The impact of the COVID-19 pandemic on access to healthcare for people living with multiple long-term conditions: An Interpretative Phenomenological Analysis

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A thesis submitted in fulfilment of the requirements of

Manchester Metropolitan University

for the degree of MSc by Research

Department of Health and Social Care

Manchester Metropolitan University

2025

Acknowledgements

I thank the supervisors, Professor Christopher Hatton and Dr Natalie Hammond for their support and guidance. I am extremely grateful to the community centres for the use of space and the CEO of the community centre in Manchester for the advice and access to the support group. Special thanks and heartfelt appreciation to the participants who took the time to talk to me and trusted me with their personal experiences. This would not have been possible without their openness and willingness to take part.

Abstract

This qualitative phenomenological study focuses on the experience of four individuals living with multiple long-term conditions (MLTC), by comparing their lived experiences before, during and after the COVID-19 pandemic for the purpose of understanding the impact of the COVID-19 pandemic on healthcare access and informing healthcare policy and delivery. Using Interpretative Phenomenological Analysis (IPA) methodology it identifies four key themes of particular significance to the participants: (a) living in the unknown: an emotional response to waiting for access to healthcare services, (b) the effects of the COVID-19 pandemic on their day-to-day life, (c) trust and faith in healthcare services and (d) the lasting effects of the COVID-19 pandemic. Within these main themes, seventeen sub-themes exemplify the meaning participants have assigned to their experience of accessing healthcare and the impact on their quality of life.

In addition to providing insights into the experience of people living with MLTC, this research has exposed limitations in healthcare provision which has become overly concerned with identifying pathways for single conditions and applies systems and processes that mitigate the ability of healthcare professionals to consider the 'whole person.' Participants' accounts illustrate that these factors were exacerbated by the pandemic, and how the reduced ability to provide services tailored to the individual continues to impact individuals' quality of life in many ways; thereby generating increased demand on healthcare services.

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List of abbreviations

Abbreviation	Full form
HCS	Healthcare Service
HCP	Healthcare Professional
LTC	Long-term conditions
MLTC	Multiple long-term conditions
PLwLTC	People living with long-term conditions
PLwMLTC	People living with multiple long-term conditions
QoL	Quality of life

1.0 Introduction

1.1 Outline

It is widely reported that the number of people living with two or more long term conditions (LTC) in England is increasing, creating rising demand for healthcare services (HCS), which affects patients' access and their experience. This has been exacerbated by the impact of the COVID-19 pandemic on services that were already under pressure because of multiple factors including an aging population and funding.

The purpose of this qualitative research study is to explore the impact of the COVID-19 pandemic in relation to HCS provided to people living with multiple long-term conditions (PLwMLTC). The study examines the experiences of four participants who volunteered to share their stories of accessing HCS for their MLTC.

A literature review examines the research literature on PLwMLTC and accessing healthcare during two separate time periods: pre-pandemic (2016-2020) and post-pandemic (2021-2025). Separating the body of knowledge in this way enabled the researcher to gain an understanding of issues relating to the delivery of HCS for PLwMLTC prior to the pandemic, before commencing the research.
The study explored the lived experience of four PLwMLTC through semi-structured interviews, to enable the identification of:

- themes specific to individuals
- recurring themes
- consequences of the COVID-19 pandemic.

Interpretative Phenomenological Analysis (IPA) by Smith and Nizza, 2022, was used to analyse the interviews. This approach and reasons for its use are described in greater detail within the methodology section 3. It is, however, worthy of note that IPA good practice required the researcher to refrain from exploring the topic in too much detail before data

collection was carried out; thereby preventing existing evidence leading the direction of the research and protecting the authenticity of participants' descriptions of events during the interpretation process. To protect the study from being led by the literature, the post-pandemic literature review was conducted after the interviews and data analysis were complete.

1.2 Context

1.2.1 Increasing number of people living with multiple long-term conditions and the increasing demand on healthcare services

The National Institute for Health and Care Excellence (NICE, 2023), describe multimorbidity as *"the presence of two or more long-term health conditions that affect quality of life, life expectancy, and health care use."* The term "*multimorbidity*" has been challenged by patients as having undesirable and inaccurate connotations (Khunti et al, 2023, no page). The term *"multiple long-term conditions"* (MLTC) is preferred by patients and will be used throughout this study.

The United Kingdom (UK) has an aging population with increasing healthcare demands. People are living longer and the National Health Service (NHS) reports increasing life-expectancy, "*it now cares for more than a million people every day and has played a vital role in increasing life expectancy by 10 years since the 1940s".* (Jeffries, 2023, no page).

However, living longer does not necessarily mean living with optimum health. 1 in 4 of the adult population are diagnosed with one or more long-term conditions. "*In the UK, approximately 20-40% of adults are living with MLTC. That figure rises to more than 50% in people over 65*." (Steell et al, 2025, p.2).

There are many reasons, as well as an aging population, why more people are living with LTC. These are referred to as risk factors and include; poor diet, smoking, alcohol, work related stress, lack of physical activity, sedentary jobs, financial pressures, widening health inequalities, ethnicity and other socio-economic influences. The Health Foundation (2022), reports on the demands on healthcare services long before the pandemic *"Even prior to the pandemic, people were living more years in poor health."* (The Health Foundation, 2022, p.01).

A consequence of poor health is lifestyle disease, which is a rising challenging for HCS to manage and service users to live with. In 2016, common lifestyle diseases include; musculoskeletal disorders, cardiovascular disease, chronic respiratory disease and diabetes (Public Health England, 2018)

For decades, national strategies have recognised the need to focus on improving services to cope with increasing and complex demands for MLTC management. However, such improvements are inadequate to deal with the demands. "*When the NHS was set up it focused on treating single conditions or illnesses, since then our health and care needs have changed, more of us are living longer and many of us have multiple conditions that require regular and on-going care. However, this hasn't been reflected in the NHS's structure. A patchwork of organisations that often work independently of each other. Navigating this can be confusing and can have a negative impact on our experience of care.*" (The King's Fund, 2022, no page).

The challenges have been further compounded by the COVID-19 pandemic. *"COVID-19 has exposed the consequences of government and wider society failing to act ambitiously enough to address the nation's poor health"*. (The Health Foundation, 2022. P.04).

There is an overwhelming volume of reports published over many decades by various organisations relating to services for LTC and the need for HCS to adapt to meet the increasing demand. It is difficult to draw direct comparisons in data without conducting a thorough quantitative analysis. However, a common approach is to list the most prevalent conditions and predict in millions the number of people who will suffer from LTC or MLTC. Pre-pandemic figures report a growing problem with 1 in 4 people, over 15 million, in England living with LTC. The NIHR stated in a post-pandemic report, "*By 2035, there will be double the number of people aged over 65 living with four or more conditions. 17% compared to 9.8% in 2015" and* "***More than*** *one in four of the adult population in England lives with two or more conditions*". (National Institute for Health and Care Research, 2021, no page).

In July 2024, for the first time in 14 years, a new UK government was elected, and Mr Wes Streeting, Secretary of State for Health and Social Care, declared the NHS as "*broken"*. Mr Streeting's declaration comes after decades of knowing the rising demands from MLTC on services; and decades of strategies that have failed to achieve improvements that benefit the QoL of nearly a quarter of the adult population in England.

In the summary letter published in 2024 by the Department of Health and Social Care from Lord Darzi to Mr Wes Streeting, he states: "*Four heavily inter-related factors have contributed to the current dire state of the NHS. They are austerity in funding and capital starvation; the impact of the COVID-19 pandemic and its aftermath; lack of patient voice and staff engagement; and management structures and systems*." Darzi states "*The NHS is in critical condition*". (Darzi, 2024, no page)

1.2.2 Impact on patient access and experience

Long-term conditions are those that cannot, at present, be cured, but people living with these conditions can be supported to maintain a good quality of life." (NHS England, 2014).

The growing demands and the state of the healthcare system impacts patient lives; both in the experience of getting the care they need and the quality of their day-to-day life. Service provision that has historically focused on treating single conditions, fails to deal with the complex needs and increasing demand of MLTC. Dr Jani, who was appointed as Primary Care Research Champion in 2021, said: *"Treatment and monitoring of long-term conditions (sometimes referred as 'secondary prevention') is largely organised with a 'one size fits all' approach"* (BMA, 2024, no page). As outlined years of NHS long-term plans. (NHS England, 2014, NHS England, 2019; NHS England 2023), the need for patient centred care remains unaddressed for MLTC.

An example of how patients are impacted by inadequate services is waiting lists. In April 2008 a referral-to-treatment (RTT) standard was set. *"92% of people waiting for elective (non-urgent) treatment should wait no longer than 18 weeks from referral to their first*

treatment. The standard was last met in September 2015. Since then, performance has declined steadily, until the COVID-19 pandemic, when it deteriorated rapidly.... waiting lists remain high at 7.5 million, in March 2024." (The Kings Fund, 2024, no page). This is compared to 3 million in 2008 and 4 million in 2016/2017.

PLwMLTC also require support alongside treatment including person-centred care and integrated specialist services that understand how to manage the individual's conditions and their symptoms. The need to address how LTC and MLTC are managed remains central to government strategies, recognising there is an impact on patients themselves that subsequently, is worsening the burden on HCS.

During the last decade there has been a significant shift towards speeding up developments to provide *"the right care for the right people at the right time"* (NHS, 2014: online) and reduce some of the pressures that face healthcare services and patients.

The Department of Health, 2013 published the long-term conditions compendium of information referring to 2010/2011 data. Figure 1 below lists long-term conditions, and the number of people affected, comparing it to 2006-07 numbers, as well as reporting the prediction of growing challenges, especially those who will have MLTCs. Every condition reports an increase in people affected by the chronic disease, with the exceptions of heart disease and heart failure. Sir John Oldham highlights the need for change.

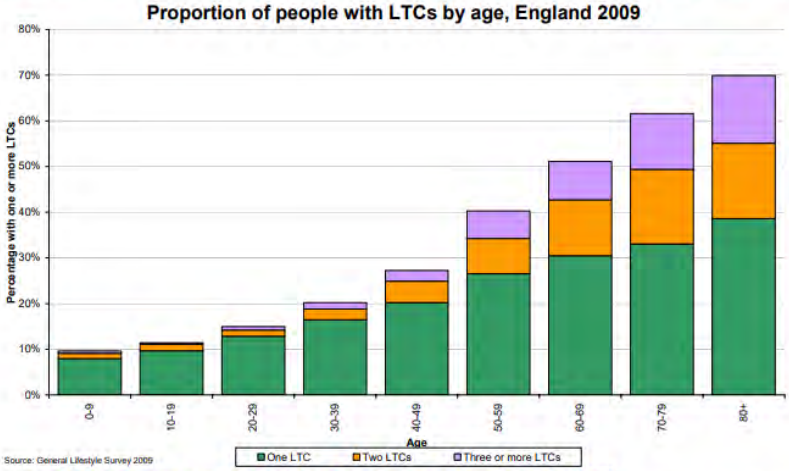
Figure 1. Long-term Conditions compendium of information, 2013.

"The increasing prevalence of long term conditions is the biggest challenge facing the NHS now and for the future. The NHS and their partners in social care and the voluntary sector have achieved so much already, but there is still a lot to do. A huge culture change is needed to put people at the centre of decisions about their care together with a spirit of innovation that embraces new technologies. I hope that the evidence and examples of excellence shown in this Compendium will continue to inspire and motivate everyone involved in making a difference to the lives of people with long term conditions"
Miles Ayling, Director of Innovation and Service Improvement, Department of Health

Type of long-term condition	Number affected 2006-07	2010-11	% change
Hypertension	6,706,000	7,460,000	11%
Depression	0	4,878,000	N/A
Asthma	3100000	3,273,000	6%
Diabetes	1,962,000	2,456,000	25%
Coronary Heart Disease	1,899,000	1,878,000	-1%
Chronic Kidney Disease	1,279,000	1,855,000	45%
Hypothyroidism	1,367,000	1,667,000	22%
Stroke or Transient Ischaemic Attacks (TI	863,000	944,000	9%
Chronic Obstructive Pulmonary Disease	766,000	899,000	17%
Cancer	489,000	876,000	79%
Atrial Fibrillation	692,000	791,000	14%
Mental Health	380,000	438,000	15%
Heart Failure	420,000	393,000	-6%
Epilepsy	321,000	337,000	5%
Dementia	213,000	267,000	25%

Age is a major factor in prevalence of LTCs but also in those who have multiple LTCs.

Proportion of people with LTCs by age, England 2009



Source: General Lifestyle Survey 2009

"This strong and comprehensive evidence base shows us why status quo is not an option."
Sir John Oldham, National Clinical Lead for Lead Quality and Productivity, Long Term Conditions and Urgent & Emergency Care QIPP Lead

- **14% of those aged under forty report having an LTC**
- **58% of those aged 60 and over report having an LTC, with 25% of over 60s having two or more**

By 2034 the number of people aged 85 and over is projected to be 2.5 times larger than in 2009, reaching 3.5 million and accounting for 5% of the population. Plans need to be put in place now to address the growing needs of these people.

[2]**People with long term conditions consistently say**:
- They want to be involved in decisions about their care – they want to be listened to
- They want access to information to help them make those decisions
- They want support to understand their condition and confidence to manage – support to self care
- They want joined up, seamless services
- They want proactive care
- They **do not** want to be in hospital unless it is absolutely necessary and then only as part of a planned approach
- They want to be treated as a whole person and for the NHS to act as one team

LTCs are not just a health issue they can have a significant impact on a person's ability to work and live a full life. People from lower socio economic groups have increased risk of developing a LTC – better management can help to reduce health inequalities. **Despite strides forwards there are still huge challenges.**

This report is particularly relevant as it captures patient perspectives when accessing healthcare services alongside the statistics. It illustrates the growing issues and what is significant to patients.

Symptoms of LTC and MLTC and their impact on the person are often not visible. Common symptoms include fatigue, chronic pain and mood changes. This affects daily life such as

maintaining a house, relationships, going to work, social activities and caring for children. People consequently require tailored healthcare support to manage a variety of different circumstances and implement lifestyle changes to gain as much QoL as possible.

The statistics below reported by NHS England (2014), highlight how patients with LTC used healthcare services before the pandemic, the inconsistencies in care and the impact on HCS.

- *"72% of people with long-term conditions used their care plans to manage everyday health. 5.4% of people with long-term conditions had a written care plan."*
- *"59% of people with long term conditions were in work, versus 72% of the general population."*
- *"Of the people who reported they lived with long term conditions, 24% had two long term conditions and 20% had three or more."*
- *"People with long-term conditions were more likely to use healthcare services: 50% of all GP appointments, 64% of all hospital out-patient appointments, 70% of all hospital bed days and 70% of total health and social care spend."*

A disproportionate amount of people with LTC do not have a written care plan, are the biggest users of primary and secondary care and are less likely to be in employment.

1.2.3 The impact of the COVID-19 pandemic

In March 2020, the UK declared the COVID-19 pandemic and imposed restrictions on people's lives including access to HCS. The restrictions changed provisions and accessibility of healthcare for PLwLTC and PLwMLTC across primary and secondary care and community services. The disruption and the lasting impact of the pandemic on healthcare is widely reported by national organisations in published papers and reports. Examples include NHS England, 2023, "*Plans to tackle waiting lists for elective care*" and The King's Fund, 2021, reporting on *"England's response to the pandemic."* These reports are among many that set out to address how England dealt with the pandemic and the aftermath effects on

healthcare, recognising there wasn't sufficient support for vulnerable groups including, PLwMLTC.

Accessing healthcare services for non-COVID-19 related conditions was disrupted during and beyond the pandemic, at a time people reported suffering more. *"The pandemic has affected the population's physical and mental health and hampered access to care. When COVID-19 care was prioritised in hospitals across the UK, delivery of non-COVID healthcare became more difficult."* (BMA, June 2024, p.13).

PLwMLTC require frequent access to a variety of services to diagnose, treat and manage their conditions. Pujolar et al, 2022, p.01, reports the disruption to services for people with LTC's to include postponed or cancelled appointments, reduced home visits and appointments moved online. Concluding *"results show a general reduction in services use in the early stages of the pandemic, as well as new barriers to access and the exacerbation of existing ones".* Patients report not attending healthcare settings through fear of contracting the virus: *"Participants reported avoidance of health care due to fear of COVID-19 infection, as well as general changes to care-seeking behaviours. "(*Moore et al 2022, p.01).

The pandemic created waiting list backlogs by disrupting the HCS. Lord Darzi (2024), exposes, *"What is less widely known is that the NHS delayed, cancelled or postponed far more routine care during the pandemic than any comparable health system. Between 2019 and 2020, hip replacements in the UK fell by 46% compared to the OECD (Organisation for Economic Cooperation and Development) average of 13%. Knee replacements crashed a staggering 68% compared to an average fall of 20%. Across the board, the number of discharges from UK hospitals fell by 18% between 2019 and 2020, the biggest drop across comparable countries."* (Darzi, 2024, no page). Delayed treatment has unique and individual effects on PLwMLTC, that this study aims to explore.

PLwMLTC experienced and continue to experience additional challenges arising from the restrictions and their legacy. PLwMLTC normality changed, they had to manage day-to-day symptoms and access services differently, making significant adjustments to daily life.
The pandemic compounded existing challenges and is now described as a potential *"double burden"* (Chan and Horne, 2021, p.01) due to focusing on managing COVID-19 care alongside an already pressurised service. McCarthy et al, 2021, no page, argue that this is not a potential problem, it is an *"obvious problem"* that cannot be overlooked and requires a long-term strategy to recognise and deal with many issues that have been overlooked and *"neglected for years".*

In 2023, a decade later, the Department of Health and Social Care issued a policy paper titled 'Major Conditions Strategy: Case for change and our strategic framework'. The policy paper outlines the urgent need to tackle MLTC focusing on six major conditions; cancer, heart disease, dementia, mental ill-health, musculoskeletal disorders, and respiratory diseases. These are "umbrella" terms that cover many lifestyle conditions including diabetes, COPD, asthma, hypertension, chronic kidney disease, and many more diagnosable conditions. The policy paper apportions the same major risk factors as previously mentioned to the increasing number of people diagnosed with MLTCs.

Despite some step changes, PLwMLTC and LTC have experienced decades of health decline caused by rising demand and many inadequate strategies to improve HCS to manage LTC and MLTC.

An example of a patient survey, reported by the Nuffield Trust in February 2024 (Nuffield Trust, 2024, p.01) details a decline in primary care support for patients with LTC.

"Until 2017, GP Patient Survey respondents were asked, "In the last 6 months, have you had enough support from local services or organisations to help you to manage your long-term health condition(s)?". Between 2012 and 2017, the proportion of respondents who answered "Yes, definitely" decreased from 54% to 51%, and those that answered "No" increased from 15% to 17%. This indicates that the NHS might be struggling to keep up with

the demand for services that provide support for people with long-term conditions. Between 2018 and 2023, there has been a visible drop in perception of support, particularly after 2020. The percentage of respondents who stated that they had enough support in the last 12 months decreased from 43% in 2018 to 28% in 2023. In the same time frame, the percentage who reported that they had not received enough support increased from 21% to 35%.".

Patient feedback is increasing in focus across the HCS, particularly as part of quality frameworks and evidencing improvements. However, Healthwatch, 2022 reports *"More than half of people with chronic and long-term conditions not asked to feed back about their care".* However, of those who were asked "*about their recent experience of accessing care, the survey revealed;"*

- *"More than two-thirds (69%) were able to be seen by their service within three weeks, outside their normal scheduled appointments."*
- *"But more than a quarter (27%) of people said the biggest challenge they faced accessing health, and social care was longer waiting times."*
- *"A fifth (21%) said ineffective or inaccessible booking systems were the main issue."*

The increasing demand and challenges for services and patients' highlights a need to act for patient's health and QoL and, to do that successfully, a need to listen to them.

2.0 Background: Semi-systematic literature review pre and post COVID-19 pandemic

Despite decades of reports highlighting the need for healthcare services to evolve to address the growing demands of MLTC, there are relatively few studies focused on the crucial perspective of the patients themselves. The impact on individual patients, if heard, can be used to help shape the transformation of services to improve patient care and QoL for PLwMLTC.

The COVID-19 pandemic is a phenomenon experienced by all. However, those with increased vulnerability will have experienced it in a way that is not yet fully understood. It is vital to understand what this is like, not only to improve service provision for PLwMLTC but also to be better prepared for any future disruptions.

The impact of the pandemic on PLwMLTC raises important research questions;

- What was it like to live with MLTC throughout the COVID-19 pandemic?
- What impact has the pandemic had on patients' health and experiences of accessing healthcare?
- What meaning do patients give to their experiences?

This study aims to address these questions, by giving patients a voice to share their individual experiences and bring to the literature any new or supporting data.

To contextualise the study, two semi-systematic literature reviews were conducted. The first search was conducted in 2022, focusing on literature between 2016 and 2020, allowing a focus on relevant data published within the four years leading up to the COVID-19 pandemic. The second search was conducted in February 2025 after the research data had been collected and analysed. The post-pandemic literature review focused on the 4 years between 2021 and 2025. Some of the pre-pandemic studies were conducted before 2020 but published in 2021 or 2022. Careful filtering was performed to ensure COVID-19 had not been included in any of the pre-pandemic literature reviews.

Rationale for a Semi-Systematic Literature Review

This research aims to explore the experiences of PLwMLTC and their experiences accessing healthcare services, focusing on how these experiences may have changed because of the COVID-19 pandemic. Given the time constraints of the study and the broad, diverse, and evolving nature of this topic; multiple chronic condition diagnosis and management, patient experience, the healthcare system and delivery of healthcare services, the decision was made to adopt a semi-systematic literature review approach.

Snyder (2019) argues that when the aim is to explore how a topic has been studied, identify key theoretical frameworks, or locate gaps in the evidence, a semi-systematic review *"could be a good strategy… [to] map theoretical approaches or themes as well as identifying knowledge gaps within the literature"* (Snyder, 2019, p. 334). These characteristics support the study's dual purpose: first, to understand what is already known about the experience of PLwMLTC , and second, to illuminate gaps and limitations in knowledge, especially in the context of multiple condition management and service changes caused by the COVID-19 pandemic.

A further reason for selecting a semi-systematic review relates to the practical time limitations of a master's-level research project. Full systematic reviews, while bringing rigour, are resource-intensive and often require extensive searching, screening, and critical appraisal, which can be impractical within the scope of a postgraduate research thesis.

Semi-systematic reviews offer a more time-efficient alternative while still maintaining academic rigour and transparency. Because they focus on mapping key themes and identifying knowledge gaps rather than exhaustively including every study, the search and analysis processes are more manageable within a shorter timeframe. This allows more time for in-depth analysis and interpretation of findings to produce meaningful insights, which is particularly valuable in exploratory studies using IPA.

Justification for Conducting Two Literature Reviews

A distinctive methodological feature of this research was the decision to conduct two separate semi-systematic literature reviews; one focusing on the pre-pandemic period and the other on the post-pandemic period. This design was informed by the recognition that the COVID-19 pandemic represented major changes in healthcare delivery and patient experience, and that a single review would risk obscuring any nuanced ways in which patient experiences have been impacted.

The first review established a baseline by exploring the experiences of PLwMLTC prior to the pandemic. It examined how patients accessed healthcare services, the barriers, and facilitators they encountered, and the challenges faced by healthcare systems in managing MLTC. This baseline is crucial to the study because it provides a contextual backdrop against which subsequent changes can be understood.

The second review focused on the post-pandemic period, capturing how HCS and patient experiences, were impacted as a response to COVID-19. The pandemic prompted significant disruptions in existing healthcare provision, such as the rapid adoption of telemedicine, increased use of remote monitoring, and the reorganisation of services to manage risk of infections.

Conducting two semi-systematic reviews across two time periods is not a conventional method; however, it is a recognised methodological approach when significant contextual changes are expected to influence the findings. The Cochrane handbook highlights there is benefit from conducting the reviews with “the addition of date limits” (Cochrane, p.45). In this study, a natural breakpoint for date limits is created by the pandemic. This approach is widely used in health research to capture temporal shifts, such as comparing outcomes before and during the COVID-19 pandemic (Moynihan et al, 2021, p.4; Rizzo et al, 2023, p.2)By bridging this gap, the present study offers a unique perspective that supports understanding of how healthcare systems and patient experiences are impacted over time, and how future service models might be designed to be better prepared for major disruptions to support those with MLTC.

When conducting the literature reviews, it was important to have a clear understanding of the terms "***access***" and "***healthcare***".

James Durkin, 2019, no page, quotes the Institute of Medicine's definition of access *"the timely use of personal health services to achieve the best health outcomes"*. Durkin states the primary foundation of all of this starts with five A's;

- Accessibility: *"this is about the time it takes for a patient to see the" HCP.*
- Affordability: *"what patients are willing to and able to afford to pay".*
- Availability: *"how easy is it for the patient" to see the HCP.*
- Accommodation: *"does the provider meet the preferences of the patient".*
- Acceptability: *"is the provider able to give the best care".*

For the purpose of this study, the broad term "***healthcare***" is the term used to describe the free public-funded healthcare system (HCS) in the UK, called the National Health Service (NHS) as well as referring to community services and groups funded by the public, charities and private healthcare services that people can choose if they have the means to self-pay or have private medical insurance. When required, clear references to distinguish between types of healthcare will be made.

Methodological Rigour

Both reviews followed key principles of systematic methodology to ensure rigour, transparency, and reproducibility (Moher et al., 2009; Higgins et al., 2022). Searches were conducted using the MMU library advisor, who directed to databases specifically for healthcare. The search produced four major academic databases with peer-reviewed articles (PubMed, Sage, Wiley, and Taylor & Francis) using predefined advanced search criteria as outlined in the diagrams below. Identical search parameters were used in both reviews to ensure consistency and comparability.

Restricting the search to those accessible via the MMU library, specific databases may have excluded relevant studies. These limitations are acknowledged and provide scope for future research to expand the breadth of inquiry.

Thematic synthesis was then employed to analyse and interpret the data based on patient experience of accessing healthcare. As the research followed an Interpretative Phenomenological Analysis (IPA) approach, it was important that the review did more than summarise existing evidence. Instead, it needed to capture the depth and meaning of patients lived experiences, which is central to IPA's focus on understanding how individuals make sense of their health and care (Smith, Flowers, and Larkin, 2009, pp. 3–5).

A fully systematic review might have offered greater replicability but would have limited the flexibility needed to explore the unique nuances of patient perspectives. Full-text articles were screened using abstracts, introductions, and results sections to identify studies exploring patient perspectives, experiences of healthcare access, and those including qualitative data and patient quotes. Focusing on direct quotations was intentional, as they provided insight into the psychological, emotional, and practical dimensions of accessing healthcare from the patient's point of view, a defining feature of IPA studies.

From this process, fourteen studies were identified as relevant. Thematic analysis was then carried out by examining the reported findings and, importantly, drawing out the patient quotations. These were coded and interpreted to identify patterns and recurring experiences across the studies. This interpretive process mirrors IPA's emphasis on meaning-making, as it moves beyond description to explore how patients understand and respond to their healthcare experiences (Larkin and Thompson, 2012, p. 107).

As a novice researcher, this approach was valuable because it allowed development of a deeper understanding of common themes while still recognising the individuality of each patient's story. By interpreting existing qualitative evidence in this way, the review provided a meaningful foundation for the study and directly supported its aim: to explore and understand how PLwMLTC experience accessing healthcare services.

What the reviews add to the existing literature.

The literature reviews evidence the on-going issues with the healthcare system and the subsequent experiences of PLwMLTC accessing healthcare services. It provides a small sample of convergence and divergence across patient experiences with MLTCs as opposed to focusing on specific conditions. It has brought together findings from multiple articles and health conditions, that individually would not be connected. By drawing together findings, it moves beyond condition-specific perspectives to provide a more holistic understanding of PLwLTC and PLwMLTC. This integrative approach highlights areas of *convergence*, where patients share common challenges such as relationships with HCP, navigating inadequate HCS, and self-management strategies. At the same time, it reveals points of *divergence*, where the nature and impact of each condition produce unique experiences and needs, such as the degree to which the patient can cope and what they specifically need to make the experience better.

In the context of this study these insights are critical to the literature by demonstrating that while patient experience is influenced by the conditions they have and the severity on their QoL the underlying systemic issues, such as, fragmented pathways, long waiting lists and an unstructured expectation to self-manage, play a vital role in the experiences of PLwMLTC. Recognising that when the combination of these issues is exposed there is a need to address them in unison to strengthen the analysis of this research. The shared and unique experiences of patients accessing HCS, alongside the system issues will inevitably manifest differently depending on the individual.

Reflecting on this synthesis reinforces the importance of cross-condition learning and integrated care that recognise both the individuality of patient experiences and the similarities that unite them.

2.1 Pre COVID-19 pandemic literature review

To provide context to the study, the pre-pandemic literature review attempted to explore patient perspectives of accessing healthcare for MLTC to help understand what it is like to live with MLTC and to explore the patient's real-life experiences of accessing healthcare.

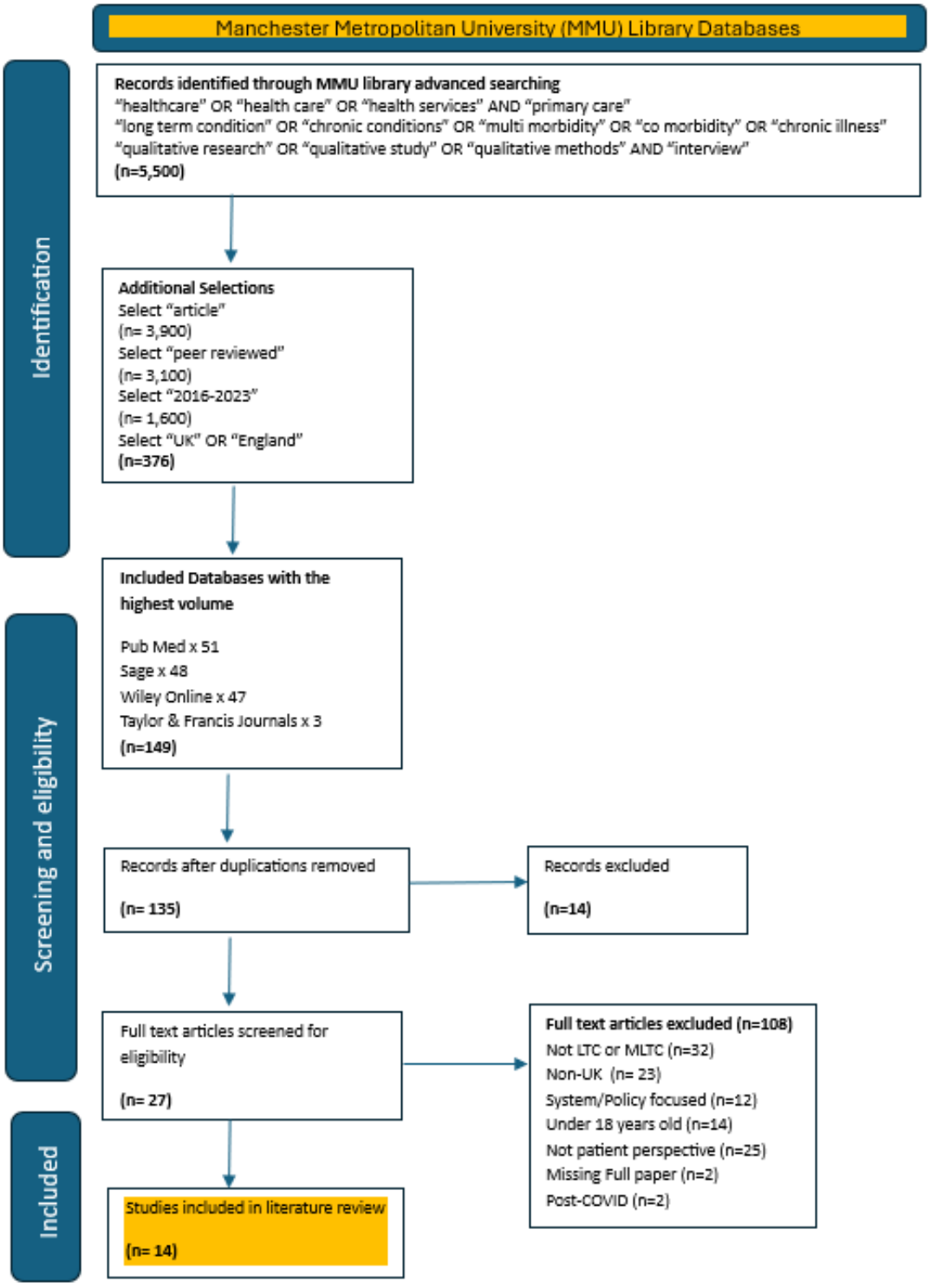
Filtering protocol:

A review of the full text articles searched for patient perspectives, MLTC and experiences of accessing healthcare using the *abstract, results and introduction* sections. A further search for qualitative methodology and patient quotes relevant to the search terms were reviewed to determine eligibility and capture the themes. Fourteen relevant articles were found. The *paper themes* were taken from the results section of each article. *Patient quotes* taken directly from the papers, describing the personal accounts of individual experiences in the patient's own words.

Each patient quote was analysed to create *study themes* that reflect the lived experience of accessing healthcare. The categories combine common themes that participants expressed as significant, when accessing services.

The review revealed, 18% (n=25) of articles were conducted in other countries such as the Netherlands, India and the USA. 23% (n=32) were not related to LTCs or MLTCs; 16% (n=12) were relevant to systems and policy e.g. telemedicine and frameworks for care. Full details of each of the 14 outputs included in the literature review are presented in Appendix 1.

The following diagram illustrates the search protocol for the pre-COVID-19 literature review. The full data set for the review is provided in Appendix 1.



Pre-COVID-19 Literature Review Findings

Eight study themes were identified:

1. importance of tailored communication
2. significance of the relationship between patient and HCP
3. receiving the right care
4. someone listening
5. getting the right diagnosis
6. significance of a support system
7. realisation to self-help, and
8. the system doesn't work.

Descriptions of each theme highlights convergence and divergence, supported by participant quotes.

1. **Importance of tailored communication**

Six studies highlighted communication of information as being a key part of patient access to care. Patients valued honest and useful information in a way that was helpful and understandable and did not make them feel stupid or confused. One patient wants information to be more direct and "brutal", and another thinks it's all "doom and gloom". This raises the need for HCPs to tailor their communication to the patient.

"I don't think it'd matter how educated or if you could read or write. It's just that when you're not a doctor that you can't understand their words, their long words and their explanations. So, I think sometimes, that's why they need to come down to our level, not that we're thick or anything, or stupid." Viv -P2 (Adams et al, 2019)

"…If it was explained to you…when they were doing the things you would understand it a little bit more…You see I'm not stupid and I like to know the reason why". Female aged 80. (Ingoe et al, 2018).

“They'd say, 'well, you're a wee bit chubby,' and I was at the time… They never said, 'You're pre-diabetic'… If the doctor had stressed that I would have done something about it… They have to be more brutal.” P08, F, Type 2 diabetes. (Talbot et al, 2021)

“I've been very fortunate with my practice in [location] because they've given me a huge amount of support in terms of information gathering. But I understand that you've only got to be a couple of miles down the road and you get nothing at all. And even if you ask the questions, the doctors feel that you're taking up their time, and in fact that's true of all doctors, I appreciate that.” PT10, Diabetes Type 2. (Pal et al, 2018)

“*The weight gain started 12 months after my wife died. I was so worried about it. I went to see the GP*, *and the practice nurse was really quite rude… She told me. “You'll lose weight if you keep that shut”* (*Gestures to mouth) … She did not give me any advice on how I should change my diet.”* P25, M, heart failure. (Talbot et al, 2021)

“So that's the big problem, it seems to me. The mainstream medical opinion seems to be all doom and gloom...If you just put that diabetes is such and such but can be controlled or managed or whatever word you want to use, through very simple means, I think that's a huge relief to people.” PT10, Diabetes Type 2. (Pal et al, 2018)

2. Significance of the relationship between patient and HCP

Seven studies highlighted PLwLTC valued the consistency of seeing the same HCP. This is due to the complexity of symptoms and health history which becomes difficult to repeatedly explain. It is important to be understood, feel cared for and have trust in the HCP.

“Now at the present one [primary care practice] it's not that there's anything wrong with it, but I've been there about five times, and I've seen five different people … I mean they've got every right to differ [in medical opinion and advice given] but I find that very difficult.” P14. (Potter et al, 2018)

"My GPs have been outstanding for me… Getting the right GP is the most important because they're your first point of call. We (GP and I) delved into (my condition) and started to find out there were more things wrong with me than I anticipated. But having him… being able to call and say,", Can you ask the doctor to call me? "… And then they do call. It's just nice." P37, F, impaired mobility. (Spiers et al, 2014).

"I did often see the same people. […] So yeah, I did feel that thing about trust." Ileostomies. (Spiers et al, 2014).

"...I'm a great believer in they're trying to help you. There's only one way; you've got to do what they say. And I'm a great believer in that". Female aged 82, Hypothyroidism. (Ingoe et al, 2018)

"I work hand in hand with my doctor, and we try to find out what's best. We look at the results together and then we see how things go". P.8; patient 4, male (O'Neil et al, 2022)

"Well, I don't get as much support now. My first worker left, I used to see her a lot. I was put onto another one, who I've only seen about two or three times. Now she's left and they've put me onto somebody else who I've never seen or been contacted by. I feel a bit let down because my first one was brilliant." (Wildman et al, 2019)

3. Receiving the right care

Six participants illustrated inconsistencies in receiving the right care. These inconsistencies were caused by a variety of factors, including unrealistic patient expectations, HCP's contradicting each other and prescribing errors. Patients had a positive experience and saw a difference when they had a care plan in place. However, when patients didn't receive the right care, it resulted in them questioning professional advice.

"*They sent me to a dietician. She was lovely, I knew all that she was telling me… she was very good with me, but it wasn't what I needed. I needed counselling."* P07, F, multimorbidity (Talbot et al, 2021)

"There's nobody willing to listen and help you with the things that you need the help with. So, you just get on with things the best you can and things you can't do you have to pay to have done for you … I had a stroke and again I thought maybe I'd get, at last, get some help, but you don't, it's a waste of time. So, I just... I don't bother asking any more, I just let it go" P18. (Potter et al, 2018)

They would kind of … both of [the nurses] would groan at the others treatment of it so you never got any constant treatment, as I said, I felt like a bit of a guinea pig. Susan, chronic leg ulceration. (Tollow and Ogden, 2019)

"It's written right on the front of your notes what I can and what I can't have, what I'm allergic to, etc. And they still say when they see it, oh well put some Atrauman on that and I go 'no you won't, I'm allergic to it', 'oh erm … ', I say 'look at the front of the notes … it gets to the point where I feel sometimes I do have to really take charge". Karen, chronic leg ulceration. (Tollow and Ogden, 2019)

"I end up having to check everything they're [the GP] going to give me… If they want to stick me on antibiotics and things like this, I'm going to have to tell them that I've got a renal problem and… because otherwise they'll give me the wrong ones. I've got to watch everything they're doing." P1 (Brand and Pollock, 2018)

"been different over the last 4 years, is because firstly I've got a care coordinator or a psychiatric nurse, I'm not actually sure of the title … I see her every 3 to 4 weeks. And that has made a huge difference, simply that they are keeping an eye on the whole purpose of not letting me get so manic and psychotic, or so suicidally depressed, that I actually then have to be admitted [followed by months or years of recovery] … the whole emphasis, like I

say, has been on prevention, you know to 'nip it in the bud'. As soon as they see symptoms, or things aren't happening, they react to it." P.39, (Potter et al, 2018).

4. Someone listening

Two studies highlighted that PLwLTC felt they are experts in their condition and wanted to be heard, and their views considered, promoting confidence in the care they receive.

"I feel that I don't really have a say, I feel like I shouldn't … I feel like I shouldn't have an opinion about anything … The fact that I've had it long enough to know what upsets it and what doesn't, but I don't feel I've got the authority to say so". Shirley, chronic leg ulceration. (Tollow and Ogden, 2019)

"Obviously the one-to one interaction between me and a nurse was really helpful, because I could talk to them and they'd listen … I did look forward to seeing them because they were nice people. I'm not saying they cheered me up and made me feel absolutely fantastic about the ulcer, but I felt, I just felt a little bit more confident." Jack, chronic leg ulceration. (Tollow and Ogden, 2019)

"They [health professionals] didn't ask me what I thought I wanted, they just did what they assumed was physiotherapy', 'I don't know what other treatments I could have got." (Fu et al, 2015)

5. Getting the right diagnosis

Four studies questioned the credibility and reliability of the HCP's advice. Not knowing a diagnosis had the effect of prolonging symptoms, reducing QoL and negatively impacting emotional well-being.

"It felt like a never-ending circle. No-one really has an answer, and everyone keeps telling me the same thing, just use compression and they don't come back – well obviously that so-

called treatment, if you like, is flawed. It's a flawed system, it doesn't work, you do everything you're told, but they still come back." James. (Tollow and Ogden, 2019)

"she had a trainee doctor in the room, and I felt she'd just put that question into our consultation as an example of good practice. I explained that I did eat well, but time was a factor sometimes… She said to me, 'If you make a small change like take a salad to work,' I felt quite insulted. I just felt it was tokenistic, really." P10, F, multimorbidity. (Talbot et al, 2021)

"Doctor came round with a few other people, with him the following morning and had a bit of a look (pause) said oh, ok, not sure what that is, gave it a bit of a tug and it came out and off. And I've no idea what it was. […] He didn't get it tested, he just basically, it got (pause) thrown away or whatever. My surgeon was never, consulted about it." Ileostomies (Spiers et al, 2014).

"signing up for a massive mortgage, which I would not have done if I had known I had MS, but he didn't tell me... " P07. (Potter et al, 2018)

6. The significance of a support system

Four studies addressed the significance of a patient's support network when managing LTC. Increasing a patient's resources of knowledge and social connectivity outside of the HCS gave additional life-changing support that the system could not provide. However, one patient found it hard to navigate the condition alongside the expectations of family, making social circles difficult.

"'can I come and see you privately?', and he said, 'don't be daft, what's the problem?', and I explained to him, and he said, 'you better come and see me at 1 o'clock today'… and [after assessment] I think he thought I was going to drop dead on him, and he got me in that week, I went in on the Thursday, and had the operation on the Friday." (Potter et al, 2018)

"Some letter came, and you know I have to wait for somebody to read for me. Sometimes you know I was sitting and I'm trying to read and I can't read. And then I'll look for somebody and, 'Can you read this for me please.' "Joyce – P6, REALM 0, Low Functional Health Literacy. (Adams et al, 2019)

"I'm dyslexic so I don't read very well … If I have a problem, you know, my neighbour helps me." David – P17, REALM 4, Low Functional Health Literacy (Adams et al, 2019)

Because we're talking about food; I mean, I go to my family, and when I say I can't eat that food, they usually think that's disrespecting them, so you've got all that as well to deal with. PT11 Diabetes Type 2. (Pal et al, 2019)

"I think it's changed my life completely…I was too fat. I had issues. Ways to Wellness has swept some of them away. It's been a very, very positive experience...I'm a happy bunny." (Wildman et al, 2019)

7. Realisation to self-help

Two studies observed a patient perspective of personal responsibility when managing LTC. Accepting there are elements of self-help was helpful to a patient improving their QoL.

"[I] Am trying to educate myself [about diabetes], and that is why I liked [these tools] because I already have that in my mind." P. 8. (O'Neill et al, 2022)

"It's all in the mind. Your attitude does have to change if you want to lose weight". P09, F, clogged artery. (Talbot et al, 2021)
"I check my BGL more, I check my weight more, monitor my diet better. My blood levels are staying more normal than over a year ago" P.6 (O'Neill et al, 2022)

8. The system doesn't work

Four studies described the healthcare system as a battle to navigate. Patients experience a lack of integration between services as tiresome, especially when appointments were needed regularly and hard to get. When support included technology, this could be a barrier to accessing care as it disadvantaged people who could not afford it.

"to even ring your GP surgery normally to make an appointment can be very tiresome for a lot of people. You can't get through." PT8. (Pal et al, 2018)

"the worst thing is, when you go along to A&E, and they say to you...they might turn around to you and say, oh when were you diagnosed? You know, and you have to start from...the whole story from the beginning." PT7 (Pal et al, 2018)

"Sometimes there is a pain in the chest, there is a severe pain in the chest, and I'm just about to call the ambulance and then I'm thinking 'if you're there with emergency people, you'll have to start from a, b, c, d' because I'm not with the cardiac department now." P21. (Potter et al, 2018)

"Yeah, it's just that you go to these hospitals, and you could be sat there for an hour or two waiting because they're behind, they're obviously busy and then you just, as I said, you just go through these big words they say to you and goodbye". (John – P4, REALM 7, Adequate Functional Health Literacy)." (Adams et al, 2019)

"It's a medical issue. They should be free really, to access full features and everything else… you know, it can be life and death. If someone has a smart phone they can have an app, but they can't access it like I said because they can't afford to." P.5 (O'Neill et al, 2022)

Summary:

Accessing healthcare

Each publication focused on one or more aspect of accessibility from the patient's perspective. There were similarities between the patients within the studies, identifying significant barriers to accessing healthcare for long-term conditions, that impacted the patient and their experience. There were also positive experiences of accessing healthcare, that facilitated positive descriptive accounts of accessing healthcare services.

The studies highlighted varied experiences from patient to patient; not necessarily relating to the condition itself but focused on what it is like to access healthcare services.

Multiple long-term conditions

Research in relation to patient experiences that include living with MLTC is limited. Eleven out of the fourteen studies focused on one condition, as illustrated in the table in Appendix 1. The three that included MLTC had a strong focus towards the healthcare system and desire for integrated care that considered individual needs.

