this gender difference then changes as Long COVID develops and nearly two times as many women than men attended the clinic with Long COVID.

Chapter 4

Results of research question two:

What is the relationship between illness perceptions and mental health for people attending a long COVID clinic?

4.1 Research Question 2. What is the relationship between illness perceptions and mental health for people attending a long COVID clinic?

This chapter investigates the relationship between illness perceptions and mental health at timepoint one (clinic attendance). Specifically, it is hypothesised that negative illness perceptions would be associated with low mood and anxiety.

4.2 Data used

The data used to answer this question was gathered at timepoint one at participant's attendance at the Long COVID assessment clinic. Data from 188 patients was used who attended clinic between January 2021 and March 2022 and completed the BIPQ. To answer this question, responses from BIPQ, GAD-7, and PHQ-9 were analysed.

4.3 Analysis

General descriptive, t-tests for mean comparisons and correlational analysis was conducted on SPSS 28 (IBM Corp, 2020). 188 patients from Long-COVID clinic lists were identified as possible participants as they had completed the BIPQ at timepoint one. These patients were contacted via post to recruit and gain their consent to participate in the study. 61 (32%) patients responded, with a mean age of 51 years (SD=10.32), with more females responding (61%). 17 participants were NHS staff members (28%) and 23 patients had been treated in hospital for their acute COVID-19 infection.

An a priori G*Power (Faul et al., 2007) calculation was conducted for a sample size estimation based on published effect sizes in Long COVID (Bierbauer et al., 2022). The average variance explained by illness perceptions was reported to be between R^2 = .28 to .37. We specified power =.90, effect size (f^2) = .20 and alpha =.05. The sample size needed with this effect size was n= 55, allowing for up to six potential control variables to adjust the model.

Table 4

Descriptive statistics of BIPQ Items and means at T1

Variable	N	Mean	SD	Range
BIPQ Consequences	61	6.7	2.3	10
BIPQ Acute/chronic Timeline	56	6.8	2.6	10
BIPQ Personal control	61	3.9	2.9	10
BIPQ Treatment control	52	5.5	2.8	10
BIPQ Identity	61	6.7	2.5	10
BIPQ Concern	61	7.5	2.5	10
BIPQ Understanding	60	5.3	2.8	10
BIPQ Emotional response	60	6.6	3	10
Total B-IPQ score T1	52	48.5	9.9	45

Note. BIPQ Brief Illness Perception Questionnaire.

4.4 Results

4.4a Brief Illness Perception Questionnaire

There were correlations among items of the BIPQ (see Table 5). Perceived consequences were positively correlated with timeline, identity, concern, and emotional response. Thus, those who perceived a greater consequence of their illness to their lives perceived that the illness would last for a longer period of time, perceived a greater number of symptoms, were more concerned about their illness, and were more affected by their illness emotionally.

The perceived longevity of their illness was positively correlated with identity, concern, and emotional response. Therefore, those who perceived that their illness would last for a longer period of time perceived more symptoms, had greater concern and a higher emotional response to their illness.

Identity was also found to be positively correlated with concern, and emotional response. This suggests that those who were more concerned about their illness

reported a greater perceived understanding of their illness and a greater emotional response to their symptoms. In addition, we found that those who were more concerned about their illness had a greater emotional response.

Age was positively correlated with BIPQ personal control ($r(59) = .27$, p<.01), treatment control ($r(50) = .32$, p<.01) and concern ($r(59) = .27$, p<.01). Therefore, older participants perceived that they had a greater amount of control over their illness and they perceived that treatment would be more helpful than younger participants. Older participants were more concerned about their illness than younger participants.

T-tests were then conducted and women had more negative perceived consequences (BIPQ Q1) than men $t(58)=-2.27$, *p*=.007, *d*=-.91 with women scoring higher for consequence (*M*=7.4, *SD*=1.7) compared to men (*M*=5.5, *SD*=2.6).

Women also reported a higher emotional response (BIPQ 8) than men, $t(59)=-3.47$, *p*=.007, *d*=-.72 with women scoring higher for emotional response (*M*=7.3, *SD*=2.4) compared to men (*M*=5.6, *SD*=3.5).

There was no significant difference in BIPQ total scores either between individuals who were hospitalised and those who were not, or between NHS staff and other participants.

Table 5

Correlations between age, PHQ-9, GAD-7 and illness perceptions at timepoint 1

Variable	n	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. PHQ-9 T1	61	-										
2. GAD-7 T1	61	.758**	-									
3. BIPQ 1 (consequences)	61	.576**	.447**	-								
4. BIPQ 2 (timeline)	56	.450**	.467**	.537**	-							
5.BIPQ 3 (personal control)	61	.011	.061	.035	.150	-						
6. BIPQ 4 (treatment control)	52	-.150	-.133	.091	-.006	.132	-					
7. BIPQ 5 (identity)	61	.410**	.303*	.689**	.357**	.013	.096	-				
8. BIPQ 6 (concern)	61	.189	.198	.538**	.604**	-.068	.209	.496**	-			
9. BIPQ 7 (understanding)	60	-.186	-.180	.187	-.185	.128	.258	.304*	.105	-		
10. BIPQ 8 (emotional response)	60	.453**	.481**	.457**	.374**	.082	.213	.384**	.491**	0.12	-	
11. BIPQ total	52	.474**	.406**	.595**	.698**	-.268	-.331*	.462**	.647**	-.208	.556**	-

Note. *Correlation significant at 0.05 level, ** correlation significant at the 0.01 level

Note. *GAD-7* Generalised Anxiety Disorder scale, *PHQ-9* Patient Health Questionnaire-9, *BIPQ* Brief Illness Perception Questionnaire.

4.4b PHQ-9

Analysis found a negative correlation with age and PHQ-9 scores, suggesting that younger people were more likely to report symptoms of depression $r(59) = -.39$, $p=.002$. Furthermore, positive relationship with GAD-7 scores was identified, indicating that those reporting symptoms of depression were more likely to report symptoms of anxiety too $r(61) = .76$, $p<.001$.

In relation to BIPQ scores, there was an overall positive correlation with total BIPQ score and PHQ-9. The research question then looked at which specific components had an association with depressive symptoms and found that perceived consequence, timeline, severity, and emotional response were all positively associated with PHQ-9 scores.

4.4c GAD-7

Similar results were found in relation to anxiety scores. An overall positive correlation with the total BIPQ score was found $r(52) = .41$, $p=.003$. Considering individual items, perceived consequence, timeline, identity, and emotional response were positively correlated with GAD-7 scores.

4.5 Summary

Overall, the results from research question two highlight several key associations. In relation to demographics, younger participants reported poorer mental health and had a negative perception of their Long COVID. Specifically, younger participants reported less control over their illness than older participants, and did not perceive treatment to be as helpful as older participants. However, older participants did report higher levels of concern about their illness.

Analysis revealed further gender differences amongst those with Long COVID. Women scored significantly higher for consequence and emotional representation than men.

The analyses in this chapter were correlational and as such causation cannot be concluded. The relationships are bidirectional and as such it is not known if poorer mental health leads to more negative illness perceptions or vice versa.

Chapter 5

Results of research question three:

An investigation into the longitudinal impact of Long COVID on quality of life and functioning

5.1 Question 3 *a) What is the longitudinal impact of Long COVID on quality of life and functioning*

b) To what extent do baseline illness perceptions and mental health predict quality of life and functioning at follow-up for people attending a long-COVID assessment clinic?

5.2 Data used

188 patients from Long-COVID clinic lists were identified as possible participants as they had completed the BIPQ at timepoint one. A postal questionnaire was sent out at timepoint two at least three months after clinic attendance. Patients were contacted via post to recruit and gain their consent to participate in the study. 61 (32%) patients responded. We looked specifically at people's overall perceived quality of life and functioning. This was achieved by sending out EQ-5D, EQ-VAS, and WSAS questionnaires to patients to measure any change from timepoint one and timepoint two.

5.3 Analysis

Paired t-tests were conducted to answer part a of this question. Regression analysis was then conducted to answer part b and establish whether illness perceptions are a better predictor of QoL and functioning over time than anxiety and depression. Analysis was conducted on SPSS 28 (IBM Corp, 2020).

An a priori G*Power (Faul et al., 2007) calculation was conducted for a sample size estimation based on published effect sizes in Long COVID (Bierbauer et al., 2022) specified a minimum sample size of 45. This was based on hierarchical multiple regression analyses predicting two health outcomes (quality of life, functioning), with nine predictors (each item of the B-IPQ). This would allow detection of a medium effect size (0.2) with a power of 0.9, with alpha set at 0.05.

5.4 a) What is the longitudinal impact of Long COVID on quality of life and functioning?

5.4a Results

5.4ai Difference in health outcomes between timepoint one and two

Table 6 presents the mean scores for each health outcome at timepoint one and timepoint two. Paired t-tests were conducted and revealed that there was not a statistically significant difference for any health outcome between timepoint one and timepoint two. The EQ-5D was broken down into the five components and there was also not a statistically significant difference between these scores from timepoint one to timepoint two.

Table 6

A comparison of EQ-5D, EQ-VAS and WSAS scores at T1 and T2

Variable	N	Mean	SD	N	Mean	SD	Paired t-test
	T1			T2			
EQ5D Q1 (mobility)	61	2.16	.99	61	2.38	1.01	t(60)=-1.46, *p*=n.s
EQ5D Q2 (self-care)	61	1.49	.81	61	1.7	.97	t(60)=-2.79, *p*=n.s.
EQ5D Q3 (usual activities)	61	2.89	1.07	61	2.72	1.07	t(60)=1.26, *p*=n.s.
EQ5D Q4 (pain/ discomfort)	61	2.54	.941	61	2.59	1.05	t(60)=-.05, *p*=n.s.
EQ5D Q5 (anxiety/ depression)	61	2.31	.96	61	2.56	1.22	t(60)=-1.67, *p*=n.s.
EQ-VAS	59	61.83	17.13	60	57.5	21.83	t(57)=1.28, *p*=n.s

WSAS	55	19.05	9.55	58	18.86	9.82	t(51)=.33, *p*=n.s.
EQ-VAS change score				50	-3.74	23.01	
WSAS change score				44	0.11	8.46	

Note. Note. *EQ-5D-5L* Euroqol-5 dimensions-5 level, *EQ-VAS* Euroqol visual analogue scale, *WSAS* Work and Social Adjustment Scale.

Figures 7 and 8 present the results from the five components of the EQ-5D at timepoint one and timepoint two. Appendix H shows the comparison between each component between timepoint one and timepoint two. There was no statistically significant change in score for any component of the EQ-5D (see Table 6).

Figures 7 and 8 do highlight that self-care at both timepoints was the component that participants reported having the least difficulties with. For mobility, usual activities, pain/discomfort and anxiety/depression, there appears to be a more even distribution of responses at both timepoints highlighting the impact that Long COVID appears to have on individuals. Without intervention between the two timepoints, these difficulties do not improve which highlights the need for specific interventions to address each component in order to improve these health outcomes.

Figure 7

The distribution of responses to each dimension at timepoint one.

Distribution of EQ-5D-5L dimension responses at timepoint 1
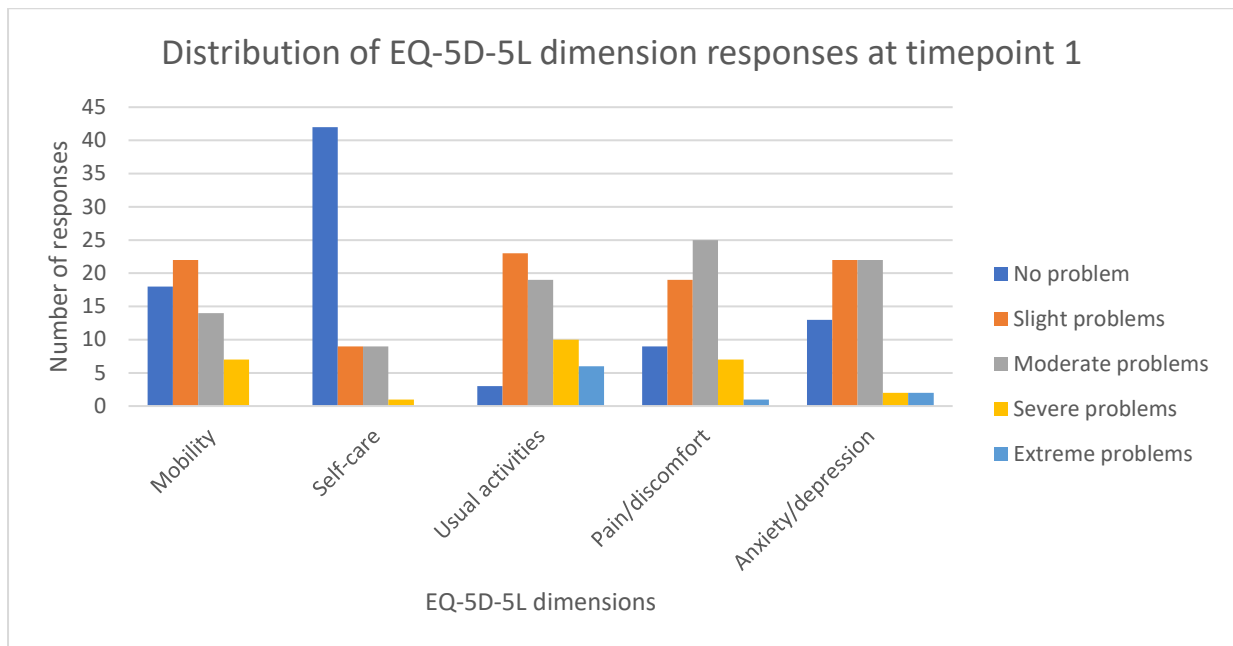
Note. EQ-5D-5L Euroqol-5 dimensions-5 level

Figure 8

The distribution of responses to the EQ-5D-5L at timepoint two.

Distribution of EQ-5D-5L dimension responses at timepoint 2
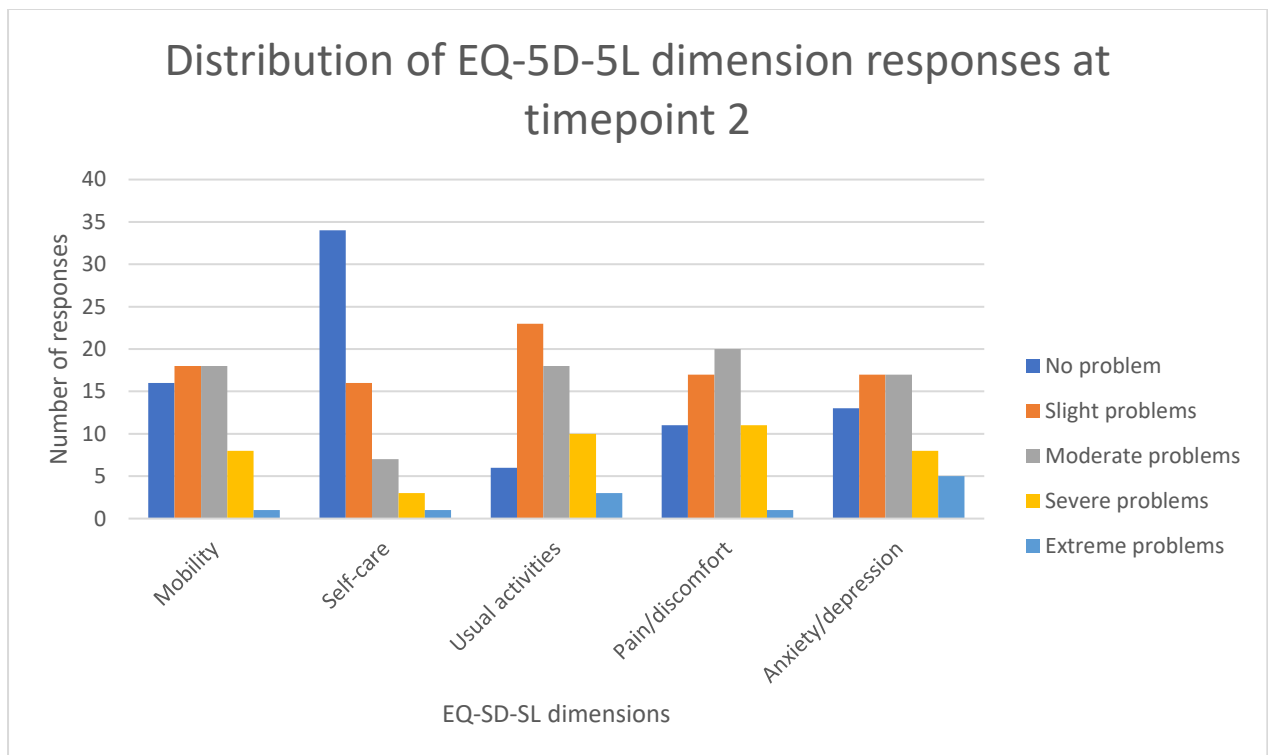
Note. EQ-5D-5L Euroqol-5 dimensions-5 level

Similarly to the EQ-5D, there was not a statistically significant difference in scores for the WSAS between timepoint one and timepoint two. Figure 9 shows the average scores at each timepoint as highlighted in Table 6.