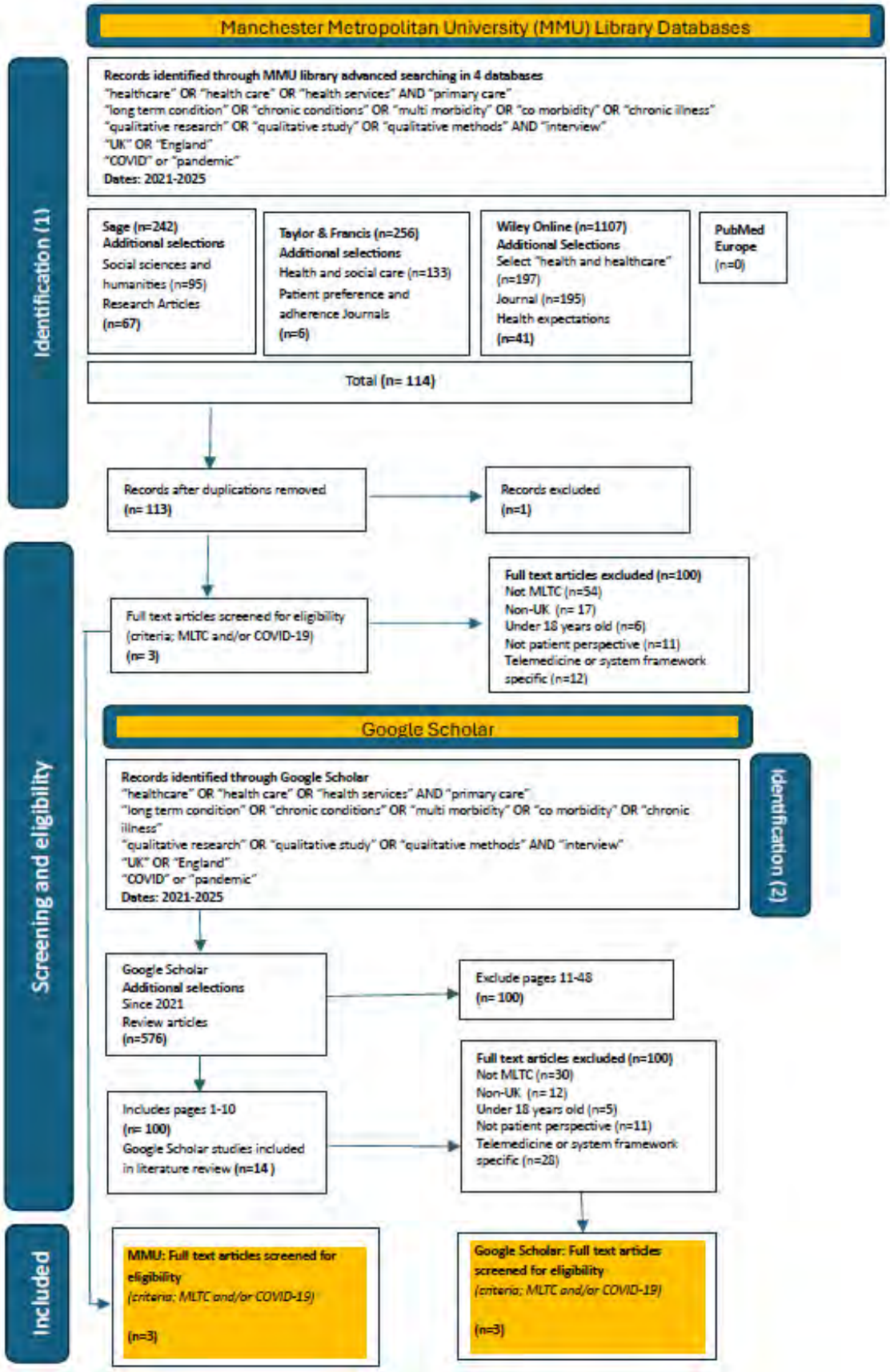
- Continuity of healthcare professional and integrated systems to prevent repeating themselves
- Receiving information in an honest and understandable way
- Someone listening and giving actionable advice; tailored healthcare
- The importance of a support system

The search identified a lack of literature surrounding MLTC from a patient perspective in the UK. It did, however, provide insight as to what it is like to live with LTC and access healthcare.

2.2 Post COVID-19 pandemic literature review

The literature review conducted post-pandemic had the additional search and filtering criteria of "*COVID*" OR "*pandemic*" to draw out records of patient experiences relating specifically to the COVID-19 pandemic. The search included the same databases within MMU library that were used for the pre-pandemic literature review. After exclusions, this search produced 3 relevant records. Due to the lack of relevant publications, the search was widened to include Google Scholar, using the same criteria. Among the 100 reviewed articles, three additional records were eligible for the review. Articles were excluded due to the following reasons; 30% (n=33) focused on system frameworks or digital solutions, for example, general telemedicine services; 29% (n=29) focused on one LTC; and 12% (n=12) were studies conducted in other countries including France, the Netherlands, and Australia. A further 11% (n=11) were excluded due to their focus on an excluded LTC.

The following diagram illustrates the search protocol for the post-pandemic literature review. The full data set for the review is provided in Appendix 2.


Manchester Metropolitan University (MMU) Library Databases
Identification (1)
Records identified through MMU library advanced searching in 4 databases
"healthcare" OR "health care" OR "health services" AND "primary care"
"long term condition" OR "chronic conditions" OR "multi morbidity" OR "co morbidity" OR "chronic illness"
"qualitative research" OR "qualitative study" OR "qualitative methods" AND "interview"
"UK" OR "England"
"COVID" or "pandemic"
Dates: 2021-2025
Sage (n=242)
Additional selections
Social sciences and humanities (n=95)
Research Articles
(n=67)
Taylor & Francis (n=256)
Additional selections
Health and social care (n=133)
Patient preference and adherence Journals
(n=6)
Wiley Online (n=1107)
Additional Selections
Select "health and healthcare" (n=197)
Journal (n=195)
Health expectations
(n=41)
PubMed Europe
(n=0)
Total (n= 114)
Records after duplications removed
(n= 113)
Records excluded
(n=1)
Screening and eligibility
Full text articles screened for eligibility (criteria; MLTC and/or COVID-19)
(n= 3)
Full text articles excluded (n=100)
Not MLTC (n=54)
Non-UK (n= 17)
Under 18 years old (n=6)
Not patient perspective (n=11)
Telemedicine or system framework specific (n=12)
Google Scholar
Identification (2)
Records identified through Google Scholar
"healthcare" OR "health care" OR "health services" AND "primary care"
"long term condition" OR "chronic conditions" OR "multi morbidity" OR "co morbidity" OR "chronic illness"
"qualitative research" OR "qualitative study" OR "qualitative methods" AND "interview"
"UK" OR "England"
"COVID" or "pandemic"
Dates: 2021-2025
Google Scholar
Additional selections
Since 2021
Review articles
(n=576)
Exclude pages 11-48
(n= 100)
Includes pages 1-10
(n= 100)
Google Scholar studies included in literature review (n=14)
Full text articles excluded (n=100)
Not MLTC (n=30)
Non-UK (n= 12)
Under 18 years old (n=5)
Not patient perspective (n=11)
Telemedicine or system framework specific (n=28)
Included
MMU: Full text articles screened for eligibility
(criteria; MLTC and/or COVID-19)
(n=3)
Google Scholar: Full text articles screened for eligibility
(criteria; MLTC and/or COVID-19)
(n=3)

Post – COVID-19 Literature Review Findings

Five out of the six articles related to studies that were conducted during the COVID-19 pandemic. One focused on general online peer support for PLwLTC.
The articles focused on six areas of patient experience living with LTC and MLTC and accessing healthcare during the pandemic.

- Physical activity and mental health
- mental health and wellbeing
- online peer support
- online health systems
- managing disruption
- experiences of healthcare

Two articles that focused on accessing online services were included due to the accelerated use of digital platforms during COVID-19 as a means of increasing healthcare access. Understanding the perspectives of patients who received online support provides insights into certain impacts of the pandemic.

During the thematic analysis, two overarching study themes were found within the six papers whilst seeking patient experiences and drawing out the meaning they give to them

1. Living with long-term conditions; the impact of COVID-19
2. Experience of healthcare during COVID-19

1. Living with Long-term conditions; the effects of the pandemic

1.1 Increased vulnerability: the threat of catching COVID-19 and the response to the threat

Most participants described feelings of fear, stress and anxiousness, even terrified by the threat of catching COVID-19. The "higher risk" category was given to some people living with chronic diseases and they were encouraged to "shield" as a means of protecting themselves against contracting the virus. This required additional navigation of the day-to-day.

Two participants across five studies described the pandemic as being out of their control however they had a reduced level of vulnerability due to having support around them. One participant describes entering a clinical setting as a judgement call depending on what the reason is.

"I'm terrified of getting this virus, because I know that if I get it, it probably is the end of me. My lungs are not good … I don't want to die in hospital, and I don't want to have that intubation and sedation" (female, 70–79, respiratory condition). (Fisher et al, 2021)

"I'm really scared of getting [COVID-19] … I think I probably would not survive if I got it, so I'm trying to keep away from it … when I heard about [COVID-19], I just automatically went, oh my God, I'm going to die. It wasn't great" (female, 30–39, CVD and respiratory condition). (Fisher et al, 2021)

"In my head, if I went to A&E and went into the hot side with Coronavirus, that's just a death sentence" (male, 30–39, multiple conditions). (Fisher et al, 2021)

I'm stuck on the 18th floor, and I can't do anything, it's quite depressing, because all I can do is look out of the window. You can only watch so much telly, watch so many DVDs, read so many newspapers. But, like I say, what else can you do? I just comfort eat. That's all got to stop. It's going to have to stop actually, because I'll just make myself worse … I say, just

cope with it [loneliness, boredom, and health issues] and hopefully it will pass … I'll just take one day at a time, that's all you can do. (Derrick–60-69–PT–IMD 1–lives alone–4). (Fisher et al, 2021)

"My medical condition, I've had it all my life so if that places me in a higher risk category, you've just got to do your absolute best to not catch it and then after that it's sort of in the lap of the Gods really isn't it? So, it didn't really upset me or stress me or worry me" (female, 40–49, respiratory condition). (Fisher et al, 2021)

Well, there is always somebody if things were really bad that I could go just three doors away or next door and get help. So, that is quite reassuring. So, I have never felt vulnerable or really, really anxious because I am thinking, "Well, there is always somebody I could go to." (Martha–70-75-F-retired-IMD-1-lives with partner-2). (Fisher et al, 2021)

"the night I had the chest pain, it mentally went through well, I'll give it another 10 minutes and see. If it hasn't gone, I will go to hospital. So I wasn't just going to sit there and think I'm going to put up with chest pain just because I might get COVID-19 if I go to hospital. I was sensible enough to realise that really, the more pressing thing's getting what seemed to be a heart attack sorted than worrying about a theoretical risk of getting [COVID-19]" (female, 60–69, respiratory condition). (Fisher et al, 2021)

"I didn't feel any anxiety about going into hospital because most hospitals are designated as red zones and green zones. Certainly, all the nurses etc. wore masks, gloves and all the rest of it. But I had excellent care, and I wasn't at any point worried that I would actually catch [COVID-19] in hospital" (female, 60–69, respiratory condition). (Fisher et al, 2021)

1.2 Adapting lifestyle

The pandemic gave rise to further requirements to adapt day-to-day life. One study focused on exercise identified that whilst all participants accepted the need to adapt, there were challenges around doing so and finding the motivation. One participant reflected on what they could have done differently but in situations when self-management techniques are

disrupted, there is an over-riding need to consider supporting adaptations and patient motivation to prevent health deterioration.

"Well, yes, that stopped us, they closed the swimming pool. No, other than as I mentioned, because I wasn't swimming, my arthritic knee got weaker, and I wasn't walking as much, and we had to force ourselves to go out. In fact, I bought a walking stick" (P11). (Ambrosi et al, 2024)

"I've lost quite a bit of mobility, it's got worse as we go on, but we try to do things that I can still, it's not what I can't do, it's what I can do. We look at it that way with my mobility and getting out and about. I can walk some distance but usually, I want to hold on to something, either my husband, or I have a walker" (P20). (Ambrosi et al, 2024)

"It's changed a bit. Instead of going to the gym I would go for a two-and-a-half-mile walk, get some cardio workout going to keep the circulation going, etc. That takes time and time is something we don't always have. The weather's not always good for walking either! I started doing walking a bit more when I was, during lockdown, on my own" (P22). (Ambrosi et al, 2024)

"*I certainly suffered depression throughout the COVID 19 period. There's plenty of things I should have done differently: I should have kept up the exercise; I should have forced myself and my wife to maintain exercise—that's what I should have done—but that was a personal failure. I do regret that, but I just lost hope in the whole exercise" (P25).* (Ambrosi et al, 2024)

"Yes. I find, if I don't exercise or do something, I get very grumpy, bad tempered—because I'm used to exercising, all my life. So, when I couldn't, it was difficult. If you're not happy, you can go for a very long walk, until you felt better" (P4). (Ambrosi et al, 2024)

So I just do the exercise in the house. I've got the DVD showing us [me] how to do them and what have you. Sometimes I can't even be bothered doing that either. (Laughter) (Brian-70-75-M-retired-IMD-5-lives with partner-2). (Morris et al, 2022)

"I guess it's just a massive thing that's outside anyone's control, so you just have to adapt. You have to be very flexible and adapt to it" (male, 50–59, diabetes). (Fisher et al, 2021)

1.3 Reliance on others

Maintaining independence, where possible, is important to people living with MLTC. Some levels of independence were reduced by the pandemic due to the need to reply on others for practical purposes such as shopping or collecting prescriptions, and to meet the emotional need to staying connected; all whilst not wanting to burden others. One participant states they felt guilty when bothering others and one other state they felt jealous of the freedoms their partner had to go out. Social media played a big part in staying connected and sharing experiences with others who have similar conditions.

"I was especially jealous of my girlfriend, who didn't have to shield. She made sure that before she starts work in the morning, she goes for a walk for at least 45 min to an hour … She also had to do the grocery shopping. And there was once or twice during lockdown that I needed my prescriptions to be refilled. She had to do that. So, in a sense, I felt overly reliant on her … So yes, that was difficult" (male, 40–49, blood condition). (Fisher et al, 2021)

"I don't like relying on people. I hated to have to ring people up. At the very beginning, lots of people were getting in touch … Then it tailed off a little bit, and I don't like ringing people and asking for help … I just felt really guilty for it. I just thought, I won't bother anybody, I'll go and do it myself" (female, 50–59, cancer, respiratory condition). (Fisher et al, 2021)

"nice "I'm a member of a couple of Facebook groups in relation to photography, and they have weekly challenges for you to do things on lockdown. So, doing photography in and around the house, macro photography and things. It's like a little bit of a competition … it gave me something to do." (Graham-60-69-M-retired-IMD 9-lives with partner-1). (Morris et al, 2022)

“Most powerful thing I've found is with the meet up groups, for example, on complex PTSD, um, it's being with other people who have similar experiences, and, um, there's a resonance there and just sharing resources and information”. (focus group 1, participant 2). (Rowland et al, 2023)

“I've discovered that there are a few people out there who have the same issues that I do, um, so it's made me feel a little bit better. And with Facebook I've joined other groups, for example, with lung conditions like myself. And we're swapping ideas or I'm, not always contributing, but I'm reading, and it does help in a way.” (focus group 1, participant 3). (Rowland et al, 2023)

“I have a peer group for one of my long-term conditions … we talk daily to each other, motivate each other, keep each other calm.” (focus group 3, participant 2). (Rowland et al, 2023)

1.4 Uncertainty around returning to normal

PLwLTC already experience uncertainties for the future. The pandemic exacerbated this problem by introducing further uncertainty about when life would return to normal. Their concerns included self-care activities like swimming and social activities such as visiting family and friends.

“how long’s the virus going to be floating around for? How long have we got to take these precautions? I can’t anticipate whether we’re talking weeks, months or a couple of years and the long-term effects are going to be floating around. The anxiety I’m sure will lessen but I think it’s going to be there for a good while” (female, 50–59, neurological condition). (Fisher et al, 2021)

“It’s fine for the moment, but obviously if I think I’m never going to see the Royal Ballet again, I can get quite tearful. And it’s things like dancing, we do dance quite a lot … obviously we can dance together, but it’s not the same as going dancing, so yes. It’s a

grieving for how quickly those things come back" (female, 50–59, cancer). (Fisher et al, 2021)

"I can't see how it is going to get back to normal for me and my life, my job, my going out, my social, like going swimming or going to a class. I can't see how it will get better really … I hope to get to visit my family … I used to go on the train, but I don't know if that will happen." (Morris et al, 2022)

2. COVID-19 and the impact of the healthcare system

2.1 Move to online

Two studies looked at the use of online platforms to deliver remote healthcare and support. While there are benefits to care delivery, there are significant practical and emotional impacts to the patient that can be positive or negative. Without understanding individuals' needs, there is a risk of widening health inequalities when it comes to accessing healthcare services.

"10 participants across the studies who gave positive responses related it to their reluctance to attend in-person appointments, which were exacerbated by COVID-19, due to having mobility constraints, chronic tiredness, frequent panic attacks or other multi-morbidities. Three respondents reacted positively to patient safety citing health benefits of not being potentially exposed to the COVID-19". (Roberts et al, 2024)

"Seven patients experienced frustration or dismay at having to explain, often complex, health history as the online system did not allow patients to seek care from a familiar practitioner, with one patient in Health Foundation who perceived patients were seen as "faceless creatures". Conversely, five patients relayed positive continuity of care sentiments where online systems allowed patients to consult with a GP familiar to them and their health history." (Roberts et al, 2024)

"This was the most prominent factor throughout all of the selected literature. with 83 respondents alluding to it and featured in nine out the 12 studies. Comments were largely positive citing reasons of ease, speed, efficiency, and affording patients the ability to fit appointments around family and work commitments. The largest volume of comments around time savings related to a reduction in travel times and waiting room attendances. Only one patient conveyed a negative response to 'convenience' which related to at-work restrictions on accessing an online device." (Roberts et al, 2024)

"Within the 21 data points, respondents reported financial barriers to access due to having non-contract, 'top-up' mobile phones with limited credit and limited data allowance to transfer multi-media files, such as photographs, requested by GPs to adequately provide care." (Roberts et al, 2024)

"Communication was the second most prominent factor and featured in 10 of the 12 studies. Comments were overwhelmingly negative in tone with patients referencing communication deficiencies in the transition to the triage and consultation processes during COVID-19, a lack of advanced notice before appointments, no indication of when a preferred practitioner was available, inability to get through by phone when experiencing system problems, and predominantly, a lack of physical communication cues when compared to face-to-face consultations. Only three positive comments were retrieved to suggest that the online platform was equitable to face-to-face contact with their GP." (Roberts et al, 2024)

2.2 Disruption to appointments

Two participants describe the impact of delayed appointments due to COVID-19. Whilst both say they understand the reasons, both feel disappointed, believing they have a serious condition they need to be seen for.

"I should have seen my neurologist in January … but that got cancelled. I contacted [the hospital] and got an answer phone, then I was told that the neurologist would be getting in touch and she never was …. A bit disappointed and I do feel like I think what I've got is a pretty serious condition, but it's obviously regarded as not that important at the moment … but I can understand why" (male, 60–69, neurological condition). (Stamm et al, 2022)

"I was supposed to have a surgical review with a view to having surgery this year, but obviously that's all stopped. The review was cancelled. Surgery will not be any time soon. It can wait, but it's also something that's disappointing. But I do understand that there will be a massive backlog now and there are many more urgent things that need sorting" (female, 40–49, respiratory condition)." (Fisher et al, 2021)

2.3. Trust in the healthcare system

Three participants described concerns that the healthcare system doesn't meet all needs, particularly around being listened to and addressing feelings. Two participants described being lost in the system and the pandemic leading to more people getting lost in system gaps. One participant praised a link worker for supporting her to get back to "normal".

"One of the biggest concerns always was that people were getting lost in the gaps in the [care] system". (United Kingdom, male, 20–29 years). (Stamm et al, 2022)
"I didn't get a letter [from the Government/National Health Service (NHS)] for ages because they weren't able to identify me and the therapy from that essential health data. So, yes it was a bloody nightmare to be honest." (female, 40–49, cancer). (Ambrosi et al, 2024)

"She [link worker] has given me so much encouragement and she tried to get me to see a positive side of things … I don't want to be spending my days crying … all I hope for is that I can get some normality coming back into my life". (Gill- 60-69-F-unemployed-IMD1-lives alone-5- shielding advised). (Morris et al, 2022)

"(…) healthcare, um, practitioners, they'll just mention, okay, um, okay, what you're doing with your condition, how you're coping, and you know, it's not how do you feel? And, and that so important to me, just asking that one simple question". (focus group 3, participant 1). (Rowland et al, 2023)

"When I was diagnosed, mental health issues didn't come into it. You had your condition and that was your condition." (focus group 2, participant 2). (Rowland et al, 2023)
"there is the underlying anxiety, as well, about how will I be treated in the future?...The healthcare worry is obviously a lot more intense, because if I need to go back into treatment, I will have to be isolated to a much greater degree, and will be much more dangerous … it's always been there, but [now] it's an increased anxiety" (female, 50–59, cancer). (Fisher et al, 2021)

"healthcare is my main priority, that really worries me, that I'm not going to get the same level of treatment as I was getting before, because there won't be sufficient money around, and a lot of services will be cut" (female, 50–59, cancer, autoimmune and respiratory conditions). (Fisher et al, 2021)

Summary:

There are very few published papers that study MLTC and the COVID-19 pandemic from a patient perspective.

The impact the pandemic had on PLwLTC further highlights a lack of person-centred care within the healthcare system, with patients bearing increased responsibility to manage day to day when the healthcare system is disrupted. The national response to COVID-19 was to

cancel routine appointments and categorise PLwLTC as vulnerable, with no or limited support from healthcare services. This increased the vulnerability of already vulnerable people, heightening the challenges of living with multiple long-term conditions.

2.3 Summary of both literature reviews.

The pre and post COVID-19 literature reviews both highlight the issues PLwMLTC and PLwLTC face in managing their conditions, coping day-to-day and the experiences of accessing healthcare services.

Before the pandemic, the literature review highlights the importance of PLwLTC accepting their conditions and making the relevant adjustments to their lives with little or, in some cases, no help from healthcare providers. The data shows, in the absence of patient-centred care, healthcare services focus on the condition(s) diagnosis and treatment but there is no consistent focus on supporting the patient in other ways e.g. emotionally or practically at home. Healthcare services fail to deliver consistent quality care resulting in variations of patient experience. Participants are saying the key priorities that make a better experience are:

- the experience of the HCP listening
- giving the right care, including accurate and understandable information
- an accurate diagnosis, and
- a system that is easy to navigate.

Participants recognise their responsibility to self-help. This can include accessing other community services that are available and understanding how social and support systems can help PLwLTC. However, not all participants receive this type of support which can give rise to inequalities and emphasises the importance of the HCS considering the whole person, over and above a solely clinical perspective.

The post-pandemic literature review shows how the above issues were compounded by the national response to COVID-19 and caused further emotional and physical health issues for PLwLTC and PLwMLTC, emphasising the need for HCS to support people to self-help when access to healthcare is taken away. The disruption to services increased vulnerabilities, forced further day-to-day adjustments to manage and cope with symptoms and increased reliability on others. The removal of community services and social distancing made this essential element to self-help challenging, if not impossible. The healthcare system, already perceived as hard to navigate and not working consistently for PLwLTC, became more so. Cancelled appointments caused disappointment and further system issues created gaps leading to patients being forgotten about. Whilst online services have some benefits for some people, this is not a one-fits all solution and individual circumstances and preferences need to be considered.

This review emphasises the difficulties patients face in living with long-term conditions, especially in relation to being supported day-to-day, and where they are expected to manage with little or no help between appointments. Once in the healthcare system there is a need for care plans that consider the whole person's needs, rather than focusing on a single condition or problem.

Whilst there are several government plans to improve healthcare for MLTC, both searches provide evidence of a gap in research that focuses on access to healthcare for PLwMLTC from the patient perspective. Pre-pandemic it was acknowledged in the NHS Long-term plan that there is a need for further research that involves patient experiences and expectations. (The Health Foundation, 2021, p.01).

3.0 Methodology and Philosophy

3.1 Philosophy: Hermeneutic Phenomenology

Qualitative research has a variety of philosophical underpinnings. This study was conducted from a relativist ontological standpoint adopting a hermeneutic phenomenological epistemology.

The philosophy of relative ontology is emerging in its use within health and social care, particularly qualitative studies that focus on understanding specific practices, individual perspectives, policy, and frameworks. It is especially useful when exploring lived experience and can help explain factors that create similarities and differences within a group of people that are experiencing a relatable phenomenon.

The philosophy of relative ontology is that reality is not one single entity but is formed by the human mind from factors like values and beliefs. Therefore, there is not one single truth, but an individual's truth relative to their experience. *"Most qualitative researchers believe that the 'truth' lies in gaining an understanding of the action, beliefs and values of others, from within the participants frame of reference"* (Grbich, 2003, p.16). Relativist ontology is also relevant to postmodernist and constructivist perspectives where knowledge and reality are socially constructed.

Qualitative research has different approaches depending on the purpose of the research and can adopt a variety of different methods for design, data collection, and data analysis. This study is centred around understanding patient lived experience related to a particular event and the meaning given to the experiences, to reveal a rich and descriptive account that is unique to the individual.

Phenomenology is an approach that uses relative ontology and will drive this study. Phenomenology is a qualitative methodology concerned with exploring and understanding an individual's lived experience of a phenomenon.

Comparatively, grounded theory, is a qualitative methodology that concerns itself with patterns and trends to produce theories to explain something, based on data analysis. *"Grounded theory is defined as the discovery of theory from data… This approach focuses on a certain development or activity that is unfolding, ideally leading to the researcher's creation of a theory regarding this series of events or process…Essentially, the theory centres on the researcher's end goal of forming a theoretical frame which sheds light upon a particular phenomenon, or series of events, including how the phenomenon began, grew, and changes."* (Delmas and Giles, 2023, no page).

Phenomenology is appropriate for this study as it is only concerned with understanding the lived experience of the phenomenon, from the individual's perspective and not concerned with developing theories from the experiences.

Husserl (1900/2001) was the first philosopher to approach phenomenology. *"He wanted to understand how the experience of a given phenomenon could be known accurately enough to determine its essential qualities."* Husserl (1900/2001) is famously quoted as asserting the need to *"go back to the things themselves"* (Smith and Nizza, 2022, p.7). Going back to the event that took place that had significant impact to an individual's experience. Heidegger (1889-1976) a student of Husserl, continued the work of this teacher looking closer at interpretation; to draw out the sense-making of the experience and apply meaning. This is the interpretative theory of *hermeneutics*. How the participant interprets their own experience and what meaning they give to their experience is not always obvious, requiring a deep dive into the data. *"Therefore, being phenomenological involves detective work, closely engaging with what is seen or said, searching for clues to work out what it actually means"* (Smith and Nizza, 2022, p.7).

The researcher also takes on an interpretative role. This is known as *double hermeneutics* (Smith and Osborn, 2003, p.51). The researcher is attempting to make sense of the individual's making sense of their experiences. *Hermeneutics* is an important concept to phenomenology in the pursuit of a truth held by the participant, based on their

experiences, values, beliefs, opinions, and ideas. *"Hermeneutic science involves the art of reading a text so that the intention and meaning behind appearances are fully understood".* (Moustakas, 1994, pg.9). According to Heidegger (1962), hermeneutics as a theory of interpretation, "*invites the researcher to bring their own preconceptions to the analysis*" and as described by Gadamer (1990), interpretation brings *"fusion of horizons between researcher and participant"* (Smith et al, 2009 p.9). The use of interpretative phenomenological analysis (IPA), described in the next section, brings these two concepts together.

"A founding principle of phenomenological inquiry is that experience should be examined in the way it occurs and on its own terms, rather than according to predefined theoretical categories." (Ashworth, 2015, no page). It is this approach that is adopted within this study; firstly, to allow the space and freedoms of storytelling to the participants and secondly, to allow the research and analysis to be conducted without an in-depth understanding or a focused direction, limiting any bias. Grbich (2003 p.30), refers to this as *"see the evolving issues more clearly".* Theorists such as Max Weber, George Mead, Erving Goffman, and Jürgen Habermas have adopted this theory as it *"draws on the perspectives from the interpretivist/interactionist position."* (Grbich, 2003, p.30).

The approach of focusing on an individual's subjective experience to gain an in-depth understanding is defined as *ideographic* and aligns to phenomenological studies that focus on the uniqueness of a person's experience rather than wanting to generalise outcomes. *Single cases can be intrinsically interesting and reveal factors that would be neglected in a group."* (Smith and Nizza, 2022, p.8).

3.2 Research Design

This research uses the principles of phenomenology and Interpretative Phenomenological Analysis (IPA) to explore the rich experiences of four eligible participants living with MLTC using semi-structured face-to face interviews.

The phenomenon, in this case is the COVID-19 pandemic. In-depth face-to-face interviews were used to collect data from volunteer participants and analysed using IPA to interpret the meaning they assign to their experiences. This approach sought limitless storytelling by the participants. IPA was chosen to analyse the data due to its core principle *"to understand people's lived experience and how they make sense of it in the context of their personal and social worlds"* (Smith et al, 2022 p.3).

Interpretative Phenomenological Analysis (IPA) has become an increasingly valuable approach within healthcare research because it focuses on the patient's voice and explores how individuals make sense of their healthcare experiences beyond clinical measures. Unlike quantitative methods, which often prioritise outcomes that can be measured and compared, IPA allows for a deeper exploration of the topic. This depth of understanding can reveal how people experience diagnosis, treatment, and the ongoing management of conditions in ways that may be neglected by a statistical approach (Smith, Flowers and Larkin, 2009, pp. 3–5). Importantly, IPA aligns closely with the growing emphasis on patient-centred care, as it captures the lived impact of health conditions and the meaning individuals attach to their experiences. As Larkin and Thompson (2012) argue, IPA seeks to offer an "insider's perspective" on the lived experience of people with health conditions, thereby supporting a richer and more person-focused understanding of healthcare that can inform more accurate, responsive and empathetic service delivery (Larkin and Thompson, 2012, p. 107).

IPA according to the foreword in Smith and Nizza 2022, pg. vii, is *"a method based on the philosophical foundations of phenomenology, hermeneutics, and ideography"*. IPA requires a deep-dive into the individual interviews which then go through a process of cross-case analysis to generate shared experiences or perspectives (*convergence*) and explore any differences in events and experiences (*divergence*).

IPA is an inductive approach, meaning that the data does not fit into pre-existing theories. Instead, themes emerge through the analysis and interpretation of the patient's description of their lived experience, to gain understanding and apply meaning. These are referred to as *experiential themes*. IPA's primary focus is to analyse the data to explore and interpret the participant experiences; *"descriptions of the experience's essence are gained through intuition and reflection... The researcher must aim to reflect as closely as possible the essence of the experience*." (Grbich, 1999, p.170).

It is fundamental to this study to understand how PLwMLTC experience accessing healthcare and the impact of the pandemic (*the phenomenon*) from the patient perspective.

3.4 Sample

"The aim of IPA studies is to illuminate individual lived experience. This aim is achieved through purposive sampling." (Smith and Nizza, 2022, pg.14). It is vital to IPA to generate deep and rich data; therefore, a small sample is used to allow the time and focus to immerse in the data. This would not be possible with a large sample size. Purposive sampling is common in qualitative healthcare research, as opposed to random or representative sampling. This method ensures a sample of people with similar characteristics relevant to the topic allowing it to be explored in-depth.

For this study, participants were chosen based on living with MLTC and requiring access to services to manage their conditions, enabling exploration of how they experienced the COVID-19 phenomenon. This technique is particularly useful when extending analysis

beyond the individual and exploring cross-case analysis for commonalities and differences in participants' experiences.

Some conditions are much more prevalent than others in those with multiple conditions. Pre-pandemic analysis of GP data in England suggests hypertension (18.2%), depression/anxiety (10.3%) and chronic pain (10.1%) were the three most common (Cassell et al, 2018, no page). "The Major Conditions Strategy strategic framework" (Department of Health and Social Care, 2023, no page) is focusing on six conditions that patients often experience two or more of; "*cancer, cardiovascular disease, chronic respiratory disease, musculoskeletal disorders, mental ill-health and dementia.* Conditions also include other non-communicable diseases and diabetes.

3.5 Inclusion/Exclusion criteria

This study excluded the following conditions: terminal illness (end of life pathway), cardiovascular disease (heart failure pathway), cancer (cancer pathway), dementia, and mental health (mental health and neurological pathway), due to these conditions having established and/or specialised pathways and services. The NHS is pathway driven and whilst PLwMLTC may fit into one long-term condition pathway e.g., diabetes, this does not take account of any additional needs arising from other LTCs.

It was therefore decided to include conditions in the government's Major Conditions Strategy, 2023, that do not have pre-determined pathways, or are not considered common combinations of MLTC and are, likely to require frequent access to healthcare services; for example combinations of: diabetes, chronic obstructive pulmonary disease, asthma, hypertension, chronic kidney disease, chronic pain, arthritis and autoimmune diseases.

Inclusion Criteria

The following inclusion criteria were applied:

- People who are aged 18+ and have 2+ long-term conditions prior to the pandemic
- People who normally live in England and speak English.
- People who can access an agreed location for interviewing.
- People who currently use healthcare services for the conditions.

Exclusion Criteria

The following exclusion criteria were applied:

- People who have a diagnosis and are being treated for terminal illness, dementia, cancer, cardiovascular disease, or mental health.
- People who cannot access a location in Preston or Manchester for the interviews.
- People who do not normally live in England.
- People who cannot speak fluent English.
- People who do not use health care services for their conditions.

An initial conversation was held with each potential participant prior to selection, to confirm their eligibility based on the inclusion criteria. It is known that mental health conditions are prevalent within this population and, if mentioned, they were included in the study.

3.6 Participants

3.6.1 Recruitment of the participants

A practice participant was selected before commencing recruitment of the four participants and given the pseudonym PPT01. Full details can be found in section 3.7.3 and Appendix 7E. PPT01 helped to practice conducting the methodology, interview, and IPA process. Subsequently, a purposive sample of four participants took part in face-to-face interviews. All four live with MLTC and frequently access healthcare services.

Prior to the recruitment of the participants, a meeting took place with the Chief Executive Officer (CEO) of a charity in Manchester. The charity is the home of many services including support groups that provide a place to go to socialise and get advice, for example, finances, housing, health, and wellbeing. The CEO provided advice to the researcher regarding the recruitment of recruit participants, leading to the redesign a recruitment poster (Appendix 3). He also, facilitated a visit to a community group that provides social connections and access to community advice. This visit helped to build trust and engage people to take part. Subsequent visits to the community group and the amended poster (poster 2) built a sense of self, honesty and authenticity replacing the clinical and constructed effects of the original poster (poster 1). Being present and entering their world, albeit temporarily, was well-received.

Simultaneously, a social media post using poster 2 was published. This attracted many people with single conditions and a younger sample that did not meet the criteria. However, two respondents met the criteria and lived in Lancashire.

All eligible participants were emailed the Participant Information Sheet (Appendix 4) and Consent Form (Appendix 5) prior to scheduling the face-to-face interviews and agreeing locations that the participants were comfortable with. All interviews took place in their local community centres.

Two people from the community group were recruited into the study. Unfortunately, they became uncontactable, so the process was repeated, resulting in the recruitment of two different eligible participants.

Arrangements were made with each eligible participant to meet face-to-face, confirming they had enough time to read the Patient Information Sheet (PIS) and sign the Consent Form. Each participant (PT) was given a pseudonym (PT01, PT02, PT03, PT04).

3.6.2 Characteristics of participants

The study included four participants. Two male and two female participants living in the North-West of England. Table A below shows the characteristics and eligibility of the participants.

	Age	Ethnicity	Gender	Employment status	Location	Conditions
PT01	67	White British	Female	Retired Nurse/HCP	Lancashire	Undiagnosed chronic pain, osteoarthritis
PT02	67	Black British	Female	Retired	Manchester	Diabetes Type 2, Nerve Pain, Arthritis, + PTSD, Depression
PT03	44	White British	Male	Full-time employment	Lancashire	Diabetes Type 2, Lupus, Hypertension
PT04	60	Black African	Male	Unable to work	Manchester	Diabetes Type 1, Visual impairment, Kidney Transplant, Hypertension

Table A: Characteristics and eligibility of participants

Each participant had two or more LTCs, experienced and/or diagnosed before 2016. The criteria originally specified diagnosed conditions, but this was widened for PT01, on the grounds that she was experiencing undiagnosed chronic disease and regularly needed to access HCS. PT02 had a mental health condition but was selected based on her mental health being well-managed and her desire to talk honestly about her experiences of her other conditions; stating that she finds comfort in talking about it and helping others.

3.7 Data Collection

Individual face-to-face semi-structured interviews were conducted using an interview guide. The full interview guide is set out in Appendix 6. This method created the opportunity for participants to tell their story in their own time and in their own way.

The interview guide used a funnel approach starting with broader questions around living with MLTC and then focusing on accessing healthcare by probing participants' thoughts and feelings about their experiences. Further questions ensured participants shared a detailed account of significant events to enable exploration of their thoughts, feelings, and sense-making of those experiences.

Conducting the conversations face-to-face removed potential barriers and helped to build trust and rapport. PT02 and PT04 were interviewed in a private room within the community centre in Manchester, PT01 and PT03 were interviewed in a private room in a community centre in Lancashire. The mutually agreed location created a natural and relaxing space for the participant to talk freely and feel listened to. Observing and responding to body language and feeling the energy in the room enabled the researcher to probe on specific experiences, thereby achieving a deeper dive into significant moments and events that the participant gave particular importance to.

3.7.1 Interviews

The participants attended their agreed locations, at pre-arranged dates and times and confirmed they had read the PIS and signed the consent form. The interview times were; PT01 – 1 hour 28 minutes; PT02 – 1 hour 11 minutes; PT03 – 1 hour 17 minutes; PT04 – 1 hour 10 minutes.

The interviews were recorded using Word, Microsoft Office 365, and an Olympus recording device. Each recording was saved using the pseudonym and the accuracy of the transcription verified using the recording device and the Word, Microsoft Office 365 recorded transcription (approved by Manchester Metropolitan University). Each recording was listened to multiple times to ensure accurate reporting of participants' words. The Microsoft Word transcripts were checked against the voice recordings and changes were made as necessary to ensure the correct words were documented.

3.7.2 Interview: Practice Participant

Prior to meeting with the study participants, a practice participant (PPT) was interviewed. This approach allowed for real-time reflexivity to build confidence in the process and make any amendments to the interview guide; as well as improving interview style and techniques. Furthermore, it allowed practice of the use of IPA methodology for data analysis, as well as informing planning and time management for the four participants interviews and analysis. The interview lasted 1 hour 57 minutes.

No changes were made to the interview guide; however, it was clear that the participant valued the opportunity to be listened to and tell their story. Allowing the participant to talk naturally rather than asking a rigid set of questions gave an authenticity to the experiences, that opened further prompting to draw out thoughts, feelings, and opinions to create meaning. During subsequent interviews, care was taken to identify whether the experiences described by participants related to pre, during or post pandemic events.

	Age	**Ethnicity**	**Gender**	**Employment status**	**Location**	**Conditions**
PPT	44	White British	Female	Working full-time	Lancashire	Fibromyalgia, anxiety, gastroesophageal reflux disease

Table B: Characteristics and Eligibility of practice participant

Applying the IPA process to the practice patient identified six themes which provides insights about the experience of living with MLTC, accessing healthcare and the impact of the pandemic:

- The healthcare system can learn from my experience
- Getting the right care to address all my needs; no defined pathway for MLTC
- The impact of COVID-19 on accessing services

- What it is like living with MLTC; effects on family, work, social life, managing symptoms
- Reduced trust and faith in healthcare services
- Self-care becomes healthcare

The practice Personal Experiential Table can be found in Appendix 7E.

3.8 Data Analysis

This study applied the IPA methodology framework as detailed in the book *Essentials of Interpretative Phenomenological Analysis* (Smith and Nizza, 2022, pp. 31-56). Leading experts who have been using the methods for many years have contributed to the book, producing usable examples of how to conduct IPA, especially useful for novice researchers.

3.8.1 Applying IPA

Each interview was analysed as a single case using the IPA methodology. Re-reading the transcripts multiple times allowed deep immersion in the data, refreshing memory of the actual interview. The following steps began in the same week as the interview to ensure the interview and any non-audible gestures were accurately documented.

Step 1

During the listening process *exploratory notes* were made in the right-hand column of the transcript. These varied between descriptive, linguistic, and conceptual notes to support interpretations of the text.

Step 2

How the participants experienced what they were describing created *experiential statements*. These were documented in the left-hand column of the transcript.

Step 3

The *experiential statements* were then gathered on a table and positioned and re-positioned into groups based on key features and connections. Some were discarded because statements were merged, or the point was made elsewhere. Each group was given a Personal Experiential Theme (PET) representing the convergence between the *experiential statements*.

Step 4

The PETs were transferred onto a Table of Personal Experiential Themes titled *Superordinate themes*, with the group themes associated with the PET transferred into the table labelled S*ubordinated theme.* Quotes taken directly from the transcript relating to the themes were then transferred to the Table of Personal Experiential Themes.

The four steps were performed in the same order for each of the four participants.

Step 5

Cross-case analysis required laying out all four Tables of PETs to allow a full view of the themes to be reviewed, eventually creating Group Experiential Themes (GET). This process allows similarities and differences to be grouped with a focus on reoccurring themes, events, and patterns to create the Table of GET.

"Group Experiential themes should demonstrate a commitment to convergence and divergence. They bring out similarities in participants' accounts of their experiences and so point to high-level connectivity between them. At the same time, they also point to the particular and different ways those participants manifest the experience." (Smith and Nizza, 2022, p.56).

The GET (Appendix 8 is the reference source for writing up the results and findings of the research.

4.0 Bias and Declarations

4.1 Bias

Hermeneutic phenomenology recognises researchers cannot set aside assumptions and experience to remain completely neutral. It requires reflexivity and declaration of bias and assumptions throughout. *"The researcher is called on an ongoing basis, to give considerable thought to their own experience and to explicitly claim the ways in which their position or experience relates to the issues being researched."* (Laverty, 2002, p. 21.).

A reflective journal is included in Appendix 9. The journal documents the researchers' reflections, assumptions, and justification for decisions from the research design to completion.

4.2 Declarations

Position Statement

I have worked in healthcare in senior operational positions for over seven years. Much of this time was spent working on clinical fitness interventions for long-term condition management and preventative community interventions for a healthcare charity, and more recently, providing community diagnostics to reduce NHS waiting lists. I have had the benefit of being exposed to experiences from the perspective of patients and solutions from a system perspective. Whilst this experience brings some understanding to this study, it requires conscious focus to treat each participant experience as its own unique position, rather than attempt to make it become part of a solution. Adhering to the principles of phenomenology and IPA methodology has ensured a neutral stance to consider different perspectives when conducting the literature reviews, participant interviews, and data analysis.

My opinion before starting this study was that the HCS is not designed to deliver the right care to PLwMLTC and as a result a disproportionate amount of the UK population is affected by the lack of support and treatment available to diagnose and manage MLTC. It is the government responsibility to ensure there is adequate care for population health needs, and this has not been achieved, at least for the people I have met whilst working with PLwLTC. Whilst developing the proposal for this study I conducted extensive research into the history of national strategies to identify and manage MLTC to provide an evidence-based background.

Reason for this study

The purpose of this research was derived whilst working with participants of a joint pain management programme. Hearing participant accounts of their experiences of accessing healthcare in this natural setting provided the realisation that if the system was going to improve, listening to the users of the system was a crucial element to success. I became intrigued by participant experience and the insights they had that could lead to valuable change.

Conflict of interest

The final year of this study is self-funded. There are no conflicts of interest that can influence the study.

5.0 Ethical Considerations

Ethical approval was obtained by Manchester Metropolitan University Health and Education Research Ethics and Governance Committee. Approval 56815 was submitted August 2023 and revised on September 2024 to update Consent and PIS date extensions, new poster design, and new transcribing software from Microsoft Teams to Microsoft Office 365, Word. Full details can be found in Appendix 10.

Safety Considerations

Consideration was given to meeting vulnerable people. For example, I ensured a public and agreed location to ensure safety of both parties. Online workplace training on safeguarding and identifying vulnerable adults was undertaken prior to meeting the participants. Participants were issued a list of support services on the PIS (Appendix 4) and again after the meeting. A key consideration prior to interviewing was to remain within the scope of a researcher and resist taking on any other role.

Confidentiality and anonymity

All data collected is pseudonymised using a code to identify each participant. Participants have also been offered a copy of the completed thesis. Patients' data is securely stored on the Manchester Metropolitan University server as required by the university's ethics committee.

Informed Consent

The PIS (Appendix 4) describing the study and participants' right to withdraw was issued prior to the interview and signed copies of the consent form received before the recording commenced. Each participant was asked on the voice recording to confirm they had enough time to read the PIS and confirm their consent to continue.

6.0 Findings and results

6.1 Descriptive summary of the participants

This study gave a voice to four participants to describe living with MLTC and their experiences of accessing healthcare. Each participant described their experience of the COVID-19 pandemic (*the phenomenon*) and the impact it had on their lives during semi-structured interviews that ensured coverage of the research questions. Using IPA (Smith and Nizza, 2022, p. 31-50), each participant interview was analysed to produce a full Table of Personal Experiential Themes (the full data set is in Appendix 7).

To understand how the participants have been impacted by the pandemic, it was necessary to establish a baseline by understanding their experience of living with MLTCs in the years leading up to the pandemic. The following section is a summary of their interviews.