Figure 9

The average WSAS score at timepoint one and timepoint two.

Average total WSAS scores at T1 and T2
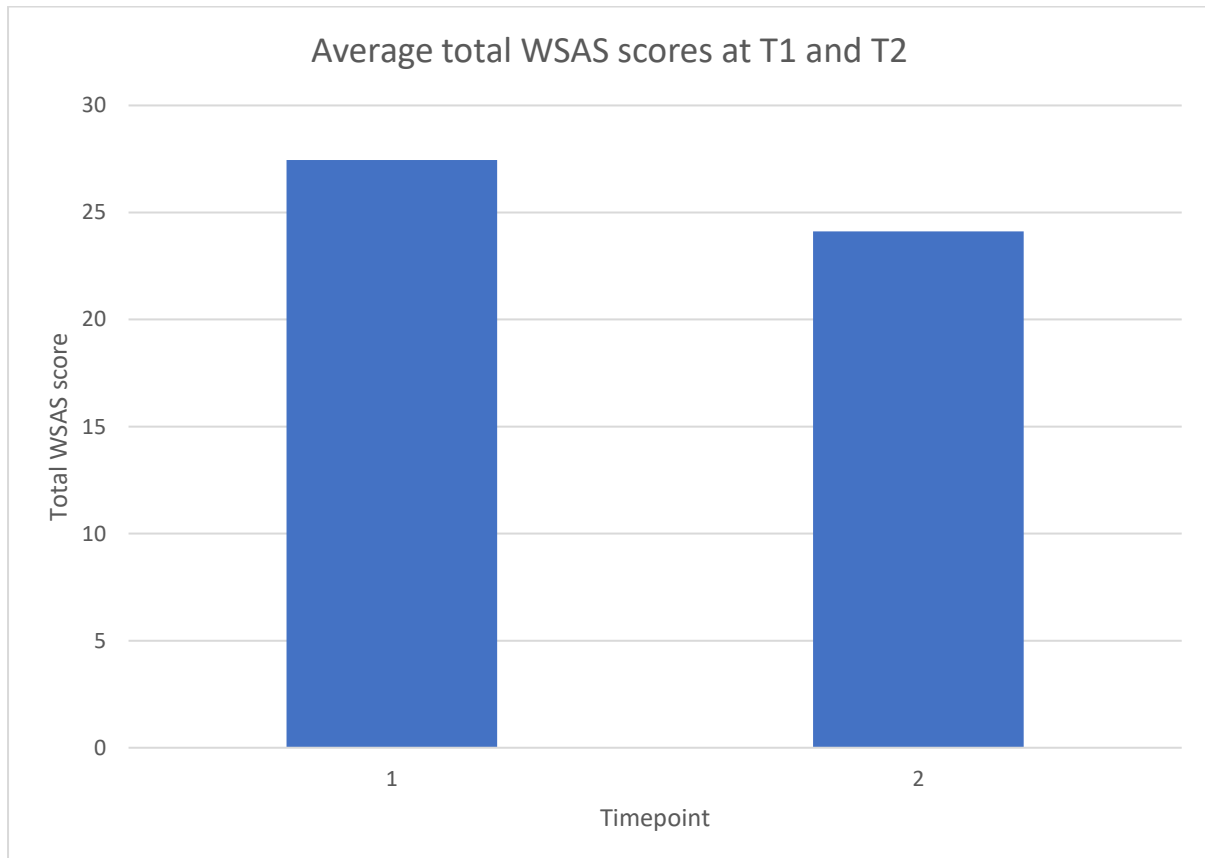
Note. WSAS Work and Social Adjustment Scale

5.4ii Change over time in health outcomes

The mean EQ-VAS declined overtime from baseline to timepoint two indicating a decline in overall perceived quality of life. Normative data for the U.K. suggest that the mean EQ-VAS score across ages is 82.8, higher than the scores in this analysis at timepoint one or timepoint two (Janssen & Szende 2014). Overall, although scores reduced slightly, there was not a statistically significant change between timepoint one and timepoint two for the EQ-VAS or the WSAS. As there

was not a significant difference in health outcomes over time, we chose to go on to investigate the relationship between predictors and outcomes at timepoint two.

5.5 Part b) To what extent do baseline illness perceptions and mental health predict quality of life and functioning at follow-up for people attending a long-COVID assessment clinic?

5.5a Results

5.5ai Relationship between overall perceived quality of life and illness perceptions

Correlational analysis in Table 7 revealed a negative association with EQ-VAS scores at timepoint two and perceived consequence, timeline, and identity. However, there was no significant association between the total BIPQ score at timepoint one and EQ-VAS scores at timepoint two.

Linear regressions were carried out with each individual illness perception. Perceived consequences were the only significant predictor of EQVAS scores at timepoint two accounting for 44% of the variance $F(8, 41) = 4.03$, $p<.001$, ($\beta = -.41$, $p = .05$). This suggests that those who perceived Long COVID to have a greater impact on their life scored lower on the EQVAS at timepoint two, thus had poorer perceived quality of life several months after their initial assessment.

5.5aii Relationship between overall perceived functioning and illness perceptions

Correlational analysis in Table 7 revealed a significant positive correlation with WSAS scores at timepoint two and overall BIPQ total scores suggesting that those struggling with functioning had more negative perceptions of their illness. In particular, WSAS was positively correlated with perceived consequence, timeline, identity, and concern. This suggests that those who perceived their symptoms to

have a greater impact on their lives, to last a longer time period, to have a greater number of symptoms and concern of their symptoms reported poorer functioning.

Table 7

Correlations between age, illness perceptions (T1) and EQ-VAS (T2), WSAS (T2)

Variable	n	EQVAS T2	WSAS T2
Age	61	0.11	.141
BIPQ Consequence	59	-.579**	.548**
BIPQ Timeline	55	-.474**	.394**
BIPQ Personal control	61	-.224	.223
BIPQ Treatment control	56	-.115	.049
BIPQ Identity	61	-.394**	.405**
BIPQ Concern	52	-.294	.307*
BIPQ Understanding	61	.041	.194
BIPQ Emotional response	61	-.246	.217
BIPQ total	60	-.244	.284*
EQVAS T1	60	-.382**	-.467**
WSAS T1	52	-497**	.638**
EQVAS T2	60	-	-.640**
WSAS T2	58	-	-

Note. EQ-VAS Euroqol visual analogue scale, *WSAS* Work and Social Adjustment Scale, *BIPQ* Brief Illness Perception Questionnaire.

*Correlation significant at 0.05 level, ** correlation significant at the 0.01 level

5.5aiii Change in scores over time

A 'change score' was calculated for the EQ-VAS and WSAS between timepoint one and two. This was calculated by subtracting the participants EQ-VAS score at timepoint one from their EQ-VAS score at timepoint two, and similarly with WSAS to generate one overall 'change score'. For example, if someone scored 50 on the EQ-VAS at timepoint one and 60 at timepoint two they would have a change score of 10. A positive change score for EQ-VAS indicates and improved quality of life, and a negative change score for WSAS indicates an improvement in functioning.

Correlational analysis revealed a positive correlation between WSAS change scores and EQVAS change scores indicating that an improvement in one was associated with an improvement in the other (r(58) = -.45, p<.001).

5.5aiv Mental health and health outcomes

We found that PHQ-9 scores at timepoint one were negatively associated with EQ-VAS scores at timepoint two (r(60) = -.41, p<.001) and positively associated with WSAS scores at timepoint two (r(58) = .45, p<.001). This suggests that symptoms of depression at timepoint one are associated with poorer perceived quality of life and functioning at timepoint two.

Similar results were found in relation to GAD-7 scores with a negative association with EQ-VAS scores at timepoint two (r(60) = -.34, p=.009) and a positive association with WSAS scores at timepoint two (r(58) = .34, p=.009). This suggests that symptoms of anxiety at timepoint one are associated with poorer perceived quality of life and functioning at timepoint two.

5.9 Predictors of health outcomes

There was a statistically significant relationship between some individual items of the B-IPQ and EQ-VAS scores at timepoint two as well as WSAS scores at timepoint two (see Table 7). In order to test the relationship between the EQ-VAS and WSAS scores at timepoint two and illness perceptions, an overall illness perception score was calculated (B-IPQ total). By creating one overall score rather than using the eight individual items as predictor variables, a smaller sample size, would be sufficient.

An illness perception of particular note was perceived consequence. Analysis found that those who perceived that Long COVID had a greater effect on their life, reported a poorer quality of life at timepoint two. In contrast, the research did not find as much evidence for an association between greater protective perceptions such as control, and improved health outcomes, although it did find that coherence was a predictor of PHQ-9 and GAD-7 scores at timepoint one. It is therefore important for clinicians working with patients with Long COVID to look at both the cognitive and emotional illness perceptions

The overall aim was to investigate whether illness perceptions and mental health outcomes at timepoint one could predict quality of life and functioning at timepoint two. In order to answer this, the following question was asked: Do variables (BIPQ total score, GAD-7, PHQ-9 scores, and demographics) at timepoint one predict quality of life and functioning at timepoint two?

In order to answer this, two hierarchical regressions were conducted investigating whether the predictor variables at timepoint one (BIPQ total score, GAD-7, PHQ-9 scores, and demographics) predicted overall quality of life (EQ-VAS) and functioning (WSAS) at timepoint two as shown in Tables 8 and 9 below.

At step one, age, gender and whether patients were treated in hospital for COVID-19 were not significant predictors of EQ-VAS scores at timepoint two $R^2 = -.02$, $F(3, 48) = .71$, $p = .55$. However, at step two when GAD-7 and PHQ-9 scores were added there was a significant increase in the variance accounted for by the

model R^2 =.1, $F(5, 46)$ = 2.1, p=.02 with 4% of variance in EQ-VAS scores. In the final model with the addition of BIPQ total score at stage three, although it did contribute an additional 7% variance (R^2 = .08, $F(6, 45)$ = 1.73, p= .79) the BIPQ total score was not a significant predictor of EQ-VAS scores at timepoint two. Therefore, in this regression, mental health scores at timepoint one were significant predictors of EQ-VAS scores at timepoint two (see Table 8).

Table 8

Hierarchical linear regression predicting EQ-VAS scores at T2

Predictor variable		ß Step 1	ß Step 2	ß Step 3	Adjusted R²	Total R²
1	Demographics				-.02	.042
	Age	-.03	-.02	-.01		

	Gender	-.22	-.05	-.04		
	Hospitalisation	.07	.02	.02		
2	Mental health				.1	.12*
	PHQ-9		-.38	-.37		
	GAD-7		-.04	-.03		
3					.08	.19
	BIPQ total			-.04		

Note. PHQ-9 Patient Health Questionnaire, *GAD-7* Generalised Anxiety and Disorder, *BIPQ* Brief Illness Perception Questionnaire

*p<0.05; **p<0.01; ***p<0.001

A hierarchical regression also revealed independent variables at timepoint one were predictors of variance in WSAS scores at timepoint two (see Table 9). At step one, age, gender and whether patients were treated in hospital for COVID-19 were not significant predictors of WSAS scores at timepoint two $R^2 = -.004$, $F(3, 45) =.93$, $p=.43$. However, at step two when GAD-7 and PHQ-9 scores were added in with gender and hospitalisation there was a significant increase in the variance accounted for by the model (25%) $R^2 = .16$, $F(5, 43) = 2.86$, $p=.008$. In the final model with the addition of the BIPQ total score at stage three, although it did contribute additional variance, ($R^2 = .15$, $F(6, 42) = 2.36$, $p=.69$) the BIPQ total score was not a significant predictor of WSAS scores at timepoint two. Therefore, in this regression, PHQ-9 scores at timepoint one were the only significant predictor of WSAS scores at timepoint two (see Table 9).

Table 9

Predictor variable	ß Step 1	ß Step 2	ß Step 3	Adjusted R^2	Total R^2

Hierarchical linear regression predicting WSAS scores at T2

1	Demographics				-.004	.06
	Age	.16	.2	.19		
	Gender	.2	.02	.01		
	Hospitalisation	-.11	-.07	-.07		
2					.16	.25*
	PHQ-9		.6*	.57*		
	GAD-7		-.17	-.18		
3					.15	.25
	BIPQ total			.06		

Note. PHQ-9 Patient Health Questionnaire, *GAD-7* Generalised Anxiety and Disorder, *BIPQ* Brief Illness Perception Questionnaire *p<0.05; **p<0.01; ***p<0.001

5.10 Summary

Overall, analysis revealed a varied picture. Correlational analysis highlighted associations between some illness perceptions at timepoint one and quality of life and functioning at timepoint two. However, when a total B-IPQ score was calculated and hierarchical regressions conducted, the overall illness perception score was not found to be a significant predictor of quality of life or functioning scores at timepoint two. However, anxiety and depression scores were found to be significant predictors of quality of life and functioning at timepoint two.

Correlational analysis revealed the illness perceptions which were found to have a significant relationship on health outcomes were consequence, timeline, concern, identity and emotional response. Understanding and control did not have a significant impact.

No statistically significant change was found in EQ-5D, EQ-VAS or WSAS scores between timepoint one and timepoint two. This finding suggests that without

intervention and ongoing support, Long COVID is likely to have an ongoing impact on quality of life and functioning for adults.

Correlational analysis revealed a positive association between WSAS scores and B-IPQ total scores, suggesting that those who were having difficulties with functioning to Long COVID had an overall more negative illness perception of their illness.

Correlational analysis found that poorer mental health, both anxiety and depression, at timepoint one was related to poorer quality of life and functioning at timepoint two. This was then investigated further with a hierarchical regression which demonstrated that anxiety and depression scores at timepoint one were both significant predictors of EQ-VAS scores at timepoint two. Furthermore, depression scores at timepoint one were also a significant predictor of WSAS scores at timepoint two.

Chapter 6

Discussion

6.0 Discussion

The aim of this research was to learn more about the psychological impact of Long COVID, a new condition emerging from the COVID-19 pandemic. In particular, the study wanted to investigate the role of psychological factors (including mental health and cognitions) on the health outcomes of Long COVID (in particular quality of life and functioning). In order to do this the study focused on illness perceptions and investigated whether these had an impact on health outcomes. Overall, the research did not find illness perceptions to be a significant predictor of health outcomes, but did find mental health to be, with poorer mental health predicting poorer quality of life and functioning over time.

In the first instance, the aim was to identify the impact of long COVID on mental health at timepoint one. This would provide a baseline and detail as to how individuals with Long COVID were presenting in assessment clinics. It had been hypothesised that those who had been hospitalised would report poorer mental health than those who had not been hospitalised, as previous literature had suggested (Malik et al, 2022). It was thought that this may in part be due to hospitalised patients experiencing Post-Intensive Care Syndrome (Sakusic & Rabinstein, 2018). However, no statistically significant difference was observed in anxiety or depression rates between those who were and those who were not hospitalised with COVID-19. A possible explanation for this is that those who were not hospitalised may have feelings of uncertainty, threat and helplessness surrounding the severity of their acute symptoms, as many had minimal contact with healthcare professionals, and some were isolated with minimal support. In contrast, those who were hospitalised may have received more clarity and support over their symptoms and were potentially better prepared for a long recovery. However, it is important to consider that all patients were seen at least 12 weeks after the acute COVID-19 infection, with many waiting longer, and as such, those who were hospitalised may have had more severe psychological difficulties early in their recovery after hospital which may have reduced in severity over time or they may have received psychological support. In the evolving pandemic, further studies are required to fully elucidate the psychological needs of those with Long COVID syndrome, including vulnerable subgroups such as those initially treated in primary

care, to ensure that patient psychological need is being fully met. Future research would benefit from qualitative research methods in order to gain more detailed insights from individuals and provide answers to some of the questions which have arisen from this research, such as whether additional psychological support was received.

The rates of anxiety (42%) and depression (59%) identified in this study are higher than the general population with 16% reporting a common mental disorder such as anxiety or depression in the U.K. (McCmanus et al., 2016). Within this subset there are gender differences with women (19%) reporting higher levels of CMD than men (12%). It is important to recognise that the figures by McCmanus et al. (2016) represent mental health rates before the COVID-19 pandemic. It is important to acknowledge the impact that the pandemic had on the general population's mental health. The ONS reported levels of depression in the first quarter of 2021 of 21% (a rise from 19% in 2019), which is lower than the 59% that was observed (ONS, 2021), which suggests that experiencing Long COVID does increase the likelihood of experiencing a decline in mental health. Houben-Wilke et al., (2022) found 35.6% of adults in the Netherlands with Long COVID to have anxiety, and 46.9% reporting depression based on the Hospital Anxiety and Depression Scale. These findings suggest that experiencing Long COVID does increase the likelihood of experiencing a decline in mental health and highlights the importance of specific psychological support for these patients.