PT01: "Why live like this"

Participant 1 is a 67-year-old white British female, living with her husband in Lancashire, retired from working in healthcare for over 40 years. She had 2 diagnosed conditions prior to the pandemic; Arterial Fibrillation (AF) and Osteoarthritis (OA) and, from 2019, an undiagnosed condition causing joint pain, fatigue and other life-limiting symptoms that started just before the pandemic was declared. PT01 describes her AF as being ***"just one episode" p.01*** although believes it may have been a trigger for her undiagnosed condition. ***"After that I expected to fully recover but I didn't, and I became tired with the listless and just not able to pick up. Aching everywhere, my upper body, all my joints were awake most of the night." p.01.*** Her symptoms resulted in a hospital stay with no diagnosis. The GP suspected fibromyalgia but there was no follow up and beforehand, suspected myeloma, however she was cleared of that just before the pandemic started. She describes this experience as ***"all very scattered" p.02*** and that there was ***"no cohesive path" p.02***. Wanting answers to relieve the chronic pain and minimise the increasing disruptions to daily life, PT01 sought out private consultations ***"I was paying for the consultations to try***

and get an answer quickly." p.02 as well as various private alternative treatments including acupuncture, tai chi and massage, to manage the pain that moves around her body. Her OA was being treated by a consultant, who she was able to see when required during open-ended appointments but later, the consultant refused to administer any more injections to relieve the pain because **"*once again the NHS ended it" p.03*.** Having worked in healthcare, she knew the consultant had a private clinic and was able to get the injections. **"I *wanted to have some joint injections for the knees, and he agreed to do it almost as a favour really." p.2.*** Since COVID-19, PT01 has asked her GP to be referred to a pain clinic to help manage debilitating daily symptoms. She is currently on a long waiting list for the pain clinic and has a two year wait for a neurological appointment, following a referral for head pains. PT01 seeks different ways to manage chronic pain and is grateful she has the means to pay for private treatments, *"**I also made arrangements to go to see a physical therapist who's local, which specialises in pain control and pain diseases and holistic medicines. And it's been absolutely fantastic." p.3**. S*he believes the NHS cannot and has not helped her. *"**A&E who obviously couldn't find anything particularly wrong with me and just sent me home to the GP and [GP] couldn't sort out what was wrong with me." p.1.***

PT01 had to adjust how she lives day to day and plans for the future. Being active, going on long walks with family and travelling to explore different countries, she found it impossible to accept her retirement is now limited by her conditions. She hasn't accepted the impact on her life and worries about the effects it is having on others. ***"I do feel like a nuisance... I feel like I'm holding him [husband] back. He's quite able to do stuff" p.30.*** She believes public funded healthcare services can help people with MLTC and has witnessed this whilst working in healthcare for over 40 years. She tearfully said, ***"Why live like this".p.36***

PT02: "To be heard is important"

Participant 2 is a 67-year-old black British female living alone in Manchester. She is mobile with crutches because of arthritis and severe pain in her knees and body. She uses community transport to access appointments and support centres. She was diagnosed with Type 2 diabetes in 2004, arthritis and nerve pain in 2014, and depression and PTSD in 2009.

She has good friends and family close but feels like a burden on her loved ones. She finds the community groups comforting and educational. She is a regular visitor of community groups to support her living with MLTC as well as mental health conditions and perceives this support as a lifeline. ***"I've been groups like this, you know... literally when I was getting them phone calls [befriending group], it was and literally a lifesaver." p.18.*** She has a deep-rooted purpose to help people after coming to terms with being sexually abused as a child and uses her story to show people they have a voice and there are people who will listen. She does this through writing poetry. PT02 has had two cancelled knee operations after attending both pre-operations. She believes the cancellations are due to COVID-19 and the subsequent backlogs and disruptions to healthcare. She requires frequent visits to healthcare services to manage her conditions, primarily to access diabetes medication, pain medication and other controlled medication.

She believes primary care is a battle to get routine appointments ***"it's about trying to get in front of somebody to keep banging that the drum essentially saying look, I'm here...I'm struggling...And try and push it through in that sense." p.21*** and disruptions in secondary care are the result of the pandemic, funding and the political landscape. ***"Because the government, because of all the changes, because we've left Brexit, because I could go on forever." p.20.*** Her mental and physical health suffers when healthcare doesn't meet her needs. She believes GPs should listen more, have the time to listen and consider the whole person. She worries for the elderly and peoples' inability to get the care they need and wishes there was more funding.

PT03: "You're probably lying to me anyway"

PT03 is a 45-year-old white British male in full-time employment living in Lancashire. He lives alone and has many friends and some family close by. He has Type 2 diabetes (T2D) diagnosed in 2013 and a lupus diagnosis in 2017 after 2-3 years of misdiagnosis and investigations. Undiagnosed lupus symptoms began in 2014, resulting in multiple visits to many HCPs and many prescriptions that did not work and sometimes aggravated his condition by causing severe side-effects. ***"That's the thing with the NHS; I became an***

experiment." p.08. This period triggered on-going scepticism of the HCS and a lack of trust and faith in mainstream HCPs to provide the help needed to manage the condition. In his view, advice from HCPs is out-dated, contradictory, incomplete or inconclusive. ***"And, when things are based on... we've done it like this for 25 years. Yeah but no. We still have evolution and the rest of it, you know." p.26*** PT03 believes the trial-and-error medications have had long term effects on his hearing. ***"I took for 18 months and at the end right at the end they said you never should've been taking that, I'm sure that's affected my hearing to this day." p.04.*** Due to the visual nature of the lupus symptoms, he suffered a lack of confidence and declined social engagements, especially after undergoing 2 biopsies on his face during the investigations. PT03 became an expert in his own conditions through extensive research. He questioned the diabetes dietary advice ***"You're telling me my sugar is through the roof, but then the first three groups you're telling me to eat, I know, are high sugar in terms of quick impact...It's almost like...they are encouraging spikes. To me it read like, have a big spike but then you'll take the pill." p.25***. Upon diagnosis of lupus, he was offered life-limiting medication to 10 years and can cause other complications. This information was not offered to him; however, he declined the medication based on his own research and personal choice to self-manage the years he has left. ***"That's what we do… I said yeah, but I've looked at that and once you start them drugs, you've got 10 years. And the response was Oh well, well, there's advancements all the time." p. 12-13***. This situation further reduced his faith and trust in the healthcare system ***"If you do this bad identifying the issue, yeah. I don't ever trust your solution" p.08.***

DT2 is well-managed with prescribed medication, vitamins, exercise and diet. ***"So, I do have a healthy, expensive vitamin habit...walking, fresh air and getting out...Good diet as much as possible." p.19.*** He walks long distances outdoors to absorb Vitamin D (despite being advised against sunshine) as well as manage weight. This has become a way of life to manage both conditions. PT03 believes the HCS does not consider a person's whole needs and is about making money. He also believes the COVID-19 vaccination is the reason he cannot walk as far and has less energy, impacting his ability to manage weight and absorb the sunshine and therefore, reduces ability to self-manage as well as before the pandemic. PT03 has accepted his conditions and is at peace with the future.

PT04: *"I'm happy that at least I'm managing on my own."*

PT04 is a 60-year-old black African male living alone in Manchester and has been diagnosed with Type 1 Diabetes (T1D) in 1999, impaired sight in 2013 because of the T1D, hypertension in 2005 and kidney failure in 2013 resulting in a kidney transplant. PT04 moved to the UK in 2005. PT04 found it easy to register with a GP in 2005 and they replaced his tablets to insulin. In 2013, he lost sight in his left eye and partially in his right eye because of the T1D. This affected his ability to work despite wanting to. He was well looked after at work and by the integrated healthcare services in Manchester. He went on to study for a bachelor's degree in health and social care and now contributes towards public services volunteering on a council board. In 2013 his kidneys began to fail "***At this time now a lot of things started to develop things. All that needed some medication, yeah. And I had no choice". p.04.*** PT04 has gratitude for the connected healthcare he experienced. He was able to get blood tests and other checks done for all conditions in one place within his community. The services share the results and contact them if further checks are required or to provide useful information e.g. taking precautions during the pandemic. Despite having kidney failure, he was able to complete his degree before starting dialysis and fortunately, received a donor shortly after graduating. This was because of the connected services helping him to delay treatment. PT04 visited his family in Zimbabwe as soon he was healthy after the transplant in December 2020. This is when the airports re-opened after the first wave of the pandemic, and he got stuck there when they closed the UK airports after Christmas 2020. Because he was well-informed by his GP, he had enough medication for the prolonged trip.

PT04 is thankful to be able to live independently and be mobile. He uses public transport to get to church and attend community groups as he enjoys listening to other people's experiences, learning from them and using this knowledge at the council, but also to give purpose to his life. He finds purpose helping others as he understands that people are suffering and there is a lot of isolation caused by ill health. ***"I never stopped doing most of the things. I continued going to church. I continued to be interacting. I visited a lot of***

centres, [this one}. Yeah, you know, I I just, I just found that is my how, that's the best way I can. You know, cope with my time, yeah." p.04

6.2 Cross-Case Analysis

To answer the research question; *How has the COVID-19 pandemic impacted access to healthcare for patients living with multiple long-term conditions* each participant's experiences were subjected to a cross-case analysis following the IPA methodology (Smith and Nizza, 2022, p. 51-56). The results of the analysis are presented in a table of Group Experiential Themes in Appendix 8.

During the interviews each participant, without prompting, described their experiences of living with multiple long-term conditions in a logical order. They vividly described significant events including navigating their healthcare before and during the pandemic and, up to the present day.

The cross-case analysis initially connected the experiences of the individual participants on a conceptual level to produce the group experiential themes. The experiential quotes provided evidence of how the participants give meaning to their unique experience of the phenomenon and highlights similarities and differences. This method respects the ideographic nature of the study and illustrates convergence and divergence within the individual experiences of the phenomenon.

6.3 Findings and Results

This process produced four main themes and 17 sub-themes. The four main themes were:

1. Living in the unknown: An emotional response to waiting to access healthcare services
2. Effects of the COVID-19 pandemic on managing day-to-day life
3. Trust and faith in healthcare services at risk, and
4. The lasting effects.

Theme 1.0: Living in the unknown – An emotional response to waiting to access healthcare services

Participants all shared experiences of living with uncertainties as part of living with MLTC. The national response to COVID-19 resulted in the removal of, or delayed access to, healthcare services that previously provided reassurances to help deal with some of the uncertainties around their health. The participants describe having no choice but to accept the disruption and wait indeterminately to be able to access them again. The following sub-themes outline the individual participants' experiences of waiting and the subsequent implications to their life. The descriptions reveal the emotional response to the disruption, addressing reduced control over managing their conditions; consequences of removing services, acceptance of the situation and the additional struggles created by a range of system failings.

Subtheme 1.1: No choice but to live with disruption to routine appointments

All participants rely on frequent access to NHS services to manage their conditions and described experiencing disruption to their healthcare access during and after the pandemic. They had no choice but to accept that services were disrupted for an unknown period and were left to find ways to cope and make sense of what was happening during the disruption and in the aftermath. Two participants described a sense of abandonment.

Accepting there are no routine appointments during the pandemic

PT04 describes being "*content*" and PT03 describes being "*at peace*" with not being able to access routine services. Prior to the pandemic these two participants were reliant on repeat prescriptions and routine tests to treat and monitor stable conditions contributing to their acceptance. However, during the pandemic PT04 considered the risks, if needed, of attending hospital during COVID-19, which he discarded as an option. PT03 had already made peace with having reduced mortality because of his conditions and trusted his own methods of self-care to manage it. PT02 recalls the removal of mental health support during COVID-19 and appears to have had no choice to accept it with no descriptive feelings attached to it, however she remembers it took a long time to regain access to these services.

PT04 *"You have to be content with it [cancelled appointments] or you go to hospital, and you know what it is like in hospital". p.11*
PT03 *"But you get texts off them, you're due this or ring us up about that. So, all that just stopped. Because they didn't know what they were doing so, that's fair. I get that, I'm at peace with that." p.27*
PT02 *"[mental health services] I didn't actually. I didn't during that time [COVID-19]. It was just coming near the end of it and it started again... it took a long time to access it." p.23*

Struggling not having routine appointments during the pandemic

Despite having no choice but to accept disruption to healthcare services all participants described their own unique struggles with the removal of access. PT03 referred to the removal of regular tests and PT04 described it as "*living in the unknown*" of how his kidneys were functioning in the absence of regular tests to reassure him.

PT04 *"Two months [after refusing the first appointment for fear] next available, I was like living in an unknown because I didn't know how the kidneys were functioning... I was adhering to the advice... But I just needed that kind of closure" p.15*

PT03 *"It almost returned to ah you need to come and have your check up for this. So, the first time I went was December 2022...I was in group 2... but all that seems to do was get COVID stuff quicker. The [groups] didn't seem to tally with anything else on the GPs". p.28*
PT*01" COVID made it even worse; you couldn't see anyone about anything." p.27*

Difficulties getting appointments after the pandemic

PT02 compared her experience prior to the pandemic when she routinely saw a GP for tests every 3 months to manage diabetes and could see a GP more easily when needing same-day appointments for pain management. She experienced the booking system not coping with the demand and it being "difficult", if not impossible, to get same-day appointments for controlled medication resulting in prolonged suffering and very bad days.

PT02 *"that's really difficult because they're telling you is ring up at 8am in the morning... it will say you're #30 in line; we'll get back to you. So, you know you're not getting an appointment that day... so that's really difficult because sometimes you need to see them at the same time." Pg.05-06*
PT02 *"they call you for blood tests quite regularly, I'd say every 3 months or so, yeah into the GP, although it's getting harder and harder to actually get face-to-face appointment." Pg.05*

Sub-theme 1.2: Suffering - trying to manage alone whilst waiting between referrals and appointments

PT01 and PT02 live with chronic pain and described suffering during the period between a referral and the appointment as being detrimental to their overall health and wellbeing. They both recognise the need to manage with no healthcare support or inadequate support during this time.

PT02 *"physio [arthritis], they'll say after six sessions or whatever it might be. So, with the physio just try to talk through it and just manage it, try to manage it the best way that I can." p.11*

PT01 *"It's just keeping yourself going really and trying to do things." p.06*

Despite doing what they can to help themselves, both participants described the physical and mental suffering while waiting for appointments. PT02 was waiting for a knee operation which had been cancelled twice after attending the pre-operations. She experienced physical harm caused by multiple falls and had developed kidney problems due to prolonged use of medication to manage the pain. PT01 described not being able to physically move whilst waiting 6 months for tests. She described feeling depressed and low and it dominates her life. This period is a significant part of the living in the unknown while waiting for help, there is no indication to when help will come, and this compounds existing issues creating physical and mental deterioration.

PT02 *"I'm gonna have an op on my knee. I've been twice and it's been cancelled. So you're left with the you know that pain and the effects." p.12*

PT02 *"I've had a few falls so it's important that I do get it done, yeah." p. 13*

PT01 *"These [additional symptoms] compounds with things and that's the problem is it is not knowing." p.16*

PT01 *"they were saying you have to wait six months to see haematologist. And I was thinking I could hardly move." p.07*

PT01 *"And it [not being diagnosed] does cause you to be a bit depressed at times as well [tearful]. Really depressed and made to feel low. And dominate." p.08*

Sub-theme 1.3: Putting trust in the service to follow up when required

There was an expectation amongst all the participants that the healthcare system would drive all follow-ups. Each participant was with a GP for their conditions prior to the pandemic and was in the system, receiving the help they needed or able to contact a GP if required.

Expecting the system to drive all follow-ups

Pre-pandemic PT03 and PT04 described routinely being contacted when appointments were due, establishing trust that the system would ensure that contact was made if required. PT04 established years of trust and faith in his local service due to previous positive experiences of diagnosis and management of all his conditions.

PT04 *"It's all up to them [GP] yeah because I don't phone for an appointment, but they give me an appointment when I'm due." p.16*

PT03 *"pre-COVID you get summoned every year for a diabetes check. But all that went out the window for a good two years... They abandoned ship on everyone during COVID...But I remember getting a phone call, I said, I thought, you thought I was dead". p.18*

Feeling neglected when the system doesn't follow up in reasonable time

Post-COVID-19, two participants have also experienced the system failing to follow-up. PT02 felt scared, abandonment and worry when important tests relating to an infection were not followed up for six weeks. PT01 said a pharmacist advised her to stop taking medication and informed her a message would be sent to the GP; however, the GP has not contacted her about this. PT01 further mentioned visiting a different GP for head pains and receiving a 2-year referral to neurology, with no follow-ups during this time and no consideration to previous visits. The GP referred to her pain as tension headaches.

PT02 *"there is some really important tests that were supposed to be done when she was looking through my notes, they said they'd call you up in six weeks and that didn't happen...You feel neglected really you feeling you feel worried, you feel scared, you feel neglected." p.6-7*

PT01 *"refer you to a neurologist... so I haven't seen one. That was January [2024], so I've got an appointment... The end of January 2026... It was just over two years, so I haven't bothered cancelling it.... and you see someone different, and he said Well... basically you're alright. We just think its tension headaches." p.15-16*

PT01 *"The pharmacist told me to stop taking it and she sent a message through to the GP, but I haven't heard back." p.17*

Sub-theme 1.4: Managing a reduced level of control

Living with MLTC demands being in control of the daily management of unique and varied symptoms. Being able to access services and working in collaboration with healthcare professionals to maintain control are key factors in coping and managing MLTC. The pandemic removed the option to book appointments when needed, created a fear of entering clinical environments to receive care and created longer waiting times to see specialists. All participants felt that there was no consideration as to how this would affect day to day management of living with MLTC, leaving them to manage alone.

Trying to take some control where possible

PT01 took control by paying privately to get answers more quickly than the GP. PT03 attempted to move an appointment pre-empting it being cancelled due to COVID-19 without success, the receptionist failed to see that he was trying to be pro-active. PT04 refused to attend a routine appointment until he felt ready, through fear of catching the virus.

PT03 *"So I'm just being pro-active ringing you up [to move appointment because of the pandemic] … If I hadn't bothered, I would have got a letter I imagine somewhere in amongst all the COVID... you're no longer with our consultant go back to your GP. And to be fair I sort of laughed." p.17*

PT04 *"the first appointment that I was offered I refused because I know of a Zimbabwean who went for a checkup and never returned". p.13*

PT01 *– " I was paying for the consultations to try and get an answer quickly." p.02*

Cannot control how and when to get treatment

The absence of a correlation between patient needs and service provision can have detrimental consequences. PT01 and PT02 could control the support they received for chronic pain and were at the mercy of what the system provided rather than what they needed.

PT01 described the consequences of the 'single problem, single appointment' system. She recounted visiting an orthopaedic consultant who could not assess an orthopaedic problem because the referral was in relation to a different body part, resulting in her returning to the GP for another referral and suffering in the meantime. PT01 mentioned several times that there is nowhere to go for symptom management while waiting for treatment.

PT02 *"a lot of the time they're saying it's because the way the health service is at the moment... I've been for a pre-op twice... it's been cancelled...they're just not ready for you." p.12*

PT01 *"[orthopaedic consultant] gave me another open-ended appointment and I said, well, my right foot is really bad and I said if you look at that and he said "no I'm not allowed", he said "the pathways on the NHS don't allow for that anymore". He said, "as ridiculous as it might sound, he said, I'll write back to your GP, and your GP will have to refer you to an orthopaedic consultant." p.19*

Sub-theme 1.5: Seeking reassurances when dealing with uncertainty

All participants sought reassurances when managing their conditions. This could be from receiving helpful information and advice, test results and sometimes just being listened to by someone who understands.

Finding reassurance in the healthcare system

PT04 gained reassurance from the HCS keeping them informed. PT04 felt relief accessing same-day blood test results on the NHS app and recalled his first test post-pandemic confirming his feelings of being well. PT04 has always had positive healthcare experiences and trusts HCPs; as such, he gained reassurance from witnessing nurses in a clinical setting interacting normally when COVID-19 guidelines were still in place. His fear of how he could contract the COVID-19 virus was reduced and he felt less afraid, giving him a sense of freedom to go out more to church and the shops, if he wore a mask and washed his hands.

PT04 *"to get the results of your tests, usually it's the same day [bloods]... they've got an app where they put your results... of course, a sigh of relief... You feel it's OK to feel well." p.15*

PT04 *"They [nurses] were just acting normal. And then that's when I ask myself... why are we all afraid when some other people are working to help us, you know, they're interacting normally... And then I think... looks like it's [COVID] not as bad as we think...It actually gave me more freedom". p.14-15*

Finding reassurance elsewhere

PT01 also found reassurance from outside mainstream healthcare services, alongside PT02 and PT03. PT01 described the benefits of accessing private healthcare as being listened to, being kept informed and receiving quicker answers, in contrast to mainstream healthcare services which left her waiting and battling to be heard. PT03 similarly found reassurance from private healthcare services because of the difference in approach, i.e. being more

inquisitive and holistic and believable, having spent years being passed to different mainstream services over several years to get diagnosis and treatment.

PT03 *"I like to go to the chiropractor because they are very, for me, a bit more inquisitive and out of the box". p.27*

PT02 *"they [community group] realised that you know when we're not coming here, that it's really really difficult for people at home. So, they had a drop in [rather than cancel] and I came along to that." p.05*

PT01 *"That in itself, he's listening to you and actually gives you faith [private therapist]". P.21.*

Sub-theme 1.6: Prioritising what is important – taking calculated risks

People living with chronic diseases are aware of risks to their health, which was highlighted when the COVID-19 guidelines advised isolating, shielding and social distancing. Feeling well and able to go about daily life is not taken for granted, knowing the possibilities of suddenly becoming unwell due to diagnosed conditions or external factors like a virus. All participants spoke about living with MLTC as requiring constant adaptations. PT01 and PT02 were led by symptoms daily. PT03 has created strict routines around diet and exercise, walking many hours a day to absorb sunlight, and PT04 was adapting to a new kidney and unable to work due to a sight impairment. All participants navigated their way around what they needed to stay well, and different priorities presented in daily life, always considering their conditions and the risks associated with them.

Risk to self-whilst prioritising others

PT04 has two homes, one in Manchester and one in Zimbabwe. Having not seen his family for years due to his kidney transplant and the COVID-19 pandemic, he wanted to visit his unwell, elderly mother. He spoke about assessing his own health against the consequences of not seeing his mother driving his decision to travel overseas during the pandemic.

PT04 *"My mom has been in and out of hospital (Zimbabwe) and me, I'm here (UK) I'm able to walk after the operation. I'm OK, I'm feeling fine, right? Why not? What if she dies.... How am I going to cope?". p.10*

PT01 *"We have got a very active lifestyle. They have to say in all of this, we've travelled a lot, we've gone all over the place with this, but it's always a real push to do it." p.08*

Overcoming challenges for self-care

PT02 and PT03 assessed the risks to their own health when prioritising activities. PT03 believes sunlight helps his lupus and could not travel in the winter months due to COVID-19. He described taking the risk of having the vaccine, despite disagreeing with it, to fly to a hotter climate in 2022. PT02 battled with getting out of the house after COVID-19 because of a decline in her mental health due to her mental health support services being discontinued. With the help of a telephone group for six months, she managed to reintegrate into her community and attend a community group, she describes it as a "lifesaver".

PT03 *"I went away two years ago. That's part of the reason [had the vaccine] I had to be able to go and get through the airport [to get some sunshine to help the lupus]. p.30*

PT02 *"so through that [telephone befriending group] were on the phone with me probably about six months, maybe longer and then they told me [about a community group] ... I managed to come to that because I was having trouble getting out of the house... that was my lifesaver." p.04*

Theme 2.0: Effects of the COVID-19 pandemic on managing day-to-day life

All participants describe their own unique challenges when navigating their life around their conditions. Strategies to cope and manage before the pandemic were disrupted because of the pandemic and additional challenges required further adaptations to their daily life.

Sub-theme 2.1: Realising increased vulnerabilities caused by the COVID-19 disease

Some people living with MLTC were categorised as "vulnerable" during the pandemic and had specific guidance e.g. advised to shield to prevent contracting the COVID-19 virus and prioritised for the vaccine. The impact of these guidelines depended on many factors including the person's interpretation of them, the nature of the condition and how stable and well-managed their conditions were. The COVID-19 disease, gave the additional threat to "vulnerable" people, creating fear and worry over catching COVID-19.

Fearful of contracting the disease

PT04 describes a variety of situations where he experienced fear of contracting the disease. Firstly, if needing to attend hospital. Secondly, whilst travelling to see his unwell mother in Zimbabwe when he received a text to say he had been near someone with the virus on the plane. Thirdly, when receiving advice from the GP to take precautions and lastly, because he had heard of someone in his community dying from the disease after attending a check-up. Fortunately, PT04 never caught COVID-19 but he lived with the fear for over 2 years, despite following the advice.

PT04 *"[hospital] that was a no go area". p.11*

PT04 *"And then the next thing is I received a message that the person who was sitting next to you [on the plane] had tested COVID positive. And that was the scariest moment." p.09*

PT04 *"knowing my conditions and also advice from the doctors...I was one of the first people to make sure every time I leave the house, I take a mask". p.06*

Factors that can make it worse

PT03 expressed the COVID-19 vaccine had been detrimental to his health. He could not walk the same distances after having the vaccines. Walking is a crucial management technique for his condition; to keep weight down, improve fitness and gain exposure to sunlight. PT03 recalled years of difficulties getting his lupus and diabetes diagnoses and showed empathy for anyone in the early stages of chronic disease during COVID-19. He felt that if he had to go through the early stages of diagnosis during a pandemic, it would be terrible. Having found ways to manage his conditions, he feels he dealt with the increased vulnerabilities better.

PT03 *"And to be fair taking the vaccine, which I wish I'd never taken, to be fair. Definitely wish I'd never taken, particularly the 3rd one, the 3rd one has proper done me." p.29*

PT03 *"To be fair I am 10 years into it [diabetes] so its not a problem. As long as they give me repeat prescriptions, it's fine. Yeah. So just like, anyway, so it not like I'm a newbie...But I can appreciate how lots of people who were the newbie or undiagnosed who knows or not. So yeah, it would've been terrible." p.32*

Sub-theme 2.2: Value of maintaining meaningful connections; for self and others

PT01, PT02 and PT04 all described the value of meaningful connections with others, in their own unique way.

Finding purpose through helping others

PT04 reported finding a sense of purpose within his community through helping others practically and emotionally. He recognises it's in his gift to listen to others and offer help when he notices people are struggling or find ways to make their day better. He finds value for himself in listening to other people's stories and presenting this information to a local

council board to support the community wellbeing agenda. PT03 mentioned volunteering as a way of giving back has also helped her. She also uses poetry to write of her lived experience in the hope it will help others to speak-out and not suffer alone.

PT04 *"I've always been involved; there's just life after [name multiple community centres]. Yeah, so I make sure I'm free, if I'm not doing anything, I just pop in have a chat with people, you know.... I've got something in me. I like to listen to other people's stories... But most people, what I've discovered is there's a lot of isolation... They don't even have someone to just say good morning... How are you feeling today?" p.20-21*

PT03 *"By writing that book, I feel like my job is done and I think it makes a difference because I've met many women and men who have been through similar experiences. who don't have anywhere to go to, so they might hear about that book and pick up my book and and feel a bit of relief from it and just a bit of knowing that they're not on their own." p.08.*

Finding ways to stay connected during COVID-19

PT01 wanted to stay connected to the people she regularly walks with despite it becoming more difficult, she appreciates they are considerate of her need to rest or sometimes not be able to go. Knowing walking with them is available makes her feel like she is still connected. PT02 values two good friends, who throughout COVID would meet on a Friday for cheese toasties and a chat. PT04 mentioned putting his neighbor's bins out before the pandemic and continued to do it during the pandemic.

PT04 *"I take their bins out...and people have got different conditions. Some cannot even get out of the bed, you know, you go knocking at their doors, you know. She told me she's not feeling well" p.21*

PT02 *"..have got really good couple of good good bessie mates. Every Friday we sit still now and have a cheese toastie and a chat, put the world to rights, things like that." p.24*

PT01 *– just about the social network of walkers as well as social walkers. Yeah, they're awesome social walkers. You've got to be on the chair and sit there, you know, and, and*

basically look after me... it's been hampered the last 12 months because my knee is not very good." p.27

Sub-theme 2.3: A variety of situations leading to feelings of isolation

Two participants referred to one or more situations during COVID-19 that led to feeling isolated. The restrictions imposed during the pandemic meant reduced or no contact with healthcare services and other significant points of contact whilst adhering to the rules. Each participant described the importance of being connected to others and/or activities to help manage and cope with MLTC but when this mechanism was removed or restricted, the impact was feeling more isolated.

PT04 *"[airport hotel] it was total isolation; you just be stuck in your room. No you don't talk to anyone." p.08*

PT04 *"and then all the way, maybe two people, you won't see anybody, you won't meet anybody... ooh it was scary you know". p.13*

PT02 *"I was really isolated during COVID for lots of different reasons [mental health services and online support groups disturbed], but to live with what I've got is a daily thing and it's worrying each day really." p.02*

Sub-theme 2.4: Increased burden on others

Living with MLTC can have an impact on significant others having to accommodate daily adjustments. It can become the lifestyle of friends and family, having to adjust to providing day-to-day practical and emotional support. PT02 and PT04 were aware of the impact of their life on others as well as their own.

Trying to protect others

PT02 discussed the burden of her conditions on her family and decided to be selective on what she shares, so as not to increase the burden on them.

PT02 *"So not that they wouldn't be helpful or, you know, but you just don't want to burden them [family] with it." p.11*

Sharing with others

PT04, conversely was happy to share his situation with friends and family to share the experience with them.

PT04 *Make everybody at home you know. Got panic? Everybody panicked. Thinking You know, thinking more, maybe it just caught up with him, but lucky enough I was fine and then, uh, with the symptoms that they talk of, you know this sweating. …Ohh and it scary. " p.08*

Sub-theme 2.5: Seeking positives – finding different levels of gratitude

Despite the challenges COVID-19 created all the participants spoke of what they were grateful for relating to maintaining independence and feeling supported by healthcare services.

Grateful for Independence

All participants were grateful for their independence and the moments they experience when they are not held back by their conditions. PT02 compared herself to others who are less mobile and felt fortunate to have crutches to get about independently. PT03 was grateful to COVID-19 giving him a break from monitoring healthcare appointments and PT04 was grateful to be able to manage alone whilst managing multiple long-term conditions.

PT03 *"In some respects it [COVID-19] was great because you were left alone and not being monitored, which is kind of like, I had no problem with that at all, it was great". p.19*
PT04 *"I've no complaints, I've got no regrets. And I'm happy that at least I'm managing on my own." p.03*
PT02 *"I'm lucky, I can get round on my crutches. But there are people who are really, really struggling." p.20*

Grateful for health service information

PT04 expressed gratitude for mental health services restarting and describes the timing as being a lifesaver, as she was feeling herself "going under". PT04 was grateful for the connected healthcare services in his community giving him access to care within the community.

PT02 *"[when mental health services started again] literally when I was getting them phone calls, it was and literally a lifesaver, you know because you can feel yourself going under kind of things and I needed something to happen." p.18*
PT04 *"You know, because of information now, access to information I have discovered that ohh instead of me booking with the GP, they do walk-in jab here." p.17*

Theme 3.0: Trust and faith in healthcare services at risk

Patient experience of healthcare is central to building trust and faith in the HCP and the system. The sub-themes address the inconsistent experiences relating to the system and the HCP delivering the service, revealing the impact of the system not meeting their complex needs. The sub-themes are focused on patient centred care and HCP unable to help resulting in on-going battles with a system that does not work and a lack of trust and faith.

Sub-theme 3.1: On-going scepticism: individual needs are not considered

Three participants had strong opinions relating to healthcare services and their needs. Three participants described a system that does not allow HCPs to look at all needs during appointments but focus on one issue at a time. Throughout the journey of diagnosis to treatment, they suffered inconsistencies in service delivery, also commenting upon side effects of medication to treat one problem with no consideration of the impact on other conditions or how they themselves wish to manage their MLTC.

The system structure hinders not helps

PT01 and PT02 mentioned not being able to discuss multiple needs in one single appointment, meaning the appointment is only addressing one single issue. PT01 worked in the health service before retirement and knew of some HCP's that were able to help her manage some symptoms. She also knew how to push to get what she needed and felt that without such knowledge and connections she could not have predicted what would have happened to her. PT03 described being "in the system" as not being as good as some people who are not in the system may think, after spending several years battling conflicting medical advice and being given the wrong medication.

PT02 *"and sometimes they just want one, one issue at a time...but it is not telling him the truth about your whole body... more than one thing at a time is happening." p.17-18*

PT03 *"conversations I've with a lot of people, family and friends, all the rest of it. Once you're in the NHS system and you understand it, it's very different to people who aren't in the system who say the NHS is great." p.06*

PT01 *"And seeing somebody who you've been referred to by the NHS, yeah, just for that [one thing]. And you can't see them for anything else. But that is just a nonsense, isn't it really." p.19*

PT01 *"I do wonder how long have gone on if I hadn't have sorted myself out. And I do wonder sometimes if maybe I hadn't kept pushing maybe, you know, what would have happened." p.08*

Conversely, PT04 had no complaints about the healthcare he received. He mentioned being well informed and described how services are connected. He discussed several scenarios where he felt heard and his needs accommodated.

PT04 *"So the results, whatever they get, you know, they share with the diabetes clinic. So, to make sure. So, if there's a false alarm, then they need to contact me, OK, and say. They've given you an appointment about ABCD. Yeah. So, I have to go to diabetes. Yeah. So, whatever they get there, they also share with them." p.17*

PT04 *"I've been well informed, well informed and nowadays, I think they've also tried, you know, there are some certain eye screens that we no longer need to go to the hospital, yeah, we, we go in and around here. Around [football] stadiums for Cancer screening for this and that. So, because our health, as in my health, is monitored by my GP. Yeah, right. So, he's [GP] the one who directs me." p.18*

Effects of medicine on self-management techniques

Creating a routine of self-management is just as important to someone living with MLTC as accessing healthcare services. They become experts in their own condition knowing what works and what doesn't work. PT03 walked thousands of steps a day to stay healthy, but since having the vaccine had not managed to maintain the level of fitness he had before. He regretted having the COVID-19 vaccinations and believed the vaccine would not have got Food and Drug Administration (FDA) approval. PT01 had been offered a variety of medications that made her unwell. Firstly, multiple types of statins, despite informing her HCP, make her unwell. Secondly, offered anti-coagulants due to family history, which were incompatible with a magnesium supplement she was taking to help her joint pain. She was aware that she couldn't take both and therefore had to choose between preventing a possible genetic condition and managing her joint pain. She was also offered medication that had previously made her unwell without being seen by an HCP.

PT03 *"[vaccines], the second one... That did it for me for probably four months in terms of walking. To the point I had the booster one... I would easy do 35-40 thousand steps a day... it knocked at least 10,000 off, I just didn't have the energy... But that to me was a big impact because I'm not getting that in, it's a negative and negative impacts on well-being, frustration of I could do it before. So, I linked it to that... I put a good stone on after the third one..." p.20*

PT01 *"She said you need to go on [anticoagulants]... so I can't really say, you know, I don't have it, I'm not down for that today. But sometimes, I do feel like all they do is try and make you." p.31*

PT01 *"and I've tried three different sorts of statins and, it makes me worse, so you're not going to go through with that." p.17*

Sub-theme 3.2: The fight for patient-centered pathways for MLTC continues

Participants with more established conditions and stable symptom management described positive experiences of receiving repeat prescriptions and regular tests pre- and post-pandemic.

In contrast, when waiting for treatment or awaiting a diagnosis and undergoing continual trials and tests, the experience was negative. These experiences highlight a gap in care provision when there is no clear pathway to receiving information, answers, and adequate care to help manage.

When there is a clear pathway and/or established treatment accessing healthcare services can be a good experience

PT04 has experienced positive and seamless care for all three conditions; diabetes type 1, sight impairment and kidney failure. He described integrated care services that monitor his health and communicate with each other when further tests are needed, as well as being able to access testing and screening in the community. PT01 described a positive experience of an acute problem as "fantastic", when her cataract surgery was done quickly.

PT04 *"that's where we go for my transplant checks... for all my checkups, even for diabetes, yeah, even for eye screening and all those things" p.13*

PT01 *"I've just had cataract... know what I've got, in one eye, and it was all fixed up in a week, you know, and I could have had the operation privately within a week.... and just went, fantastic." p.13-14*

Where there aren't clear pathways accessing healthcare is not a good experience

A very different experience was described by PT01 and PT02 in relation to osteoarthrosis and joint pain. PT02was angry and frustrated that there was no help whilst waiting for a knee operation, as this was adding to her mental health problems. She was worried about kidney problems from pain medication and the risk of having more falls.

PT01 felt like no-one listens in the mainstream HCS, and you have to fight for what you want. She compared it to private healthcare and the benefits she received from being listened to and consideration of all symptoms. She described difficulties associated with seeing a different HCP every time and no continuity of care leading to an inadequate diagnosis. Having spent her career in healthcare, she believed there are no adequate pathways for chronic pain and the elderly.

PT02 *"I feel a bit angry and frustrated, although I keep saying I understand. I think there should be something that helps people with conditions like myself, and to be able to, you know, it adds to the mental health problems, things like that because you worry all the time." p.13*

PT01 *"in the healthcare system as I see it, for more things you have to fight for what you want and you have to charge of your health care yourself, which from, you know working in the health service most of your life feels a bit like a slap in the face." p.13*

PT01 *"My GP, there is no coordination. No, I just tried a couple of times to make him listen. I don't go very often because you sort of lose faith." p.22*

PT01 *"If you have a car accident, if you have a brain tumor, you know, you wouldn't wish for a better service... But the chronic pain management, the care of the elderly is just rubbish." p.35*

Sub-theme 3.3: Variations of feelings towards healthcare professionals

Three of the participants expressed empathy for healthcare professionals. PT04 saw them as other human beings with their own problems. PT01 and PT02 felt supportive of them doing their best whilst dealing with COVID-19 and appreciate they have on-going battles with system demands and inefficiencies. However, PT03 does not show empathy and believes they are just doing the job like any other emergency service.

Empathy for healthcare workers

PT04 *"I don't want to complain because there's, there's no need for me, you know, and the people who are trying to help me, they are also human beings. They've got their own issues as well... so overall my experience with COVID, I don't have any complaints." p.17*

PT02 *"She was saying it might be quicker to go to the walk-in... to sit there for hours and hours, I just can't do it... she's trying to help me and I understand that, but in a way its passing it to us, passing the buck." p.09*

PT02 *"I feel really, I'm really supportive when it comes to anybody from the NHS because I realised what a difficult battle they've had to face and the fact that they have to ask for more pay and footballers are getting however many thousands and people who are really helping out there." p.06*

PT01 *"I went to see the nurse; I went to see the consultant at the GP and then she asked me to go back again and all I got was a prescription for two tablets. Then that could have been done at the same time. She acknowledged that that was..." p.15*

A lack of empathy

PT03 *"Because it's a virus and they're doing their jobs. Good, well or badly but just because they keep turning up for work every day in COVID. They don't stand up clapping the army for doing their job, or the police for doing their job." p.17*

Sub-theme 3.4: Varying ability to get medication

Living with MLTC often requires regular access to medication. PT02, PT03 and PT04 access regular prescriptions to manage their diabetes conditions, and PT04 has a regular prescription for his kidney transplant. However, where there is no diagnosis, this was not possible without additional complications such as attending hospital. In these circumstances, access to controlled same-day medications has become difficult.

No issues getting medication needed

PT03 and PT04 were informed they could still access their prescriptions throughout the COVID-19 pandemic and PT04 was informed during the pandemic that he could access more medication in the event of a pharmacy closure.

PT04 *"because we have been advised here [UK] the pharmacies, they're closing on everyone, so they gave us 3 months medication...so I had lots of medication in the house" p.08*

PT03 *"[during covid] the only thing that you had to engage with was repeat prescriptions... That was the entire COVID conversation with the GPs, of how to get your prescription." p.27*

Struggled to get medication needed

In contrast, due to specific medication requiring GP prescription, PT02 was left in pain. PT01 describes having nowhere to go to get help, as her condition had no diagnosis and, therefore, no management plan in place.

PT02 *"you can't see the GP in time, so you have more times that you have been going through that pain because you can't access him to get the drugs that you need." p.10*

Theme 4.0: The lasting effects

Despite the pandemic being declared over, there are significant and lasting effects described by the participants. The sub-themes address the immediate impact of the pandemic on their physical and mental wellbeing and the future effects of the HCS for themselves, others and future generations.

Sub-theme 4.1 Lasting impact of COVID-19

Two participants described how COVID-19 caused lasting effects that they were still experiencing; and three participants discussed how they expect these effects to continue in the future.

Immediate impact

Despite accepting the pandemic's response to healthcare services and his overall adherence to guidelines, PT04 describes entering healthcare settings as still scary for others having previously described moments when he too was scared to enter a clinical setting. He stops short of acknowledging that he too may have lingering fears. PT03 apportions not being able to walk as far to be a lasting impact of the COVID-19 vaccine. He further mentions being labelled an "anti-vaxxer" if he voiced his view.

PT04 *"And also, appointment from the GP were starting to be available, you know, yeah, you know, people were scared still to go anyway." p.16*

PT03 *"from COVID, even now, I still don't get the number in [steps] that I was getting. I don't have the energy" p.34*

PT03 *"And, as more time goes on, you're not allowed to say anything negative because you are then anti vax or whatever, but there's more and more speculation about what these things do...If they try to push those drugs now, they'd never get FDA approval. But given the scenario they got approval." p.31*

The future impact

PT01, PT02 and PT03 all considered the future. PT03 spoke about the lack of contact from the GP and Consultant to manage lupus post-COVID and wondered if they will eventually make contact to reignite the previous conversations and arrangements around medication. He has reconsidered his response to future conversations from a perspective of reduced trust and faith in the services. PT01 and PT02 worried that their future care needs won't be met due to the increased burden on the services caused by COVID-19 and question what their end of life will be like.

PT03 *"even if for some reason they push me back to the consultants in the next 12 months, the next 12 days, to have the blood test from the consultant again. I would be like it's taken you months and I'm still not taking your pills." p.21*
PT02 *"It is quite fearful really, to think what it's gonna be like in the end" p.06*
PT01 *"if someone told me I'm gonna be taking more years. I'm going no thank you. Why live like this." p.36*

Sub-theme 4.2 Can't see healthcare services getting any better

PT01, PT02, and PT03 have strong opinions about the HCS and explain why they believe the situation is the way it is for PLwMLTC to provide their views on the national picture now and in the future.

Strong opinions about the system

Three participants highlighted systemic issues that create negative experiences when accessing healthcare. PT01 referred to her experience working in healthcare and reflects that the issues she encountered were present over 40 years ago. She believes the healthcare service has become about making money. PT03 believed the system is poorly

managed, wastes money and that this was reflected in his negative experiences of being "stuck" in the system.

PT03 *"Once you're in, it's a battle to get out... I'll see you're here and then you go away and whatever happens will happen, and I'm not due to see you again until here and then that's how the system government... in the system that is used to tick a box." p.06*

PT01 *"they [patients] go into chronic management phase and it's when it goes into that it all goes wrong. You know I'm interested and working in the NHS for like 40 years, I did, I can, I could always see that." p.30*

PT01 *"I think it's a money thing right, I think every time you go back they get £135 or whatever it is." p.23*

Worry for self and others caused by reduced trust and faith in healthcare services

PT01 and PT02 worried about their health getting worse for themselves and others through not having access to the care they need due to system issues and increasing demand. They have no trust and faith that it will get better within their lifetime. P

PT02 *" you worry that things might get worse before they get better because of the way you are." p.13*

PT02 *"I think it's getting worse. It's gradually getting worse. I see people I know getting worse, I listen to people's stories, and you know, they're having things cancelled left, right and centre, people who actually I'm lucky, I can get round on my crutches. But there are people who are really, really struggling." p.20*

PT02 *"I'm not sure it's gonna happen in my lifetime. I'm hoping for my grandchildren things will get better." p.07*

PT01 *"I think that I think there's a lot of people who are like me who are. Struggling at home with pain and different things on that. So, I think I think some you know, the pain services need to be holistic, and I think and they need to be obviously much better funded…but I guess nobody ever will really." p.32.*

7.0 Discussion

This study set out to explore the lived experience of PLwMLTC and the impact the COVID-19 pandemic has had on their access to healthcare. The aim was to gain an understanding of what it is like to live with MLTC from the patient perspective and dive deep into their experiences and the meaning they give to them.

The researcher's experience within the healthcare sector, hearing the stories of PLwMLTC struggling to get the care they need and the resulting deterioration of health, wellbeing and QoL were the drivers for this study. Working in community healthcare brought an awareness of LTC management as an unmet need; reinforced by firsthand accounts of the challenges PLwMLTC face just to live their life, and the physical and mental health benefits they received from community and lifestyle interventions.

The chosen methodology of semi-structured interviews and rigorous IPA analysis, described earlier in this study, enabled the researcher to gain deep insights into the lived experiences of the participants and identify areas of commonality and difference. The purposive selection of four participants brought a variety of conditions, ages and backgrounds to the study to unearth commonalities between their experiences of accessing healthcare, rather than focusing on condition-specific experiences. Limiting the study to four participants, all of whom live in the north-west of England, enabled the researcher to explore their experiences in depth, but also limits the scope for generalisation of the findings. Participant experiences in this discussion have therefore been compared alongside existing literature reviews (pre and post COVID-19), as well as referencing the state of the UK healthcare system to provide explanations as to why certain experiences may occur.

This section includes some *later reflections* written after the initial submission of the thesis, offering a more developed and critical perspective on the analysis. These reflections are indicated throughout the text and build on the original discussion to provide deeper insight into the interpretation of findings and their implications.

Later Reflections

Reflections on the methodology, particularly the literature reviews and participant cohort, highlight the need for more inclusive, patient-centred research that reflects the complexity of PLwMLTC. Findings from this study show that, despite differences in individual circumstances, patients encounter common systemic barriers that remain underexplored across conditions. Recognising these gaps not only strengthens the justification for this study but also points towards future research that embraces diversity, focuses on shared experiences, and investigates how healthcare systems can adapt to meet the needs of this growing population. This provides a strong foundation for the final discussion on implications for policy, practice, and future research.

As a novice researcher, conducting a semi-systematic literature review across two time periods was both valuable and challenging. Dividing the review into pre- and post-pandemic phases provided important context, showing how COVID-19 compounded existing issues and introduced new challenges for PLwMLTC accessing care. Themes emerged organically without pre-determined criteria, allowing meaningful comparison of how healthcare delivery and patient experience changed over time.