There was a statistically significant association between gender and hospitalisation rates, with men more likely to have been hospitalised with COVID-19 which is in line with current research (Ghio et al., 2022). There are various proposed reasons as to why this may be, including different immune responses between genders, as well as behavioural differences such as smoking and prevalence of comorbidities (Mukherjee & Pahan, 2021). However, this gender difference then changes as Long COVID develops and nearly two times as many women than men attended the clinic with Long COVID. This is in line with current research which have similarly found that women are more likely to develop Long COVID (Bai et al., 2022).

Literature and information relating to Long COVID syndrome are predominantly based on post-hospitalised patients and management specific to this cohort. Patients with more severe disease were more likely to require and receive further supportive or psychological therapy (Bell et al., 2021). The current study looks at both those who were and who were not hospitalised with COVID-19 and demonstrates the significant and burdensome psychological impact and sequelae for individuals who were not hospitalised with COVID-19. For the latter group, information and guidance on management remains less abundant or clear, with a result that a large proportion of individuals are left feeling worried. Wang et al., (2021) provided a possible explanation for this and proposed a chain model to describe the link between physical and mental health symptoms via the need for health information. They found that excessive and contradictory health information could increase the perceived impact of the pandemic. It is therefore important that further information and support should be developed to support this group.

Illness perceptions were then considered in question two, and correlational analysis revealed that an overall more negative B-IPQ total score at timepoint one was associated with poorer mental health at timepoint one, both for depression and anxiety. This is in line with previous literature which suggests that illness perceptions can influence coping mechanisms, which in turn can impact mental health (Petrie et al., 2007). Therefore, negative illness perceptions can lead to poorer mental health as individuals may find it more difficult to engage in coping strategies that can improve their cognitive and emotional responses. This is a bidirectional relationship and the current study cannot ascertain whether negative illness perceptions lead to poorer mental health or vice versa, but what this finding does highlight is the importance of addressing negative illness perceptions and poorer mental health in order to support those with Long COVID.

Further analysis revealed that younger participants reported poorer mental health than older participants. This in line with normative data from the general population which found that adults of working age are more likely to experience anxiety and depression than those over 65 (McManus et al., 2016). Symptoms typically peak in the 16-24 year old age group for women and again in midlife (45-54) whereas the rates in men were more stable between the ages of 25 and 64. This is

also supported by a recent study in the USA which similarly found poorer mental health in younger participants (Bruine de Bruin, 2021). Researchers looked at COVID-19 risk perceptions and mental health and found that although older adults had a greater perceived risk of dying from COVID-19, younger adults were more likely to perceive that they would contract COVID-19 and experience additional difficulties such as not having enough money. This group also reported higher levels of anxiety and depression. One hypothesis as to why this may occur, is that this is perhaps a reflection of where people are in their lives, and younger adults are likely to have less savings as they have not worked for as many years, as well has having higher outgoings such as mortgages and dependent children. It is therefore important to take a holistic approach when working with people with chronic health conditions such as Long COVID, and consider other stressors that may be impacting their recovery.

Women scored significantly higher for consequence and emotional representation than men. Previous research looking at gender differences in illness perceptions for those with osteoporosis did find women to hold more negative illness perceptions than men (Edelstein et al., 2012). Furthermore, Martin et al., (2005) found that in patients who had suffered from a heart attack, males were more inclined to attribute the cause to lifestyle modifications and were more willing to adopt these changes. It is unclear if this is the case for Long COVID and further research could investigate the impact of lifestyle changes on prognosis. Overall, these findings would suggest that individuals may benefit from tailored interventions based on their gender.

An illness perception of particular note was perceived consequence. In line with previous research by Bierbauer et al. (2022), the study found that those who perceived that Long COVID had a greater effect on their life reported poorer health outcomes. This research is in line with previous studies which suggest that higher threat-related perceptions such as consequences, identity, duration, and emotional representations will result in poorer health outcomes (Hagger et al., 2017; Meuleman et al., 2015). In contrast, the current study did not find as much evidence for an association between greater protective perceptions such as control, and improved

health outcomes. It is therefore important for clinicians working with patients with Long COVID to look at both the cognitive and emotional illness perceptions

The link identified in this analysis between negative illness perceptions and poorer mental health is in line with previous literature. Petrie et al., (2007) highlights that illness perceptions can influence coping mechanisms, which in turn impact mental health, thus negative illness perceptions can lead to poorer mental health as individuals find it more difficult to engage in coping strategies that can help improve their cognitive and emotional responses.

Correlational analysis in research question three identified associations between some individual illness perceptions (consequence, timeline, concern, identity, and emotional response) and quality of life and functioning at timepoint two. This is in line with previous research which looked at illness perceptions and Long COVID (Bierbauer et al., 2022). Specifically, they reported that a higher perceived consequence of their illness was correlated with poorer quality of life. This research builds on this finding and demonstrates that this relationship is maintained over time.

Understanding and control did not have a significant impact. This finding is contradictory to that by Haines et al., (2019) who suggested that for adults with CFS the illness perceptions which clinicians should focus on are control, comprehension, and identity. This difference in findings may be an indication that cognitions associated with CFS and Long COVID are not as similar as clinicians thought. Reduced control and comprehension are something that not just patients experienced, but also medical staff. With a new condition, particularly in the early days, medical professionals had a limited understanding of the condition and little control in the sense of minimal treatment options. This may have impacted patients' illness perceptions and they may have been more accepting that there are unknowns about this illness, which may have redirected their attention to other illness perceptions such as emotional response and identity. As this finding is contrary to research into other conditions, it would be beneficial to look into these illness perceptions further.

When considering illness perceptions it is common to refer to them as positive and negative or adaptive and maladaptive illness perceptions. For example, a high score of control could be considered as positive or adaptive perception as it can be associated with better health outcomes (Haines et al., 2019). However, it is important that illness perceptions remain realistic. It would not be beneficial to design an intervention for Long COVID with the focus on changing an individual's perception so that they feel that Long COVID is completely within their control. This may provide false hope and ultimately set the patient back, as we know there are some biological factors involved in Long COVID, for example with the immune system (Raveendran et al., 2021). It is important that individuals perceive an element of control, for example lifestyle changes that can help improve symptoms such as pacing, but within a realistic context.

Finally, in research question three hierarchical regressions were conducted and did not find overall B-IPQ scores to be predictors of quality of life and functioning at timepoint two, however anxiety and depression scores were found to be significant predictors. Future research could use mediation analysis to investigate whether mental health mediates the relationship to illness perceptions and health outcomes. As the analysis only used the total B-IPQ score due to a small sample size, it would also be beneficial to look at the individual illness perceptions and see if any perception on its own is a predictor of quality of life and functioning.

Despite previous research highlighting the strengths of the CSM and illness perceptions in relation to understanding health outcomes the current study has not found such strong support for the model. As already mentioned, this is perhaps a reflection of the extraneous variables unique to the time period studied and the effect of the COVID-19 pandemic, such as physical distancing from people, 'lockdown' where individuals were restricted in how often they could leave their homes, and large numbers of people passing away. These variables, and other changes to the environment, are not taken into account in the CSM model. As the model currently stands, cognitive and emotional factors are considered, but perhaps a third strand should be considered taking into account environmental factors. These could include social factors similar to those in the biopsychosocial model, and consider variables such as housing, finance, and relationships. Literature from other conditions can be

used to guide research, but we must not forget that Long COVID emerged out of a pandemic that no one has experienced in their lifetime before, the impact that will not be fully understood for years to come. These same reasons may also explain why difficulties with anxiety and depression were so high amongst this population.

6.1 Implications for clinical practice and recommendations

This research has highlighted the significant impact that Long COVID can have on mental health and highlighted the need for psychologists to be involved with the care of patients with Long COVID as early as possible. Interventions to help manage low mood and anxiety and improve illness perceptions could prove valuable in patients' recovery. In particular, Health Psychologists can provide the tailored support required such as psychoeducation, support with motivation and behaviour change, as well as support with functioning and mental health.

It has been proposed that illness perceptions can be changed through interventions which focus on cognitions (top down) or by targeting behaviours (bottom-up) (McAndrew et al., 2008). In relation to Long COVID, Health Psychologists could support not only in the 'top down' interventions such as educating patients about the timeline of Long COVID, but also 'bottom-up' interventions such as teaching behaviours about fatigue management such as pacing, which would target perceptions of controllability and consequences of their symptoms. It is proposed that a combination of interventions targeting both cognitions and behaviours is the most effective approach (Broadbent, 2010).

Broadbent (2010) also highlights that for many patients with somatic illnesses they are usually highly motivated and have normal cognitive functioning. The use of illness perception interventions with this population, such as those with Long COVID, can be effective, with some interventions taking much less time than standard cognitive-behavioural-therapy. Effective interventions have been demonstrated to work in three half hour sessions (e.g. Petrie et al., 2002) or even 15 minute discussions (Petrie et al., 2007). With the NHS seemingly under more pressure than

ever before and a shortage of Applied Psychologists, the use of Health Psychologists and illness perception interventions appear an effective option.

6.2 Limitations

A key limitation of this research, particularly question two, looks primarily at correlational analyses, and although it is important to identify associations, we cannot conclude causation from them. It does however, provide a good foundation to build further analysis such as the regressions conducted in the last section.

Another limitation is that it was not possible to design this research with the input of patients from the outset for several reasons. This project was initially designed during the COVID-19 pandemic and the hospital had strict rules in place as to when patients were allowed into the hospital and what staff were allowed to do. Patients had appointments put on hold, and only essential work, mainly treating COVID-19 patients, was allowed to happen. In addition, most research was put on hold, and special allowances were made for projects like this, but it was not possible to hold any focus groups. As a result, this study could not be co-designed with patients and hear what was important to them in terms of research topics, as well as how best to engage participants. In addition, by the nature of the subject, there were few patients who could be contacted at the beginning. This was a new illness, and due to NHS demands the service had to be set up incredibly quickly. As a result of these factors, it was only possible to contact patients retrospectively. The study did gain a lot of insight from patient satisfaction surveys collected, feedback received in subsequent groups as well as feedback received during this project. Now that rules have been relaxed within the NHS, future research would benefit from speaking to patients, including a mix of those who have and have not recovered from Long COVID, to find out which areas of research would be important for them.

This study also relied upon self-reported outcome measures which carry an element of subjectivity, However, the measures used were validated and commonly used for illness perceptions. In future, it could be beneficial to use objective health outcomes alongside the self-reported measures such as the results of lung function tests. It is also important to highlight that the common-sense model of illness self-

regulation, focuses on perceptions and their relationship with coping strategies in response to health threats (Leventhal et al., 1984). In contrast the current study focuses on the associations between illness perceptions and health outcomes and does not take into account coping strategies. It would therefore be useful to look further at the role of coping strategies and Long COVID in future research.

This study does not account for individual differences and large variations in the time interval between timepoint one and two. The time difference varied between participants and some may have received additional support privately, whereas others may not. It would be interesting to see if a randomised control trial with an intervention over this time period affected outcomes, whether this be psychological or physiological. It is also important to highlight that previous research indicates that illness perceptions can change over time and so it would be useful to conduct future research which reassesses illness perceptions as well as health outcomes (Bijsterbosch et al., 2009).

Currently, there is a broad definition of Long COVID. The main diagnostic criteria for patients who attended the South Tees clinic was to have had an acute COVID-19 infection at least 12 weeks prior, and to have ongoing symptoms. As the range of literature mentioned in the introduction highlights, there is a broad range of potential symptoms. The clinicians did their best to rule out other conditions in the MDT clinic, but further research is required to gain a better understanding of the physical symptoms and develop more robust diagnostic tests. For example, with persistent fatigue, brain fog, or low mood, it is difficult to be sure if these are a result of COVID-19 or in fact reactions to the last two years of restrictions, uncertainty, and huge changes to the way we live our lives.

Despite these limitations, this is one of the first pieces of research to look at patients' perceptions of Long COVID and how these impact on health outcomes over time. Overall, the present study has found that correlational relationships with some illness perceptions and quality of life and functioning. Furthermore, analysis revealed that poorer mental health, specifically anxiety and depression, are predictors of poorer overall quality of life (EQ-VAS) and poorer functioning (WSAS) at least three months later and highlights the impact that Long COVID has on patients over time.

The study highlights the impact that the perceived consequences and emotional impact that Long COVID has on individuals and their association with poorer health outcomes. Clinicians working with individuals with Long COVID should seek to address these and tailored interventions should be studied targeting these illness perceptions. This study highlights the profound psychological impact of Long COVID and the impact that this has on longer-term health outcomes.

6.3 Reflections

As part of my reflections I have used Gibb's Reflective Cycle to help shape my thoughts (Gibbs, 1988). This is an ongoing process and describing what has happened, how I felt, evaluation of the experience, conclusions, and considers any actions going forward.

Although the past two years have been challenging and it was daunting to work and conduct research into an area where there was little known, I have enjoyed this new challenge. It has been interesting to learn about a new condition alongside my colleagues from different disciplines and we had a sense of learning together, despite different levels of expertise in our respective areas. It has been rewarding to see what can be achieved when there is the interest and enthusiasm, money, and resource available at the same time. As COVID-19 infection rates appear to be slowing down and Long COVID referrals have reduced at the time of writing, we are reaching a new phase in the development of the service. As explored in this study, we now have a vast array of data, and it now feels the right time to take a step back and review what we have achieved and how we could improve things going forward. A key addition which we are now working on is treatment, both on an individual and group basis. The findings from this research will help inform the approach we use, but approaches such as Acceptance and Commitment Therapy, as well as psychoeducation will be important to address some of the threat-related perceptions highlighted.

Conducting this research while working in the NHS during the COVID-19 pandemic was incredibly challenging at times. I found myself trying to understand a new condition while managing expectations of those around me. NHS staff were required to work in exceptional circumstance, working longer hours, in roles that were often unfamiliar or different to that of the job one was employed for. Priorities regularly changed and work was expected to be done exceptionally quickly. Similarly, universities were adapting to a new way of working and the expectations of the course did not change. I found myself managing conflicting priorities between the NHS and university, all while being in training. As a student you are often the one to be guided, but I had to learn to speak up and guide the expectations of each party

and establish compromises that worked for both parties. It was essential that I developed good communication skills in order to achieve this. These are skills which I will take forward as a Health Psychologist.

While conducting this research I have gained a deeper understanding of illness perceptions and the unique role that Health Psychologists can play in addressing illness perceptions through both the cognitive (top down) and behavioural (bottom up) interventions. I was surprised that the overall illness perception score was not a predictor of quality of life and functioning.

As highlighted in the introduction, Long COVID is similar to other post-viral illnesses such as chronic fatigue syndrome, but which have had much less resource. As such the Long COVID clinics may adapt into post-viral clinics or perhaps unexplained symptoms clinic. The MDT approach has been an effective one, and with a combination of Health Psychology, medical doctors, physiotherapists, and occupational therapists we would be in a good position to help a broad range of people. We have begun to see patients who have been referred because they have a complex mix of symptoms that a GP has been unsure of how to address and been able to offer support and refer on to appropriate services. This could be a key opportunity to provide more equity amongst conditions and provide more people with the holistic care required. As more research comes out, I also hope that the expansion of support for patients with Long COVID is more equitable across the United Kingdom.

Despite numerous challenges, I am proud that I have produced original research, and one of the first studies to look at Long COVID from a health psychology perspective.

7.0 References

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9.0 Appendices

Appendix A

The Brief Illness Perception Questionnaire

The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

| **How much does your illness affect your life?** |
| 0   1   2   3   4   5   6   7   8   9   10 |

0   1   2   3   4   5   6   7   8   9   10
no affect at all / severely affects my life

How long do you think your illness will continue?
0   1   2   3   4   5   6   7   8   9   10
a very short time / forever

How much control do you feel you have over your illness?
0   1   2   3   4   5   6   7   8   9   10
absolutely no control / extreme amount of control

How much do you think your treatment can help your illness?
0   1   2   3   4   5   6   7   8   9   10
not at all / extremely helpful

How much do you experience symptoms from your illness?
0   1   2   3   4   5   6   7   8   9   10
no symptoms at all / many severe symptoms

How concerned are you about your illness?
0   1   2   3   4   5   6   7   8   9   10
not at all concerned / extremely concerned

How well do you feel you understand your illness?
0   1   2   3   4   5   6   7   8   9   10
don't understand at all / understand very clearly

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)
0   1   2   3   4   5   6   7   8   9   10
not at all affected emotionally / extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused your illness. *The most important causes for me:-*

1. _____
2. _____
3. _____

Appendix B

NHS Trust Ethical approval

Dear Sarah,

South Tees Hospitals NHS FT: Approval to proceed with service evaluation

Having reviewed your service evaluation application, I hereby confirm Trust approval for this project to proceed on the basis that you comply with the Trust's IG policies and kindly keep us updated on any publications or further developments.

Thank you for making those updates to the patient documents which I have reviewed and for your general support in completing the application process.