However, this approach added complexity. Conducting two reviews led to a more fragmented synthesis. A single review spanning the whole timeframe might have produced clearer, more cohesive findings and reduced repetition. Furthermore, using the first review to shape the second may have influenced interpretation, potentially limited new themes and introducing bias.

Focusing on two distinct periods also reflected an implicit assumption of a “step change” in healthcare experiences. While this structure was useful, it risked oversimplifying continuous trends and overstating the pandemic’s impact. Many issues highlighted post-pandemic, such as long waiting times, fragmented care, and limited patient-centred approaches were already present but compounded due to the pandemic.

Despite these limitations, the approach was appropriate within the project’s time constraints and helped identify gaps between the two periods. With more time, a broader,

combined review could have deepened the analysis and provided a richer understanding of patient experiences and service delivery.

Developing themes iteratively provided flexibility but introduced some subjectivity shaped by my prior knowledge. In future, creating a more formal analytical framework or involving supervisory input could reduce this and enhance rigour.

Overall, the process highlighted the importance of reflexivity, methodological transparency, and adaptability. While not fully systematic, the review strengthened research skills in evidence searching, synthesis, and thematic analysis. Most importantly, it demonstrated how methodological choices shape findings and highlighted the potential value of a single, comprehensive review to capture both continuity and change in healthcare experiences.

The participant cohort in this study illustrates these gaps clearly. The sample was small and heterogeneous, with differences in age, background, and the types of conditions participants lived with. On one hand, this diversity could be viewed as a limitation because it complicates direct comparisons and may limit the generalisability of findings. On the other hand, it reflects the reality of the MLTC population, where diversity is the norm rather than the exception. Including participants with varied circumstances aligns with the aim of the study; to explore shared experiences across a group that met the inclusion criteria and did not have defined care pathways.

Despite their differences, most participants reported significant similar challenges in accessing healthcare, obtaining diagnoses, and receiving coordinating care before and after the pandemic. These shared experiences demonstrate that systemic barriers persist across patient groups and are not confined to specific conditions or demographics. This reinforces a key gap highlighted in the literature: current healthcare systems are still designed around single-condition models and are inadequate to meet the complex, intersecting needs of PLwMLTC.

Evaluating this alongside the literature review also raises questions about the limitations of existing research. Many studies fall short of including diversity within the MLTC

population, either by excluding complex cases or by limiting the exploration of common themes across varied patient experiences for specific conditions. By including rather than excluding heterogeneity, this study begins to address that gap and shows that shared experiences can be identified even within diverse populations. These findings suggest that future research should continue to adopt inclusive approaches and investigate the systemic issues that affect PLwMLTC, rather than focusing solely on condition specific care models.

This process has also deepened my understanding of how methodological choices influence the contribution research can make to existing knowledge. Working with a disparate cohort taught me that diversity is not only a challenge but also an opportunity; one that can generate more nuanced insights into how healthcare systems function in practice and the impact they have on patients. It also highlighted the importance of designing research that reflects the real-world complexity of patient experiences, something the current literature is lacking.

Original Discussion

Sections 1 and 2 position the current state of HCS and unexpectedly highlighted decades of NHS strategies that recognised LTC and MLTC management as an increasing burden on health services. (Department of Health, 2013, NHS England, 2019, NHS England 2023). Despite this knowledge little has been done to improve the service's ability to cope with the growing and complex demands of MLTC. The unexpected pandemic has further compounded this burden, leading to 15 million people in the UK, living with 2 or more LTCs (Chan and Horne, 2021; McCarthy et al., 2021; Imison, 2021). The main impact on PLwMLTC is reduced QoL often including hidden symptoms like fatigue and chronic pain and people are getting unwell younger due to known risk factors. This raises the question; why have we known about this for decades and done little about it?

The main finding was the continuity of themes between the participant experiences within the literature reviews and this study. This is discussed in the following paragraphs.

The literature reviews discovered very little research centred around MLTC. Most focused on a single condition or a particular part of the system. Is it because the system focuses on

single conditions that the research follows suit; or could it be that it is a lot easier to measure and report on single conditions and the pathways used to treat them?

Common themes within the pre-pandemic literature review and this study were participants voicing that they did not have a healthcare system that meets their needs (PT01, PT02, PT03). Participants in the literature were saying continuity of HCP relationships, system coordination, being listened to and mutual acknowledgement of conditions are important to receiving the right care and coping in their daily lives, which this study's findings support. (Adams et al., 2019, Potter et al., 2018 and Tallow and Ogden., 2019). Potter highlights the role healthcare systems *"may play in either helping or hindering people's efforts to cope with chronic illness"*, proposing *"coping is a social process"* and there are many other factors that play vital roles in PLwLTC living well. Tallow and Ogden (2019) emphasises the HCP role as being able to "*enhance and undermine*" experiences drawing on themes of *"failure"* and *"powerlessness"* leaving patients *"feeling they have no voice".* Whilst Adams et al., 2019, highlights patients find *"health care systems complicated."*

In addition, consistent quality of care delivered by the HCP is important. This study found that failure to deliver the right care affects patient trust in healthcare services (PT01, PT02, PT03). Spiers et al. (2014), supports Tallow's theory about the significance of the HCP role, focusing on the training of HCP to offer the right care, recognising "*more training given*" to HCP so that *"more could be done to support them [patients] more fully" because people have "a very mixed experience of multi-disciplinary teams and treatments"* which are needed to manage LTC and MLTC. Talbot et al. (2021) fully supports the idea that HCP need to understand LTC and how to deliver patient-centred care to address whole-person needs and develop patient trust, where it is currently getting lost. *"Interventions from GPs would be welcome if conducted in a sensitive, non-judgmental manner and based on sound evidence about what works"*. (Talbot et al., 2021, p.1)

Patients want understandable and actionable information from HCPs who have time to listen to their needs and tailor care around those needs, facilitated by clear communication

(Arnold et al., 2022; Fu et al., 2016; Adams et al., 2019; Karadag et al., 2022). Arnold et al. (2022) address the need for HCP to be *"aware"* and *"knowledgeable"* about conditions and *"should avoid language which is blaming or minimising of patients' experiences"*. However, this is only useful if there are available options to help.

Pal et al. (2018) discuss outdated services, focusing on medical management and, patient information and education that are failing to meet the more complex needs of patients. He addresses some of the unmet needs described by participants in this study (PT01, PT02, PT03) raising the importance of *"placing an emphasis on emotional and role management, being available at all times, having up-to-date evidence-based guidance for patients, and providing access to peer-generated and professional advice."* (Pal et al., 2018, p.1).

Brand and Pollock (2018), recognise PLwLTC need to attend a variety of healthcare settings and address the need to meet patient expectations depending on the service being provided. *"The differences between primary and secondary care in terms of patient expectation and experience should be recognised to ensure effective models of care are implemented which both meet patient expectations and improve their experience of care."*

Participants in this thesis and the literature mostly recognise the importance of self-help to manage their condition to improve their QoL. (Karadag et al., 2022, O'Neill et al., 2022, Talbot et al., 2021) discuss varying levels of patient's engagement and adherence. This signifies the need for services and others to support PLwLTC to self-help in a way that is effective and meaningful to them. When patients are engaged in their own self-help, taking the role of investigator to find ways to cope and manage e.g. changing diet, exercising, natural remedies and therapies, support improving QoL (PT01, PT02, PT03, PT04). Karadag et al., 2022, believes *"At the point of diagnosis, patients would benefit from information about [their condition], as well as how it may impact day to day life from doctors".*

This study illuminates the specific effects of waiting when it comes to receiving healthcare (Theme one, p.70). The pandemic disrupted services leading to cancelled and/or postponed services and increased backlogs, showing how much PLwMLTC rely on having

access to healthcare services for reassurances, answers, medication, diagnosis and treatment, to manage their conditions and reduce feelings of fear and worry (PT01, PT02, PT04).

This study highlights the significance of *where* the participant is on their diagnosis to treatment journey. The disruption caused by the pandemic, leading to the cancellation of HCS had a bigger impact on PT01, who had no diagnosis and was seeking answers and treatment, as opposed to PT03 and PT04 who had more established and routine condition management. However, all participants still seek reassurances that their condition was being managed, and the absence of tests and checkups left them feeling uncertain about their health. All participants felt abandoned during the pandemic and had increased worry.

In the pre pandemic literature (Talbot, et al., 2021, Potter et al., 2018) and post pandemic literature (Fisher et al. 2021, Ambrosi et al., 2024) and this study (PT01, PT02), participants continuously highlight there not being anywhere specific to go to get the care they need and want. Post-pandemic all participants discuss that it has become much harder to get appointments and waiting lists are longer (Stamm et al., 2022) leading to further deterioration in their physical and mental health, leading to feeling "scared" (PT02), *"why live like this"* (PT01) and increased scepticism about the system (PT03).

PLwMLTC describe managing their health as being part of everyday life (Theme 2 p.80). The pandemic compounded these struggles and added increased vulnerabilities to daily life; fear of catching COVID-19 (PT04), feelings of isolation through *"shielding"* (PT02) as well as the need for further adaptations to everyday life (PT01, PT03), for example; keeping social connections, maintaining physical activity and managing the burden that is imposed on significant people in their life (Fisher et al., 2021, Ambrosi et al., 2024, Morris et al., 2022). Fisher et al. (2021, p.1) looks closely at "the impact of the pandemic on mental health and wellbeing of people living with physical health conditions" and concludes there needs to be *"focus on how best to provide practical and social support to people living with LTCs during a pandemic, particularly if they have to shield or isolate"*. Stamm et al. (2022, p.1) calls for *"care redesign after the pandemic"* and confirms the importance of patient

engagement in healthcare *"since preferences and personal meaning drives behaviour and could be the foundations for targeted interventions, they must be considered in all groups to increase society's resilience as a whole".* Morris et al. (2022) highlights inequalities in relation to *"deployment of important resources"* recognising *"resilience was common in people with LTCs, this was sometimes at detrimental cost to themselves".*

Remaining independent is essential to maintaining QoL (Fisher et al., 2021). However, the pandemic categorised people into *"vulnerable"* and *"high risk"* groups, without clear guidance or advice to what that means for them specifically. Careful consideration needs to be made when labelling people to ensure the advice is both *"feasible and tolerable"* (Fisher et al., 2021). This would help people to create their own self-protection and management strategies providing some reassurance to their decision-making when going about their life, as evidenced by participants in this thesis (PT02, PT04).

This study shows that self-management is a significant part of living with MLTC. Developing self-care strategies and adopting them into everyday life becomes a form of healthcare to PLwMLTC. Coping and managing is a way of life, as a result PLwMLTC want to understand their conditions and be informed about choices that will help. Living with MLTC is complex as it affects every part of life leading to patients becoming experts in their own conditions; what works, what doesn't, preferences and needs. In many ways, they create their own person-centred care that would be helpful for HCPs to understand if they had the time and tools to listen and apply this knowledge to co-create meaningful care plans.

Self-management strategies support some of the patient's needs in the absence of the system routinely failing to fulfil them. A cause of this appears to be rooted in the single appointments for single conditions framework of the NHS. The time limited system does not allow HCP to take the time required meet all patient needs, resulting in multiple visits and time taken up repeating complex needs to a different HCP at each appointment. The system is potentially creating its own demand for services by not dealing with the issues in one appointment and subsequently, driving multiple visits.

The healthcare system is itself, creating a lack of trust and faith in services (Theme 3, p.85), evidenced by the varied and inconsistent participant experiences of accessing HCS. (Taylor et al., 2025, p.05).

PLwMLTC throughout this study specifically discuss the barriers to healthcare access causing reduced trust, faith and dissatisfaction; hard to get routine appointments (PT01, PT02, PT03, PT04), calling for same day appointments being a lottery (PT02) and hospitals not being the places for PLwMLTC to go (PT01). The participants experience further dissatisfaction and challenges to receiving quality and meaningful care, including; trial and error medication (PT03), side-effects of medications (PT02 and PT03), contradictory HCP advice (PT01 and PT03), falling through the cracks of poor system coordination (PT01, PT02, PT03), no follow-ups or delayed follow-ups (PT01, PT02, PT03) and longer waiting lists (PT01, PT02).

The post-pandemic literature further highlights the pandemic-led disruptions to HCS and the need for PLwMLTC and LTC to adapt their already challenging lifestyle to manage the disruption; managing and coping with their daily life, staying connected and managing their reliance on others (Ambrosio et al., 2024, Morris et al., 2022, Rowlands et al., 2023). The further impact of longer waiting lists and no definite date in sight causing additional *"uncertainty"* and the need to deploy *"tactics"* to cope and reduce worry (Morris et al., 2022). These experiences are consistent with the findings in this study so far as PLwMLTC have worsened physical and mental health and there is no immediate resolution.

These findings show *continuity* as a key component to what matters to PLwMLTC pre and post pandemic. The withdrawal of services because of the pandemic has brought these to the forefront, presenting opportunities and key considerations for service improvements.

It is not all doom and gloom. The participants in this study have a desire to direct their own healthcare. If they can acquire the right information, help and support from the HCS, they will take charge and feel reassured and confident the service is providing some help, subsequently supporting their health and wellbeing in a positive way.

There are examples in the literature and in this study's findings, where the healthcare system does get it right (PT04). These include examples of integrated care, providing useful information and communication at the right time, and increasing access to care within the community (PT04) or via technology (Robert et al., 2024). These all contribute to positive patient experiences and as a result, generate more trust and faith in the system.

One of the most striking findings of this study is the impact on the health and wellbeing of the participants in relation to waiting for the right care and support. The pandemic has delayed getting the right care, to the right people, at the right time and PT01, PT02 and PT03 are concerned with the lasting effects of the pandemic, now and in the future (Theme 4, p.92).

Later Reflections

Post-research reflection and critical analysis revealed that condensing and refining the themes and sub-themes could have provided a more meaningful and in-depth interpretation of the data. A revised GET analysis removed around one-third of the original quotes and merged several sub-themes (see Appendix 8A). For example, combining themes around isolation, burden, and resilience highlighted the tension between increased vulnerabilities and the need to adapt.

Reducing and reorganising the thematic structure would have allowed for deeper exploration of key issues, including managing uncertainty, self-management, worsening symptoms, isolation, burden, resilience, and the erosion of trust in healthcare services. This sharper focus would have supported a more critical analysis of how the COVID-19 pandemic shaped the experiences of PLwMLTC and how these experiences are influenced by wider systemic challenges. It would also have enabled closer examination of how feelings of isolation and burden intersect with resilience, and how these dynamics affect patients' trust in healthcare systems.

Such refinement would have strengthened the discussion by linking individual experiences more clearly to broader structural issues, including service disruption, fragmented care, and patient-centred care gaps. For instance, analysing the erosion of trust in greater depth might reveal how repeated barriers and inconsistent support shape patient behaviour, potentially contributing to delayed help-seeking or disengagement. Similarly, exploring the relationship between burden, resilience, and self-management could provide richer insight into how patients adapt or struggle to adapt within under-resourced healthcare systems.

Sharpening the analysis also reveals how certain themes were shared yet experienced differently across participants. While uncertainty and increased self-management affected everyone, the extent of worsening symptoms, isolation, burden, and resilience varied significantly, reflecting differences in individual circumstances. These disparities highlight how lived experiences are influenced by factors such as access to resources, motivation, personal relationships, and interactions with healthcare services.

Overall, refining the thematic framework would not have altered the core findings but would have enhanced the depth of interpretation. It could also have strengthened the study's contribution by offering a more nuanced explanation of how PLwMLTC navigate healthcare systems not designed to meet their complex needs, and by highlighting the interplay between shared challenges and individual's unique characteristics and circumstances.

Original discussion

The UK has a new government that has declared the NHS as "*broken*" and we await the imminent release of the 2025 plan to fix it. Will the plan include any consideration of the factors relating to PLwMLTC? Will it be mainly concerned with inputs, outputs or outcomes? Will it recognise the efficiency benefits of looking at the "whole person"? Will it address immediate actions that can be taken to deal with the issues PLwMLTC face now?

Whilst waiting for the government to fix the *"broken"* service, what care is being provided for 15 million people, 1 in 4 of the adult population, who need care and cannot get it? We will never provide a service adequate for PLwMLTC whilst we have a system that is not

designed to deal with the biggest challenge faced by healthcare in decades. A different approach is required to simultaneously address immediate and future needs to prevent 15million people with MLTC and 7million people on waiting lists experiencing deterioration of mental and physical health and reduced QoL. This will require an evidence-based approach and efficient ways of providing the right care, at the right time for PLwMLTC, which takes account of the issues raised in this study.

PLwMLTC tend to be over 40 years old. Most are over 60 years old and living with reduced QoL, fully aware the system cannot meet all their needs. They worry what their remaining years will be like while healthcare services attempt to reform to deal with this growing problem. There is a clear danger that in 20 years' time the UK will be in a worse situation due to an aging population, risk factors, retiring later in life and PLwMLTC whose health continues to deteriorate – unless significant steps are taken to develop the capacity and capability to provide better patient centred healthcare services.

A participant in this study raises a valid question: *"Will it get better in my lifetime?"*

7.1 Strengths and Limitations

A key strength of IPA qualitative studies is allowing a deep dive into lived experiences to understand the meaning of significant events to an individual. The interviews conducted during this study elicited detailed descriptions of experiences and captured unique perspectives would not emerge in quantitative methodologies. Although the sample size is small and all participants live in the North-West of England, there are clear connections between participants' experiences that can inform national policy and delivery improvements, particularly relating to patient-centred care.

Whilst the sample-size may limit the scope for generalisation, the close engagement with the participants has produced rich data and offers valuable insights that can help to improve healthcare access for PLwMLTC. The rigour required for IPA is time consuming, but if used collectively across multiple areas and systems, this type of qualitative research

can guide improvements in a meaningful, insightful and actionable way; often where healthcare policy completely misses the point.

The diversity within this sample has given strength to the study, highlighting the importance of different characteristics and preferences being considered when designing patient-centred care and tackling the complex needs of PLwMLTC.

The study has generated deep insight into what the participants want and need from a national HCS which can be found in the next section.

It is acknowledged that the researcher's previous experience working in the healthcare sector, specifically relating to long-term condition management, may have influenced the study by seeking to identify and address barriers to healthcare for PLwMLTC. Using semi-structured interviews helped to ensure the participants were describing their own events in their own way, as opposed to answering leading questions. To mitigate this, the interview guide was critically reviewed by a PhD student that had used IPA and the supervisory panel to assess any assumptions. No changes were required.

Later reflections

The interpretative methodology could have been strengthened to reduce potential researcher bias. Bracketing bias is a crucial element of phenomenological research, as it seeks to ensure that participants lived experiences are represented authentically and free from researcher preconceptions (Tufford and Newman, 2012, p. 81). Within this study, efforts were made to acknowledge and mitigate potential bias through careful research design, open-ended questioning during interviews, and participant-led narratives. Techniques such as using non-leading prompts ("Can you tell me more about that?"; "How did that make you feel?") encouraged participants to construct meaning in their own words, thereby reducing the influence of researcher assumptions during data collection.

However, the process of bracketing could have been strengthened by incorporating additional reflexive strategies and greater transparency regarding the researcher's positioning. Including a section that explicitly detailed my expectations and preconceptions prior to data collection, as suggested by Chan, Fung and Chien, 2013, p. 3, would have provided valuable insight into how personal experiences or professional background may have shaped the research lens. Similarly, having a peer or supervisor interview the researcher about personal assumptions and anticipated findings could have served as an external check, illuminating unconscious biases that may not have been recognised through self-reflection alone.

Despite ensuring that after each participant the analysis process commenced immediately, so to keep it current and fresh in the researcher's mind, during data collection and analysis, the use of reflexive field notes immediately after interviews could have further enhanced awareness of bias. Recording reflections specifically on what surprised or did not surprise me, as recommended by Ahern (1999, p. 408), would have provided a structured means to examine the impact of my reactions and expectations on interpretation. Instead, these notes, found in Appendix 9 are standalone. Additionally, conducting member checking, such as presenting Patient Experience Tables (PETs) back to participants for confirmation of accuracy, would have ensured that findings remained faithful to the participants' intended meanings and reduced interpretative distortion (Lincoln and Guba, 1985, p. 290).

Failure to adequately bracket bias poses significant methodological and ethical challenges. Without explicit procedures for recognising and managing preconceptions, there is a risk that the researcher's worldview will shape the data, undermining the study's credibility and authenticity (Van Manen, 1990, p. 182). In phenomenology, this is particularly problematic, as the aim is to reveal the essence of lived experience; an aim that can only be achieved when the researcher adopts a stance of openness and reflexivity. Embedding systematic bracketing strategies not only demonstrates methodological rigour but also assures readers that the integrity of participants' voices has been preserved and that findings emerge from the data rather than from the researcher's prior assumptions (Finlay, 2008, p. 7).

Original text

The semi-systematic literature review mainly produced articles focused on PLwLTC and lacks studies that address the needs of PLwMLTC from the patient perspective. The pre-COVID-19 search was limited to the MMU databases, and the post-COVID-19 search was extended to Google Scholar, due to the lack of relevant articles.

Future studies would benefit from understanding the gaps in the literature, and in particular the apparent lack of research replating to experiences of PLwMLTC and how the failing to apply patient-centred approaches is creating further demands on services that are already over stretched. Future research would also benefit from understanding the attempts that the HCS has made to deliver care for PLwLTC and why they have failed to be delivered consistently. This study uniquely adds to the literature relating to MLTC, illuminating the barriers PLwMLTC face and the challenges and consequences of an out-dated system. Future research would benefit from finding ways to gather rich patient data that can be used to drive improvements to national healthcare service.

7.2 Implications and recommendations

Policy makers need to focus on system reform to tackle MLTC as the biggest demand on HCS. A phased approach is recommended, with short-, medium- and longer-term plans that are transparent and have visible and meaningful reportable outcomes, that include the patients lived experiences.

In the short-term creating a system that recognises individual patients with MLTC and allowing them longer appointments. This would have minimal impact on the HCS as these patients are already returning for multiple appointments. Developing the existing NHS App to inform patients of waiting times for their consultations and treatments would reduce worry and anxiety and help them plan whilst waiting for treatment. HCP to receive phased training on how to manage patients with MLTC, starting with taking the time to listen in the longer appointments to address the whole-person needs, including support if they are on waiting lists.

Medium and longer term requires system reforms are required to create patient-centred care that is accessible for all. HCP to be given the resources needed to co-create and deliver patient centred care plans and training to deal with the complexities of managing PLwMLTC, including signposting to integrated support services, handling conflicting medications and self-help support that is tailored to individual needs and preferences.

Failure to present a transparent, actionable and timely strategy for 2025 and beyond will have implications for 15million people living in the UK with MLTC and HCP. A plan is required to prevent further decades of increasing demand and deteriorating QoL for PLwMLTC.

7.3 Conclusion

Pre pandemic issues relating to MLTC were known to be creating a burden on the HCS. Despite being recognised for decades, HCS lacked the ability to deal with them as a growing challenge effecting patient's health and QoL. This was exacerbated by the pandemic. Four themes have emerged through this study which illustrate the impact of the COVID-19 pandemic on PLwMLTC accessing healthcare.

- Living in the unknown: An emotional response to waiting to access healthcare services.
- Effects of the COVID-19 pandemic on managing day-to-day life
- Trust and faith in healthcare services at risk
- The lasting effects.

PLwMLTC struggled and still struggle to access meaningful and effective healthcare support that they need, experiencing worsening physical and mental health as a result.
Patients recognising the need for and benefits of taking responsibility to self-help and seeking ways to manage on their own has been beneficial to some, but more support is required for this to be part of a solution. The current situation is unsustainable and will not be resolved if the HCS continues to take the approach of single appointments, for single

problems and failing to meet the needs of the whole person. It is apparent that policy makers have been aware of these issues for some time, but there continues to be no established way forward causing increased worry and a lack of trust and faith in the HC.

7.4 My reflections

The researcher offers the following reflections on her experience of conducting this study.

This research was an incredible journey of understanding the UK health service and a privilege to read patient lived experiences and listen first-hand to recent experiences. Developing the philosophical knowledge and constructing the design was always centred around the participants experience. Although this approach and methodology was extremely rigorous and time consuming, it was a joy to carry out. Watching the themes emerge with no expectation, began to tell a story that aligned to the literature, but also gave a voice to the participants to recount their unique stories.

It is hard to comprehend that decades of government plans recognised the problems associated with PLwMLTC but failed to bring about significant improvements in the delivery of care needed by over 21% of the population. Failing to address the issues identified by the patients themselves and the significance of this to the population and the economy has raised more issued for consideration. E.g. What is the reason for this and who is accountable? Why did the UK badly manage the COVID-19 pandemic when looking at comparable healthcare system in other countries? Is the NHS mis-managed and/ or under-funded?

What is apparent is that UK healthcare is missing the point of meeting the nation's healthcare needs and people are suffering daily as a result.

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Appendices

Appendix 1: Pre-COVID-19 pandemic literature review.

Searched February 2022 – April 2022.

Year of public-ation	Author	Area	No. of pts	Health Conditions	Method	Paper and Study themes	Patient quotes
2018	Potter, C. M. *et al*	Oxfordshire and Northwest London	48	Cancer Chronic obstructive pulmonary disease (COPD) Ischaemic heart disease (IHD) Diabetes Depression Inflammatory Bowel disease (IBD) Multiple sclerosis (MS) Osteoarthritis (OA) Schizophrenia Stroke/transient Ischaemic attack (TIA)	Qualitative study	**Paper Themes:** Mutual acknowledgement of illness. Continuity of relationships System-wide coordination **Study themes** The healthcare system Continuity of care Relationship with HCP The right care Social network	**The healthcare system** *"You see I'm not worried about the diabetic problem, I'm not worried about my kidney problems, but I am worried for my heart problem because it's my every moment problem, and when I'm going up … I've got the toilet upstairs … I'm going by the stairs and then I have to wait [because of chest pains], and I'm just busting for the toilet you know, I just sit down [HEAVY SIGHS] … Sometimes there is a pain in the chest, there is a severe pain in the chest, and I'm just about to call the ambulance and then I'm thinking 'if you're there with emergency people, you'll have to start from a, b, c, d' because I'm not with the cardiac department now." P21* *"So, is it that you feel you don't want to have to explain everything to people, or that you don't feel you can explain to people?" Interviewer* *"I can explain. To whom I should explain dear, to whom?" P21* *"Now at the present one [primary care practice] it's not that there's anything wrong with it, but I've been there about five times, and I've seen five different people … I mean they've got every right to differ [in medical opinion and advice given] but I find that very difficult." P14* **Relationship with HCP** *"what's been different over the last 4 years, is because firstly I've got a care coordinator or a psychiatric nurse, I'm not actually sure of the title … I see her every 3 to 4 weeks. And that has made a huge difference, simply that they are keeping an eye on the whole purpose of not letting me get so manic and psychotic, or so suicidally depressed, that I actually then have to be admitted [followed by months or years of recovery] … the whole emphasis, like I say, has been on prevention, you know to 'nip it in the bud'. As soon as they see symptoms, or things aren't happening, they react to it." P.39* **The right care** *"There's nobody willing to listen and help you with the things that you need the help with. So, you just get on with things the best you can and things you can't do you have to pay to have done for you … I had a stroke and again I thought maybe I'd get, at last, get some help, but you don't, it's a waste of time. So, I just… I don't bother asking any more, I just let it go" P18* *"Signing up for a massive mortgage, which I would not have done if I had known I had MS, but he didn't tell me … "P07* **Social Network** *"can I come and see you privately?', and he said, 'don't be daft, what's the problem?', and I explained to him, and he said, 'you better come and see me at 1 o'clock today'… and [after assessment] I think he thought I was going to drop dead on him, and he got me in that week, I went in on the Thursday, and had the operation on the Friday."*
2019	Adams, J. *et al*	UK	18	Non-MSK comorbidities including; Cardiovascular, pulmonary, renal, gastrointestinal, ophthalmic, skin, and mental health disorders	Qualitative study	**Paper Themes:** Health Literacy Engaging with health care services; Interpreting the health care providers' message; and Facilitating participation in	**Communication/Information** *"You know she did explain that. She does explain everything to me". (Rachel – P14, REALM 0, Low Functional Health Literacy).* *"I will not, you know, I wouldn't go to these places if I know I gotta read and sign and write things. (Brian – P8, REALM 1, Low Functional Health Literacy).* *"I don't think it'd matter how educated or if you could read or write. It's just that when you're not a doctor that you can't understand their words, their long words and their explanations. So, I think sometimes, that's why they need to come down to our level, not that we're thick or anything, or stupid. "(Viv -P2, REALM 7, Adequate Functional Health Literacy).*

						MSK self-management. **Study themes** Communication/Information Social network Time The right care	*"You got booklets out anyway explaining it all, but it's not … it does never seem plain enough to me for people to understand it properly you know, they come out with all these 'osteoarthritis' and, but they don't … they just tell you, you've got it, they don't explain exactly what it is." (Bill – P1, REALM 7, Adequate Functional Health Literacy).* *"Well, the only information you get is what they know…. all I can do is take a tablet. The thing is what else can they do?" (Brian – P8, REALM 1, Low Functional Health Literacy)* **Social Network** *"Some letter came, and you know I have to wait for somebody to read for me. Sometimes you know I was sitting and I'm trying to read and I can't read. And then I'll look for somebody and, 'Can you read this for me please.' "(Joyce – P6, REALM 0, Low Functional Health Literacy).* *"When I'm in pain I don't tend to want to go the hospital I won't even go to the GP, and I'll just go and find out for myself …. And that's when sort of, it would be a last resort to go to the doctor." (Carole – P13, REALM 6, Adequate Functional Health Literacy).* *"I'm dyslexic so I don't read very well … If I have a problem, you know, my neighbour helps me." (David – P17, REALM 4, Low Functional Health Literacy* **Waiting times** *"Yeah, it's just that you go to these hospitals, and you could be sat there for an hour or two waiting because they're behind, they're obviously busy and then you just, as I said, you just go through these big words they say to you and goodbye". (John – P4, REALM 7, Adequate Functional Health Literacy).* **The right care** *"…but I mean, leaflets are not going to do much good about it. I live my life as I live my life. I don't think a leaflet will change that" (David – P17, REALM 4, Low Functional Health Literacy)* *"Even then they said, 'Rachel, you're on the strongest tablets. Go away!'" (Rachel – P14, REALM 0, Low Functional Health Literacy)*
2018	Eysenbach, G. et al	London	20	Diabetes Type 2	Qualitative study	**Paper themes:** Burden of a diabetes diagnosis on emotional wellbeing, work, social life and physical health. Services being able to meet the user's needs. **Study themes** The right care Communication Social network Healthcare system Time Communication The right care	**Information** *"But sometimes it's a question of having too much information and you can't take it all on board and you can't make all the changes overnight. [PT20] And where are the tools that help me to understand it? You know, I'm looking at carbs and sugar, and it's all very confusing and highly complicated". PT16* **Social Network** *"Because we're talking about food; I mean, I go to my family, and when I say I can't eat that food, they usually think that's disrespecting them, so you've got all that as well to deal with". PT11* **Quality and consistency of care and information** *"I've been very fortunate with my practice in [location] because they've given me a huge amount of support in terms of information gathering. But I understand that you've only got to be a couple of miles down the road and you get nothing at all. And even if you ask the questions, the doctors feel that you're taking up their time, and in fact that's true of all doctors, I appreciate that." PT10* **Communication** *So that's the big problem, it seems to me. The mainstream medical opinion seems to be all doom and gloom...If you just put that diabetes is such and such but can be controlled or managed or whatever word you want to use, through very simple means, I think that's a huge relief to people. PT10* **Healthcare System** *"To even ring your GP surgery normally to make an appointment can be very tiresome for a lot of people. You can't get through." PT8* *"the worst thing is, when you go along to A&E, and they say to you...they might turn around to you and say, oh when were you diagnosed? You know, and you have to start from...the whole story from the beginning." PT7*
2018	Brand and Pollock	UK	13	Chronic kidney disease		**Paper themes:** Patient experience of continuity: time	**Time** *"I don't mind [who I see]. The quickest one in and out". P9*

						being known knowledge, knowing the system responsibility **Study themes** Time Relationship with HCP Trust The right care Choice	**Relationship with HCP** *"They all seem to know us. 'Even the receptionists.' 'Within three visits in the clinic… every person knew my first name… It tells me that they're just a caring… They've got a caring attitude" Wife of P8* **Trust/The right care** *"I end up having to check everything they're [the GP] going to give me… If they want to stick me on antibiotics and things like this, I'm going to have to tell them that I've got a renal problem and… because otherwise they'll give me the wrong ones. I've got to watch everything they're doing." P1* **Choice** *"It's my choice to [have blood samples done before clinic] because I feel as though I'm doing my bit to help them to help me." P1*
2018	Ingoe, L.E. et al	North-East England	18	hypothyroidism	Qualitative study	**Paper themes:** Older individuals' knowledge of symptoms, confidence in diagnosis and understanding of clinical management regime to understand hyperthyroidism. **Study themes** Communication Trust	**Communication/Information** *"I don't really know what the symptoms where I wasn't told what the symptoms were…I mean it wasn't explained by the doctor nor nothing. I didn't even know what my thyroid was ….I've just kind of accepted it it's just been since then part of my life."* Female aged 80 *"Oh, I think [its] at least three years since it's been adjusted. But I'm always told about it…there's no details except [that] it would be better – "we are going to increase your dosage. But don't worry".* Female aged 85 *"…If it was explained to you…when they were doing the things you would understand it a little bit more…You see I'm not stupid and I like to know the reason why".* Female aged 80 **Trust** *"...I'm a great believer in they're trying to help you. There's only one way; you've got to do what they say. And I'm a great believer in that". Female aged 82*
2022	Karadag, P., Morris, B. and Woolfall, K.	UK	15	Inflammatory bowel disease (IBD)	Qualitative study	**Paper themes** *Misdiagnosis and hesitation caused frustration and prolonged suffering,* *Information needs at the point of diagnosis* *Access to specialist staff facilitated trust and a change for the better* *Positive and negative impacts of IBD upon individual wellbeing* *Family and partners as a source of emotional and practical support* *Sharing experiences and reducing stigma- the benefits of social media communities* **Study themes** Self-management The right care	**The right care (mis diagnosis/hesitation)** *"I felt left to my own devices for quite a while" (Katie, aged 32)* "kept being written off by the doctors" *(Maddy, aged 22).* *"We had to push a lot for them to believe that it was like actually a physical kind of condition rather than just a mental one" (Jack, ages 22)* **Information** ***Steve, aged 40:*** *I don't think I was given a lot of information. (just given a leaflet)* ***Katie, aged 32:*** *I think maybe at least being given a leaflet or something to take away when you're in hospital would be massively helpful.* ***Sally, aged 27:*** *I don't feel like I will have got any of that directly from the NHS… it's more about you know real-life – how it genuinely affects people. (got info online, not NHS)* **Self-management** ***Katie, aged 32:*** *I only did one google search and then it started to scare me… your mind takes over about all of the things that can go wrong.* *"One participant recalled viewing a post on a Facebook group shortly after diagnosis, which gave her an "*end of the world situation in my head" *(Chloe, aged 25). However, eight years on she reflected that her own personal experience* "wasn't half as bad" *(Chloe, aged 25*). **The right care (specialist)** *'I've got a very very good IBD nurse'* (Kirsty aged 35) and *'my IBD nurses, that team are incredible'* (Katie aged 32) ***Noah, aged 25:*** *they were only kind of a phone call away…I'd phone them on the Monday, and they'd have me in clinic on the Thursday.* ***Sally, aged 27:*** *I think definitely she's been like an integral part of like my mind set now as well, and like my road to recovery cause I just feel like she's just sorted it all for me*
2022 (data collecte	Arnold, S., Fernand	UK	20	Vulval Lichen Scleroses	Qualitative study	**Paper themes:**	**Relationship with HCP's / communication**

d during the pandemic)	o, S. and Rees, S.					Missed opportunities learning to live with a long-term condition a secret life **Study themes** Relationship with HCP Communication The right diagnosis Continuity Social networks Information .	*'I went to a gynaecologist, but she was horrible to me … she just dismissed it. So, I think it's already hard enough to bring it up with your doctor to start with. But when you get dismissed it's just, it really gets you down sometimes.' (Madeleine)* *'… the ones that were quite dismissive of me made me feel ten times worse … it's hard when somebody's telling you it's in your head. It just makes you feel like you're going crazy.' (Grace)* **The right diagnosis** *'And when I kept going backwards and forwards to the doctor, no one would examine me, no one would, no one was really bothered or interested … I was very raw, and it was painful just to even have a wee. And she gave me a different treatment for thrush. And it still didn't get any better, funnily enough.' (Hazel)* *'I was shocked and a bit angry that it had just been put down to being post-menopausal.' (Elizabeth)* *'She made me feel confident that I would be okay, that I was being cared for. I thought, "Well, thank God for that. At least I'm gonna find out what's up with me."' (Patricia)* **Being dismissed** *'I remember driving home and crying, it was just such a horrible experience to have to show an intimate area of myself to someone who was quite dismissive and, sort of, derogatory in the way that they spoke to me.' (Amanda)* **Continuity** *'… the American people, and the Canadian people, they seem to, because they do have, have gynaecologists as a way of life … they, they get monitored. And that's something that's totally lacking here …' (Fiona)* *'They examine me and make record of any changes, and I can talk over any concerns with them and they keep a close eye on me which is wonderful.'* (Janice) **Social networks** *'… it's a phenomenon, isn't it, that when women get together, they help each other, and Facebook has been unbelievable in that respect.' (Carol)* *'I know there are other people like me who have changed how their life is because of it. And we do it secretly 'cause you don't tell anyone. It's not something you talk about; I don't discuss this with anyone.' (Sandra)* **Lack of information** *'I was angry that as a woman, we're always told to check our breasts, but we're never told to check [our vulvas] …* *'No-one ever gave me any information. Nobody told me to use like a moisturizer or anything at all. That wasn't discussed.' (Paula)*
2016	Y. et al	UK	10 papers systematic review	Chronic Back pain	Qualitative study	**Paper theme:** 1. communication, 2. mutual understanding, roles of health professionals, 3. information delivery, 4. patients' involvement, individualised care 5. healthcare service **Study themes** Communication Relationship with HCP Information Co-creation Getting the right care	**Getting the right care** *'To get pain medicine is like fighting Muhammad Ali', or in contrast, 'they [health professionals] kept wanting to push more medicines, more medicines [when not necessary]"* **Co-creation** *"Patients suggested that taking time over explanations and effective listening by health professionals would help them gain a better understanding of their conditions and expectations. On the other hand, health professionals felt that it was important for patients to appreciate the professionals' perspective on pain management so that they could work with each other in the long term"* *"Some patients complained about the manner of their health professionals and were very emotional about being treated as 'a number but not an individual person"* *"Patients' involvement increased when the health professional applied their understanding of the patients' values, preferences and lifestyle to the development of individualised exercise programmes."* **Information** *"Patients expected to receive information about pain, including diagnosis and prognosis, treatment processes, self-management strategies, patients' roles and responsibilities for caring for themselves and managing their own pain….*

							Even though all of this information did not make the pain better, patients described it as a good feeling to understand what was wrong in their bodies." *"They [health professionals] didn't ask me what I thought I wanted, they just did what they assumed was physiotherapy', 'I don't know what other treatments I could have got"* **Relationship with healthcare professional** *"patients were seeking a 'professional mentor', referring to a health professional who has the ability to offer individual care with a supportive treatment approach."*
2022	Gardener, A. C. et al	UK	21	COPD	Mixed	**Paper themes:** "I'm fine" patients. Disavowed their needs. **Study themes identified:** Trust Relationship with HCP	**Trust** *I must say when I had my pneumonia they said, 'use that [inhaler] four times a day,' but I never bother. […] Because when I walk to the (shopping centre) I'm out of breath because of my walk…. So, it's not a reason, it seems to me, why I should take it. What I need is to rest and then I'll recover, and I think it's just not necessary to take it. [P 023-41}* *"But I mean I'm OK. I make myself OK. It's why I don't trouble the doctors. If I feel bad, I know what I have to do…so you just get on with it, it's a fact of life." (P010–301)*
2018-2019	O'Neill, M. et al	UK	14 studies	Type 2 diabetes	Qualitative study	**Paper themes:** Key themes identified under the health, information and technology zones of the HITAM revealed the benefits of mHealth apps, barriers to their use, their perceived usefulness and ease of use. **Study themes** Self-Management Healthcare System Relationship with HCP Information .	**Self-Management** *"I check my BGL more, I check my weight more, monitor my diet better. My blood levels are staying more normal than over a year ago" (p.6; participant 'Keith')* *"[I] Am trying to educate myself [about diabetes], and that is why I liked [these tools] because I already have that in my mind". (p. 8)* *"Even if I did [everything I'm supposed to], starting to use [the app] on a regular basis is going to be hard too. Because it's not that I'm unwilling, which is partly true, I am unwilling—I shouldn't have to do this" (, p. 8; participant in low engager or dropout group)* *"Sometimes it's actually just easier to smartphone it than it is to find your book and write it down and fiddle around like that, you just tap it in." (p.7; 45 years female app user)* **Healthcare System** *"It's a medical issue. They should be free really, to access full features and everything else… you know, it can be life and death. If someone has a smart phone they can have an app, but they can't access it like I said because they can't afford to." (p.5; 45-year-old female, app user)* **Relationship with the HCP** *"I work hand in hand with my doctor, and we try to find out what's best. We look at the results together and then we see how things go". (p.8; patient 4, male)* **Information** *"I wish there was something that could give me some advice about nutrition and things like that. It didn't do that at all. It was more of an overview, reminders, and everything related to measuring blood sugar" (p.7; participant 8, male)* **IT literacy** *Some are not literate enough that they could use a computer or even a cell phone to text. So not to expect a 70-year-old, all 70-year-olds to be at the same level. It's just not going to happen" (p.7)*
2019	Wildman, J. M. et al	North-East England	24	Service user perspectives of link worker social prescribing	Qualitative study	**Paper themes:** Reduced social isolation and improvements in their condition management and health-related behaviours **Study themes** Social network	**Continuity of care** *"Well, I don't get as much support now. My first worker left, I used to see her a lot. I was put onto another one,* *who I've only seen about two or three times. Now she's left and they've put me onto somebody else who I've* *never seen or been contacted by. I feel a bit let down because my first one was brilliant."* **Social network**

						Continuity of care	*"I think it's changed my life completely…I was too fat. I had issues. Ways to Wellness has swept some of them away. It's been a very, very positive experience...I'm a happy bunny."* **Social network** *"…it's important to have someone there, who has a finger on the pulse, knows all these different things. Doctors can't know everything, and I mean, what they know obviously helps improve your health, but things like support in the community and things, I don't think enough of them know about it. I don't even know that the practice nurses know enough about it."*
2019	Tollow, P. and Ogden, J.	UK	21	Chronic leg ulceration	Qualitative study	**Paper themes:** Failure Powerlessness Relationships **Study themes** Continuity of care Getting the right care Communication Co-creation Time	**Continuity of care** *"They would kind of … both of [the nurses] would groan at the others treatment of it so you never got any constant treatment, as I said, I felt like a bit of a guinea pig." (Susan)* **Getting the right care** *"It's written right on the front of your notes what I can and what I can't have, what I'm allergic to, etc. And they still say when they see it, oh well put some Atrauman on that and I go 'no you won't, I'm allergic to it', 'oh erm … ', I say 'look at the front of the notes … it gets to the point where I feel sometimes I do have to really take charge." (Karen)* *"It felt like a never-ending circle. No-one really has an answer, and everyone keeps telling me the same thing, just use compression and they don't come back – well obviously that so-called treatment, if you like, is flawed. It's a flawed system, it doesn't work, you do everything you're told, but they still come back." (James)* **Relationship with the HCP** *"I feel that I don't really have a say, I feel like I shouldn't … I feel like I shouldn't have an opinion about anything … The fact that I've had it long enough to know what upsets it and what doesn't, but I don't feel I've got the authority to say so." (Shirley)* **Time** *"You always feel sometimes when you do see consultants and whatever, that their time is valuable, of course it is, I'm not the only patient they're going to see on that day, but you do feel as though they're a bit *interviewee makes rushing noises*, trying to get all the questions out in the space of two minutes and then they're off to see the next patient". (Karen)* **Relationship with HCP** *"You're sometimes treated as if you don't have any intelligence or you don't know, kind of, what's going on." (Susan)* *"Obviously the one-to one interaction between me and a nurse was really helpful, because I could talk to them and they'd listen … I did look forward to seeing them because they were nice people. I'm not saying they cheered me up and made me feel absolutely fantastic about the ulcer, but I felt, I just felt a little bit more confident." (Jack)*
2014	Spiers, J. *et al*	UK	21	Ileostomies	Qualitative study: IPA	**Paper themes;** Relationship with multi-disciplinary teams: negative and positive Issues around treatment Issues around medications Reversal surgery **Study themes:** Acceptance Quality of care Relationship with HCP Continuity of care Information	**Reversal surgery / Acceptance** *"It's quite major surgery; there's a 30% failure rate. […] And with two small children, it was just, not really a possibility and, my stoma hasn't really affected my life."* *"When I woke up in ICU, the first time (pause) it was basically almost like seeing an old friend. It probably sounds weird, but (laughs), it was a bit of a relief!"* *"I've got this (pause) very (pause) strong anxiety in the back of my mind. I mean rationally, I think, I've got a sort of 99 per cent chance to be alright. […] If they said to me, well no, you've got this for life now and I kind of slightly, emotionally, preparing myself, just in case that happens. I'm hoping that […] even if they did say that I wouldn't fall to pieces. But it would be a huge blow."* **Quality of care/neglect/negative experiences** *"Doctor came round with a few other people, with him the following morning and had a bit of a look (pause) said oh, ok, not sure what that is, gave it a bit of a tug and it came out and off. And I've no idea what it was. […] He didn't get it tested, he just basically, it got (pause) thrown away or whatever. My surgeon was never, consulted about it."* *"A doctor came and I said look, I'm not elevating, and it's really swollen and, you know, it's uncomfortable and he asked the nurse to get me a stool. So that I could elevate it. […] And, he went away, and the nurse said, well just*

							cos some, doctor asked me to get a stool, doesn't mean I'm actually going to do it". *"A big clot come out, so she showed it to the next nurse and the nurse's reaction was oh, God no, put it away. And I seen her do that. And I felt quite frustrated, I thought, that's your job. […] It was sort of very (pause) you know, just disregarding."* **Relationship with HCP/Continuity** *"I did often see the same people. […] So yeah, I did feel that thing about trust."* *"He gave me the option of, think about a hemi colectomy which won't last. Or a stoma. […] But you'll need a stoma eventually and I thought oh, I don't want to go through it twice so and he said that's the right decision cos I can't do a hemi colectomy. So, I said so why did you offer me one? He said because if I'd told you needed the stoma, you'd have run a mile (laughs). […] Clever man!"*
2021 interviews in 2018	Talbot, A. et al	UK	41	Weight related Long-Term conditions: arthritis irritable bowel syndrome Type 2 diabetes, cancers epilepsy fibromyalgia high blood pressure sleep apnoea multiple sclerosis osteoarthritis heart conditions	Qualitative study	**Paper themes:** perceiving weight as "doctorable"; and weight doctoring in primary care **Study Themes:** Communication Getting the right care/Trust Relationship with HCP Self-management	**Communication/ Getting the right care/Trust** "*I have to go to the GP quite a lot, and they don't seem to be interested in my weight… They just say," Oh, we'll treat this or that, do not worry about weight. "I think they're embarrassed because I'm obviously very big and they don't know what to say." (P07, F, multimorbidity)* **Relationship with HCP / Trust / Communication** "*the weight gain started 12 months after my wife died. I was so worried about it. I went to see the GP, and the practice nurse was really quite rude… She told me," You'll lose weight if you keep that shut"* (*Gestures to mouth) … She did not give me any advice on how I should change my diet" (P25, M, heart failure).* **Knowledge/ Communication/ integrated HCS/ The right care/Trust** *she had a trainee doctor in the room, and I felt she'd just put that question into our consultation as an example of good practice. I explained that I did eat well, but time was a factor sometimes… She said to me, 'If you make a small change like take a salad to work,' I felt quite insulted. I just felt it was tokenistic, really." (P10, F, multimorbidity).* "*They sent me to a dietician. She was lovely, I knew all that she was telling me, it's all on the television now… she was very good with me, but it wasn't what I needed. I needed counselling." (P07, F, multimorbidity).* **Relationship with HCP** *"My GPs have been outstanding for me… Getting the right GP is the most important because they're your first point of call. We* (GP and I) *delved into* (my condition) *and started to find out there were more things wrong with me than I anticipated. But having him… being able to call and say,", Can you ask the doctor to call me? "… And then they do call. It's just nice" (P37, F, impaired mobility)"* **Self-management** "*It's all in the mind. Your attitude does have to change if you want to lose weight". (P09, F, clogged artery)* **Communication/Honest** "*They'd say, 'well, you're a wee bit chubby,' and I was at the time… They never said, 'You're pre-diabetic'… If the doctor had stressed that I would have done something about it… They have to be more brutal." (P08, F, Type 2 diabetes)*

Appendix 2: Post-COVID-19 pandemic literature review.