Thank you,
Joe

Joe Millar

Research Governance Manager, Durham Tees Valley Research Alliance

County Durham and Darlington NHS FT / North Tees and Hartlepool NHS FT / South Tees Hospitals NHS FT
Pronouns: He/Him
07773 740784
joe.millar@nhs.net
dtvra.projects@nhs.net for Chief Investigator and Sponsor study queries
stees.dtvra@nhs.net for general R&D queries

Appendix C

University Ethical Approval

UNIVERSITY of STIRLING

University of Stirling
Cottrell 3B1
Stirling
FK9 4LA

16/05/2022

Dear Sarah

Ethics Application Form : Do illness perceptions predict health outcomes in adults with Long COVID? 7301

Thank you for your submission of the above ethics application.

The ethical approaches of this project have been approved and you can now proceed with your project.

Please note that should any of your proposal change, a further amendment submission will be necessary.

If you have any further queries, please do not hesitate to contact the Panel by email to ethics@stir.ac.uk

Yours sincerely,

NHS, Invasive or Clinical Research

Appendix D

Participant letter

UNIVERSITY *of* STIRLING

NHS South Tees Hospitals
NHS Foundation Trust

May 2022

Dear Sir/Madam

RE: The Psychological impact of Long COVID

South Tees NHS Hospital's Foundation Trust is conducting a service evaluation of their Long COVID clinic with the University of Stirling. The study wishes to follow up with people who have attended the Long COVID clinic to see if there have been any changes to people's quality of life and adjustment. This service evaluation is part of Sarah Keith's thesis for their Professional Doctorate in Health Psychology at the University of Stirling.

You have been contacted to consider taking part because you attended an appointment in the Long COVID clinic at Redcar Primary Care Hospital between November 2020 and February 2022. Participation is entirely voluntary; you do not have to participate if you do not wish to.

The information you provide in this study is anonymous; there is no name on the questionnaires to identify you. Information you provide is linked to your clinic data by a unique identifier on the questionnaire. The principal investigator will be the only person who will have access to this data.

This study is not connected to any treatment you may receive from the Long COVID clinic or South Tees Hospitals NHS Foundation Trust. If you decide to participate in this study or not, any treatment you are receiving will not be affected.

The study involves completing and returning two questionnaires enclosed in this letter which measure quality of life. We want to see if our initial assessments can help us predict how people will be feeling at least three months after attending the clinic. Alternatively, you can complete the questionnaires via this weblink http://bitly.ws/rVre or QR code at the bottom of this letter.

I have included a Participant Information Letter which explains more about the study and what is involved. Please take the time to read the information. If you would like to participate, please fill in the consent form and two questionnaires included in this letter and return these using the stamped addressed envelope enclosed.

If you would like more information before you make your mind up, please contact Sarah Keith via email at sarah.keith@stir.ac.uk.

Many thanks for taking the time to read this letter.

Yours sincerely

Sarah Keith
Principle investigator & Trainee Health Psychologist

Appendix E

Participant information sheet

Participant Information Sheet

Title: The Psychological impact of Long COVID

Principal Investigator: Sarah Keith, Trainee Health Psychologist

Address: Medical Psychology, DSC, James Cook University Hospital, Middlesbrough, TS4 3BW

You are invited to take part in a study. Please take time to read the following information to decide whether you wish to take part. Please contact us if there is anything that is not clear and if you would like more information.

Purpose of this Study

The purpose of this service evaluation is to examine whether illness perceptions and the psychological impact of Long COVID affect overall health outcomes in adults with Long COVID.

Sample

This study is looking to recruit patients who were seen in the Long COVID clinic at Redcar Primary Care Hospital between November 2020 and February 2022.

1. **What would I need to do?**

If you decide to take part in this study, you will be asked to complete two questionnaires which look at quality of life and are enclosed in this letter, the EQ-5D and the Work and Social Adjustment Scale (WSAS) and return these using the stamped addressed envelope enclosed. We will then compare your answers to those in your medical record which you completed when you attended the Long COVID clinic.

Alternatively, you can complete the questionnaires via this weblink http://bitly.ws/rVre or QR code at the bottom of this letter.

2. **Possible Risks or Discomfort**

The study does involve completing questionnaires about your quality of life which may be distressing. There are no known risks to participating in this study. We will inform you immediately about any developments that arise out of this study that may affect your willingness to continue to take part.

3. **Possible Benefits**

You will not benefit directly by taking part in this study; however, your participation will help us gain a better understanding of the longer-term impact of Long COVID.

4. **Financial Considerations**

We appreciate that taking part in this study will take up your time, however, we are not able to offer any reward at this time.

PIS V3 25/04/2022

Professional Doctorate in Health Psychology   Student number: 2112040

5. Confidentiality

Data will be collected and stored in line with the Data Protection Act 2018. For your protection, all personal information, including your contact details, in this study will be treated as confidential. Data will be stored in a password-protected file on an NHS computer which will also be password protected. Only the principal investigator and their research supervisor within the NHS will have access to this. After the questionnaires have been analysed they will be destroyed. The results of the study may be published for scientific purposes, but publications will not contain your name or any other personal information that could identify you. However, any records or data obtained as a result of your participation may be checked by an ethical committee that oversees research to ensure that human subjects are protected.

The only instance in which confidentiality cannot be guaranteed is if you disclose a risk of harm to yourself or others at which point as your clinician, I would conduct a risk assessment with you in line with the Medical Psychology procedures within South Tees NHS FT.

Stirling Data Protection Registration Number: 7301

You are free to choose whether or not to take part in this study, and you will not be penalised in any way if you decide not to take part. You can stop participating at any given time. Your participation may also be stopped if the sponsor of the study (South Tees NHS Hospitals Foundation Trust) decides to cancel the study.

6. Ethics Review

This study has been approved by South Tees Hospitals NHS Foundation Trust and the University of Stirling

Available Sources of Information

If you have any questions or require additional information about the study and your rights as a participant, please contact Sarah Keith: sarah.keith@stir.ac.uk

If you wish to go further and complain about any aspect of the way that you have been approached or treated during the course of this study, you should email the Chair of the Ethics panel: ethics@stir.ac.uk.

Appendix F
Participant consent form

UNIVERSITY of STIRLING

NHS
South Tees Hospitals
NHS Foundation Trust

Stirling Data Protection Registration Number: 7301

Participant Identification Number:

Participant Consent form

Project title: The Psychological impact of Long COVID

Principal Investigator: Sarah Keith, Trainee Health Psychologist

Name of participant: _____

Date of birth: _____

Please complete this form after you have read the Information Sheet.

If you have any questions arising from the Information Sheet, please ask the researcher before you to decide whether to join in.

Please initial each box to confirm your consent.

Please initial box

I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

I understand that this project requires me to complete two questionnaires which look at quality of life and these scores will be compared to my previous scores when I completed these questionnaires in the Long COVID clinic.

☐

I consent to the comparison of my questionnaire responses to previous responses on my medical record.

☐

Consent form. V2 06.04.2022

I understand that participation in this study is entirely voluntary, and I can withdraw from the study at any time without giving a reason and my treatment will not be affected.

I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately knowing that my responses will be destroyed.

I consent to the processing of my personal information for the purposes of this research study.

I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 2018.

I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Comments or concerns during the study: If you have any comments or concerns you should discuss these with the Principal Researcher (sarah.keith@stir.ac.uk). If you wish to go further and complain about any aspect of the way that you have been approached or treated during the course of this study, you should email the Chair of ethics panel ethics@stir.ac.uk.

If you would like to be contacted with the findings of this study please tick this box.

_____   _____   _____
Participant's signature   Print name   Date

Thank you for your interest in taking part in this research.

Consent form. V2 06.04.2022

Professional Doctorate in Health Psychology   Student number: 2112040

Appendix G

Participant reminder letter

UNIVERSITY *of* STIRLING

NHS
South Tees Hospitals
NHS Foundation Trust

May 2022

Dear Sir/Madam

RE: The Psychological impact of Long COVID

South Tees NHS Hospital's Foundation Trust is conducting a service evaluation of their Long COVID clinic with the University of Stirling. The study wishes to follow up with people who have attended the Long COVID clinic to see if there have been any changes to people's quality of life and adjustment. This service evaluation is part of Sarah Keith's thesis for their Professional Doctorate in Health Psychology at the University of Stirling.

You have been contacted to consider taking part because you attended an appointment in the Long COVID clinic at Redcar Primary Care Hospital between November 2020 and February 2022. Participation is entirely voluntary; you do not have to participate if you do not wish to.

The information you provide in this study is anonymous; there is no name on the questionnaires to identify you. Information you provide is linked to your clinic data by a unique identifier on the questionnaire. The principal investigator will be the only person who will have access to this data.

This study is not connected to any treatment you may receive from the Long COVID clinic or South Tees Hospitals NHS Foundation Trust. If you decide to participate in this study or not, any treatment you are receiving will not be affected.