Searched February 2025

Year of public-ation	Author	Area	No. of pts	Health Conditions	Method	Paper themes and Study themes	Patient quotes
2024	Ambrosio, L. et al	UK	368	LTCs during COVID-19	Online survey and sub sample of n=26 interviewed	**Paper themes** People with 1 LTC are more physically active than those with 2+, presenting higher well-being and lower levels of anxiety and depression. A range of coping strategies to cope with the impact of 1) changeability and the 2) consequences of the pandemic restrictions 3)Coping during the pandemic 3) Physical exercise and mental health **Study themes;** **Living with LTCs** Adapting Deterioration of health Increase vulnerability Self-help Reflections	**Changeability** *"In terms of daily life, I don't think it stops me doing much. I still drive. I maybe get a bit tired sometimes and later on in the day, I maybe have got a wee bit slower but other than that, I don't think it really impacts me a great deal" (P17).* *"I've lost quite a bit of mobility, it's got worse as we go on, but we try to do things that I can still, it's not what I can't do, it's what I can do. We look at it that way with my mobility and getting out and about. I can walk some distance but usually, I want to hold on to something, either my husband, or I have a walker" (P20).* **Consequences of the pandemic restrictions** *"I think the fear of getting COVID is stronger than the fear of the cancer, if that makes sense. I didn't really want to get out the house, I felt safe in my little bubble…I felt secure and looking back, yes, more walking but I was more concerned about getting COVID than anything" (P20).* *"Well, yes, that stopped us, they closed the swimming pool. No, other than as I mentioned, because I wasn't swimming, my arthritic knee got weaker, and I wasn't walking as much, and we had to force ourselves to go out. In fact, I bought a walking stick" (P11)* *"Yes, it really affected it, but I did walk because that's all there was. I did want to start doing open water swimming, but the whole COVID thing I found so frightening that I really didn't want to go out if I thought there might be other people" (P9).* **Coping during the pandemic** *"I think as long as I'm exercising, I'm helping myself, so I suppose it's like self-medicating almost. I view exercise as medicine. As long as I'm able to exercise, I've got that positivity that I'm helping myself" (P17)* *"It's changed a bit. Instead of going to the gym I would go for a two-and-a-half-mile walk, get some cardio workout going to keep the circulation going, etc. That takes time and time is something we don't always have. The weather's not always good for walking either! I started doing walking a bit more when I was, during lockdown, on my own" (P22).* *"It is good to get out of the house, so I don't want to stop exercising, but to the level I want to live, the level I wants to exercise, it doesn't really affect. I sort of live within my parameters rather than trying to do things and get frustrated because I can't because of emphysema, or COPD" (P2)* **Physical exercise and mental health** "*I certainly suffered depression throughout the COVID 19 period. There's plenty of things I should have done differently: I should have kept up the exercise; I should have forced myself and my wife to maintain exercise—that's what I should have done—but that was a personal failure. I do regret that, but I just lost hope in the whole exercise" (P25).* *"Yes. I find, if I don't exercise or do something, I get very grumpy, bad tempered—because I'm used to exercising, all my life. So, when I couldn't, it was difficult. If you're not happy, you can go for a very long walk, until you felt better" (P4)*
2021	Fisher, A. et al	UK	36	Cancer, respiratory and cardiovascular	Phone based interview	**Paper themes** 1) high levels of fear and anxiety related to perceived consequences of catching COVID-19, 2) impact of shielding/isolation	**Heightened levels of risk** *"My medical condition, I've had it all my life so if that places me in a higher risk category, you've just got to do your absolute best to not catch it and then after that it's sort of in the lap of the Gods really isn't it? So, it didn't really upset me or stress me or worry me" (female, 40–49, respiratory condition).* *"There's been some degree of added stress, I suppose, because it became relatively clear, relatively early, that [COVID-19's] something that really, given my circumstances, I should be careful not to catch." (male, 30–39, cancer).*

						on mental health and wellbeing, 3) experience of healthcare during the pandemic and 4) anxiety created by uncertainty about the future. Fourteen subthemes were identified, including concerns about accessing essential supplies and the importance of social support. **Study themes;** **Living With LTCs** Every day is different Deterioration of health Increase vulnerability Self-help Reflections Independence Social network Control The lasting impact **The health care System** Communication and Information from HCS Postponed/cancelled appointments Uncertain future	**Concerns about access to supplies** *"I actually made sure that I had an extra stock [of medication]. I put an extra repeat prescription in before the lockdown and I've just put another one in..." (female, 40–49, cancer).* *"I didn't get a letter [from the Government/National Health Service (NHS)] for ages because they weren't able to identify me and the therapy from that essential health data. So, yes it was a bloody nightmare to be honest" (female, 40–49, cancer).* **Fear of hospitalisation, ventilation and death** *"I'm terrified of getting this virus, because I know that if I get it, it probably is the end of me. My lungs are not good … I don't want to die in hospital, and I don't want to have that intubation and sedation" (female, 70–79, respiratory condition).* *"I'm really scared of getting [COVID-19] … I think I probably would not survive if I got it, so I'm trying to keep away from it … when I heard about [COVID-19], I just automatically went, oh my God, I'm going to die. It wasn't great" (female, 30–39, CVD and respiratory condition).* **Immediate social network strongly influenced experience of shielding** *"Most of the time [the family are] in the house … Everybody's on the same page … Maybe if I hadn't had gone through everything I went through last year and when kids see you poorly and what have you, and its cancer, so it's the C word, isn't it? It's made everybody think on the same wavelength … it's had its moments … But as a family, we've done well with it to be honest" (female, 50–59, cancer).* **Loss of independence and reliance on others** "I was especially jealous of my girlfriend, who didn't have to shield. She made sure that before she starts work in the morning, she goes for a walk for at least 45 min to an hour … She also had to do the grocery shopping. And there was once or twice during lockdown that I needed my prescriptions to be refilled. She had to do that. So, in a sense, I felt overly reliant on her … ... So yes, that was difficult" (male, 40–49, blood condition). "I don't like relying on people. I hated to have to ring people up. At the very beginning, lots of people were getting in touch … Then it tailed off a little bit, and I don't like ringing people and asking for help … I just felt really guilty for it. I just thought, I won't bother anybody, I'll go and do it myself" (female, 50–59, cancer, respiratory condition). **Mixed views of attending a healthcare setting in person** *"In my head, if I went to A&E and went into the hot side with Coronavirus, that's just a death sentence" (male, 30–39, multiple conditions).* *"I didn't feel any anxiety about going into hospital because most hospitals are designated as red zones and green zones. Certainly, all the nurses etc. wore masks, gloves and all the rest of it. But I had excellent care, and I wasn't at any point worried that I would actually catch [COVID-19] in hospital" (female, 60–69, respiratory condition).* *"The night I had the chest pain, it mentally went through well, I'll give it another 10 minutes and see. If it hasn't gone, I will go to hospital. So, I wasn't just going to sit there and think I'm going to put up with chest pain just because I might get COVID-19 if I go to hospital. I was sensible enough to realise that really, the more pressing thing's getting what seemed to be a heart attack sorted than worrying about a theoretical risk of getting [COVID-19]" (female, 60–69, respiratory condition).* **Postponement of non-essential treatments** *"I should have seen my neurologist in January … but that got cancelled. I contacted [the hospital] and got an answer phone, then I was told that the neurologist would be getting in touch and she never was …. A bit disappointed and I do feel like I think what I've got is a pretty serious condition, but it's obviously regarded as not that important at the moment … but I can understand why" (male, 60–69, neurological condition).* *"I was supposed to have a surgical review with a view to having surgery this year, but obviously that's all stopped. The review was cancelled. Surgery will not be any time soon. It can wait, but it's also something that's disappointing. But I do understand that there will be a massive backlog now and there are many more urgent things that need sorting" (female, 40–49, respiratory condition).* **Anxiety created by uncertainty of the future** *"[uncertainty's] something that I wouldn't say I'm an expert in dealing with, but I'm very experienced in dealing with it. But it doesn't make it any easier.*

							But it seems to be something I've had to deal with, at least on the back burner, all my adult life" (male, 50–59, diabetes). **Impact of pandemic on treatment access with progression of LTC** *"there is the underlying anxiety, as well, about how will I be treated in the future?...The healthcare worry is obviously a lot more intense, because if I need to go back into treatment, I will have to be isolated to a much greater degree, and will be much more dangerous … it's always been there, but [now] it's an increased anxiety" (female, 50–59, cancer).* *"healthcare is my main priority, that really worries me, that I'm not going to get the same level of treatment as I was getting before, because there won't be sufficient money around, and a lot of services will be cut" (female, 50–59, cancer, autoimmune and respiratory conditions).* **Fear of restrictions being relaxed and plans to continue isolating** *"Even now shops are opening and stuff. I'm too anxious to go out and about …. I'll just keep monitoring what's going on and make my own decision as to when I feel it's safe for me to get back into the big world" (female, 50–59, neurological condition).* *"And I personally feel that it will take a while before I would feel comfortable going out. So, regardless of what the government says, I will be preferring my own guidelines" (female, 60–69, cancer in remission, CVD).* **Not having an end in sight** *"How long's the virus going to be floating around for? How long have we got to take these precautions...I can't anticipate whether we're talking weeks, months or a couple of years and the long-term effects are going to be floating around. The anxiety I'm sure will lessen but I think it's going to be there for a good while" (female, 50–59, neurological condition).* *"It's fine for the moment, but obviously if I think I'm never going to see the Royal Ballet again, I can get quite tearful. And it's things like dancing, we do dance quite a lot … obviously we can dance together, but it's not the same as going dancing, so yes. It's a grieving for how quickly those things come back" (female, 50–59, cancer).* **Acceptance most protective for mental health** *"I guess it's just a massive thing that's outside anyone's control, so you just have to adapt. You have to be very flexible and adapt to it" (male, 50–59, diabetes).* *"what's the point of railing against it? All you're doing is making yourself upset. The situation is the situation … you've just got to accept that it will be what it will be, and you make the best of it" (female, 70–79, neurological and musculoskeletal conditions).*
2022	Stamm, T. et al	24 count-ries		18 different chronic diseases	Qualitative	**Paper themes** Patient perspectives on healthcare during COVID-19 **Study themes** **The healthcare System** Trust in the Healthcare System	**Increasing Inequity in the Context of Care** *"One of the biggest concerns always was that people were getting lost in the gaps in the [care] system. But now, even the more educated ones are struggling, and many more [less-educated people] are slipping through. I suspect there will be more long-term consequences because of that than COVID death". (United Kingdom, male, 20–29 years* **Telehealth is not suitable for everything** *"I was supposed to have a six-month check-up in February this year. But because of COVID, they said that people could only come in if it were an emergency or something happening. So, I spoke to the doctor on the phone, and she said, "Do you feel any differences?" When I said "No", we left it. And then I went back, and it [the eye melanoma] was twice as size as it had been before. So, I don´t know if I had gone in February whether anything would have been different or not? Maybe not. But yeah, that will always be kind of in the back of my mind, I think, just wondering what if we caught it when it was smaller". (Australia, female, 40–49 years)*
2022	Morris,S .et al	UK	15	Long-term conditions	Qualitative interviews via telephone	**Paper themes** Managing LTC's during the COVID-19 pandemic 1) deploying social, digital and financial capital to self-manage	**Deploying social, digital and financial capital to self-manage** *Well, there is always somebody if things were really bad that I could go just three doors away or next door and get help. So, that is quite reassuring. So, I have never felt vulnerable or really, really anxious because I am thinking, "Well, there is always somebody I could go to." (Martha–70-75-F-retired-IMD-1-lives with partner-2)* *"we've been doing the dietary thing together … which has been a great help for us both" and "We've got some weights, hand-held weights … we were doing them pre-lockdown anyway".*

						2) relying on tactics to make life 'habitable' 3) experiencing 'zones of impossibility **Study Themes:** **Living with LTCs** Social network Independence Self-help Uncertain future Increased vulnerability **Healthcare system** Relationship with the HCP	*"Nice friends, neighbours and what have you" who were "all keeping in contact with each other" whilst "maintaining the social distancing, standing at the end of drives". He was also able to walk his dog outside on the "loads of walkways" and "green fields" in the area and "have a chat with other dog walkers". He said he had "convivial chats" with his link worker* *"I'm a member of a couple of Facebook groups in relation to photography, and they have weekly challenges for you to do things on lockdown. So, doing photography in and around the house, macro photography and things. It's like a little bit of a competition … it gave me something to do." (Graham-60-69-M-retired-IMD 9-lives with partner-1)* *"My son comes online every day and talks, well, every evening. And he talks to me with his fiancée. So, life for me is quite nice, actually, compared to some people" (Sarah-60-69-F-retired-IMD 1-lives alone-3)* **Tactics to make life 'habitable'** *"I don't like to have to depend on anybody else … I look at it this way, there are a load of people worse off than me. Let them [the social prescribing service] concentrate on them and I'll just get away with it."* *"So, I just do the exercise in the house. I've got the DVD showing us [me] how to do them and what have you. Sometimes I can't even be bothered doing that either." (Laughter) (Brian-70-75-M-retired-IMD-5-lives with partner-2)* *"They come and they sit out in the garden, and we sit in the house and talk through the back door. We have all kept our distances. That has kept my husband going … Yes, they are saying you should not do that, but the end of the day, if you have got somebody who is just diagnosed with [progressive illness] - He wanted to see the family, so that is what we have been doing. Then I disinfect everything when they go. "(Rosalind– 70-75-F-retired-IMD-2-lives with partner-3)* *"The changes in messages recently ['stay alert'], we weren't too happy about that … we've just stuck to what the original messages ['stay at home'] were, for now …. We had a discussion about it with the girls, and I think we almost felt that it was a time to be more aware than we were previously, because more people would be out and about." (Jessica-40-45-F-full-time employment- IMD-5-lives with family-4)* *"It's been quite hard. Predominantly, I suppose, because he [son] probably shouldn't have been going [to his grandparents' house] but I had no other option". (Kate-40-45-F-part-time employment-IMD-1-lives with child-1)* *"Yeah, I think WhatsApp [has] been really good for me … so I can see people and I can ring them and talk to them whenever …. my girls [daughters] put me on it." (Amanda-50-59-F-unemployed-IMD-5-lives alone-6)* **Experiencing zones of impossibility** *"You've just got to put up with it I think and get on with it. But occasionally I have thought, "Gosh. If I feel like this, I can't imagine when people" - It is awful. It's really hard …. But there are a lot worse off than me … That's what I tell myself …. For me I hope this isn't a permanent thing... "* *"I can't see how it is going to get back to normal for me and my life, my job, my going out, my social, like going swimming or going to a class. I can't see how it will get better really … I hope to get to visit my family … I used to go on the train, but I don't know if that will happen."* *"It's really, really hard actually, to keep upbeat for me. Although I have so many hobbies … that I could do … But I'm finding it harder and harder to motivate myself. I think it's partly being on my own and partly not feeling it to do things, and the fear I have of going out … You know, I just got over all of that and here we are again, frightened to go out again because there is something terrible out there." (Reena–60-69–F–Part-time employed–IMD-2–lives alone–4- shielding advised).* *"I'm stuck on the 18th floor, and I can't do anything, it's quite depressing, because all I can do is look out of the window. You can only watch so much telly, watch so many DVDs, read so many newspapers. But, like I say, what else can you do? I just comfort eat. That's all got to stop. It's going to have to stop actually, because I'll just make myself worse … I say, just cope with it [loneliness, boredom, and health issues] and hopefully it will pass … I'll just take one day at a time, that's all you can do". (Derrick–60-69–PT–IMD 1–lives alone–4)* *"Everybody is quarantined so we haven't really helped each other, we've been sticking to the guidelines … She's scared to go out in case the coronavirus is still about". (Sadia-40-45-unemployed-IMD 2- lives with family-3)* *"She [link worker] has given me so much encouragement and she tried to get me to see a positive side of things … I don't want to be spending my days*

							crying … all I hope for is that I can get some normality coming back into my life" (Gill- 60-69-F-unemployed-IMD1-lives alone-5- shielding advised)
2023	Rowlands, H. et al	UK	10 (6 = MLTC)	Living with long-term conditions	Qualitative	**Paper themes** Perspective on online peer support (1) relationship between self and outside world; (2) past experiences of peer support; (3) philosophy and vision of peer support. **Study themes:** **Living with LTCs** Independance It takes over Self-help Social network **Healthcare system** Being listened to	**Relationship with self and the outside world** *"(…) healthcare, um, practitioners, they'll just mention, okay, um, okay, what you're doing with your condition, how you're coping and you know, it's not how do you feel? And, and that so important to me, just asking that one simple question". (focus group 3, participant 1)* *"When I was diagnosed, mental health issues didn't come into it. You had your condition and that was your condition. But now when we're asked to talk about how we feel … I find it really hard". (focus group 2, participant 2)* *"(…) other people can make goals, long term goals and stuff but I just take each day as it comes." (focus group 3, participant 2)* *"I struggle with asking for help. I have to have a mental breakdown and then someone says, let me help you, and that's when I'll allow it". (focus group 2, participant 2)* **Past experiences of peer support** *"Most powerful thing I've found is with the meet up groups, for example, on complex PTSD, um, it's being with other people who have similar experiences, and, um, there's a resonance there and just sharing resources and information". (focus group 1, participant 2)* *"I've discovered that there are a few people out there who have the same issues that I do, um, so it's made me feel a little bit better. And with Facebook I've joined other groups, for example, with lung conditions like me. And we're swapping ideas or I'm, not always contributing, but I'm reading and it does help in a way". (focus group 1, participant 3)* *"I have a peer group for one of my long-term conditions … we talk daily to each other, motivate each other, keep each other calm". (focus group 3, participant 2)* **Philosophy and vision of peer support** *"Cause I felt that [being a member of the Facebook peer support group], um, it was … Further, sort of underlining the fact that I did have, um, these conditions. And it just, I just sort of wanted to get away from it. And, you know, for a sense of normality". (focus group 3, participant 1)* *"And trying to do the technology frustrates me because if I can't hear, if I can't see, or, uh, there's breaking up, and then I just throw myself outside and then I overdo it." (focus group 2, participant 2)* *"Well I've found, um, it's been a strangely positive experience in the way that, um, that, uh, I quite enjoy being on my own and it's given me a lot of time to reflect and to do a lot of Zooming around in different groups". (focus group 1, participant 2)*
2024	Roberts, C. George, J. and Jenkins, J.	UK	12 Studies	Patient experiences of online platforms during COVID-19	Systematic review (1st review of online triage and consultation systems, from patient perspectives since COVID-19)	**Paper themes** Accessibility – Affordability Accessibility – IT Literacy Accessibility – Equality Care Delivery – Care Quality Care Delivery – Patient Safety/Privacy Care Delivery – continuity of care System Functionality – usability System functionality – convenience	*"Within the 21 data points, respondents reported financial barriers to access due to having non-contract, 'top-up' mobile phones with limited credit and limited data allowance to transfer multi-media files, such as photographs, requested by GPs to adequately provide care"* *"Within the 21 data points, respondents reported financial barriers to access due to having non-contract, 'top-up' mobile phones with limited credit and limited data allowance to transfer multi-media files, such as photographs, requested by GPs to adequately provide care"* *"All four participants coded under Inequality in Verity, expressed frustration that online systems marginalised them further for reason of a lack of formal identification to use the health service, low written literacy levels and a perceived discriminatory reluctance for physical health examination. Inequalities over access to care were also raised by breastfeeding women, mental health patients the elderly, dementia patients and blind or deaf patients without interpretation assistance."* *"This theme featured heavily (23 out of 54 responses) in Oxleas patient survey of health service users in the Southeast London region during the first few months of the pandemic. Participants broadly felt the remote delivery of care matched that of in-person care quality. This perception was aided by the availability of a video consultation option with several respondents positively reporting that this enabled them to effectively communicate symptoms and pain, removed stress and anxiety of in-person attendance and delivered satisfactory treatment and outcomes. This was balanced by some negative perceptions that included: an aggravation of mental health conditions, a lack of emotional connection and an over-reliance on outdated patient records which, due to a lack of physical examination, were perceived as not reflecting patients' current condition."*

						System Functionality – Communication **Study themes:** **Healthcare system** Barriers and facilitators to online systems Relationship HCP	*"10 participants across the studies who gave positive responses related it to their reluctance to attend in-person appointments, which were exacerbated by COVID-19, due to having mobility constraints, chronic tiredness, frequent panic attacks or other multi-morbidities. Three respondents reacted positively to patient safety citing health benefits of not being potentially exposed to the COVID-19."* *"Seven patients experienced frustration or dismay at having to explain, often complex, health history as the online system did not allow patients to seek care from a familiar practitioner, with one patient in Health Foundation who perceived patients were seen as "faceless creatures". Conversely, five patients relayed positive continuity of care sentiments where online systems allowed patients to consult with a GP familiar to them and their health history."* *"Elements of frustration included a lack of system notifications, unfamiliar software within the bespoke platforms, restrictions on certain types of devices, the use of jargon, and disparate points of access requiring multiple login credentials."* *"This was the most prominent factor throughout all of the selected literature with 83 respondents alluding to it and featured in nine out the 12 studies. Comments were largely positive citing reasons of ease, speed, efficiency, and affording patients the ability to fit appointments around family and work commitments. The largest volume of comments around time savings related to a reduction in travel times and waiting room attendances. Only one patient conveyed a negative response to 'convenience' which related to at-work restrictions on accessing an online device."* *"Communication was the second most prominent factor and featured in 10 of the 12 studies. Comments were overwhelmingly negative in tone with patients referencing communication deficiencies in the transition to the triage and consultation processes during COVID-19, a lack of advanced notice before appointments, no indication of when preferred practitioner was available, inability to get through by phone when experiencing system problems, and predominantly, a lack of physical communication cues when compared to face-to-face consultations. Only three positive comments were retrieved to suggest that the online platform was equitable to face-to-face contact with their GP".*

Appendix 3: Posters

Poster 1

Poster 2

Participants wanted for a research study:

COVID-19 impact on patient access to healthcare

I am a post-graduate researcher at Manchester Metropolitan University and I am looking to recruit 4 participants to talk about what it is like to like to live with long-term health conditions and discuss experiences accessing healthcare from a personal perspective.

Do you.... Or know anyone who?

- ✓ Has 2+ long term conditions diagnosed before 2016 (not including, terminal illness, cardiovascular disease, cancer, dementia, mental health)
- ✓ Speaks English
- ✓ Lives in England
- ✓ Accesses healthcare services to support managing the conditions
- ✓ Can meet face-to-face, in a local and agreed location in Preston or Manchester, for a conversation lasting approx.. 90mins.

I would really appreciate your time if you can help. Please contact me if you are interested, or have any questions.

Email: paula..moore@stu.mmu.ac.uk

I believe, patient experiences are key to shaping our healthcare services and together we can share real stories to make a difference.

Manchester Metropolitan University

Appendix 4 : Participant Information Sheet

Participant Information Sheet

Healthcare access for people living with 2+ Long conditions; the impact of the COVID-19 pandemic

1. Invitation to research

I am a post-graduate research student at Manchester Metropolitan University in the Department of Health and Social Care. I would like to invite you to participate in a qualitative study exploring the impact of the COVID-19 pandemic on accessing healthcare. The aim of the research is to understand the lived experiences of patients before and after the pandemic. Your contribution will take the form of 1 conversation between you, the participant and me, the researcher.

2. Why have I been invited?

You have been invited to take part in this study as you:

1) have 2+ diagnosed long-term conditions
2) your conditions were diagnosed before COVID-19
3) you currently access healthcare services
4) you live in England and speak English

3. Do I have to take part?

No, you do not have to take part - it is up to you to decide. I will describe the study in this information sheet and then invite you to sign a consent form if you wish to take part. Participation or non-participation will not affect your access to healthcare.

If, after reading this information sheet, you have additional questions or would like to take part please email the lead researcher, paula.a.moore@stu.mmu.ac.uk

4. What will I be asked to do?

Once you have fully read and understood the participant information sheet, you will be invited to indicate your consent via a consent form. You need to consent to all the fields in the form to take part. You have a minimum of 48 hours to consider taking part. If you decide to take part you will be invited to attend a personal interview with Paula Moore, the lead researcher. The interviews will be more like a conversation about the topic and will be

conducted in person, at an agreed venue. The interviews are likely to last approximately 90 minutes. You will be asked to comment on your experiences when accessing healthcare for your conditions pre, during and post pandemic. The discussion will be audio recorded using a recording device. Once the conversation is finished your participation in the study will be complete.

Please note, you will be able to take breaks at any time throughout.

Your participation in this study will be completely confidential. I will provide a report for the master's thesis on the outcome of the study; however, this will include analysis of personal data from which you will not be identifiable. Any quotes that are used from this research will also be presented anonymously.

What information about me will you collect and why?

Any data collected will be anonymised and reported on using a unique identifier. The data will be kept on an authorised MMU database and all recordings deleted once the study is complete. I will use your personal email and telephone number as a means of contacting you for the study.

How will you use my information?

Your anonymised data will be used as part of a master's by Research post-graduate degree thesis (MRes).

5. Are there any risks if I participate?

The risks associated with participation are low, however, there is a possibility that reflecting on your experiences could be emotive and/or distressing. Should you experience any distress, please find some relevant resources at the end of this information sheet.

In addition, if you are concerned that your mental wellbeing or condition(s) is continuing to affect your daily routine and working practices, we encourage you to either contact your GP or occupational health. Resources are included at the bottom of this form.

You can withdraw from participation at any point during the discussion, with the audio recording of the discussion deleted. If you have completed an interview and subsequently decide that you would like for your data to be removed from the study, please note you will have up to **the end of the data collection period (31st December 2024)** to notify Paula Moore, the researcher or Christopher Hatton, the supervisor, of your request. Before 31st December 2024, we can discuss removal of all or partial data.

If you decide to withdraw after the submission, it will not be possible for anonymised data to be removed from the thesis. However, data bases containing audio-recordings, transcripts, consent form and any data that can be identifiable can be destroyed.

Contact for withdrawal requests:

paula.a.moore@stu.mmu.ac.uk

C.hatton@mmu.ac.uk

6. Are there any advantages if I participate?

This research aims to produce a report as part of a post-graduate research thesis, that will identify how the COVID-19 pandemic has impacted people living with 2+ long-term conditions accessing healthcare services. The results of this study will highlight any similarities and/or differences in participant experiences pre and post COVID-19 and could inform improvements in healthcare provision.

8. What will happen with the data I provide?

When you agree to participate in this research, I will collect from you personally identifiable information. (name, age, ethnicity, email address, telephone number and gender).

The Manchester Metropolitan University ('the University') is the Data Controller in respect of this research and any personal data that you provide as a research participant.

The University is registered with the Information Commissioner's Office (ICO) and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University's Data Protection Policy.

The way we look after your information is ruled by UK law. Under UK law, we need to have a very good reason for using your information (this is called a 'lawful basis'). Sometimes, we might also want to use sensitive information about you, like information about your health, religion, and ethnic background. This is called 'special category information'. We collect all this information from you to help with our research, which aims to benefit everyone (this means that it is in the 'public interest').

I will only retain your personal data for as long as is necessary to achieve the research purpose. This will be approximately 30th April 2025.

For further information about use of your personal data and your data protection rights please see the University's Data Protection Pages (https://www2.mmu.ac.uk/data-protection/).

What will happen to the results of the research study?

Results from this study will be analysed and presented as part of a post-graduate master's thesis. Results may also be disseminated within the scientific community as a peer-

reviewed scientific article or conference presentation. Your identity will not be revealed in any of these publications. You may request a summary of anonymised results that will be emailed to you directly at the conclusion of the study. Your decision does not impact your participation with the study.

Who has reviewed this research project?

This project has been reviewed and approved by the Faculty of Health and Education Ethics Committee at Manchester Metropolitan University.

Who do I contact if I have concerns about this study or wish to complain?

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/

For any remaining questions regarding this project, please contact:

Paula Moore: **paula.a.moore@stu.mmu.ac.uk**

Should you wish to complain, please direct correspondence to:

Faculty Head of Research Ethics and Governance: *FOHE-ethics@mmu.ac.uk*

If you experience any psychological distress, please contact your GP in the first instance.

Further resources:

Samaritans

Phone: 116 123

SHOUT

Text: 85258

MIND

Phone: 0300 123 3393

Long COVID Guidance and Advice

https://www.yourcovidrecovery.nhs.uk/

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT.

Appendix 5: Consent Form

CONSENT FORM

Post-graduate research study:

Healthcare access for people living with 2+ Long conditions; the impact of the COVID-19 pandemic

Participant Identification Number:

	Please tick your chosen answer	YES	NO
1.	I confirm that I have read the participant information sheet for the above study.	☐	☐
2	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐	☐
3	I understand that my participation is voluntary and that I am free to withdraw from the study on the terms outlined in the participant information sheet, without giving any reason, without my legal rights being affected.	☐	☐
4	I agree to participate in the project to the extent of the activities described to me in the participant information sheet.	☐	☐
5	I agree to my participation being audio recorded and transcribed for analysis.	☐	☐
6	I understand and agree that my words may be quoted anonymously in research outputs.	☐	☐
7	I wish to be informed of the outcomes of this research. I can be contacted at: _____ _____	☐	☐
8	I give permission for the researchers named in the participant information sheet to contact me in the future about this research or other research opportunities.	☐	☐

Name of participant Date Signature

Name of person taking consent Date Signature

Appendix 6: The interview Guide

Welcome and Introduction;

My name is Paula Moore; I am a Post-Graduate Researcher at Manchester Metropolitan University. This study aims to explore your experiences when accessing healthcare pre and post pandemic. I would like to remind you that you do not need to say anything that makes you feel uncomfortable, and we can stop or take a break at any time.

1. ***This is about accessing healthcare for your conditions, what does accessing health care mean to you?***

Prompt: (Accessibility, Affordability, Awareness, Adequate, Available, Appropriate)

2. ***How does having to access HC make you feel? (or not having access)***

3. ***How have you accepted your condition as part of your everyday life?***

4. ***Can you describe to me what healthcare you typically access?***
- How do you access that healthcare?
- What are your thoughts about that?
- How does that make you feel?
- Why do you think that is the case/happening?

5. ***What are the most important reasons you need healthcare for?***
- Are there any specific conditions?
- Do you use regular healthcare on a regular basis for any reason?
- What do you think accessing healthcare should be like?
- What are your thoughts about that?
- How does that make you feel?

6. ***Can you describe the last time you needed to access healthcare?***
- What happens before you go? (from the moment an appointment is scheduled to the moment you leave)
- What happens when you are there?
- What did you do (if things went wrong? Who did you tell?)
- Tell me more about x (clinical encounters, making appointments, understanding of next steps)
- How did that make you feel?
- What are your thoughts about that?

- Why do you think this was happening?
- What are your thoughts about that now?
- What are your thoughts /feelings about having to access it again?
- How does this compare to pre post pandemic? (depends on when example is)
- What happens when you access healthcare today (is that different to before the pandemic and why?)
- Think back to times before the pandemic, do you remember anything memorable about that time? What happened? How did this make you feel then? Have your feelings/thoughts changed since then? (Why? How?)

7. ***How do you know what healthcare you need?***

- What do you need to know?
- What do you think you need to do?

8. ***What is it like to live with your conditions?***

- What is the impact on your daily life?
- What are your priorities? Why are these important for you?
- How does the healthcare provided to you support you in your daily life?

9. ***Have you ever needed to access HC for a specific HC condition?***

- What was the specific condition?
- Walk me through your experience, what happened
- How does this compare to now?
- What are your thoughts/feelings about that now?
- What is it about X that makes you feel that way?

10. **What is it like to access healthcare for multiple conditions?**

- Can you describe how you feel about the healthcare you access?
- Why do you think healthcare for your X number of conditions is the way it is?
- What are your thoughts /feelings about having to access it again?
- What is it about X that makes you feel that way?
- How does this compare to accessing healthcare for a single condition?

11. **What's it like living with your condition post pandemic / today? (sense-making)**

Why do you think healthcare post-pandemic is X (different or similar) to what it was during the pandemic? Or even before the pandemic?

How does that make you feel?

What are your thoughts about x?

What is it about X that makes you feel that way?

Why do you think this is the case?

If your experience had been different, do you think it would've made a difference? (Why? How?)

12. **What other ways have you identified to manage your condition outside of healthcare services?**

- Why/what motivated you to manage your LTC?
- Is there anyone that helps you to manage it? (who, how and why)
- Is there anything, or anyone, who you think could help manage it better? (Who? How? why?

13. **Based on your experiences, what are your hopes for healthcare access in the future?**

Closing questions.

How did you find today?

Is there anything you thought we would cover, that we haven't?

Is there anything we have discussed that you would like to explore in more depth?

How did I do as an interviewer?

Is there any help/support you need after today?

Thank you for your time and participation today.

Prompts

How did that make you feel?

Can you tell me more about….

Can you please explain….

What do you mean by?

What does that experience mean to you?

Which do you prefer?

Why do you think this has happened?

What made you believe that to be true?

Appendix 7: Personal Experiential Tables

Appendix 7A: Table of Personal Experiential Themes PT01

Superordinate theme	Subordinate theme	Experiential Quotes
Theme 1 Undiagnosed condition - emotions		
	Endless attempts to get a diagnosis	*"I was struggling to get referrals because of protein in my blood." Pg.02* *"**he wondered if I got fibromyalgia, but I was never followed up from that."** Pg.01* *"from a diagnostic point of view and he said [pain consultant] I've got what sounded like parasympathetic or sympathetic overdrive. So, I've got that." Pg.05* *"no one looks at anything holistically." Pg.13* *"But there is no test. Right. Yeah. No way of saying yes, that's what it is. It's just a set of symptoms." Pg.25*
	COVID disrupted access to mainstream and private healthcare services.	*"I spoke to him [private therapist] online and he said I can't really do very much [COVID-19]. It was just as healthcare was stopping." Pg.03* *"COVID made it worse, couldn't see anyone about anything." Pg.27* *"as soon as I can see you, I'll contact you and we'll see you again [private]." Pg.03* *"To my cardiology point of view, everything kind of stopped and just had a few phone calls since COVID I don't have those now." Pg.02* *"[2018-2021], Aching joint pains and other symptoms] Yeah. you see, COVID came along, yeah. And that's it. And when you, when I hear now about people who've got post COVID symptoms and I think, yeah, that's me." Pg.06*
	Impact of waiting for referrals between 1-2 years	*"that's why I said I want to the pain management course. And you know, that would have been helpful, but there's huge, huge queues for that." Pg.26* *"he would refer me for that [pain management clinic], but I'm sure there's lots of people and I think the huge, huge list at the moment." Pg.11* *"refer you to a neurologist. So, I haven't seen one. That was January [2024], so I've got an appointment.... the end of January 2026.... It was just over two years, so I haven't bothered cancelling it." Pg.15* *"Well, you feel lots of waste of time into it, really." Pg.15* *"So, I did that [private therapies] and the pain consultant [NHS friend] took me on the NHS then for pain management and I have sort of annual, they're really obviously stretched." Pg.04* *"They were saying you've got to wait six months to see hematologist. And I was just thinking I couldn't hardly move." Pg.07* *"When are you waiting for that like thank goodness, you're on the list." Pg.30* *"**I was paying for the consultations to try and get an answer quickly.**" Pg.02* *"I was really struggling to get referrals because my protein was very high... we've got to wait." Pg.01*

	Trying to make sense of not knowing the diagnosis	*"Possibly I might have been somebody who would have gone that way any, you know, ... I've got sort of my cousins got M.E and so this bit of a family history of things around." Pg.06* *"These [additional symptoms] compounds with things and that's the problem is it is not knowing." Pg.16* *"But it's sort of it's a debatable thing whether it because there's no actual test to say that that's what it is... It's it sits in a bag of unknown." Pg.05*
Theme 2 **A system that is not fit-for-purpose**		
	Getting the right care is a fight	*"in the healthcare system as I see it, for more things **you have to fight** for what you want and and you have to take charge of your health care yourself, which from, you know, working in the health service most your life feels a bit like a slap in the face." Pg.13* *"My GP, there's no coordination. No, I just tried a couple of times to make him listen. **I don't go very often because you sort of lose faith." Pg.22*** *"Then, and there's some Bloods done, so I've got the app on my phone. So, I had a look and most things seem to be OK to me, but I have some knowledge, you know, knowledge of it.... but I thought, well, I'm supposed to go back. What am I supposed to do? Yeah. So, I went back. As you see someone different and and he said Well...basically you're alright. We just think it's tension headache." Pg.16*
	Falling through the cracks due to poor communication between HCPs	*"Ohh. Well, I have stopped taking this. The pharmacist told me to stop taking it and she sent a message through to the GP, but I haven't heard back." Pg.17* *So that's right, OK. I made another appointment, went back, she said I had to come back. And I said because you told me to. Yeah, to talk to you about statins. Ohh. Well, you need to be on that subject line and then just send me a message. So, I sent a message and nothings come back? So, there's like no flags on follow through." Pg.18*
	Desire for appointments to consider all my symptoms	***"And so, the difference between going to see somebody looks like you holistically, yeah.** And seeing somebody who you've been referred to by the NHS, yeah, just for that [one thing]. And you can't see them for anything else. **But that is just a nonsense, isn't it really." Pg.19*** *"[orthopedic consultant] gave me another open-ended appointment. And I said, well, my right foot is really bad. And I said if you look at that and he said no, I'm not allowed, he said the pathways in the NHS don't allow for that anymore. He said, ridiculous as it may sound, he said, I'll write back to GP, and your GP will have to refer you to an orthopedic consultant." Pg.19* *"And I said Well this is I said Well I [will] talk to you about statins cause had two other statins - ah you have to make another appointment for that. I said why? Ohh, no, I can't see you for that. I can't." Pg.18*
	There are no clear pathways for MLTC's that looks at the whole person	*"They can offer you gabapentin. They cannot see you. That's the one that blows your mind [the medication] ... it's not a clear pathway to follow and the NHS is very pathway driven." Pg.35* *"Because it's not anything that it's got any structure or pathways for. It's just care. And it's about people listening to you and it's about people wanting to help you and not just and trying to understand where you're going." P.35* *"And no, no, I haven't [seeked help with depression]. No, I haven't. I haven't really. I don't, I don't really. I don't really talk to other people about it. Yeah, but it is too hard sometimes, hard to explain and it it's just too hard to be able to do it. It just gets weird, just gets wearing and you think you know." P.28* *"There was no cohesive path... it was very scattered." P.02*

		"They go [patients] into the chronic management phase and it's when it goes into that. It all goes wrong. You know, I'm interested and working in the NHS for like 40 years. I did, I can, I could always see that." P.30 *"Yeah well, no, they don't even try that to manage it. It's it's just yeah." Pg.16* *"I think that I think there's a lot of people who are like me who are. Struggling at home with pain and and different things on that. So, I think I think some you know, the pain services need to be holistic and I think and they need to be obviously much better funded. Really. Like, yeah, I don't know what's up with this, but I guess nobody ever will really." Pg.32* *"If you have a car accident, if you have a brain tumor, you know, you wouldn't wish for a better service... But the chronic pain management, the care of the elderly is just rubbish." Pg.35* *"And the NHS hasn't got the resources and the facilities for that. But unfortunately, there's now a lot of people coming down those routes." Pg.35* *"I asked to go on the pain management course." Pg.30* *"I must be on a register for chronic illness. Yeah, so I think I'm on a register for chronic illness. And so, they started. They've been trying to get me on statins. But statins make your joints worse. I don't say stuff. So, I wasn't very happy with it. And also, my cholesterol has gone down, so I don't know why there's one system that has it high." Pg.17* *"At one stage I think a physiotherapist gave me an injection. But you have one injection, you never see them again, you know." Pg.07*
	There is nowhere to go to get help for chronic pain	***"I don't know where to go."*** *Pg.21* *"A&E who obviously couldn't find anything particularly wrong with me and just sent me home to the GP and [GP] couldn't sort out what was wrong with me." Pg.01* *"There's nowhere to go to other than A&E, and A&E is not the place to go." Pg.24* *"[nurse] I've seen the doctor says, well, there's nothing really that we can do." Pg.24* *"And I just could not get out of bed. I could not. And my husband had to help me and to get dressed and go downstairs and he rang the GPS and the GPS said, although we can't see her this morning." Pg.24* *"So anyways, they [hospital] rang up and they said, we'll see her. So, I went off to the GPS and, and, and nothing, you know, they listened to me at that point in time. They did. But I wasn't an accident. I'm not an emergency. Not acute." Pg.24* *"when you go to the doctors, you feel like you're at the nuisance and the, and the, oh, she's got chronic pain management, you know, issues, you Like one of those, it's not, it's not anything that I can, it's not acute". Pg.34* *"And then the doctor [hospital] came in and she said, I don't know what to do. She said, I've asked, I've been to talk to senior doctor. I've seen the doctor says, well, there's nothing really that we can do." Pg.13* *"Well, the thing is, you've got something that's chronic that nobody really understands and that not really gonna make you better." Pg.35*
	The healthcare system is set up to make money not help patients	*"I think it's a money thing right. I think every time you go back, they get £135. or whatever it is that they get for each consultation. And, and I think that's when you go, it's not, it's not heaving... It isn't really hidden if you join the dots because it says every time anyone misses a GP appointment, it costs £135." Pg.23.* *"And you know, I suppose if who's ever going to do that and they're gonna get paid every time you go back, you know, you think so. I went to see the nurse; I went to see the consultant at the GP and then she asked me to go back again and all I got was a prescription for two tablets. Then that could have been done at the same time. She acknowledged tha.t" Pg.23*

	Good experience when have a diagnosis	*"I've just had cataract. Know what I've got, in one eye. And it was **all fixed up in a week**, you know, and I could have, I could have had the operation **practically within a week** because we **chose** an external provider and, and then we just went, fantastic." Pg.13-14*
Theme 3 **Fear of vulnerabilities**		
	Questioning medical advice	*"The other thing was this year my risk factor has gone up. And it's, it's basically because my, I've got a really high family history of clots and cardiac problems with mum and yeah, so I am on anticoagulant." Pg.18* *"[anticoagulants} and you have a choice to not particularly; it was just advised that did it. And to be honest, you know, sometimes you sit there and and stuff like I don't, I don't want to go on these. And and then I actually thought about it as I was talking to, and I thought I actually can't not to know because." Pg.31* *"I just cannot get my head around it at all is I went to see my GP because the nurse said to me your risk factor is gone because you over 65 now. So, you need to go on [anticoagulant] as you have family history. She said you need to go on. And that's why you need to see the GP." Pg.18* *"[anticoagulants} So I, I can't really say, you know, I don't have it. I'm not that down for that today. But sometimes I do feel like all they do is try and make you." Pg.31*
	Medication side effects make feel worse	*"He tried me on really strong painkillers suggested I should try that, but it's knocked me for six and I didn't really want to be starting to take drugs like that". Pg.02* *"And I've tried three different sorts of statins and. It's it makes makes me worse. So, you're not gonna go through with that." Pg.17*
Theme 4 **Living with chronic conditions is a daily battle**	Reduced quality of life/ questions own mortality	*"I think I might have been in bed forever." Pg.05* *"**I keep thinking because I don't, you know, I could be dead by the time we get this bloody place**. But it's taking a long time. I mean, at the time I thought it was two years, you know. That's fine, That's absolutely fine." Pg.10* *" If somebody told me I'm gonna be taking more years. I'm going no thank you. **Why live like this?**" Pg.36*
	Need to make daily adjustments	*"We have got a very active lifestyle. They have to say in all of this, we've travelled a lot, we've gone all over the place with this, but it's always a real push to do it." Pg.08* *"Like today, I can do about half an hour and then have to sit down. And that's really upsetting because you feel like going backwards, you know." Pg.10* *"It's been hampered [walking with family] this last 12 months by the fact that my knee is not very good and my ankles not very good and I thought that my foot not very good and sometimes I can go for a walk, and my foot will hurt." Pg.26* *"Obviously I get, I'm at that stage in my life. I'm getting older as well. But yeah, I, I can't, I would say it's put at least 10 years of my life on my ability to do things. You know, I feel like I can probably do things that what is expected to do as an average of 70 odd year old, mid 70s and mid 60s. And, and I'm just about managing to do them really." Pg.26* *"And Italy, the way that I, he would go around Italy because I can't walk up the hills. Yeah. And I. Not down the hills, you know, restricts us. That's been hampered just purely by the fact that I've got osteo, in my knee and and and my foot turn it in, but it's also it's not. [just that]. Also, by the fact that this general condition also makes it that I get too tired to do it." Pg.29-30* *"And, and, you know, [husband] will say things like, well, I'd quite like to go around South Africa, you know, and I think that's just a step too far for me." Pg.2*

		"can't run and I can try to keep walking. And you know, I do the exercises, but I can't do them every day, you know, so I just have to sort of manage that." Pg.26 *"I've been quite active into my 40s and 50s... it's so painful on the heart. Ohh. No, I'm old. Sometimes it really is hard. Really hard. [cries]." Pg28* *"Hopefully it should be it should be done soon. But you know, if I'll be able to actually do things because I'm a stage now where I sometimes I can potter around all day and I'm OK, sometimes I can't." Pg.10* *"They sort of say, well, we're gonna walk up into town and ask, well, hopefully you are walking, they're walking this fine, I think, ohh, that's too much for me and I'll be in house." Pg.12* *"And sometimes even just dance around. You wanna go... Yeah, yeah, yeah. You know, and I'll do things and I'll get in the car and music [dances in her chair and smiles]. So. And I think this is really good. I feel 20 years younger." Pg.28*
	Not feeling ones-self	*"I bought myself a pair of Archies flip flops. Flip flops with arch supports... I think they have [helped] so, but you can't bring them all the time. So, I put some clear plastic ones." Pg.27* *"And I forgot to mention actually not very long ago I did stop wearing high heels. That's for sure." Pg.26* *"Hate being un-elegant and you know it goes. Guess what's in you have to say you know, you know, it's it, it alters the way you are you really, you know and so." Pg.32* *"We went around Malaysia and all the trips that we did, it was, I mean, cruises [are for] older people." Pg.30* *"You know, I mean, they're getting older as well. Something keeps telling [them]. I'm telling you I am 10 years older." Pg.11*
	Planning the future with caution	*"actually, the first thing I do will be put it up for sale [abroad house]. I bought. To say local hosting service to sell because I actually couldn't physically manage. On my own." Pg.29* *"It is a worry that you can't do things, you know. And so, I just, I just feel that I'm 10 [years older]. He is on that should be really and you know, thinking about things. But anyway, it's just as it is. Isn't it and and you just have to get on with it." Pg.29* *"You know, why are we bothering doing all this [buying a house abroad]?" Pg.28* *"It's hard to finally imagine because you don't know today as well. It is hard to do much. It's hard to plan." Pg.29* *"Sometimes difficult because I've got different expectations and [husband] think we'll be there for 10 years, 15 years and I think I'll be, OK if I get 5, then it's not necessarily because I've got anything that's fatal. Yeah, it's because kind of managed to get there, you know, it's that sort of thing. If I managed to make it look nice [abroad house]." Pg.28*
	It takes over your life	*"And I do I do all sorts of trying all sorts of weird things and I do hate this everything I've got to take for pain management". Pg.17* *"So yeah, it's a full-time occupation. Well, yeah, because it's so varied and so, yeah, sometimes it's absolutely brilliant you know, I just feel alright. Well, not often." Pg.31* *"it's my entire life to try have no pain." Pg.32*
	Putting on a brave face	*"it's not necessarily that I've got a low pain threshold, but I certainly haven't from that point of view." Pg.07* *"It's it's just keeping yourself going really and trying to do things." Pg.06* *"So, I just deal with whatever happens, really. And, and sometimes I look back and I think, yeah, I managed quite well with that, you know, managed really well." Pg.27*

	Struggling emotionally	*"And and it does cause you to be a bit depressed at times as well [tearful]. Really depressed and made a low. And dominate." Pg.08* *"And that's really upsetting because you feel like going backwards." Pg..10* *"And but, you know, today I'm not so good. And so, then it gets you down a bit [cries]. And indeed, it does get you depressed a bit, you know, and I think, I don't know, like, how do you wanna, like, how do you wanna ...All the emotions." Pg.15* *"And and it does cause you to be a bit depressed at times as well [tearful]. Really depressed and made a low. And dominate." Pg.09* *"I feel like I've I've let myself down a bit and I feel like I've let them down because not very good" Pg.10* *"I've just got this altered lifestyle [tearful] that is quite dramatic really, but it's not an acute health scare. So, there doesn't seem to be anywhere for this to go really. There's no support." Pg.25* *"I feel like I've I've let myself down a bit and I feel like I've let them down because not very good." Pg.10* *"it, it knocks you down a bit." Pg.32*
Theme 5 **Private Healthcare**	Someone listening gives her faith	*"That in itself, he's listening to you and actually gives you faith" [private therapist]." Pg.21* *"I do wander sometimes it's just somebody who actually listen to and looked at you in a holistic way." Pg.04* *"To have someone just understand, I know because you think it's because it's so varied, I suppose you tend to be a bit dismissive of it yourself or more. Like, I don't put it all on that it's just that, you know, but if someone goes, I'm gonna listen, you know, let's just have to think about that. You know, it makes a big difference, you know, or somebody who actually believes you and doesn't make you feel like you're nuisance. Cause you do feel like you're a nuisance in the day-to-day today." Pg.34* *"While all that was going on as well, I also made arrangements to go to see a physical therapist who's local, which specialises in pain control and pain diseases and holistic medicines. And it's been absolutely fantastic.... I pay for that. Yeah, it's, it's £50 for whatever he does." Pg.03* *"[orthopedic consultant; feet] Well, it's just it's just nonsense, isn't it? You know, it's it's just like the and the difference is, is that I went back [to the physical therapist]." Pg.19* *"Well, usually when had acupuncture, either not much different for a couple of days or I'm and maybe even a little bit more tired. But then a couple days later I started to get better. And so, I'll see him, you know, maybe every three weeks, 4 weeks." Pg.21*
	Seeking explanations and understanding	*"When I went to see him [Private therapist, 2021]. He said that he thought that it was like either fibromyalgia... or probably have been brought on as obviously I'd looked up things as well. And by the facts of that, I'd had the cardioversions, and it was an assault on the body." Pg.03* *"From a diagnostic point of view and he said [pain consultant] I've got what sounded like parasympathetic or sympathetic Overdrive. So, I've got that." Pg.05* *"it's a bit like you wonder whether people actually believe that you've got something wrong with you sometimes, you know." Pg.11* *"Other people don't identify with it as much as you know, if you say you've got headache, people can identify with that. Or you can say if you've broken your leg, people can identify but when it's something more complex, but even a doctor can't diagnose and yeah, it changes so often. It does. And. And there's no, there's no testable. Ohh, yeah, she's got that tick." Pg.34*
Theme 6 Importance of having a choice	Direct access to a specialist is comforting	*"I hadn't seen him for two years, but I got an open-ended, I can go and see him when I'm wanting" Pg.05* *"I don't mind seeing someone online and I've had telephone appointments with the pain consultant. That's, that's been fine." Pg.33*
	Care that fits in with life	*"So, it's having something that is yeah, that can adapt to your life. It's like, you know, kind of at the time I was looking after our grandchild." Pg.33*

		"You have to help yourself and you have to make sacrifices to do it. But sometimes it just doesn't fit in with what you're doing." Pg.33 *"Then on the other side of town, it was like, it was like 1/2 a day. [to access free course]." Pg.33*
Theme 7 **Impact on significant others**	Feels like she is a burden to others	*"I do feel a nuisance; there's no doubt about it. And it said I always do more than we should. Like, you know, things like that. I feel the nuisance." Pg.30* *"He plans holidays and things, he plans it with the fact that. Well, I, you know, we can't go. We can't go and have a look." Pg.29* *"Feel like I'm holding him back. He's quite able to do stuff, you know, and that's of course, that's like a lot of couples really, isn't it? Well, I think yeah. I mean, it's a bit different when you're in with chronic pain and you're just in your life" Pg.30* *"And the way his [husband] would, Italy, go around... Went by the fact that this general condition also makes it that I get too tired to do it and so it's it's sort of like on on the. Different. I can't do things, and you can't leave." Pg.29*
Theme 8 **Not knowing is a battle**		
	Doesn't know what symptom what is	*"GP about the numbness [feet] and and they were must have been about 3 or 4 years ago and they didn't know what it was at that point in time. And so, I kind of just think. Everything I've got belongs with this condition." Pg.08* *"Oh well, it's [headaches] just. As I do, it's just part and part of this is just a different, a different symptom than feeling anything." Pg.14* *"I thought maybe I'm a bit susceptible to these sorts of things because I've got, you know, it sort of goes hand in hand a bit of a real battle syndrome." Pg.16* *"These last few days I feel really, really bad. But whether that is because I've got some, you know, it could be a COVID type thing or you just don't know." Pg.21*
	Wanting honest information from HCP's	*"My left is no worse and said it needs to do it in, but it's not screamingly needs doing. And because of all the other things, which I can totally understand, he's saying maybe you wouldn't get the relief of it that you really want to get." Pg.07*
Theme 9 **Self-help is also healthcare**		
	Conscious that one thing you do/take can impact another	*"So I am on anticoagulant, so I used to take magnesium, but I can't take that now cause on anticoagulant. But I still take turmeric, and I use them oils as well, which do really good for pain." Pg.18* *"I decided that maybe I needed an arch in in my shoe support, the support options in my shoe. Yeah, so and I thought and I read about it a bit and I found out that actually sometimes it's not helpful" Pg.26*
	Grateful to be able to pay for help	*"I'm fortunate enough that I can afford to pay." Pg.05* *"But I mean, we are fortunate we can do a lot of things that other people can't do from a funding point of view, and you know. Ohh you know, we've got a nice house here. We've got nice things." Pg.29*
	Directing own healthcare to find what works	*"So, he [private therapist] did all those [regression therapies] for me as soon as he possibly could see me. So, I had those and it did seem to help". Pg.03* *"Its [trying different things] got quite hard work. Takes me an hour. Ohh, I'd put that much energy in. But I have to have goals? And guess what? I just try a different thing. If I hear of anything, I think let's try." Pg.17*

		"So that's my goal. Found something that works. Yeah, it seems to work but I'm a Pincushion, but there you go." Pg.06 *"I must have paid. Thousands on seeing people, you know, privately and directing my own care". Pg.05* *"I thought we'll see if I go on without it, you know but there's definitely better with it, although at the moment I feel rubbish [acupuncture]." Pg.20* *"I interrupted the pathway with private consultations because I just didn't know where to go". Pg.07* *"I don't take painkillers, right.....but it doesn't seem to particularly help and that's the reason for not taking it because it doesn't help because I feel that it doesn't help and I also feel that's nowhere to go if it goes worse, right." Pg.30* *"Driver to get that in a in a timely way that way for me. Yeah. I mean, I do wonder how long have gone on if I hadn't have sorted myself out. And I do wonder sometimes if maybe if I hadn't kept pushing [for help] maybe you know, what would have happened. I really don't know." Pg.08* *"When I first had help of the hypnotherapist and regression the pain became much better in my upper body. If I'm tired, it's still aching but nothing like it used to be." Pg.07* *"The turmeric I don't take anything else other than I apply oil and I use. I use, uh, paracetamol on the very infrequent basis I have a I have. Trials of making yourself take it every four to six hours and see if I get better and things like that, but it doesn't seem to particularly help." Pg.31* *"And I'm glad we decided we buying abroad because it would be, I'm better when it's warmer there." Pg.10*
Theme 10 Importance of connecting with others		
	Consistent HCP develops trust	*"I went to my GP and, and it was to be about January time and I've had it [headaches] about four or five weeks, maybe more. And he said, ohh, we'll refer you. So, I told him everything that I had, he looked at me like I've gone a bit [mad]." Pg.14* *"Face to face...you always come out to be better. Because I've seen him and he said yeah. And it's. And there is, there is that there is having that faith in someone as well, you know." Pg.34* *"Because the thing is you see someone different yes every single time, so I looked at him, he looks to me like I got a bit strange and said Well what is it you want then" Pg.14* *"When you see different people all the time, it's. So, I suppose it's something about having someone who you used to consistent." Pg.34*
	Identified with how others describe their experiences	*"Once read about somebody, and they said waking up is like waking up with an elephant sat on your chest. And it is. And you can identify with that." Pg.32*
	Network of connections in the HCS has been invaluable	*"fortunately, and I knew a pain consultant myself, so I made arrangements to speak to him.... I wanted to have some joint injections for the knees, and he agreed to do it almost as a favour really" Pg.02* *"We popped me on the end of the list [pain consultant]. Pg.04* *"I think if I had [not] all those connections, I think it would have been really bad. And I have to say about, especially because I've got those connections anymore at that time, I hadn't long been finished work and I'm fortunate enough that I can afford to pay." Pg.05* *"The pain consultant [NHS friend] is just being a little gem. And I haven't had to pay him at all. And he sorts of bless him. He he sort of just put me on the end of the list." Pg.05*

		"And then when I went to see the orthopaedic consultant who's an absolute gem, you know, and he sort of said to me, how are you? And I said, well, I'm not good and you know. And we discussed money and decided we'd wait and gave me another open-ended appointment." Pg.19

Appendix 7B: Table of Personal Experiential Themes PT02

Superordinate theme	Subordinate theme	Experiential Quote
Theme 1 **A system that is not Fit-for-Purpose**		
	Unmet needs because single appointments are not enough	*"Just because you'll go in and they're already trying to write your prescription as you go in. So soon as I go in, I'll say I've got three things I need. So yeah. And because quite often you can only go with one thing and I said I need to know these three things. I can't leave here again without knowing. And he says need another appointment." Pg.17* *"And sometimes they just want 1, 1 issue at a time...but it's not telling him the truth about your whole body then you just go in cause more than one thing at a time is happening." Pg.17-18*
	Lack of personal care plan to reduce the impact of living with MLTC	*"They [Doctors] could help a lot because sometimes you just need a listening, someone who understands, you know, what's going on because you don't want to burden your family and friends with it. That's what I find." Pg.11* *"Affects your mental health greatly I've found, one having all of them conditions, but then having problems that you can't get them treated or why you can't get them treated." Pg.11*
	The difficulties getting routine appointments or same day appointments	*"They call you for blood tests quite regularly I'd say every three months or so, yeah, into GP, although it's getting harder and harder now to actually get a face-to-face appointment." Pg.05* *"that's really difficult really because what they're telling you is ring up at 8:00 in the morning, I'll be at the surgery for 8:00 for when they open. When you get there, there's always a long queue anyway. If you try to ring up, it will say your #30 in line, we'll get back to you. So, you know you're not going to get an appointment that day by the time they get back to you. So that's really difficult because sometimes you need to see them at the time." Pg.05-06* *"It's come much, much harder [recently]. You can't see your GP when you want to." Pg.09* *"She was saying you might be quicker going to the Walk-in and explaining to me. Your symptom, but for you can't sit there for hours and hours. I just can't do it... she's trying to help me and I understand that, but in a way, it's passing it to us, passing the book." Pg.09*
	Problems having to rely on unreliable community transport	*"The taxis and hospital Ring and Ride, which is a service, a brilliant service that although the, like I said this morning [late today due to the service] that they're not very punctual at times, but I understand why." Pg.09* *"Because they've not been punctual. Yes, I've missed many appointment... You can't stick to stick to the times because they might not turn up. So that that hinders a little bit." Pg.10*
	Feelings of neglect when important follow-up tests were missed	*"There is some really important tests that were supposed to be done and when she was looking through my notes, she was saying things like, ohh, they said they'd call you up in six weeks and that didn't happen... There were at least three things that they hadn't done which were quite important.... That are not followed through... You feel neglected really you feeling you feel worried, you feel scared, you feel neglected." Pg 6-7*
	Needing to fight and be vocal to be seen and heard	*"Yeah, voice it yeah or I write them [GP] a letter, they have to hear it one way or another, right?" Pg.18* *"So, it's about trying to get in front of somebody to keep banging that the drum essentially saying look, I'm here, yeah, I need to see I'm struggling...And try and push it through in that sense. But then obviously that's more appointments." Pg.21*

	Left with no communication or information	*Couldn't tell you to be quite honest [when knee operation will be], I really don't know. just playing the waiting, waiting game." Pg.19* *"Really important tests have not happened. You know, you're sat waiting for the letter to go in and you're not hearing anything." Pg.21* *"And people don't realize you can ask for double appointments and things like that. You know, you've got a lot you need to get off there. And people should hear about that and know that it is available." Pg.18*
Theme 2 **Disrupted and delayed healthcare**		
	Harder to access emergency medication	*"You can't see the GP in time, so you have more times that you have been going through that pain because, you can't access him to get the drugs that you need." Pg.10*
	Multiple cancelled appointments	*"a lot of the times they're saying because it's the way that the health service is at the moment they're inundated with, which I understand backlogs of operations, and I've been for a preop twice. I'm gonna have an op on my knee. I've been twice it's been cancelled...because pre-OPS they do suppose to do a couple of weeks before and apparently yeah and they're just not just ready for you." Pg.12* *"And through COVID and yeah, lack of money." Pg.23*
	Demand means services need to change	*"Maybe they need to open the doctor's surgeries for longer and make it more accessible to myself and especially to elderly people, but to people who can't access to the services find it difficult to access them anyway." Pg.11*
	Paused Mental Health support during COVID	*"No, I didn't actually. I didn't during that time [COVID]. It was just coming near the end of it [COVID], it started [again].... It's still ongoing now, which is a good thing, but it took a long time to access it." Pg.23*
Theme 3 **Impact of waiting for care**		
	Left to cope alone whilst waiting for appointments	*"It means that I'm I'm holding on to things that really could do with seeing too. It's making my pain. Linga um. It's just. I don't know. It's just quite fearful really, to think what it's gonna be like in the end.". Pg.06* *"physio [arthritis], they'll say after six sessions or whatever it might be. So, with physio just try to talk through it and just manage it, try to manage it the best way that I can." Pg.11* *"I'm gonna have an op on my knee. I've been twice it's been cancelled. So, your left on going with the you know that pain and the effects." Pg.12*
	The daily struggles and ripple effects of living with MLTC	*"Those symptoms have proved to you have a knock-on effect on on all the things that are happening. So, it kind of like in a way controls my life." Pg.03* *"So, it depends on what kind of night you have and whether been up since 3:00 or1:00 or things like that, it has a knock-on effect." Pg.03* *"it's not always as painful [nerve pain]. But you are conscious that it's there all the time. It affects lots of things. It's it's affects where I go, what I do, how I live. Yeah. Makes it hard to plan." Pg.11*

		"Tremendous amount of pressure That's on me. But you and and your family feel it, you know, I mean, because ultimately, if you've got family, you're close to, they don't want to see you unwell. So, it impacts on their lives. It's just that ripple effect." Pg.21
	Trying to understand through increasing fear and worry	*"I feel a bit angry and frustrated, although I I keep saying I understand. I think there should be something that helps people with conditions like me and. To be able to, you know, it adds to the mental health problems, things like that, because you worry it all the time." Pg.13* *"You worrying that things might get worse before they get better because of the way that you are..." Pg.13* *"I've had a few falls and so it's important that I do get it done yeah." Pg.13*
	Understanding of her own experience of isolation during COVID	*"I was really isolated during COVID for lots of different reasons, but to live with what I've got is a daily thing and it's it's worrying each day really... and I am getting out now because this brilliant group here [community centre] and got me back into the real world's kind of thing." Pg.02* *"so, through that were on the telephone with me probably about six months, maybe longer and then they told me [about the community group]. So, we've got invited to their Christmas group dinner. I managed to come to that because I was having trouble getting out of the house." Pg.04*
	Fear of side-effects from medication whilst waiting for op	*"I don't want it to get any worse because it's already started kidney problems from the medication that I've had to take." Pg.03* *"You're worried that you have to take all these tablets and they have them. Side effects as well and things like that." Pg.13*
Theme 4 **The power of connecting with others**		
	Having somewhere to go; belonging and trust	*"They {the community group] realized that you know when when we're not coming here, that it's really difficult for people at home. So, they had to drop in [rather than cancel] and I came along to that." Pg.05* *"Cup of tea and aa piece of toast seems like that's all you need." Pg.19*
	The significant role of others is lifesaving	*"They [mental health services] have the befriending group and they telephone you once a week and that was my lifesaver." Pg.04* *"To be heard is definitely important, especially when it comes to your health. Yeah, that's when it comes to your health. I think it's really important." Pg.16* *"I've been groups like this, you know, you know, when I said to Mags, literally when I was getting them phone calls, it was and literally a lifesaver, you know, because you can feel yourself going under kind of thing and I needed something to happen." Pg.18* *"[got through COVID loneliness] Family and friends have got really good couple of good, good bessie mates. Every Friday we sit still now and have a cheese toastie and a chat, put the world to rights and things like that." Pg.24*
	Knowing I am not alone and I am normal	*"But you don't want to come and burden and everybody else. So, it's nice coming and coming and being in the group because everybody's got something." Pg.04* *"That you're not on your own, it's really a big thing.... makes a big difference." Pg.04*
	Finding comfort and benefits from	*"I've seen different faces over the last couple of weeks. Actually. It's been really nice. There are the same faces. But then this. Yeah, different ones, yeah. Makes it like, yeah, interesting." Pg.05*

	sharing experiences	*" it's not that it [public reading] doesn't get you there [puts hand on heart]. Do, you know what I mean, yeah, but you know that people are listening. Yeah, you know, and that makes a difference." Pg.16*
	Sharing of information	*"I think I have through coming to groups like this. And yeah, because they know it's World Mental Health Day you know, all the rest of it. It it, you know, it makes a difference." Pg.18*
	Feeling a burden on family	*"So not that they wouldn't be helpful or, you know, but you just don't want to burden them with it." Pg.11*
Theme 5 **Self-help**		
	Overcoming fears by facing the real world	*"I managed to come to it and then I've never looked back from there really." Pg.04* *"I feel sometimes it's a bit daunting. And to be honest, you come in and sometimes you try not to put on your face, but you might have had a really difficult time." Pg.04*
	Benefits from writing as a way of not holding onto problems	*"It keeps me sane. Putting words down on paper. That's where I get my relief and. Instead of keeping them in your head, a lot of people keep them in their head, and it doesn't do you any favours." Pg.13*
	Milestones are important to managing MLTC; reduce loneliness, give back.	*"Joined an online group which really helped it's called hearts and Minds and we're all over 60 yeah. And we produce radio programs for six- to 10-year-olds called Active Adventure and it's amazing. It keeps you young, it keeps you active, keeps your mind going and that's on the Thursday and and I look forward to it." Pg.07* *"So, these two things are really important days for me". Pg.07*
	Understands she has lifestyle choices	*"I wasn't surprised because it's in the family and diabetes, asthma, kidney problems, running the family. So, I wasn't quite surprised. And I am a bit overweight, and I don't eat the best. And things like that. So, you know, it affects my life quite a lot and in the day-to-day living really and I have to be careful about what I eat and drink." Pg.03*
Theme 6 **Uses experience to help others**		
	Empathetic towards NHS workers	*"I feel really I'm really supportive when it comes to anybody from the NHS because I realized what a difficult battle they've had to face and the fact that they have to ask for more pay and footballers are getting however many thousand and the people who are really helping out there." Pg.06*
	Worry for the elderly who are less able to get help	*"I think about a lot of the elderly and how they're coping. just to be able to get through on an appointment and you know, to go through all the rigmarole that you have to go through to do it. I often think about people who can't converse, and you know what I mean? Find it difficult to explain things and who's helping them." Pg.09*
	Feels a sense of duty to help others	*"By writing that book, I feel like my job is done and I think it makes a difference because I've met many women and men who have been through similar experiences. who don't have anywhere to go to, so they might hear about that book and pick up my book and and feel a bit of relief from it and just a bit of knowing that they're not on their own." Pg.08*

		"And it's just touching other people and making them realize that, you know, the world not what you want it to be. But there are different ways that you can do things about it with the help of other people." Pg.13 *"And it is really, really important to me to get that the message gets across to all the people. So that's how strongly a feel about it because it's too much." Pg.13* *"Over the years done some volunteering for different things that helped me, like I've done volunteer for ChildLine, for Manchester Aid crisis and the Women's Aid. I've always believed in giving something back." Pg.19*
Theme 7 **No faith in the system**		
	The NHS is broken	*"NHS in isnt. They're in erm, they are broken really from all that's going on and. They've not had a good time." Pg.06* *"Because that's the big issue. You feel all alone when you're left, not just by GP's but other caring facilities, everybody's feeling the strain of it." Pg.08* *"Because the government, because of all the changes, because we've left Brexit, because I could go on forever." Pg.20* *"I think it's getting worse. It's gradually getting worse. I see people I know I know it's getting worse I listen to people's stories, and you know, there having things cancelled left, right and center, people who actually I'm lucky, I can get around with my crutches. But there are people who are really, really struggling." Pg.20*
	Disproportionate government funds/priorities	*"Not saying football doesn't play its part, but they absolutely should prioritize." Pg.06* *"And too much money goes on the MP's and expenses and. Money being put in the wrong places and things prioritize. I like a good bit of football, you know what I mean and and it's good for some people, you know, to have something that sport that they enjoy. Ohh flipping ek."* *You're not telling me that nurses and doctors and work all those long hours don't deserve some More money. Why you fighting it?" Pg.20*
	Fear for future generations	*"I'm not sure it's gonna happen in my lifetime. I'm hoping that for my grandchildren things will get better. But the the world in itself is not going to be a nice place, you know, with all that's going on, global warming. And everything else and, and you know, it's our children's children, who are gonna realize the impact of that which is happening now to us but it's gonna get 10 times worse I'm sure of it." Pg.07*
Theme 8 **Positive experiences when accessing healthcare**		
	GP signposted to Mental health services	*"My doctor's been absolutely brilliant, and I've got a psychologist who's absolutely brilliant". Pg.04* *"Mental health services and they sign post you to different things that help you cope with your needs and so that that's quite helpful. Yeah, it's really helpful. The fact that I can sit and talk about it because I wouldn't even talk about it at one point, but I can sit and talk about." Pg.13*
	Thankful for community transport	*"That [ring and ride service] makes a difference for People who are not very mobile...it means that you can access things you wouldn't normally be able to access". Pg.10*

Appendix 7C: Table of Personal Experiential Themes PT03

Superordinate theme	Subordinate theme	Experiential Quotes
Theme 1 **Mis-diagnosis**		
	I became an experiment: Trial-and-error medication	*"If you do this bad identifying the issue, yeah. I don't ever trust your solution. Then that's the other thing, you become an experiment. That's the thing with the NHS; I became an experiment." Pg.08* *"Given all sorts of prescription drugs that I never should have taken and then get to the [lupus] diagnosis at the end." Pg.01* *"ohh you got a new skin infection so try this and then just layered me with ohh Try this steroid cream, try that steroid cream, and all they do was peeling skin they layer of your skin off all the time." Pg.02* *"Many of which made me feel like absolute rubbish." Pg.03* *"Nothing there's none like that definitely works. It just doesn't work." Pg.03* *"Was very frustrating in terms of try this, let's try this. In the meantime, keep taking this, but it was it might have been two weeks. For two weeks or whatever it was and then don't take any of that, take a month of these sorts of things." Pg.03* *"They're merrily going. Yeah. Try that. Try this." Pg.04* *"I took for 18 months and at the end right at the end they said you never should've been taking that, I'm sure that's affected I'm hearing to this day." Pg.04* *"I just could just tell and headaches they gave me were just horrendous. They say Stick with the process and all this." Pg.04* *And we got to the point of diagnosis was at [local] hospital. dermatology. And I sat there and she went, right. it's definitely lupus.... So, this time I'm still taking medication every single day.... You should stop taking them, you should never take them, which I've taken since biopsy from the year before as their solution. Something like you never should've took them...Alright, she said, so what we do now is we're gonna start a whole new regime of pills for lupus." Pg.12* *"Is is wrong to me. On the thing of it [medication] might help and just because they have the leaflet in there that expands the size of your tele that's always, so they can't be sued, that's just big pharma covering their backs isn't it." Pg.07* *"At that point, they made me groggy is probably the best description while I was coming off that stuff [wrong medication] I've been on for so long. Three months maybe, well it all gone out... And, then I started noticing my hearing is rubbish compared to how it was before." Pg.15* *"Ironically not taking the pills. And it flared-down. So, they really, really weren't helping. The supposed cure was actually aggravating it." Pg15* *"Dermatology.... But the guy there basically runs the unit at [the local hospital], right? So, he was. So, then he was like, ohh, yes for £400 I can fix this in 2 weeks for you. Sort of nonsense. Well, you could just go back to your GP with... Because when you go to the private one's your GP needs to say you can go.... so, I'll send this back to GP to get you on this form of stuff to use in the shower. And there's all sorts of variations. And I was like, OK, so so anyway, that was complete red herring." Pg.03*
	Side effects of wrong medication	*"It's not even worth to do it, it makes it even worse as it were but just eating away at your skin but then over time, even if it's like, ohh, you've cleared this bit up. Well, you're left with the scar tissue." Pg,03*

		"And I can tell you without even looking necessarily immediately where there is scar tissue, like here, here and here." Pg.02 *"So, I used to have bat type hearing... now I've got a permanent sort of like tinnitus, and my hearing is really, really dull and that was never like that until I took those pills." Pg.04* *"So particularly because it was flaring here [due to blood pressure medication], around my jaw and my teeth. So, like around my jaw and in my teeth, I dreamed about pulling my teeth out. That's the sort of pain I'm talking about and that's what it felt like, the pain and he said need to start taking blood pressure." Pg.09* *"it's like the minute I got chest infection, and ear infection. 8 weeks ago I think it was the last week of September went to the doctor and got diagnosed and some antibiotics, which I've taken that many antibiotics in my life, that they have to well I have to take a lot know for them to actually do anything. They haven't got rid of it, I'm still infected." Pg.20*
	Impact of the COVID-19 Vaccine	*"The second one [vaccine] I had. I wanna say around March or May and that did me for probably four months in in terms of walking up until that point. To the point I had the booster one, I think it was the booster one, I would do easy 35-40 thousand steps a day and for a good 4 months and in the summer as well, it knocked at least 10,000 off, I just didn't have the energy.... but that to me was to me was a big impact because I'm not getting that in, it's a negative and negative impacts on general well-being, frustration of I could do it before I can't do it now can only be from that. We are in the good months, it's light, the weather is as good as it gets. it's not like now [dark, winter]." Pg.30* *So, I linked it to that. So, when I had the, I think the third. I put a good stone on after the third one... knowing how I felt afterwards [would have declined the vaccine]. So, I couldn't have known it in advance. So, it's an experiential situation... But again, but that whole fatigue combined with the weight gain was like. I was good. I was good. This is just very disappointing and annoying." Pg.30* *"Then let's say from the COVID, even now, I still don't get the numbers that I was getting [steps walking]. I don't have the energy." Pg. 34* *"Yeah, yeah, yeah, definitely. And to be fair taking vaccine. Which I wish I'd never taken, to be fair. Definitely, wish I'd never taken. Particularly the 3rd one, the 3rd one has proper done me." Pg.29*
	Stress and feeling down whilst waiting for an accurate diagnosis	*"It took 2 and a bit year of misdiagnosis [lupus]." Pg.01* *"I went 2 Decembers on the trot, could've been 2016 and I had one 2017. Anyway, they call them plunge ones [biopsy]...they go into your cheek and plunge, the first one was inconclusive, they stitch it back up and away you go. Then another year of try, this and try that." Pg.05* *"But just this entire period of time feeling very ill, and then at the same time you've got your life going on, then it was just a long time to feel.... With feeling like it's not, it's not even... What's the solution? So, you've not identified a problem." Pg.07* *"It took far too long. Umm, and the notion of just handing out pills like Toffees." Pg.07* *"Negatively, negatively, a strain all round really and feeling down a lot." P.08* *"That's the thing, see, when you start, you got ooh, it's ooh its rosacea, that was all about Rosacea treatment. Yeah. So actually, start down all these things they will go with common stuff first. It must be this or that or the other." Pg11-12* *"And also, there's an inner peace to just knowing [diagnosis] because the stress of not knowing is a stress your body... I'm very, very, very, very unbelievably peaceful at knowing as I say I don't and that was my whole point. just tell me and all the stress of not knowing was so bad for my body, because stress is bad for the body. So, I do as much as I can to not stress about stuff for the same reasons." Pg.19-20* *"It took too long for the lupus too, so much other damage to get, so I don't know how it would be if diagnosed in a much more proactive, in three months. Rather than 2 1/2 years, who knows." Pg.33*

	Various healthcare professional in the mainstream system didn't know what do	*"At the time way back when that started, they never got anywhere near lupus as an idea because the conversation I always had with the various doctors was like they never even mentioned lupus." Pg.01* *"back then you actually got to see a doctor so I need to see the doctor but you don't see the same doctor at the surgery, but then you know the next time gets into the nurse, whether it's practitioner or whatever, as it is and then after they all got fed up." Pg.03* *"GP perspective they were like, we will just refer you to the hospital then [dermatology], she said because you've seen somebody from hospital now. So now you're in their sphere as it were." Pg.03* *"I remember reaching the point where I got somebody rang me up. We've got team meetings on Wednesday, and we're all going to sit and talk about it. It's like quite a long way because like I said, we're not going to get anywhere, we can tell you are frustrated. So, then after that they were like, let's do another biopsy, alright? OK." Pg.06* *"So, I took some [blood pressure pills] and it just flared, it flared my lupus and. So, the lupus would come out worse, and the pain will be worse. So, I said I'm not taking them. He said try these ones in the two weeks, same thing, I'm not taking them, I'm not taking them, So, then they start...well you're refusing medication. But yeah, so because until you give me something that doesn't give me this pain. Then we think that your your hypertension is more important than your other symptoms. You know, you need to sort your heart out." Pg.08* *"This time it was try this and try that from a consultant from this hospital for like every Three or four months turned up and somebody else some different again." Pg.05*
	Abandoned during and after COVID-19	*"[COVID] It almost returned to ah you need to come and have you check up for this. So, the first time I went to was December 2022." Pg.28* *"Even if for some reason they push me back to the consultants in the next 12 months, the next 12 days, to have the blood test from the consultant again. I would be like it taken you months now and I'm still not taking your pills." Pg.21* *"But you get texts of them, you're due this or ring us up about that. So, all that just stopped [during COVID]. Because they didn't know what they were doing so, that's fair enough. I get that, I'm at peace with that." Pg.27* *"I was in Group 2 because it was a combination of the diabetes and the lupus. But all that seemed to do was get the COVID stuff [vaccination] quicker. Yeah, the [groups] didn't seem to have a tally with anything else on GP." Pg.28* *"You have to stay have these bloods, and we will check your organs. I've not had it done since COVID.... But it was every Six months." Pg.14* *"I've never seen anyone for the lupus since [COVID]. I've had conversations with my GP when I've been about other things yeah, and they say oh you have lupus. I'm definitely in the proverbial cracks of any sort of monitoring for my lupus." Pg.18* *"The supposed release back to the GP, which you would then assume if you want to apply logic to the notion should trigger something like GP to go you're now back with us for this so. We will contact you about this, but that's never happened." Pg.18* *"[during COVID] The only thing that, the only, that you had to do or engage with was repeat prescriptions...That was the entire COVID conversation with the GPs of how you get your prescriptions?" Pg.27* *"As a world we got further more into COVID and you know the whole you know, you don't go out, you stop in, you do this and that, they still like very much standoffish and still don't send comms... It was very that that was like just abandoned basically." Pg.27* *"pre-COVID, you'd get summoned every year for a diabetes check. But that all went out the window for a good two years in COVID...they abandoned ship on everyone during COVID. The notion pre-COVID was very much. You got to come to this all the time. We need keep an eye on you. Yeah. And for two, years [stopped]. When they eventually did. I don't remember the date, But I remember getting a phone call. I said I thought, you thought I were dead. Well, no. You know,*

		we're trying to get back to normal with it now, but you know you abandoned ship on everybody." Pg.18 *"In some respects, it [COVID] was great because you were left alone and not being monitored, which is kind of like, I had no problem with that at all, it was great." Pg.19*
Theme 2 **Living with long-term conditions**		
	Visual condition effecting appearance and self-confidence	*"yeah, so it was like a blistering, a skin blistering, it all started on my face and then in my beard line and ear and then moved around my face." Pg.01* *"Another biopsy at Christmas. So, you're walking about with a big plaster on your face, it's like the work Christmas do. I'm not going because all I will get asked about is what's up with my face... it was it was a horrible time which again, you know. They don't consider that... kind of like a self-conscious situation all the time." Pg.10*
	Daily disruption to day-to-day quality of life	*"Part of the reason that I don't wet shave ever, because as was doing it, it brings like these blisters that surface and makes the lupus active." Pg.01* *"It sounds stupid, but they gave me a shampoo, wash thing and was like try this Try that, try another. Yeah. So, there's no there's no hiding from it." Pg.11* *"I was going to go away June ... But I felt that ill I cancelled.... Well, that I was going for the heat because I would have been the week it would got completely rid of it [infection/cold] ... it's a permanent impact". Pg.20-21* *"And then the idea of trying to get the minutest bit of its [cream], just onto the bit. It's impossible to do, even if using cotton buds and stuff because, you know, in bed you roll over you take your top off. You do anything, you're rubbing your face, aren't you?" Pg.02*
	Effects Mental wellbeing	*"And so, when I get ill it becomes very like depressing. Because I'm 8 weeks into this now and it will carry on now because its dark weather and rubbish like this." Pg.20* *"We haven't had any sunshine for Three weeks and a bit of rain. I'm a bit fed up but that's more a time of year. I'm not fed up because I feel ill. just a general like mmmmeh." Pg.31* *"Then they start going what about blood pressure, you seem stressed, what about hypertension. And I say well you would have [high blood pressure] if you were in my scenario.... bone pain, one of the pains I get." Pg.09* *"Yes, but I'm going to pull my teeth out taking your pills. I don't want to be alive. I'm not arsed about my heart [offering Blood Pressure medication], to me that top trumps." Pg.10*
Theme 3 **Lost trust and faith**		
	Initially trusted the process	*"yeah, it took a long time and a lot of, from my perspective, trusting them to try different pills to then over the process of this two- and a-bit years be told different things, different people. Before eventually getting to the lupus." Pg.02*
	HCP's contradicting each other	*"And she [a new role in the GP reviewing medication] went I would never like, put that in my body shouldn't have it for more than two weeks. Six weeks on the trot?, yeah, that's not right... So then with things like that you start to think, why am I believing anybody." Pg.04* *"I was talking to I mean the consultants probably he's more of that [experienced]. He's got like lupus but the other ones where we've done a biopsy – no he has not." Pg.08*

		"So, the notion of just being in the system and of yeah the NHS, clap your pans and all that – you start to think erm OK, Well, I've been taking stuff that this woman is telling me she would not out that in her body." Pg.04 *"Yeah, you just get an appointment through the post to go and see the consultant but yeah, so basically at point in time, I'm just – I'm done with you." Pg.14*
	Lost faith due to prolonged diagnosis	*"Like nobody, has proved me wrong on this. My understanding is that, The caveat is that diagnosing men with lupus is very rare comparable with women, which is part of the reason, no one has said it directly, you know what I mean." Pg.08* *"If you do this bad identifying the issue, yeah. I don't ever trust your solution." Pg.08* *"Well, again, at this point you're 16-17 months into feeling lousy and again, from that perspective, that faith was already lost, in what they're offering anyway [2nd biopsy] ... So, you're probably lying to me anyway, you've probably not had the meeting sort of feeling. Yeah. I feel like rubbish and you're doing nothing to help, so tell me whatever you want, yeah whatever sort of thing." Pg.06*
	Incomplete information	*"I said no I'm not taking them [life-limiting lupus medication]. So, did she offer that information? No, I found it and I questioned her, then obviously ethically she couldn't lie to me and say no that's not true, if it was an absolute fabrication. She could've said, where have you read that, that rubbish. She didn't do that. She went for the, well there is break-throughs all the time." Pg.13*
	Trust the private HCP's	*"Because they're [chiropractor] looking at entirely different, in my view they are not looking at the textbook in the same way as other NHS look at the textbook, they look at a different book that the regular NHS don't like look at." Pg.27* *"[GP] Because you should've seen her face when I mentioned the Chiropractor. Because they don't all like them, it's like you've been to see a witch Doctor. [laughs] didn't say it, didn't have to her face said it. And I thought, I believe him over you to be fair." Pg.27*
	COVID-19 disruption to routine appointments	*"No, it's was literally like, NO we are not doing that [routine appointments] It was just we'll talk to you if you're ill, like colds flus. Sort of whatever. Yeah, we are dealing with that and that's what we are dealing with. They will have been doing cancer patients and all the rest of it." Pg.28* *"I was in Group 2 because it was a combination of the diabetes and the lupus. But all that seemed to do was get the COVID stuff [vaccination] quicker. Yeah, the [groups] didn't seem to have a tally with anything else on GP." Pg.28* *"The beauty of COVID it's almost my own fault. I got an appointment for the Christmas 2019... So, I said I'm not going for check-up at 4pm on Christmas eve.... New year's eve, same thing. I'm like, I'm not coming, it's not happening again, family, life Christmas... OK, fine, April the 24th, 2020.... [COVID} well that's not going to happen is it so I ring them up and say I've got this appointment, but you guys will end up cancelling this aren't you... She said, I don't know what you mean you mean, I said, you will end up cancelling this appointment. I'm trying to be proactive here and say where shall we move it to and she's going you can't cancel 3 on a trot they will kick you out of the system and send you back to GP and I'm like but you're going to be cancelling me. So, I'm just being pro-active ringing you up. No, no that's it I'll refer you back to your GP, That's it, bang [phone down]. If I hadn't bothered, I would've got a letter I imagine somewhere in amongst all the COVID.... you're no longer with our consultant, go back to your GP. And to be fair, I sort of laughed and said Yeah, I'm not surprised by this beautiful level of service." Pg.17*
	Depends on the experience of the HCP	*"You end up feeling alright. I believe now that it's not about the individual people necessarily it's their job, but they have a variation of mentality of the mechanics." Pg.05* *"But that's the nature of anything in any walk life, isn't it? I appreciate that experience is a thing and that fair enough. Yeah, that's that's any job that is one that's fair enough." Pg.08* *"My last actual visit with the nurse was like a week ago and we had quite good chat about it, which was more informative than any chat id had with any of them for about seven or eight years to be fair. But again, she was very experienced." Pg.22*

	More faith and trust in established pathways and honest conversations (diabetes)	*"But because while you're there you're chatting away, they ask ask these questions, right, OK. [GP surgery] I can't remember, but it wasn't for anything that I was associated with diabetes. And so yeah, they were like start you in the world of diabetes." Pg.24* *"[diabetes] whereas the metformin it just permanently is regulating how you lose processed stuff and how you balance whether you have food in you or not. That's why it's not really what's its designed for, but it works really well." Pg.21* *"[diabetes] nurse check your feet. I've got a foot appointment every year. Then you've got to go to the health centres to to check your eyes for glaucoma. So, you got these annual eye test. So there all the tests that you go for that are a by-product." Pg. 24*
Theme 4 **Self help**		
	Understanding my conditions	*"By this time because they're gone on about lupus so much, I started googling not googling, but the decent articles... Basically you're gonna pump me up with the treatment you give somebody that's had transplants, which is anti-rejection, so you don't reject your organs. That's what we do... I said yeah, but I've looked at that and once you start them drugs, you've got 10 years. And the response was Ohh well, well, there's advancements all the time." Pg. 12-13* *"I'm Alright with that [diabetes, 2013], that's pretty easy... But at first, I was taking two or three metformin every day, which is one of the options they give you. So, the metformin wasn't designed for diabetes, it had another different purpose originally but turns out to be good to help you regulate insulin." Pg. 21* *"But, over time on like Diabetes UK and just talking to people." Pg.22* *"I interpret the lupus, is my body doesn't know that I'm ill, so it's not fighting, but in the meantime, it could think this finger is falling off, so it sends all the blood cells to this finger and not to the organs. Yeah. And then it ends up breaking down the healthy organ because it thinks something wrong with healthy organ in the meantime because of the infection." Pg.20* *"because of the nature of what lupus is, my blood pressure would go high anyway. Because your body doesn't know when you're ill and when you're not. That's the key thing about lupus." Pg.10* *"To be fair I am 10 years into it [diabetes] so it's not a problem. As long as they give me repeat prescriptions it's fine. Yeah. So just like, anyway, so it not like I'm a newbie." Pg.28*
	Finding what works	*"[showing pictures] You know, here, this is like August it was sunny part so you can't see it then because of sunshine. Ohh yeah. Because of sun helping." Pg.11* *"Holistically stuff, mindsets, going to be out in sunshine... I take vitamins. When I got the diagnosis, I take a lot of supplements for skin. One good for deoxidizing stress. And skin and I take loads of Vitamin E and D and K2. Loads of that. Loads of immune stuff. So, I do have a healthy, expensive vitamin habit...walking, fresh air and getting out and sunbed and recently got a steam sauna. Which again. You know, my research said it's good for your pores, but also again, for blood pressure and cardiovascular systems and what have you... Good diet as much as possible." Pg.19* *"People are all different because obviously, you know, different. But regulating what I eat and drink, I have no problem with it. Particularly like when I'm on my own whatever. It's an absolute doddle. What is a pain for is breaking down fat and staying lean ...Just change diet really and and then even when with family, whatever, just like I'm not going to eat that, I'll eat something else. But a lot of people can't do that can they...Knock all the white stuff on the head and then all you end up doing that is going into the system, of right, we'll see." Pg.24* *"It's another reason why I like to the chiropractor because they are very for me a bit more inquisitive and out of the box. and you get the other NHS. By the way, last time to see GP around this chest thing and this GP she was pleasant enough. Because you should've seen her face when I mentioned the Chiropractor. Because they don't all like them, it's like you've been to see a witch, Doctor. [laughs] didn't say it, didn't have to her face said it. And I thought, I believe him over you to be fair." Pg.27*