The study involves completing and returning two questionnaires enclosed in this letter which measure quality of life. We want to see if our initial assessments can help us predict how people will be feeling at least three months after attending the clinic. Alternatively, you can complete the questionnaires via this weblink http://bitly.ws/rVre or QR code at the bottom of this letter.

I have included a Participant Information Letter which explains more about the study and what is involved. Please take the time to read the information. If you would like to participate, please fill in the consent form and two questionnaires included in this letter and return these using the stamped addressed envelope enclosed.

If you would like more information before you make your mind up, please contact Sarah Keith via email at sarah.keith@stir.ac.uk.

Many thanks for taking the time to read this letter.

Yours sincerely

Sarah Keith
Principle investigator & Trainee Health Psychologist

Appendix H

Comparison figures at timepoint one and timepoint two for each EQ-5D dimension

Figure 10. Comparison of Participants' self-reported scores for EQ-5D-5L mobility at timepoint one and timepoint two.
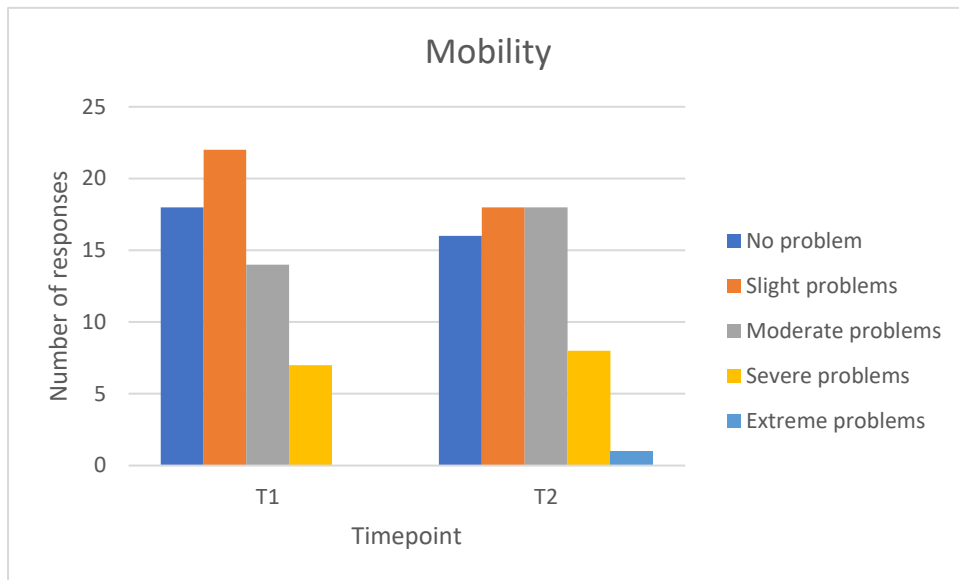

Figure 11. Participant's self-reported scores for EQ-5D-5L self-care at timepoint one and timepoint two.
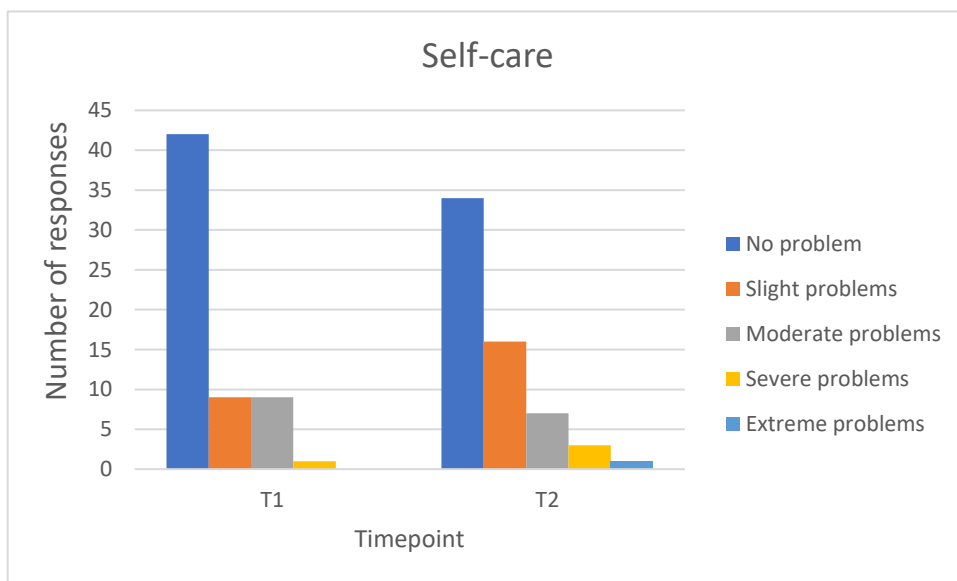
Figure 12. Participant's self-reported scores for EQ-5D-5L usual activities at timepoint one and timepoint two.
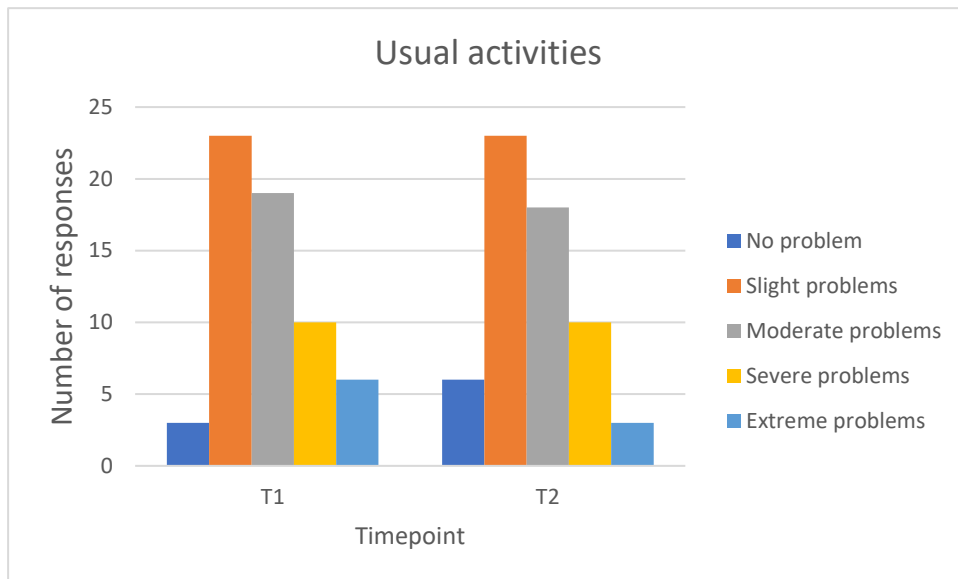

Figure 13. Participant's self-reported scores for EQ-5D-5L pain/discomfort at timepoint one and timepoint two.
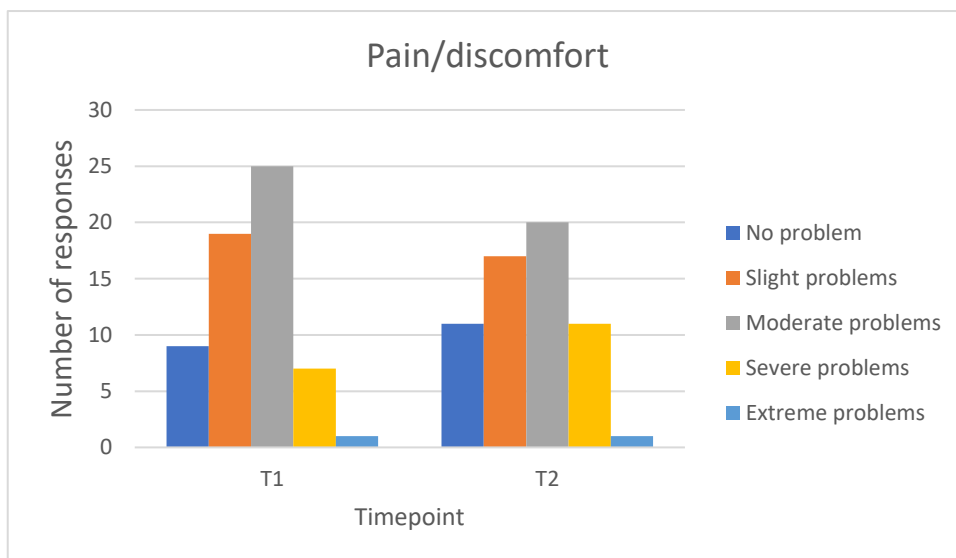
Figure 14. Participants' self-reported scores for EQ-5D-5L anxiety/depression at timepoint one and timepoint two.