		"today I was [at work] at 7am and I came away from the office at 12:30 to get 40 minutes of walking in daylight sort of thing ...people that just walk around town or walk around where your offices and that's fine, but I had to push it like Vitamin D, even though there is not so much sun out, I need as much skin exposure you can get to actually absorb it and walking around dressed for work, where you're not getting any. Yes, you're getting the exercise from the walking, but in terms of exposure to actual natural light, you're not getting it... we have flexible way of working ..." Pg.32 *"I will walk in the dark. But it's a harder slog. You know, it's not just, I mean, I won't go out for 45 minutes now. If it means I could jeopardize the next three weeks and cause some sort of injury, that would drive me insane... instead go I'll go on the cross-trainer and do it that way." Pg.33*
	Questioning medical advice	*"They [consultants] ask me how I am and have interesting conversations about being in and not being in the sun and just take my bloods to see if its spreading." Pg.15* *"And, then what I have found throughout the entire process, is that they do not like it when you say no to them. Any NHS profession, be it reception, the nurse, nurse practitioner, the new GP, the experienced GP, the consultant who's on the £500 a day who's not bothered about anything. If we said no. They all pull the same face. Because they know better and again, I can live with it as that's how they're trained to be and they also deal with people with very low IQ all day long. So I get that as well." Pg.13* *"She said are you not concerned with your blood pressure, I said no, I'm not taking it...This is part of the reason I walk so much." Pg. 13-14* *"And it was very much like, no, screw you [consultant], I'm gonna start again and spend loads of time in the sun. It's part of the reason I go to the sunbeds. To actually manage the lupus". Pg.14* *"[diabetes] They over hall your diet.... They send you to this thing called Desmond, which is like a a support group of food, because again, you're in a system now, you got to do this, you do that, you do the other. And, I came away and was like, I'm not doing it...but Desmond the first it does is say to you every day start your day with a bowl of cereal and milk....Why on earth, when you're trying to regulate your sugar would you start your day with a Kellogg's bowl of cereal? But that's the NHS idea of how you can fix it and start your day." pg.22-23* *"Some of it I didn't follow [laughs], but yeah [diabetes]." Pg.24* *"You're telling me my sugar is through the roof, but then the first three groups you're telling me to eat, I know, are high sugar in terms of quick impact, they're not feeding you up throughout the day. It's not like they say you have porridge or have shredded wheat, or something more low release. It's almost like...they are encouraging spikes. To me it read like, have a big spike but then you'll take the pill. So, then that'll see you through 3 or 4 hours or whatever. They have this notion of like little and regular. Have a bit more, spike, then have another pill." Pg.25* *"Yeah OK, but it's like BMI. But nobody is the same size as they were in 1967, when this started. It's been around for a long time hasn't it, it's meaningless. But on the BMI chart it shows 11 stone, and you should be dead." Pg.26* *"And, when things are based on... we've done it like this for 25 years. Yeah but no. We still have evolution and the rest of it, you know, so I think that's where it does come from, the mind set of people who do this and do that and then have whatever for their tea. We'll get off all that. but I didn't do that anyway. I always cook and have an interest in food. So, you read and see its nonsense." Pg.26*
Theme 5 **No faith in the System**		*"Conversations I've with a lot of people, family, friends, all the rest of it. Once you're in the NHS system and you understand it, it's very different to people who aren't in the system who say NHS is great." Pg.06* *"Because it's a virus and they are just doing their jobs. Good. Well, or badly, but just because they keep turning up to work every day in COVID. It's their job. They don't stand up clapping the army for doing their job, or the police doing their job." Pg.17*

		"Yeah, you just get an appointment through the post to go and see the consultant but yeah, so basically at point in time, I'm just – I'm done with you." Pg.14 *"And, as more time goes on, you're not allowed to say anything negative because you are then anti vax or whatever, but there's more and more speculation about what these things do...So it basically changes your DNA doesn't it and your function... but what I've seen, the way that they're built. If they try to push those drugs out, they'd never get FDA approval. But given the scenario they got approval." Pg.31* *"I'd stop throwing money at it like that is the solution. Because all the, all the. Every consecutive government seem to do, Ohh, NHS needs more money. There's no its badly managed. If it was private. Any private organization couldn't just have continuing money thrown at it when something isn't right". Pg.33*
	More faith in private healthcare	*"It's another reason why I like to the chiropractor because they are very for me a bit more inquisitive and out of the box. and you get the other NHS....And I thought, I believe him over you to be fair." Pg.27*
Theme 6 **NHS system doesn't care about my needs**		*"I say to people don't get in the system. Once you're in, it's a battle to get out, because you just fall into these brackets of well I'll see you're here and then you go away and whatever will happen happens and I'm not due to see you again until here and then that's how the system government ..in the system that is used to tick a box." Pg.06* *"But when you say no to things it's like, well, who are you to say no to us? It's my body, I'll do what I want with it. You've pumped me full of rubbish for over two years on a whim, I'm not taking it. And she was like, oh, you can't, and I said I can, I just won't put it in my mouth. Simple as that. Oh, oh, oh, and they don't know what to do then, because they just want to move you in the system." Pg.13* *"No, I never went to the group, I got the pamphlet and threw it in the bin. And, said I'm not doing that. It's like joining holiday clubs, have one of these pamphlets, have a nice time [laughs]. Yeah, right sound. Erm No. Next one. No. Next one. No. 3 in and all in the recycle bin." Pg.26* *"See if they are actually pay attention because they see that many people or whatever. It's just this conveyor belt." Pg.05* *"if you do not make a fuss, they will let you carry on doing nothing forever and you got to start saying I'm not an idiot, I'm not gonna go away, I will complain. I will keep coming back to you. See if they are actually pay attention." Pg.05*
Theme 7 **It's my choice**		
	Directing my own care	*"No, we didn't even get to a prescription [lupus medication]. So instead, what happened was the the agreement shall we say, was go to the blood clinic in the hospital and this is pre-COVID when they had the forms. Not the printed out ones, it was like a completely different form, not like the ones you see in the GP. It was a Brown form, It had all these tests on that I've never seen before. She said in that case what we will do, is every time you come for a consultation. You have to stay have these bloods, and we will check your organs." Pg.14* *"To be fair, I've got them blocked. [NHS text reminders]." Pg.27*
	Choice taken away	*"I found that annoying because it was kind of like I should've said, no [COVID vaccine] ...But again you couldn't just say no. Well, you could but if you did they say say you can't do this, you can't do that... Well, you couldn't go places you if you didn't have your stamps. You couldn't go away. Because I wanted to go away in the October and I went away October two years ago. That's part of the reason [had the vaccine] I had to be able to actually go and get through the airport because you have stamps [to get some sunshine to help the lupus]". Pg.30*

	Protecting family and friends	*"About that, yes because it would be start taking the pills [life-limiting medication] and then I'll say no because I'd be dead in 10 years, which isn't really conversation when you're like 38 and you want to help your partner? Because again, if we talk about 10, We could all die tomorrow, it is what it is. But anyway, but the notion of 10 is, there's no telling you what the 10 years will be on like when you're on said pills, but I imagine the last five as much fun as the first five." Pg.15* *"And, rightly or wrongly, I didn't really tell anybody. I didn't tell anybody actually. It became my choice. [Girlfriend] knew a little bit, the kids knew naff all other than the visual. And I never told her full details about the 10 years and that's that, not that it matters now [single]." Pg.14*
	Comparing myself to others	*"But I can appreciate how for lots of people who were the newbie [to a long-term condition] or undiagnosed who knows or not. So yeah, it [cancelling routine appointments] would've been terrible." Pg.29* *"I know who they're miles further down that that and age-wise not dissimilar. One girl is at the top of the Kidney transplant list, so her liver and kidney function is at 12% or something ridiculous. She's buggered and I don't what to be like that and People will go, well you'll end up like that, but I say no she's been taking their medication. I don't wanna be like that and that in that part of the system. That's not a life. I feel for her, you know? In her scenario and I hope she gets new kidneys. But, even when she does, they will pump her full of drugs to not reject them. And then what does she get, another go, a reset of the 10 years, well no because her liver is paggered as well. Then she's gonna move around the organs." Pg.21-22*

Appendix 7D: Table of Personal Experiential Themes PT04

Superordinate theme	Subordinate theme	Quotes
Theme 1 **A healthcare system that works and I can trust**		
	One stop shops for all routine checks	*"[hospital clinic] that's where we go for my transplant checks.. For all my checkups, even for diabetes, Yeah, even for eye screening and all those things." Pg.13* *"So, the results, whatever they get, you know, they share with the diabetes clinic. So to make sure. So, if there's a false alarm, then they need to contact me, OK, and speak. They've given you an appointment about ABCD. Yeah. So, I have to go to diabetes. Yeah. So whatever they get there, they also share with them." Pg.17*
	Feels good and relief from being informed and advised by the GP and via the app	*"Knowing my conditions and also advice from the doctors, you know, they just said they were talking of people with chronic diseases. It was like this thing [COVID-19] was more for us than other people... But it just so happened the doctors, yeah, they also managed to call us. I don't know. I was phoned myself and I was informed to to take extra caution." Pg.06* *"Because we have been advised here [in the UK] the pharmacies, they're closing in everyone, so they give us three months medication... Yeah, yeah [good that got the information]. So I had lots of medication in the house and I also I wasn't sure myself of this situation, so I made sure I collected yes, my medication for the three months." Pg.08* *"I've been well informed, well informed and nowadays, I think they've also tried, you know, there are some certain eye screens that we no longer need to go to the hospital, yeah, we, we go in and around here. Around [football] stadiums for Cancer screening for this and that. So, because our health, as in my health, is monitored by my GP. Yeah, right. So, he's [GP] the one who directs me. So when I'm sent to those services [community screening], they are the ones who determine whether I need further scrutiny and then I sent to hospital for further investigations." Pg.18* *"To get to to get the results of your tests, usually it's the same day... So, if you if your blood in the morning. Usually around 3-4pm, yeah, there we have sent, they've got an app where they put your results and you are the only one who can open, you know, and then access the results... of course, a sigh of relief. Just feel well, yeah, you know, [sighs, happy] you feel it's OK to feel well" Pg.15*
	Access is harder now than it used to be	*"Super easy. [registering for a GP in 2005] Not like what it is now, you know. Yeah. You have to wait for weeks and you need load of paperwork and you know that kind of thing. Yeah. Once we give the address. And that, that's what they wanted. But now they, they, they want a lot of information. Yeah.". Pg.19* *"And then you know what happened from there it will take ages for somebody to get an appointment, right? Be it at the GP. Or at the hospital, OK? Because this thing [COVID-19] continued". Pg.10*
	Likes to stay informed and knowledgeable about what is available	*"So, it's I discovered that, uh. You know, because of information now, access to information I have discovered that ohh instead of me booking with the GP [for Flu and COVID-19 vaccines], they do walk-in jab here.... And the van was in the back [of the community centre] ... I saw the van was here and then I had a jab. OK, yeah. And then they said ohh, if you want coffee or tea, just go to floor 2. You know, and then, um. Oh, oh, I came here. And the day that I came here. There were people from the chemist. There were people from waste- away. There were people from Nuffield Health. Yeah, right. So, there was some activities going on. Yeah. Right. Which coincided with the jab. ...Who would inform you of what they do? Yeah. So that's when I picked up that there was this well-being group, yeah, you know, around my area because I've known of diabetic groups, I've known of, you know, I've been to all those and here, I also found that that no, you actually meet a lot of people, people who can advise you on debts, people who can advise you on their energy bills with, with people who come here and talk to you about all sorts of things, you know? .. If you're not sure of anything, this is the*

		place to be because they're always sign post. If they can't do it here, they always sign post you." Pg.20 *"[transport system] moving around Manchester is is not much of a problem. Now there's every 10 minutes you are sure; you know that you get there somehow." pg.23*
	Trusts the system will supply what is needed	*"I'm still going [to check-ups]. It's all up to them [GP] Yeah, because I don't phone for an appointment. OK, but they give me an appointment. Yeah. When I'm due". Pg.16* *"They said whatever happens to your eyes we will never operate them because we are lucky in that at least you still got a bit of sight". Pg.03* *"Then whilst when I was about to complete my studies, there was talk now at the hospital that I I might need. Um, I might need to to get some tubes fitted on me and then go for dialysis. Ohh OK. And then, uh, you know. These healthcare professionals, they always consult each other, umm, and then. When I told them that I'm almost like completed my studies, then they decided that let's let's just stop. But we continue monitoring him right on his kidneys and other conditions to make sure." Pg.05* *So, when I finished in 2016. Then, when I was being prepared for dialysis, yeah, it so happened that I got a donor." Pg.05*
	Confirmed Diagnosis, information and treatment throughout all needs	*"I called an ambulance and was taken to the hospital. And, uh, they discovered that, uh. I had, they were saying it was kidney failure." Pg.03* *"So, since 2005, up to date, I've been using insulin instead of tablets, right. Yeah. So it didn't hinder my working progress or what I just continued working as normal." Pg.01* *"Whilst I was going through all that I had a couple of operations. I think maybe I'm talking of about four, if not 5. One for cataracts, other one for cleaning, you know a lot. And then the last one they said whatever happens to your eyes we will never operate them because we are lucky in that at least you still got a bit of sight". Pg.03* *"[pre-COVID-19] I was going to the doctors for the kidney after every three months. So you can imagine three months, you just go, they see you, they take blood samples from you and then they give you the results and then they tell you maybe there's an issue with your sugar or your BMI, you know, that kind of thing." Pg.11* *"Can you come back to the surgery maybe [2005], you know, they do their reviews after after the day's work and that kind of thing. Yeah. And then they said no, no more tables for you. We're going to put you on insulin straight away, because also from the family history." Pg.18*
	Difficulties managing increase medication for multiple conditions	*"I had a lot of tablets to contend with. A lot of tablets, yes. Yeah. Medication. A lot of medication... before was just normal, like blood pressure tablets. This was it, you know, yeah, which was manageable. At this time now a lot of things started to develop things. All that needed some medication, yeah. And I had no choice." Pg.03*
	Everyone helped and considered all my needs	*"There was talk now at the hospital that I I might need...dialysis...These healthcare professionals always consult each other. When I told them that I'm almost like completed my studies, then they decided that let's let's just stop. But we continue monitoring him right on the his kidneys and other conditions". Pg.05*
Theme 2 **Living with MLTC**		
	Grateful didn't need services during COVID	*"Did you ever go to hospital? No, that was it wasn't no go area...To be honest whether it is from my belief that God's timing is the best, you know. I never had any issue, right? Yeah. I never called anyone like the doctors, or you know, there was this helpline 111, one would advise you on what to do. You know, if you're having difficulties in breathing and things like that, you know you didn't need it" Pg.11*
	Believes luck plays a part	*"And then the last one they said whatever happens to your eyes we will never operate them because we are lucky in that at least you still got a bit of sight". Pg.03*

	in what happens	*"I prepared to go to work and everything of which I, I managed to lucky enough I wasn't driving, so I managed to get the bus right". Pg.03* *"So, when I finished in 2016. Then, when I was being prepared for dialysis, yeah, it so happened that I got a donor... And then on the 17th of July 2017, yeah, I had the kidney transplant at [hospital]... To me, it was a success story, yeah, because I never since that kidney transplant up to today, I I haven't had any issues" Pg.05* *"Screened at the airport [Zimbabwe] and then they are, you know, like isolated for further tests and things like that. But I went through all that and there was nothing wrong with me." Pg.07* *"Yeah. OK, so that that worked out, albeit it was a, you know, difficult logistically to navigate [stuck in Zimbabwe and quarantine]". Pg.10*
	Adhered to all rules and medical advice	*"I haven't had any issues, have been attending all my appointments. Now I go for appointments maybe after maybe six months". Pg.05* *"I went through. Went through all the process and after the bloods I was told to go home. Yeah. Ohh getting home, make sure it was easy because we have to take off the mask you were using in the hospital, you take off the one that you have come with and the door, you take a new one, right? You went through sanitizing. Yeah, right. And then you follow the way. Yeah, when you're done. Must out sanitize, then new one. Yeah, you know. And then? Come, come back home. Make sure. I threw away, sanitize myself right and then just waited and thinking up maybe, who knows." Pg.15*
	Acceptance of poor health	*"So, I have to live with that [loss of sight in left eye and reduction of sight in the right eye]." Pg.03* *"I accepted the situation [kidney failure and more medication] that I was in, and then I continued. Lucky enough I was discharged." Pg. 04* *"One day in 2013, right. I just woke up from home but unfortunately, I couldn't see where I was going. And then? I thought maybe it was just something. Yeah, it will be over, you know". Pg.02*
	Attitude of gratitude and empathy	*"The period that I'm talking of the NHS things were moving well. I have no complaints; I've got no regrets. And I'm happy that at least I'm managing on my own." Pg.03* *"I don't want to complain because there's, there's no need for me, you know, and the people who are trying to help me, they are also human beings. They've got their own issues as well. They've also lost their loved ones, you know, somehow someone with the same so overall my experience with COVID. I don't have any complaints." Pg.17*
	Reducing isolation for self and others	*"Like I said, I've always been involved. There's just just life after [a community group]. Right. Yeah, there's [another community group] There's [another community group], Yeah. And here a [this group]. Yeah, so I make sure. If I'm free, if I'm not doing anything, I just pop in every chat with people, you know? Here it is like, uh. The place is so welcoming, you know. I can talk to [staff] about anything, you know? Yeah. I've had help with a lot of things. That's really good, you know, yeah. And. Interaction wise, you know. And if I just walk outside? Even crossed the road. Always find something Ohh. Hi, Oh, hi, hi. " Pg.20* *"I've got something in me that. I like listening to others, people's stories, yeah, hear what they say, you know? I like listening to other people's stories, I'm also learning something from other people's stories. ...But most people, what I've discovered is there's a lot of isolation... They don't even have someone to just say good morning...How are you feeling today?" Pg.21* *"These are four neighbours of mine, right? And what I, what I make sure I do for them is when I see them, I greet them, right? Every Monday, right? A takeout their bins. Right, yeah, and also return them.... Is it's, it's my, it's my business. You don't, don't worry about your bins... And people have got different conditions. Some cannot even come out of the bed, you know, and if you go about knocking at their doors, you know. She told me she's not feeling well, he's not feeling well. And you know that kind of thing, you see. "Pg.21*
	Intimate relationships are hard	*"Yeah, I I've tried. To to have relationships and that that thing. I've got children but it's just like it's not working for me... it's all about money, money, money, money, you know, they want your money. I've got a place where I live. You have somebody who comes and joins you think it's a now we have a partner and then they don't contribute to anything. It was like more of manipulation than anything else you see." Pg.12*

	Important to be independent	*"I started living with friends and just after a few months I got a place of my own. And then um. Also got a job at, guess what [high energy voice], Manchester Metropolitan University.". Pg.02* *"I have no complaints; I've got no regrets. And I'm happy that at least I'm managing on my own." Pg.03*
Theme 3 **Impact of COVID-19**		
	Living in fear of contracting the COVID-19 virus	*"And then the next thing is I receive a message that the person who was sitting next to you [on the plane], had tested COVID positive. And that was the scariest moment." Pg.09* *"With the symptoms that they talk of you know this sweating. So, everything you, you wake up from your sleep and your bit sweaty or something. Ohh and it scary." Pg.09* *Knowing my conditions and also advice from the doctors, you know, they just said they were talking of people with chronic diseases. It was like this thing [COVID-19] was more for us than other people. ...I was one of the first people to make sure every time I leave the house, yeah, I take a mask with me...Though it was not compulsory by that time, yeah. Because they said it's easy for you guys, you know? To get this, uh, this, uh, illness". Pg. 06* *"But I just needed that kind of closure. How am I feeling? Yeah, no. Considering the trips to Zimbabwe, coming back and going through this and then it's maybe now five months I haven't had the check up, you know. So, I had no choice [to risk entering a clinical environment]. I just need reassurance. Yeah, yeah. So, I went." Pg.14* *"People just knocked at the doors and then we detect swabs from us and, you know, go to the lab. Lucky enough. That came out clean [negative COVID-19 test]". Pg.09*
	Living in the unknown as routine appointments were cancelled for nearly 2 years	*"And then you know what happened from there it will take ages for somebody to get an appointment, right? Be it at the GP. Or at the hospital, OK? Because this thing [COVID-19] continued...Yeah, to maybe to the later stages of um 2021" Pg.10* *"I was getting my bloods taken. That they were just screening for, you know, for COVID. Ohh. Anything else. OK. It was more of COVID." Pg.13* *"Two months, two months. Next available, Next available [appointment for routine check after refusing the first one] ...I was like living in an unknown because I didn't know how the kidneys were functioning. I was feeling OK. Yeah. I was adhering to the advice of exercising, walking, and, you know, that kind of thing. But I just needed that kind of closure." Pg.14* *"[after first check-up post-COVID] So everything was fine. Kidney function was great, was working well. So. So how did you feel once you got those results? Ohh, of course, a sigh of relief. Just feel well, yeah, you know, [sighs, happy] you feel it's OK to feel well" Pg.15* *"Yes, I've heard some people saying hours and time here this what but. I've I've not been to A&E for a while, yeah, so I cannot talk of what I don't know." Pg.17* *"You have to be content with it [not having routine appointments] or you go to hospital and you know what it is like in hospital. So, the choice was yours, right? Did you ever go to hospital? No, that was it wasn't no go area... I never had any issue, right" Pg.11*
	Clinical environments created increased fear	*"You would use one entrance. Right... And then all the way, maybe two people. You won't see anybody. You won't meet anybody...Ohh it was scary, you know? And you just follow instructions; you don't want to touch anything." Pg.13* *"Now people were actually getting it in hospital than from outside. So, you were scared of contracting it." Pg.13* *"I remember the first appointment that I was offered. I refused because I know of a Zimbabwean who went for check-up, never returned, because they contracted the disease there" ... let me decline this, I say no, I'm not available. So, they they gave me another date... Pg.13* *"[2021] there those days they were strictly time. Yeah, if you miss your slot, yeah, then it would be very difficult. So, my appointment was for half ten, I was there by 10 and I had to wait outside.*

		...Around 20 past got there, they're checking temperatures. Follow the signs everywhere ... And then, uh, one thing I realised is when I got in there, I'm used to going there, you know, but because of these changes, the, the normal entrances were now closed, you know, you had to follow a certain pattern you know, yeah. And then one thing that is the Nurse is in there. Ohh. They were just acting as normal. And then that's when I ask myself. But what exactly why? Why are we all afraid when some other people are working to help us, you know. So, they're interacting normally, normally [couldn't believe it]. So they are, yeah, whatever, however the virus is spreading there, but they're the ones treating you to just use the normal, you know, the hands [sanitizer], the hands washing, whatever, put their mask every time they deal with somebody new. Take off the mask and everything they go through the cleaning process; they put a new one on before they come to you. I mean, that highlighted me to say oh, oh, so these people are doing this every day, and we are at home, we are afraid, you know. And then I think, that's sort of motivated me to say, you know, to say, oh, well, looks like it's not as bad as we think, you know, and then." Pg.14 *"[seeing nurses interact normally] It actually gave me more freedom. Because now those restrictions were starting to be removed. Relaxed. Yeah, yeah. So. I was more out and about, yeah than staying indoors. Yeah. You know, it's good getting your steps. Yeah. Getting my steps and all. Going out shopping, yeah, you know, that kind of thing. And by then, even churches were open. Yeah. And then I would still go to church... As long as you are protected. .. Still wearing the masks. Being cautious, everybody moving around" Pg.15-16* *"Everything was lifted. That was 2022... Everything decided to come back to normal, right? Yeah, and. Of course, places like hospital, they continued. Yeah, they continued. They didn't relax. Once you go there, but everywhere else yeah, things were starting to even people walk into Morrisons without a mask. It was all up to you you know as an individual. OK right yeah but there are certain places if you're going to the GP and. And also, appointments from the GP, we're starting to to be available, you know, yeah, you know, people were scared still to go anyway" Pg.16*
	Taking calculated risks to see family in Zimbabwe	*I was only able now to travel in 2019 [after the kidney transplant]* *... to Zimbabwe... No, COVID started". Pg.05* *"And then it so happened that. Just before Christmas. You know, yeah, rules were relaxed... And then I said, well, why not since since my kidney transplant, 2017 to 2020, yeah, I've not seen my mom. She has not been well? Ohh. Why not go to see her. I flew to Zimbabwe. OK, no worries. No COVID in Zimbabwe, just isolated cases. Lots of sunshine in there, all was well.". Pg.06* *"My mom has been in and out of hospital and me, I'm here, I'm able to walk after the operation. I'm OK, I'm feeling fine, right? Why not? What of if she dies? What? If anything, bad happens there? How am I going to cope? You know so. This is some of the driving forces that they made a decision, yes, and the fact that here we had restrictions and they were lifted." pg.10* *"Yeah, I think it was the right decision [to fly to Zimbabwe]. Yeah. For me, it's my condition. Yeah, you know, it's my conditions." Pg.10* *"This yes, that's fair to substantial amount [airport quarantine rules] unfortunately I didn't have I wasn't insure when I went for and they they were saying nobody could because they said this was a natural disaster...You see that? Your own risk. Yes. So, insurance companies will say to me, you know, we are even at a loss ourselves, you know?" pg.08* *[flew to Zimbabwe in December]...about the Christmas, yeah. Then they opened the doors for people to enjoy Christmas. Yes, and then they realize Ohh made the mistake and then January yes, now in total clamp down was put in...But no, the restrictions, you know, from DWP and you know, things like that, yes, they require you to come back [to the UK}. But those days no one was flying; no plane was there. So yeah, I got stuck there [Zimbabwe]. Pg.07* *"Yeah. And then up until maybe March or April, that's when people started flying now, and then we had to come in. To the UK, yeah. Yes, had to go through quarantine for about 14 days and you have to pay for staying in the hotel." Pg.07* *"You're taken by bus at Heathrow after a lot of screening and then taken to a hotel, go through a lot of screening". Pg08*
	Must deal with feeling isolated	*"[in airport hotel] because it was total isolation. You just be stuck your room. No, you don't talk to anyone". Pg.08* *"And to make it worse is when every shop was locked" Pg.11*

	Planning and preparation for any situation	*"When I used to go to Zimbabwe, for whatever period that I'll be going, I'll get all my medication. Yeah, for two, for three months, right, they give me... So, when I went to Zimbabwe, right, that was December [2020], so into January, February, March, I was still OK, ...I could manage to buy from pharmacies because there were no closures in Zimbabwe. OK, things were just running as normal." Pg.08* *"So lucky enough I came up with a plan and then, looked for couriers. And then I sent all the luggage except the the small case. ...So, I knew very well that I'll be be home first. Before leaving. Yeah, they deliver. So, I left the hotel [London]... use the trains. Go to Manchester. Go to home [taps hands like steps of a process]." Pg.08*
Theme 4 **Finding purpose and meaning to living with chronic diseases**		
	Working is an important part of life	*"I was like driving, uh, around London, east London area for about 150 miles every day...for five days, maybe we'll do six days if there were some maintenances going on". Pg.02* *"And then my eyesight for one reason it improved as well. Ohh. And then I'm I tried to go back to work.... The manager there, uh, just advised me that, um. With all the powders and the type of work that you do, I would suggest you take a rest". Pg.04* *"We don't get paid for for for doing that [council meetings], but on my CV... That's good yeah. And that's exactly because I did health and social care yes, even housing to going into health, the social setups and you know that kind of thing...so now it's more about exposure, yeah, do projects. You know, get involved in the day-to-day running [desire to have meaningful paid job]". Pg.23* *"There are some opportunities there [Manchester] to further your education, whichever field you wanted, and you know, that kind of thing. And to me. That sounded. Quite attractive and I moved [from London] to Manchester". Pg.02*
	Keeping busy in the community when couldn't work	*"I never stopped doing most of the things [when couldn't work, 2013]. I continued going to church. I continued to interacting. I visited a lot of centres... I just found that is my how, that's the best way I can. You know, cope with my time, yeah. Having some interest yeah knowing my community." Pg.04* *"I don't know many people and then [When moved to Manchester in 2010]... Keeping busy. Keeping busy makes you get more information." Pg.04-05*
	Determination to learn and contribute to society	*"So, I just came across Flyers that was some courses going on at Bolton bought university. Then I applied to do a health and social care...and then I obtained the BSc, you know, honours in health and social care [2014-2016]." Pg.05* *"I managed to, I managed to [study whilst having kidney failure and T1D." Pg.05* *We can sit down and listen [council meeting]. There are conversations, you know, all deliberations going on there, you know, and will always give feedback, you know? Yeah, so. On its own. So maybe like last night we had our 1st 2025 meeting. You know. And then, uh. We have got health scrutiny meetings. Where you go and they discuss about the general health because like you said, they are, they've come to realize that there are certain areas here in Manchester, right? For example. If we take Openshaw. And then convert it to. Trafford. Hmm. Right. Yeah. That's [Trafford] more elite than it is here, yeah. So, you find information that is shared in Trafford, right? There are people walking quickly utilize. Yeah. And then there are certain here, people not in the picture who are left behind. You see, they don't, they don't, they don't know. What is happening? Umm, you, see? Yeah. So how best can we equate? Pg.22*
Theme 5 **Support network**		

	Sharing worry with people close	*"It made everybody [at home]. Make everybody at home you know. Got panic? Everybody panicked. Thinking You know, thinking more, maybe it just caught up with him, but lucky enough I was fine". Pg. 09* *"My neighbors are now afraid of me [returning from Zimbabwe in 2021]. But I'm telling them there's nothing like we are talking of. Yeah, in Africa, yeah, people are going about their business. There's nothing." Pg.10*
	Help from others is invaluable	*"I was getting assistance from the Union [2013] who would advise me on how to apply for personal independent payment and because of my conditions and whatever I was going through, and then finally in 2014, I was, I went into the support housing right? ... And then? Um, continued with life." Pg. 04* *"I opted to leave [London] and then from talking with friends and. Yeah. Other colleagues. Um, and friends from Zimbabwe to just told me that, well, why not move out of London, come to Manchester, you know". Pg.02* *"I informed one of my colleagues that I don't know what, I just woke up today and my sight is not very good, you know, so they called the supervisors. And um. They advised me to go to hospital, to the Eye Hospital. And it's only when I go to the Eye Hospital that I realized that it might be a big issue". Pg.03*
	Respects other choices	*"[2022] So it's about. Personal choice now, the experience that they went through, you know, yeah, if you have seen somebody with COVID, you know, yeah, maybe there was a lesson for you to make sure you every time you know, just continue." Pg.16*

Appendix 7E: Table of Personal Experiential Themes PPT

Superordinate theme	Subordinate theme	Experiential Quotes
Healthcare system can learn from my experience		
	Healthcare system can learn from my experience	*"Being able to speak to somebody, a doctor, consultant, when I need to about aspects of my condition that I may or may not be able to manage myself. Being able to access appropriate medication and speak to people about it. And being able to access support networks for people who have similar conditions or the same condition who may be able to provide insights that might make my life a bit easier for managing those conditions. And over and above all, having doctors and consultants that actually understand the condition so you're not dismissed almost when you walk into the room and they're like, oh that's a load of rubbish or made to feel like what you're talking about is a load of rubbish". Pg.01* *"Long COVID is effectively post-viral fatigue syndrome, which presents exactly as fibromyalgia. Plenty of study into long COVID, but you have to have a diagnosis of long COVID. But actually, they're researching the same symptoms as fibromyalgia. Where's the joined-up thinking that it could be long COVID as a post-viral rather than specifically COVID, and therefore could also apply to all these other things? When they mentioned those studies, it was like, have we had a breakthrough here? Actually, no. The study is too narrow to specifically patients that have had COVID. Interesting." Pg. 38* *"I'm fairly confident in managing my own medication. I would like the doctor to make sure that I can actually access the right strength of tablets rather than having to cut pills in half because that's not an accurate dosage. It's the ease of management and, again, reassurance. Just if things had been different, if I'd been able to check in with the pain team, I'd be like, yeah, I'm fine, I'm okay. Yeah, I've got to manage it, but I'm okay. I know I'm on the right meds". Pg.41* *"Some kind of healthcare, somewhere to go that when I've got maybe a concern that isn't enough for a GP, doesn't warrant a referral, but I have a question. Some kind of, like I say with the baby clinics, you've got a question about your baby, you drop in on a Monday between 10 and 12. Where's the chronic pain manager? There's a lot of people manage various chronic pain conditions. Where's the community if it's once a month? Knowing that I've got somewhere to go or someone to speak to or a way, when I don't need to bother the doctors that I'm not going to get a straight answer out of and go through the whole referral process. The pharmacists can't do the medication at the moment, but perhaps they could. It's a dosage adjustment within a limit. I'm not walking in there and asking for a permanent prescription of morphine. I'm just asking to split my 50s into 225s. Why can't a pharmacist do that? Why do I have to go through the whole... It's just... Yeah." Pg. 44*
	Receiving the right level of care; unhelpful HCP and passed from pillar to post, not considering the whole person. No defined pathways for MLTC	***Negative*** *"At one point I did change GP surgery because the doctor that I was seeing at the time, I knew something wasn't right, but she basically went, we all get tired love, we all have aches and pains and refused basically to do anything about it. No tests were done, no scans were done, nothing was done. I knew that what I was feeling wasn't normal but actually just getting somebody to listen. Pg.01* *Another example being a course that I was sent on where I was told I could basically think my pain away. If I was to sit there and think I'm not in pain, I would not be in pain. It doesn't work like that". Pg.01* *"It's going to be an awful life for me, for my son who was quite young at the time. But what else can I do but just get on with it? Something's not right. What if this is part of something more serious? I was just basically shown the door" Pg.01* *"But that plus I'd had an acute back injury around the same time and trying to access physio through the surgery was part of what prompted the move. I thought, this surgery is doing nothing. Why am I even fighting to get a doctor's appointment to see somebody*

		to be dismissed every single time? Perhaps if I move surgeries, something... And it worked" Pg.01 *"To get to the point where I could actually speak to somebody who might actually understand. It was a hassle". Pg.02* *"At least every couple of months. I'd go into one appointment and they'd say, give it another 6-8 weeks. If you're still ill in 6-8 weeks, come back and see us again. So, in 6-8 weeks I'd ring up and then I'd have to wait 3-4 weeks for an appointment. And then I'd go back. And then they'd be like, we'll do a blood test for this. So, then I'd have to go away, get the blood test, wait for the results, then book an appointment. So, then another 8 weeks after that, 12 weeks maybe, then I might actually see somebody. Oh well, it's not showing up anything on that result.* *If you're still ill in a couple of months, come back. So, I was in and out of the doctors probably every 3-6 months for a couple of years. So, I had meningitis back in 2014, which I believe is the trigger for a lot of these conditions. That was diagnosable as that's the particular condition. It was only 2016 that I was like, I'm not getting any better here. I am knackered, and I mean not just tired, but exhausted, tired". Pg.04* *"At the same time as I was going through meningitis, I was going through the messiest divorce in the history of the world. So all of that happening at once, we can now link the two to say, well that's probably, prior to that I was healthy, fit and well, never in the doctors other than a couple of minor pregnancy-related illnesses that were perfectly normal for pregnant people to have. Never in the doctors, never needed to see anybody for anything". Pg.04.* ***Positive*** *"The first blood test, she said, right, we're going back to square one here. I can see you've had a couple of blood tests here. And we've picked up a couple of things, like your vitamin D was low, so I've taken supplements ever since. So, we know it's not that that's caused anything now. The first blood test, she sent me away with tests for something like 17 different things. And I went for that blood test, and I was just stood there with my arm out and they were just pulling blood out into vials for all these different tests. She literally did everything". Pg.06* *"My symptoms, that was my grandmother that had that, my symptoms resembled her early symptoms. Now I've had the necessary scans to show that I don't have MS. But my concern was it was going to turn out to be something like that". Pg.07* *"At that point the new doctor said to me we may never know what this is. There are a number of diagnoses and fibromyalgia was mentioned within a list of about five or six possible things that they were going to try and have a look at first. It was early 2018, once we'd had some blood test results through, that she said I think, I cannot formally diagnose you as I am not a rheumatologist, but I think we could be looking at fibromyalgia here or chronic fatigue syndrome which is a very closely linked, very, very similar condition. We will start you on an appropriate treatment path for that. However, we will have to refer you for rheumatology to do some further investigations, etc. It was 2019 before I got in to see the rheumatologist and they confirmed at that point that they thought it was fibromyalgia". Pg.08*
Impact of COVID		
	Impact of COVID; Disrupted then, removal of pain clinic support. Poor communication. Hard to get a GP appointment. A fight to get help.	*"I haven't accessed healthcare for these conditions for a couple of years. OK. Once you have the diagnosis... So, pre-COVID, there was talk of this course and that course. I did a pain management course literally in the weeks before the pandemic. It finished the same sort of time as Boris decided to shut all the schools down. I'm like, well, at least I've got it out of the way". Pg.11* *"That was the course where they told me to think my pain away and the woman at the front trying to run the course had very, very clearly never had any experience of fibro. And I did initially keep in touch with a couple of people from the course and we all said the same, that she doesn't know what she's talking about. If we couldn't think the pain away, we wouldn't be sat here right now thinking our pain." Pg.11*

		"Thinking we're in pain. It's not a thought process as such that I'm not sat there going, oh, I'm in pain today. You can't think it away. Yeah, I'll decide not to be today. Yeah, oh, I'm not going to be in pain today. I can decide that I'm going to plod on regardless, but it doesn't mean I'm not in any less pain for it." Pg.11 *"So, I did that just before COVID. And then since then, during COVID I had a little bit of contact with the pain team, but it was a fight to get anything because initially everybody got redeployed for COVID services. Then the pain management team sent everybody a letter saying, you've not accessed our services yet." Pg.13* *"If you don't need us, please let us know or we're going to take you off the list. And we all had to ring up and go, actually, I do still need you and I do want to still be on your list. It's not changed. And you're the reason that we didn't see you. I had a couple of video calls with a consultant from there. And then since then, it's been a case of, right, well, we've found you a medication. We've given you tips to manage it. Please go away and manage these things. If you need to come back to us at some point in the future, you will need to revisit your GP for a re-referral." Pg.13* *"And having had the hassle of the first lot, I do actually need to visit my GP at the moment to have a medication adjustment formally put through, but I've adjusted my own medication and trying to get a meds review with the doctors at the moment is now an impossible because they're short-staffed. It's not considered urgent enough. So, I just have to get on with it. There's no, I don't know where to go other than the GP. Pharmacy can't help because the GP has to sign it off. The GPs are like, well, just do what you need to do." Pg.13* *"I'm like, you've taken one of my medications off my prescription completely. And yeah, it's...I just wasn't able to order it anymore. So, the pain team put me up to 75 of amitriptyline. We worked our way up to that and found that that was the optimum dose. As I became better at managing it, I dropped that back briefly to 50, which didn't work. I wanted to go back up to the 75, which was a combination of a 50 and a 25 tablet to find that the 25s were no longer available on my repeat prescription. And they took them off because I hadn't ordered them one month. So, I'm stuck with the 50 tablets. So, I've been on 50 ever since, until recently where I've been fiddling with my medication again and trying to... Over time it's become less effective and now I'm having to cut pills in half to get the 25 so that I can take a 75 dose if I want to." Pg.13.* *"And I never heard anything for about another six months. It was the second sort of wave of the pandemic before I actually heard anything back from them to say, all right, well, we might actually be able to see you now. By which point I've been on the list for a very, very long time." Pg.13* *"And I fully understand why people were redeployed during COVID, but just to send us a letter saying, oh, we're taking you all off the list. It's taken all this fight to get to this stage. What was the point? Why am I still fighting? I almost gave up." Pg.13*
	Impact of living with MLTC; effects loved ones, unpaid work to attend appointments, managing feeling tired and in pain, social life,	*"COVID had some benefits in a way in flexible working, and certainly for me, I was never able to work from home prior, and now I can, but not all the changes have been for the better." Pg. 32* *"My son has learnt to live with it. He knows mummy has bad days, but he's grown up with that. He knows that that's how things are sometimes. That's normal to him. I do feel bad, but I do try at the very least, if I've got to choose between activities that I can do, his will be priority. So, if it's football training or mowing the lawn, it's football training. Yeah. So that he gets his activities." Pg.17* *"It had an effect on life. The doctors are only available pretty much Monday to Friday, 9am-5pm. My surgery, neither the previous one nor the current one, offer weekend appointments on a regular basis. And then I have to take time off work for those appointments. At that particular time, I was office based and not home working. So, I would have to take time off to go to these appointments. It had a knock-on effect on that. That meant I was either using leave or taking unpaid or having to make hours up, which has an effect on the rest of family life and things like that as well." Pg.02* *"Somebody at work commented on the amount of painkillers I was taking. I was popping them like smarties, I probably hadn't really noticed quite how many painkillers I was taking. But yeah, I was popping them like smarties. I was constantly tired, in pain, achy, sore, just felt grotty, permanently grotty." Pg.04*

		"It's being able to put a label on it and to explain to people, why has she cancelled last minute again on some planned activity? Oh, actually no, she's got a condition that means she may cancel at the last minute. Why has she been up for this for months and then all of a sudden got... Why is she saying, oh, I can't come for a brew, I feel shattered today, you're welcome to come here but I isn't going out. Why is she in bed at lunchtime on a Saturday? That sort of thing. It was being able to give people a reason that there is something wrong." Pg.09 *"I wanted to go out, have friends, go places, go and do things with him. But we couldn't necessarily do that because I just wasn't well enough half the time to do it. He'd already been impacted enough when I was in hospital with meningitis and stuff like that." Pg.10* *"In the immediate aftermath, he was quite young, so he doesn't know any different than Mummy being quite ill when he was a baby. But, yeah, it just... We couldn't go out and go to baby groups and things. I did try, but I would have liked to have done more." Pg.10* *"Once I did start finding a few friends again in later years, it was very much, oh, you're going to have to come to me because some days I just can't. Things might not get done or whatever. I'm like, I just can't do it." Pg.10* *"I'm like, what is the point of doing all of this? I'm back to, this is never going to be over. Is this going to be my life for the next 50 odd years? Either fighting to get access to healthcare or putting up with symptoms that if we just fiddled with the tablets, perhaps we could do something to alleviate some of these symptoms. But yeah."* *Pg.15*
	No help from services between appointments	*"During COVID, and that's it. They no longer check-in with me if I need to speak to somebody. It would be a GP referral."* *"The GP isn't knowledgeable enough about fibro. They would have to refer me to the pain management team. Then I'd have to go back on the waiting lists."* *"There's no check-in or follow-up or anything. It's been three years at least since I spoke to the pain management team. They don't know whether I'm still managing my pain."* *"I'm fortunate in a way that I'm bright enough to understand medication, the effects of medication, and self-manage my medication. Not everybody is going to be in that position or want to be in that position. There's no check-in, there's no follow-up, this is a condition for life, but I'm not actually under any consultant for it." Pg.28*
	Consequences to faith and trust in the HCS	*"No faith in our healthcare system at all. I couldn't get any help. Just dismissed. Almost unworthy. Why can't I get this help? Why is nobody investigating this? Something's not right." Pg.01*
	Self-care becomes healthcare	*"By that point, I'd done enough research on my own. Now there's a family history of multiple sclerosis in my family." Pg.09* *"I'd already started looking at how could I manage this myself? Because the wait for the rheumatology was like a year's wait just to see a rheumatologist." Pg.09* *"One of the things I like to do for my mental health is go out for a daily walk. During a flare-up, I don't get my daily walk. Or it might be a short, it might be an adapted walk. It's things like making sure I've always got batch cooking or ready meals in the freezer. Because on a bad day, I'm not standing in front of the oven, trying to cook anything. It's going to be a freezer tea. It could be, I do have a social life now, it could be ringing somebody up and going, not up to it today. Really can't do it today. Or, if I planned to mow the lawn, saying to the neighbour, would you mind? I'm really not up to it today". Pg.16* *"Support groups. Facebook. I'm on a couple of groups on Facebook. I don't get to post, but I do read. I'm speaking to other people. I know a couple of other people who've got the same or similar conditions that require the same or similar kinds of management." Pg.17*

Appendix 8: Group Experiential Themes (GET)

Key Themes	Subordinate Themes	Experiential Quotes
1.0 Living in the unknown – the emotional response to waiting to access healthcare services	1.1 No choice but to live with disruption to routine appointments	**Accepting there are no routine appointments during the pandemic** *PT04 "You have to be content with it [cancelled appointments], or you go to hospital, and you know what it is like in hospital". Pg.11* *PT03 "No it was literally like; NO we are not doing that [routine appointments] ... They will have been doing cancer patients and all the rest of it." Pg. 28* *PT03 "But you get texts off them, you're due this or ring us up about that. So, all that just stopped. Because they didn't know what they were doing so, that's fair. I get that, I'm at peace with that." Pg.27* *PT02 "[mental health services] I didn't actually. I didn't during that time [COVID-19]. It was just coming near the end of it, and it started again... it took a long time to access it."* Pg.23 **Struggling not having routine appointments during the pandemic** *PT04 "Two months [after refusing the first appointment for fear] next available, I was like living in an unknown because I didn't know how the kidneys were functioning... I was adhering to the advice... But I just needed that kind of closure" Pg.15* *PT03 "It almost returned to ah you need to come and have your check up for this. So, the first time I went to was December 2022." Pg.28* *PT03 "I was in group 2... but all that seems to do was get COVID stuff quicker. The [groups] didn't seem to tally with anything else on the GPs". Pg.28* *PT02 "Because that's the big issue. You feel all alone when you're left, not just by the GP but other caring facilities, everybody's feeling the strain of it." Pg.08* *PT01" COVID made it even worse; you couldn't see anyone about anything." Pg.27* **Difficulties getting appointments after the pandemic** *PT04 "And then, you know what happened from there it will take ages for somebody to get an appointment right? Be it at the GP. Or at the hospital, OK. Because this thing [COVID-19] continued." Pg.10* *PT02 "that's really difficult because they're telling you is ring up at 8am in the morning... it will say you're #30 in line; we'll get back to you. So, you know you're not getting an appointment that day... so that's really difficult because sometimes you need to see them at the same time." Pg.05-06* *PT02 "they call you for blood tests quite regularly, I'd say every 3 months or so, yeah into the GP, although it's getting harder and harder to actually get face-to-face appointment." Pg.05* *PT02 "It's come much much harder. You can't see your GP when you want to". Pg.09*
	1.2 Suffering - trying to manage alone whilst waiting for referrals and appointments	**Recognising the need to self-manage** *PT02 "physio [arthritis], they'll say after six sessions or whatever it might be. So, with the physio just try to talk through it and just manage it, try to manage it the best way that I can." Pg.11* *PT01 "It's just keeping yourself going really and trying to do things." Pg.06* *PT02 "I've had a few falls so it's important that I do get it done, yeah." Pg. 13* *PT01 "There's nowhere to go to other than A&E, and that is not the place to go." Pg.24* **Suffering while waiting**

		PT02 "I'm gonna have an op on my knee. I've been twice and it's been cancelled. So, you're left with the you know that pain and the effects." Pg.12 *PT02 "It means I'm holding onto things that I could do with seeing to. It's making my pain linger um." Pg.06* *PT02 "I don't want it to get any worse because its already started kidney problems from the medication that I've had to take." Pg.03* *PT01 "These [additional symptoms] compounds with things and that's the problem is it is not knowing." Pg.16* *PT01 "they were saying you have to wait six months to see hematologist. And I was thinking I could hardly move." Pg.07* *PT01 "And it [not being diagnosed] does cause you to be a bit depressed at times as well [tearful]. I was really depressed and made to feel low. And dominate." Pg.08*
	1.3 Putting trust in the service to follow up when required	**Expecting the system to drive all follow-ups** *PT04 "It's all up to them [GP] yeah because I don't phone for an appointment, but they give me an appointment when I'm due." Pg.16* *PT03 "pre-COVID you'd get summoned every year for a diabetes check. But all that went out the window for a good two years... They abandoned ship on everyone during COVID...But I remember getting a phone call, I said, I thought, you thought I was dead". Pg.18* *PT03 "I've never seen anyone for the lupus since [COVID-19]. I've had conversations with my GP when I've been about other things, yeah, and they say oh you have lupus. I'm definitely in the proverbial cracks of any monitoring of my lupus." Pg.18* **Feeling neglected when the system doesn't follow up in reasonable time** *PT03 "they still like very much standoffish and still don't send comms... it was very that was like just abandoned". Pg.27* *PT02 "there is some really important tests that were supposed to be done when she was looking through my notes, they said they'd call you up in six weeks and that didn't happen...You feel neglected really you feeling you feel worried, you feel scared, you feel neglected." Pg.6-7* *PT01 "that's why I said I want to the pain management course. And, you know that would've been helpful, but there's huge huge queues for that." Pg. 26* *PT01 "refer you to a neurologist... so I haven't seen one. That was January [2024], so I've got an appointment... The end of January 2026... It was just over two years, so I haven't bothered cancelling it." Pg.15* *PT01 "The pharmacist told me to stop taking it and she sent a message through to the GP, but I haven't heard back." Pg.17*
	1.4 Managing a reduced level of control	**Trying to take some control where possible** *PT03 "So I'm just being pro-active ringing you up [to move appointment because of the pandemic]. No no that's I'll refer you back to your GP. That's it bang [phone down]. If I hadn't bothered, I would have got a letter I imagine somewhere in amongst all the COVID... you're no longer with our consultant go back to your GP. And to be fair I sort of laughed." Pg.17* *PT04 "the first appointment that I was offered I refused because I know of a Zimbabwean who went for a check-up and never returned". Pg.13* *PT01 – " I was paying for the consultations to try and get an answer quickly." Pg.02* **Cannot control how and when get treatment** *PT02 "a lot of the time they're saying it's because the way the health service is at the moment... I've been for a pre-op twice... it's been cancelled... because pre-ops they are supposed to do a couple of weeks before and apparently, yeah and they're just not ready for you." Pg.12*

		PT02 "affects your mental health greatly I've found, one having all of them conditions, but having problems that you can't get them treated or why you can't get them treated." Pg.11 *PT01 "[orthopaedic consultant] gave me another open-ended appointment and I said, well, my right foot is really bad and I said if you look at that and he said "no I'm not allowed", he said "the pathways on the NHS don't allow for that anymore". He said, "as ridiculous as it might sound, he said, I'll write back to your GP, and your GP will have to refer you to an orthopaedic consultant."" Pg.19* *PT01 "There's nowhere to go to other than A&E, and A&E is not the place to go. I'm not an accident. I'm not emergency." Pg.24*
	1.5 Seeking reassurances when dealing with uncertainty	**Finding reassurance in the healthcare system** *PT04 "to get the results of your tests, usually it's the same day [bloods]... they've got an app where they put your results... of course, a sigh of relief... You feel it's OK to feel well." Pg.15* *PT04 "They [nurses] were just acting normal. And then that's when I ask myself... why are we all afraid when some other people are working to help us, you know, they're interacting normally... And then I think... looks like it's [COVID] not as bad as we think...It actually gave me more freedom". Pg.14-15* *PT01 ""When are you waiting for that like thank goodness, you're on the list." Pg.30* **Finding reassurance elsewhere** *PT03 "I believe him [chiropractor] over you to be fair." Pg.27* *PT03 "I like to go to the chiropractor because they are very, for me, a bit more inquisitive and out of the box". Pg.27* *PT01 "I spoke to him online and he said he can't really do very much. It was just as healthcare was stopping... as soon as I can see you, I will contact you and we'll see you again" Pg. 03* *PT02 "they [community group] realised that you know when we're not coming here, that it's really really difficult for people at home. So, they had a drop in [rather than cancel] and I came along to that." Pg.05* *PT01 "... and the pain consultant [NHS friend] took me on the NHS then for the pain management and I have sort of annual; they're really obviously stretched." Pg.04* *PT01 "I was paying for the consultations to try and get an answer quickly." Pg.02* *PT01 "That in itself, he's listening to you and actually gives you faith [private therapist]". Pg.21*
	1.6 Prioritising what is important: taking calculated risks	**Risk self-whilst prioritising others** *PT04 "My mom has been in and out of hospital (Zimbabwe) and me, I'm here (UK) I'm able to walk after the operation. I'm OK, I'm feeling fine, right? Why not? What if she dies.... How am I going to cope?". Pg.10* *PT01 "We have got a very active lifestyle. They have to say in all of this, we've travelled a lot, we've gone all over the place with this, but it's always a real push to do it."* Pg.08 **Overcoming challenges for self-care** *PT03 "I went away two years ago. That's part of the reason [had the vaccine] I had to be able to go and get through the airport [to get some sunshine to help the lupus]. Pg.30* *PT02 "so through that [telephone befriending group] were on the phone with me probably about six months, maybe longer and then they told me [about a community group] ... I managed to come to that because I was having trouble getting out of the house." Pg.04*
2.0 Effects of the COVID-19 pandemic on managing day-to-day life	2.1 Realising increased vulnerabilities caused by the	**Fearful of contracting the disease** *PT04 "[hospital] that was a no go area". Pg 11* *PT04 "And then the next thing is I receive a message that the person who was sitting next to you [on the plane], had tested COVID positive. And that was the scariest moment." Pg.09*

	COVID-19 disease	*PT04 "knowing my conditions and also advice from the doctors...I was one of the first people to make sure every time I leave the house, I take a mask". Pg.06* *PT04 "the first appointment that I was offered I refused because I know of a Zimbabwean who went for a check-up and never returned". Pg.13* **Factors that can make it worse** *PT03 "And to be fair taking the vaccine, which I wish I'd never taken, to be fair. Definitely wish I'd never taken, particularly the 3rd one, the 3rd one has proper done me." Pg.29* *PT03 "But I can appreciate how for lots of people who were newbies or undiagnosed who knows or not. So yeah, it would have been terrible". Pg.29* *PT01 "these last few days I feel really really bad. But whether that is because I've got some, you know, it could be a COVID type of thing." Pg.21*
	2.2 Value of maintaining meaningful connections; for self and others	**Finding purpose through helping others** *PT04 "I've always been involved; there's just life after [name: community centre]. There's [name: another community centre], there's [name: another community centre]. And here [a group in a community centre] Yeah, so I make sure I'm free, if I'm not doing anything, I just pop in have a chat with people, you know.... I've got something in me. I like to listen to other people's stories... But most people, what I've discovered is there's a lot of isolation... They don't even have someone to just say good morning... How are you feeling today?" Pg.20-21* *PT04 "I take their bins out...and people have got different conditions. Some cannot even get out of the bed, you know, you go knocking at their doors, you know. She told me she's not feeling well" Pg.21* **Finding ways to stay connected during COVID-19** *PT02 "...have got really good couple of good good bessie mates. Every Friday we sit still now and have a cheese toastie and a chat, put the world to rights, things like that." Pg.24* *PT01 – just about the social network of walkers as well as social walkers. Yeah, they're awesome social walkers. You've got to be on the chair and sit there, you know, and, and basically look after me... it's been hampered the last 12 months because my knee is not very good." Pg.27*
	2.3 A variety of situations leading to feelings of isolation	**Isolated by things that happened out of my control** *PT04 "screened at the airport and then they, you know, like isolated for further tests and things like that. But I went through all that and there was nothing wrong with me". Pg.07* *PT04 "[airport hotel] it was total isolation; you just be stuck in your room. No, you don't talk to anyone." Pg.08* *PT04 "and then all the way, maybe two people, you won't see anybody, you won't meet anybody... ooh it was scary you know". Pg.13* *PT04 "And to make it worse is when every shop was locked." Pg.11* *PT03 "Let's say from the COVID [vaccine], even now, I still don't get the numbers that I was getting [steps]. I don't have the energy." Pg.34* *PT02 "I was really isolated during COVID for lots of different reasons [mental health services and online support groups disturbed], but to live with what I've got is a daily thing and it's worrying each day really." Pg.02* *PT01 "I don't know where to go." Pg.21*
	2.4 Increased burden on others	**Sharing with others** *PT04 "Make everybody at home you know, got panic? Everybody panicked. Thinking you know, thinking more, maybe it just caught up with him, but lucky enough I was fine" Pg.09* **Trying to protect others** *PT02 "So not that they wouldn't be helpful or, you know, but you just don't want to burden them [family] with it." Pg.11*

		PT01 "[deteriorating health with no diagnosis or help] And, you know [husband] will say things like, well, I'd quite like to go around South Africa, you know and I think that's a step too far for me." Pg.29 *PT01 "Cause you do feel like a nuisance in the day-to-day." Pg. 34*
	2.5 Seeking positives – finding different levels of gratitude	**Grateful for Independence** *PT03 "In some respects it [COVID-19] was great because you were left alone and not being monitored, which is kind of like, I had no problem with that at all, it was great". Pg.19* *PT04 "I've no complaints, I've got no regrets. And I'm happy that at least I'm managing on my own." Pg.03* *PT02 "I'm lucky, I can get round on my crutches. But there are people who are really, really struggling." Pg.20* *PT01 "I'm fortunate enough that I can pay [for private treatments]." Pg.05* **Grateful for health service information** *PT02 "[when mental health services started again] literally when I was getting them phone calls, it was and literally a lifesaver, you know because you can feel yourself going under kind of things and I needed something to happen." Pg.18* *PT04 "You know, because of information now, access to information I have discovered that ohh instead of me booking with the GP, they do walk-in jab here." Pg.17*
3.0 Trust and faith in healthcare services at risk	3.1 On-going scepticism: individual needs are not considered	**The system structure hinders not helps** *PT02 "and sometimes they just want one, one issue at a time...but it's not telling him the truth about your whole body... more than one thing at a time is happening...and people don't realise you can ask for double appointments...and people should hear about that and know what is available" Pg.17-18* *PT03 "conversations I've with a lot of people, family and friends, all the rest of it. Once you're in the NHS system and you understand it, it's very different to people who aren't in the system who say the NHS is great." Pg.06* *PT01 "And seeing somebody who you've been referred to by the NHS, yeah, just for that [one thing]. And you can't see them for anything else. But that is just a nonsense, isn't it really." Pg.19* *PT01 "and I've tried three different sorts of statins and, it makes me worse, so you're not going to go through with that." Pg. 17* *PT01 "I do wonder how long have gone on if I hadn't have sorted myself out. And I do wonder sometimes if maybe I hadn't kept pushing maybe, you know, what would have happened. I don't really know." Pg.08* *PT04 "Then whilst when I was about to complete my studies, there was talk now at the hospital that I I might need. Um, I might need to to get some tubes fitted on me and then go for dialysis. Ohh OK. And then, uh, you know. These healthcare professionals, they always consult each other, umm, and then. When I told them that I'm almost like completed my studies, then they decided that let's let's just stop. But we continue monitoring him right on his kidneys and other conditions to make sure." Pg.05* **Effects of medicine on self-management techniques** *PT03 "[vaccines], the second one... That did it for me for probably four months in terms of walking. To the point I had the booster one... I would easy do 35-40 thousand steps a day... it knocked at least 10,000 off, I just didn't have the energy... But that to me was a big impact because I'm not getting that in, it's a negative and negative impacts on well-being, frustration of I could do it before. So, I linked it to that... I put a good stone on after the third one..." Pg.20 "And to be fair, taking vaccine, which I wish I've never taken". Pg.29* *PT01 "She said you need to go on [anticoagulants]... so I can't really say, you know, I don't have it, I'm not down for that today. But sometimes, I do feel like all they do is try and make you." Pg.31* *PT01 "So I am anticoagulant, so I used to take magnesium, but I can't take that now cause on anticoagulant. "Pg.18*

	3.2 The fight for patient-centred pathways for MLTC continues	**When there is a clear pathway and/or established treatment accessing healthcare services can be good experience** *PT04 "that's where we go for my transplant checks... for all my checkups, even for diabetes, yeah, even for eye screening and all those things" pg.13* *PT04 "I haven't had any issues, have been attending all my appointments. Now I go for appointments maybe every six months." Pg.05* *PT03 – "To be fair I am 10 years into it [diabetes] so it's not a problem. As long as they give me repeat prescriptions it's fine. Yeah. So just like, anyway, so it not like I'm a newbie"* *PT01 "I've just had cataract... know what I've got, in one eye, and it was all fixed up in a week, you know, and I could have had the operation privately within a week.... and just went, fantastic." Pg.13-14* **Where there aren't clear pathways accessing healthcare is not a good experience** *PT02 "I feel a bit angry and frustrated, although I keep saying I understand. I think there should be something that helps people with conditions like myself, and to be able to, you know, it adds to the mental health problems, things like that because you worry all the time." Pg.13* *PT01 "in the healthcare system as I see it, for more things you have to fight for what you want and you have to charge of your health care yourself, which from, you know working in the health service most of your life feels a bit like a slap in the face." Pg.13* *PT01 "My GP, there is no coordination. No, I just tried a couple of times to make him listen. I don't go very often because you sort of lose faith." Pg.22* *PT01 "I do wonder if sometimes it's just somebody who actually listens to and looked at you in a holistic way." Pg.04* *PT01 "they can offer you gabapentin. They cannot see you. That's the one that blows your mind... It's not a clear pathway to follow." pg.35* *PT01 "and you see someone different and he said Well... basically you're alright. We just think its tension headaches." Pg.16* *PT01 "If you have a car accident, if you have a brain tumour, you know, you wouldn't wish for a better service... But the chronic pain management, the care of the elderly is just rubbish." Pg.35*
	3.3 Variations of feelings towards healthcare professionals	**Empathy for healthcare workers trying to help** *PT04 "I don't want to complain because there's, there's no need for me, you know, and the people who are trying to help me, they are also human beings. They've got their own issues as well... so overall my experience with COVID, I don't have any complaints." Pg. 17* *PT02 "She was saying it might be quicker to go to the walk-in... to sit there for hours and hours, I just can't do it... she's trying to help me and I understand that, but in a way its passing it to us, passing the buck." Pg.09* *PT02 "I feel really, I'm really supportive when it comes to anybody from the NHS because I realised what a difficult battle they've had to face and the fact that they have to ask for more pay and footballers are getting however many thousands and people who are really helping out there." Pg.06* *PT01 "The pain consultant [NHS friend] is just being a little gem. And I haven't had to pay him at all. And he sort of bless him. He he sort of just put me on the end of the list." Pg.03* *PT01 "I went to see the nurse; I went to see the consultant at the GP and then she asked me to go back again and all I got was a prescription for two tablets. Then that could have been done at the same time. She acknowledged that that was..." pg. 07* **A lack of empathy** *PT03 "Because it's a virus and they're doing their jobs. Good, well or badly but just because they keep turning up for work every day in COVID. They don't stand up clapping the army for doing their job, or the police for doing their job." Pg.17*

	3.4 Varying ability to get medication	**No issues getting medication needed** *PT04 "because we have been advised here [UK] the pharmacies, they're closing on everyone, so they gave us 3 months medication...so I had lots of medication in the house" Pg.08* *PT03 "[during covid] the only thing that you had to engage with was repeat prescriptions... That was the entire COVID conversation with the GPs, of how to get your prescription." Pg.27* **Struggled to get medication needed** *PT02 "you can't see the GP in time, so you have more times that you have been going through that pain because you can't access him to get the drugs that you need." Pg.10*
4:0 The lasting effects	4.1 Lasting impact of COVID	**Immediate Impact** *PT04 "I've no complaints, I've got no regrets. And I'm happy that at least I'm managing on my own." Pg.03* *PT04 "And also, appointment from the GP were starting to be available, you know, yeah, you know, people were scared still to go anyway." Pg.16* *PT03 "from COVID, even now, I still don't get the number in [steps] that I was getting. I don't have the energy" Pg.34* *PT03 "And, as more time goes on, you're not allowed to say anything negative because you are then anti vax or whatever, but there's more and more speculation about what these things do...If they try to push those drugs now, they'd never get FDA approval. But given the scenario they got approval." Pg.31* **The future impact** *PT03 "even if for some reason they push me back to the consultants in the next1 2 months, the next 12 days, to have the blood test from the consultant again. I would be like it's taken you months and I'm still not taking your pills." Pg.21* *PT02 "It is quite fearful really, to think what it's gonna be like in the end" Pg.06* *PT01 "if someone told me I'm gonna be taking more years. I'm going to thank you. Why live like this." Pg.36*
	4.2 Can't see healthcare services getting any better	**Strong opinions about the system** *PT03 "I'd stop throwing money at it, like that is the solution... it's badly managed." Pg.33* *PT03 "Once you're in, it's a battle to get out... I'll see you're here and then you go away and whatever happens will happen, and I'm not due to see you again until here and then that's how the system government... in the system that is used to tick a box." Pg.06* *PT02 "because of the government, because of all the changes, because we've left Brexit, because I could go on forever." Pg.20* *PT01 "they [patients] go into chronic management phase and it's when it goes into that it all goes wrong. You know I'm interested and working in the NHS for like 40 years, I did, I can, I could always see that." Pg.30* *PT01 "I think it's a money thing right, I think every time you go back they get £135 or whatever it is." Pg.23* **Worry for self and others caused by reduced trust and faith in healthcare services** *PT02 "you worry that things might get worse before they get better because of the way you are." Pg.13* *PT02 "I think it's getting worse. It's gradually getting worse. I see people I know getting worse, I listen to people's stories, and you know, they're having things cancelled left, right and centre, people who actually I'm lucky, I can get round on my crutches. But there are people who are really, really struggling." Pg.20*

		PT02 "I'm not sure it's gonna happen in my lifetime. I'm hoping for my grandchildren things will get better." pg.07 *PT01 ""I think that I think there's a lot of people who are like me who are. Struggling at home with pain and different things on that. So, I think some of you know, the pain services need to be* holistic *and I think they need to be obviously much better funded. Really. Like, yeah, I don't know what's up with this, but I guess nobody ever will really." Pg.32* *PT01 "the healthcare system as I see it, for more things you have to fight for what you want." Pg.13* *PT01 "I keep thinking I don't know, you know, I could be dead by the time we get this bloody place [house abroad]." Pg.10* *PT01 "It's just keeping yourself going really and trying to do things." Pg.06*

Appendix 8A: Revised Group Experiential Table (GET)

Key Themes	Subordinate Themes	Experiential Quotes
1.0 Living in the unknown – the emotional response to waiting to access healthcare services	1.1 Disruption to routine care and struggling with the increased need to self-manage	**Accepting disruption to routine care** *PT04 "You have to be content with it [cancelled appointments], or you go to hospital, and you know what it is like in hospital". Pg.11* *PT04 "Two months [after refusing the first appointment for fear] next available, I was like living in an unknown because I didn't know how the kidneys were functioning... I was adhering to the advice... But I just needed that kind of closure" Pg.15* *PT02 "Because that's the big issue. You feel all alone when you're left, not just by the GP but other caring facilities, everybody's feeling the strain of it." Pg.08* *PT01" COVID made it even worse; you couldn't see anyone about anything." Pg.27* **Difficulties getting appointments after the pandemic** *PT02 "that's really difficult because they're telling you is ring up at 8am in the morning... it will say you're #30 in line; we'll get back to you. So, you know you're not getting an appointment that day... so that's really difficult because sometimes you need to see them at the same time." Pg.05-06* *PT02 "they call you for blood tests quite regularly, I'd say every 3 months or so, yeah into the GP, although it's getting harder and harder to actually get face-to-face appointment." Pg.05* **Struggling with the increased need to self-manage** *PT02 "physio [arthritis], they'll say after six sessions or whatever it might be. So, with the physio just try to talk through it and just manage it, try to manage it the best way that I can." Pg.11* *PT01 "There's nowhere to go to other than A&E, and that is not the place to go." Pg.24* *PT02 "I'm gonna have an op on my knee. I've been twice and it's been cancelled. So, you're left with the you know that pain and the effects." Pg.12* *PT01 "they were saying you have to wait six months to see haematologist. And I was thinking I could hardly move." Pg.07* *PT01 "And it [not being diagnosed] does cause you to be a bit depressed at times as well [tearful]. Really depressed and made to feel low. And dominate." Pg.08*
	1.2 Trust and neglect in the system	**Expecting the system to drive all follow-ups** *PT04 "It's all up to them [GP] yeah because I don't phone for an appointment, but they give me an appointment when I'm due." Pg.16* *PT03 "pre-COVID you'd get summoned every year for a diabetes check. But all that went out the window for a good two years... They abandoned ship on everyone during COVID...But I remember getting a phone call, I said, I thought, you thought I was dead". Pg.18* **Feeling neglected when the system doesn't follow up in reasonable time** *PT02 "there is some really important tests that were supposed to be done when she was looking through my notes, they said they'd call you up in six weeks and that didn't happen...You feel neglected really you feeling you feel worried, you feel scared, you feel neglected." Pg.6-7*

		PT01 "refer you to a neurologist... so I haven't seen one. That was January [2024], so I've got an appointment... The end of January 2026... It was just over two years, so I haven't bothered cancelling it." Pg.15 *PT01 "The pharmacist told me to stop taking it and she sent a message through to the GP, but I haven't heard back." Pg.17*
	1.3 Loss of control and coping strategies	**Trying to take some control** *PT03 "So I'm just being pro-active ringing you up [to move appointment because of the pandemic]. No no that's I'll refer you back to your GP. That's it bang [phone down]. If I hadn't bothered, I would have got a letter I imagine somewhere in amongst all the COVID... you're no longer with our consultant go back to your GP. And to be fair I sort of laughed." Pg.17* *PT04 "the first appointment that I was offered I refused because I know of a Zimbabwean who went for a check-up and never returned". Pg.13* *PT01 – " I was paying for the consultations to try and get an answer quickly." Pg.02* **Cannot control treatment** *PT02 "a lot of the time they're saying it's because the way the health service is at the moment... I've been for a pre-op twice... it's been cancelled... because pre-ops they are supposed to do a couple of weeks before and apparently, yeah and they're just not ready for you." Pg.12* *PT01 "[orthopaedic consultant] gave me another open-ended appointment, and I said, well, my right foot is really bad and I said if you look at that and he said "no I'm not allowed", he said "the pathways on the NHS don't allow for that anymore". He said, "as ridiculous as it might sound, he said, I'll write back to your GP, and your GP will have to refer you to an orthopaedic consultant."" Pg.19*
	1.4 Seeking reassurances when dealing with uncertainty	**Finding reassurance in the healthcare system** *PT04 "to get the results of your tests, usually it's the same day [bloods]... they've got an app where they put your results... of course, a sigh of relief... You feel it's OK to feel well." Pg.15* *PT04 "They [nurses] were just acting normal. And then that's when I ask myself... why are we all afraid when some other people are working to help us, you know, they're interacting normally... And then I think... looks like it's [COVID] not as bad as we think...It actually gave me more freedom". Pg.14-15* **Finding reassurance elsewhere** *PT03 "I like to go to the chiropractor because they are very, for me, a bit more inquisitive and out of the box". Pg.27* *PT02 "they [community group] realised that you know when we're not coming here, that it's really really difficult for people at home. So, they had a drop in [rather than cancel] and I came along to that." Pg.05* *PT01 "That in itself, he's listening to you and actually gives you faith [private therapist]". Pg.21*
	1.5 Prioritising what is important	**Risk self-whilst prioritising others** *PT04 "My mom has been in and out of hospital (Zimbabwe) and me, I'm here (UK) I'm able to walk after the operation. I'm OK, I'm feeling fine, right? Why not? What if she dies.... How am I going to cope?". Pg.10* *PT01 "We have got a very active lifestyle. They have to say in all of this, we've travelled a lot, we've gone all over the place with this, but it's always a real push to do it."* Pg.08 **Overcoming challenges for self-care**

		PT03 "I went away two years ago. That's part of the reason [had the vaccine] I had to be able to go and get through the airport [to get some sunshine to help the lupus]. Pg.30 *PT02 "so through that [telephone befriending group] were on the phone with me probably about six months, maybe longer and then they told me [about a community group] ... I managed to come to that because I was having trouble getting out of the house." Pg.04*
2.0 Effects of the COVID-19 pandemic on managing day-to-day life	2.1 Realising heightened vulnerability and feelings of isolation	**Fearful of contracting the disease** *PT04 "[hospital] that was a no go area". Pg 11* *PT04 "And then the next thing is I receive a message that the person who was sitting next to you [on the plane], had tested COVID positive. And that was the scariest moment." Pg.09* *PT04 "knowing my conditions and also advice from the doctors...I was one of the first people to make sure every time I leave the house, I take a mask". Pg.06* **Factors that can make it worse** *PT03 "And to be fair taking the vaccine, which I wish I'd never taken, to be fair. Definitely wish I'd never taken, particularly the 3rd one, the 3rd one has proper done me." Pg.29* *PT01 "these last few days I feel really really bad. But whether that is because I've got some, you know, it could be a COVID type of thing." Pg.21* **Isolated by things that happened out of my control** *PT04 "[airport hotel] it was total isolation; you just be stuck in your room. No, you don't talk to anyone." Pg.08* *PT02 "I was really isolated during COVID for lots of different reasons [mental health services and online support groups disturbed], but to live with what I've got is a daily thing and it's worrying each day really." Pg.02*
	2.2 Value of maintaining meaningful connections ; for self and others	**Finding purpose through helping others** *PT04 "I've always been involved; there's just life after [name: community centre]. There's [name: another community centre], there's [name: another community centre]. And here [a group in a community centre] Yeah, so I make sure I'm free, if I'm not doing anything, I just pop in have a chat with people, you know.... I've got something in me. I like to listen to other people's stories... But most people, what I've discovered is there's a lot of isolation... They don't even have someone to just say good morning... How are you feeling today?" Pg.20-21* *PT04 "I take their bins out...and people have got different conditions. Some cannot even get out of the bed, you know, you go knocking at their doors, you know. She told me she's not feeling well" Pg.21* **Finding ways to stay connected during COVID-19** *PT02 "...have got really good couple of good good bessie mates. Every Friday we sit still now and have a cheese toastie and a chat, put the world to rights, things like that." Pg.24*
	2.3 Increased burden on others	**Sharing with others** *PT04 "Make everybody at home you know, got panic? Everybody panicked. Thinking you know, thinking more, maybe it just caught up with him, but lucky enough I was fine" Pg.09* **Trying to protect others**

		PT02 "So not that they wouldn't be helpful or, you know, but you just don't want to burden them [family] with it." Pg.11 *PT01 "[deteriorating health with no diagnosis or help] And, you know [husband] will say things like, well, I'd quite like to go around South Africa, you know and I think that's a step too far for me." Pg.29* *PT01 "Because you do feel like a nuisance in the day-to-day." Pg. 34*
	2.4 Seeking positives – finding different levels of gratitude	**Grateful for Independence** *PT03 "In some respects it [COVID-19] was great because you were left alone and not being monitored, which is kind of like, I had no problem with that at all, it was great". Pg.19* *PT04 "I've no complaints, I've got no regrets. And I'm happy that at least I'm managing on my own." Pg.03* *PT02 "I'm lucky, I can get round on my crutches. But there are people who are really, really struggling." Pg.20* **Grateful for health service information** *PT02 "[when mental health services started again] literally when I was getting them phone calls, it was and literally a lifesaver, you know because you can feel yourself going under kind of things and I needed something to happen." Pg.18* *PT04 "You know, because of information now, access to information I have discovered that ohh instead of me booking with the GP, they do walk-in jab here." Pg.17*
3.0 Trust and faith in the healthcare system at risk	3.1 On-going scepticism of the system and the fight for patient-centred care	**The system structure hinders not helps** *PT02 "and sometimes they just want one, one issue at a time...but it's not telling him the truth about your whole body... more than one thing at a time is happening...and people don't realise you can ask for double appointments...and people should hear about that and know what is available" Pg.17-18* *PT03 "conversations I've with a lot of people, family and friends, all the rest of it. Once you're in the NHS system and you understand it, it's very different to people who aren't in the system who say the NHS is great." Pg.06* *PT01 "And seeing somebody who you've been referred to by the NHS, yeah, just for that [one thing]. And you can't see them for anything else. But that is just a nonsense, isn't it really." Pg.19* *PT01 "I do wonder how long have gone on if I hadn't have sorted myself out. And I do wonder sometimes if maybe I hadn't kept pushing maybe, you know, what would have happened. I don't really know." Pg.08* **When there is a clear pathway and/or established treatment accessing healthcare services can be good experience** *PT04 "that's where we go for my transplant checks... for all my checkups, even for diabetes, yeah, even for eye screening and all those things" pg.13* *PT01 "I've just had cataract... know what I've got, in one eye, and it was all fixed up in a week, you know, and I could have had the operation privately within a week.... and just went, fantastic." Pg.13-14* **Where there aren't clear pathways accessing healthcare is not a good experience** *PT02 "I feel a bit angry and frustrated, although I keep saying I understand. I think there should be something that helps people with conditions like myself, and to be able to, you know, it adds to the mental health problems, things like that because you worry all the time." Pg.13* *PT01 "in the healthcare system as I see it, for more things you have to fight for what you want and you have to charge of your health care yourself, which from, you know working in the health service most of your life feels a bit like a slap in the face." Pg.13*

		PT01 "My GP, there is no coordination. No, I just tried a couple of times to make him listen. I don't go very often because you sort of lose faith." Pg.22 *PT01 "If you have a car accident, if you have a brain tumour, you know, you wouldn't wish for a better service.... But the chronic pain management, the care of the elderly is just rubbish." Pg.35*
	3.2 Variations of feelings towards healthcare professionals	**Empathy for healthcare workers trying to help** *PT04 "I don't want to complain because there's, there's no need for me, you know, and the people who are trying to help me, they are also human beings. They've got their own issues as well... so overall my experience with COVID, I don't have any complaints." Pg. 17* *PT02 "She was saying it might be quicker to go to the walk-in... to sit there for hours and hours, I just can't do it... she's trying to help me and I understand that, but in a way its passing it to us, passing the buck." Pg.09* *PT02 "I feel really, I'm really supportive when it comes to anybody from the NHS because I realised what a difficult battle they've had to face and the fact that they have to ask for more pay and footballers are getting however many thousands and people who are really helping out there." Pg.06* *PT01 "The pain consultant [NHS friend] is just being a little gem. And I haven't had to pay him at all. And he sort of bless him. He he sort of just put me on the end of the list." Pg.03* **A lack of empathy** *PT03 "Because it's a virus and they're doing their jobs. Good, well or badly but just because they keep turning up for work every day in COVID. They don't stand up clapping the army for doing their job, or the police for doing their job." Pg.17*
	3.3 Varying ability to get medication	**No issues getting medication needed** *PT04 "because we have been advised here [UK] the pharmacies, they're closing on everyone, so they gave us 3 months medication...so I had lots of medication in the house" Pg.08* *PT03 "[during covid] the only thing that you had to engage with was repeat prescriptions... That was the entire COVID conversation with the GPs, of how to get your prescription." Pg.27* **Struggled to get medication needed** *PT02 "you can't see the GP in time, so you have more times that you have been going through that pain because you can't access him to get the drugs that you need." Pg.10* *PT01 "She said you need to go on [anticoagulants]... so I can't really say, you know, I don't have it, I'm not down for that today. But sometimes, I do feel like all they do is try and make you." Pg.31*
4:0 The lasting effects	4.1 Lasting impact of COVID-19	**Immediate Impact** *PT03 "from COVID, even now, I still don't get the number in [steps] that I was getting. I don't have the energy" Pg.34* *PT03 "And, as more time goes on, you're not allowed to say anything negative because you are then anti vax or whatever, but there's more and more speculation about what these things do...If they try to push those drugs now, they'd never get FDA approval. But given the scenario they got approval." Pg.31* **The future impact** *PT03 "even if for some reason they push me back to the consultants in the next1 2 months, the next 12 days, to have the blood test from the consultant again. I would be like it's taken you months and I'm still not taking your pills." Pg.21* *PT02 "It is quite fearful really, to think what it's gonna be like in the end" Pg.06*

		PT01 "if someone told me I'm gonna be taking more years. I'm going no thank you. Why live like this." Pg.36
	4.2 Can't see healthcare services getting any better	**Strong opinions about the system** *PT03 "Once you're in, it's a battle to get out... I'll see you're here and then you go away and whatever happens will happen, and I'm not due to see you again until here and then that's how the system government... in the system that is used to tick a box." Pg.06* *PT01 "they [patients] go into chronic management phase and it's when it goes into that it all goes wrong. You know I'm interested and working in the NHS for like 40 years, I did, I can, I could always see that." Pg.30* *PT01 "I think it's a money thing right, I think every time you go back they get £135 or whatever it is." Pg.23* **Worry for self and others caused by reduced trust and faith in healthcare services** *PT02 "you worry that things might get worse before they get better because of the way you are." Pg.13* *PT02 "I think it's getting worse. Its gradually getting worse. I see people I know getting worse, I listen to people's stories, and you know, they're having things cancelled left, right and centre, people who actually I'm lucky, I can get round on my crutches. But there are people who are really, really struggling." Pg.20* *PT02 "I'm not sure it's gonna happen in my lifetime. I'm hoping for my grandchildren things will get better." pg.07* *PT01 "I think that I think there's a lot of people who are like me who are. Struggling at home with pain and and different things on that. So, I think I think some you know, the pain services need to be* holistic *and I think and they need to be obviously much better funded. Really. Like, yeah, I don't know what's up with this, but I guess nobody ever will really." Pg.32*

Appendix 9: Reflective Journal

Date:15th February 2023

Stage: Research proposal

Summary: Before starting the research, my belief is that there should be equitable healthcare for all. That there is widening health inequalities to access adequate services, especially in areas of deprivation. I am employed by a healthcare charity that offers interventions for people with MSK conditions plus others, like Diabetes and Hypertension, to help manage chronic pain. I have noticed a lack in national healthcare services that understand and help each person and their individual needs to manage their condition(s). I notice when physiotherapy and medication no longer help, or does not help, people are left without support, unless seeking it themselves. I hear of increased waiting times for care, cancelled clinics and support groups no longer in existence since COVID-19. Some of the participants I come across, talk about losing hope, feeling like they don't matter, or not wanting to be a burden because they know the services are under pressure. I feel the change in energy and hear the positivity when someone listens to them and cares about what they are going through. One lady talked to me about not being able to wash as she only has a bath and couldn't get in and out of it. She was waiting for a shower to be installed by the council but had been waiting over a year. The basic need to wash and be clean was hard for her. This was hard to hear, but she smiled and hugged me, thanking me for sitting for a few minutes and listening to her. A gentleman told me that community support group helped him reduce his medication and now he is more active and has much less pain, allowing him to walk about and take pictures with his camera like he used to. He was extremely grateful saying he has his life back again after losing hope, believing that he would be sat indoors for the rest of his life.

Insights: Impact of waiting lists, lack of joined up services that support chronic disease management, people's lives are affected in ways that are not understood because there is a lack of patient perspectives within the research and decision making of services.

Decisions/Justifications: To give patients a voice to highlight the impacts of living with multiple long-term conditions, how accessing healthcare effects their lives and how the COVID-19 pandemic has impacted patients themselves.

Next Steps: Conduct a literature review pre-COVID-19, looking at people accessing healthcare with multiple conditions. Set the research questions, look at different philosophical standpoint and qualitative research methodologies and complete the proposal.

Date: March 2023

Stage: Exploring the questions

Summary: The personal driver for this study is an inquisitive one. I want to understand the current state of healthcare services in the UK for chronic disease and learn of why so many people feel let down by the service and do not receive the care they need. I want to understand what it is like to live with multiple long-term conditions from a patient perspective. I'm asking; do the government strategies deliver the right care to 1 in 4 people with chronic disease, even in the face of a pandemic, if so, how? if not, why not? What do the patients themselves think and feel about accessing healthcare for multiple conditions and the impact of the pandemic.

Insights: Need to understand what it is like living with chronic diseases from a patient perspective. What accessing healthcare is like. What impact the COVID-19 pandemic has had on their conditions and their lives.

Next Steps: Assess the current healthcare landscape for long-term chronic disease management and look for gaps in the research or where the demand on services are challenging.

Date: April 2023

Stage: Writing the proposal

Summary: Looking at different qualitative methodologies. Wating an inductive approach that is focus on the patient perspective giving justice to their experience. Whilst, comparing their experiences to current literature.

Gaps identified; lack of research in multiple long-term conditions, varying reports on waiting lists and government plans and reporting measures, making it hard to know how this topic tracks improvements in healthcare services. Different chronic conditions have different healthcare approaches; some are more established than others e.g. cancer care versus chronic pain. Cancer has clear pathways, and chronic pain does not.

Insights: Phenomenology, Interpretative phenomenological analysis and semi-structured interviews was appropriate to the criteria. It is important to reflect individual patient experience of their health and healthcare and in relation to the COVID-19 phenomenon. There are 2 challenges; healthcare varies depending on the conditions and the impact of the COVID-19 pandemic is not known.

This feels like a challenge as a novice researcher. I need to stay focused on the philosophy and approaches that drive this methodology. Being a novice researcher can be helpful, as

I don't have academic experience in other forms of research and therefore, can immerse in this approach with no conflict.

Next Steps: Write the RD1 proposal and present to the panel.

Date: May 2023

Stage: Presenting the proposal

Summary: Proposal accepted

Insights: Interviewing twice could be a challenge. Explore other options to the method. Be clear to justify selected health conditions, sample and methodology throughout.

Next Steps: Prepare and submit a GANT plan.

Date: June and July 2023

Stage: Ethics and Protocol; preparing resources and setting the inclusion/exclusion criteria.

Summary: Writing the ***protocol and resources*** (Consent for, Patient Information Sheet and Protocol) was within my skill set and comfort zone. However, the interview guide was more challenging and took longer than I imagined. My positioning in the workplace, is usually to fix an identified problem, rather than facilitate exploration of experiences to produce data.

Deciding the ***inclusion criteria*** was also a challenge. I wanted to include participants that have frequent access to healthcare for multiple reasons. Therefore, made the decision to exclude mental health, dementia and cancer and terminal illness because these conditions have existing and established pathways within the NHS.

Insights: I sought counsel from a PhD student who had done Phenomenology and IPA to help me refine the interview questions. This was beneficial to understand how to draw out the meaning of participant experience with the "*why*" questions and get feedback to how to make the questions answer the research questions. It is very important to the study draw out *meaning* and be able to use this to highlight the importance of patient voice to create service improvements. A personal challenge is trying not to fix a problem but hear the experiences so I can interpret them and give meaning to them, adopting a position as an IPA researcher.

Next Steps: Prepare protocol and submit ethics

Date: July 2023

Stage: Writing the interview guide and re-planning the interview structure

Summary: As a novice researcher using IPA, I verified by first draft with a PhD student who has just completed an IPA study. I further, got feedback from a lecturer within MMU who advice not to interview the participants twice, as this would require specific memory recall of events. Instead, interview once and allow the participants to tell their story and remain conscious of time periods during the interview. This was welcomed advice to support a natural and open conversation with the participants, but also from a practical perspective to manage time.

Date: August - September 2023

Stage: Ethics submission.

Summary: This took longer than anticipated due to not understanding the Manchester Metropolitan University process. It wasn't clear to me at the time. This unfortunately, delayed me a few weeks. I could have started my participant recruitment.

Insights: MMU processes are not clear for remote students. In the meantime, I was awaiting feedback on the interview guide and literature review.

Next Step: Practice Patient

Date: October 2023 – January 2024

Stage: Disruption

Date: February 2024

Stage: Re-enrolment difficulties and could not access MMU systems. Could not get clarity of the recording and transcription software and the booking a device did not allow me to keep a recorder for a few months, so I bought one.

Date: February-April 2024

Stage: Revised GANT, Revisited the thesis proposal and progress so far.

Summary: Writing the thesis to date was a great experience to reconnect with the data. This allowed clarity of the approach going forward. Creating a framework at this stage

was very valuable. Updating ethics to reflect the new recording device and transcribing process.

Insights: Time is tight. Not allowing for MMU administrative delays I need to start the data collection and analysis process.

Next Step: Practice Patient

Date: February-April 2024

Stage: Revised GANT, Revisited the thesis proposal and progress so far.

Summary: Writing the thesis to date was a great experience to reconnect with the data. This allowed clarity of the approach going forward. Creating a framework at this stage was very valuable.

Insights: Time is tight. Need to start the data collection and analysis process. Upon reflection this could have been started earlier.

Next Step: Practice Patient

Date: June 2024

Stage: Practice Participant

Summary: Practice participant. Really enjoyed listening to the participant experiences and could feel myself sympathising and in some cases empathising. Some parts were hard to hear, knowing they were upset and had to accept living with pain and discomfort with no satisfactory help, effecting quality of life. I wish I had probed more on some points, particularly the impact on family members and the meaning they gave to this point. I had an awareness of the challenges facing the healthcare system and why they were experiencing what they were. Feeling of frustration knowing the negative impact I was hearing and not being able to help. Followed by my own feelings of acceptance "that's the way it is". I left with a heavy heart. The interview became repetitive, so I knew I had covered the journey of the participant. I felt 1-hour 57mins went quick, but this would be too much data to analyse for four more as it took over 3 weeks to process.

Insights: During the data analysis process, I learnt the techniques of IPA. Familiarising myself with the steps to produce personal experiential themes was valuable. Learning to look for "experiential" words, asking myself "h*ow did the patient experience that event?* And, *what meaning did that have to them*?" I became worried that the participants talk a lot about "living with multiple long-term conditions" and not necessarily the impact of the pandemic. I became conscious to ask more of this in future interviews.

Next Step: Recruit four participants

Date: July2024

Stage: Research

Summary: The new government announcing the NHS is “broken” gave me a sense of relief. I understand not all patients have positive experiences and the negative experiences have detrimental effects on people’s lives. From the literature review conducted pre-COVID and speaking to people in day-to-day life, there is a sense the NHS is not fit-for-purpose, in some cases damaging people’s health more. This sense of relief comes from a feeling of hope that the healthcare system will now start make progress in getting the right help to people that need it.

Insight: In light of the government response to HealthCare services and the aftermath of the pandemic.

Next steps: Further research needs to be conducted to account for the current landscape.

Date: July 2024

Stage: Recruiting participants

Summary: I had a meeting with the CEO of a Manchester charity that provides a variety of support services to the community to discuss the study and possible recruitment of participants. They gave valuable feedback on the poster and invited a natural discussion about why I was doing the study, subsequently advising to change the look and feel of the poster to be less clinical looking and more about myself to build rapport and trust that would engage potential participants in a more natural and honest way.

Insight: This was valuable insight from someone who engages daily with people that would be relevant to the study.

Next Steps: Visit the group to meet people who may wish to take part.

Date: August - September 2024

Stage: Recruiting participants

Summary: I attended the group several times and spoke to eligible participants. However, this took longer than expected. I arranged to meet 2 eligible participants twice, but they did not attend for reasons of ill-health and getting a new puppy. However, during my visits met with two other eligible participants that were willing to take part.

I also, added the poster to social media and asked if anyone knew of anyone who met the criteria. I received two referrals who were eligible.

Insight: Recruitment takes longer than expected and more time to allow to plan availability and disruptions would have been useful. Decided to remove diagnosed from the inclusion criteria after conversations to potential participants and the practice participant about chronic diseases that are hard to diagnose.

Next Steps: Interview PT01 and PT02

Date: October 2024 -

Stage: PT01 interview and analysis

Summary: *Before the interview*, I was a bit apprehensive that I won't ask the right questions to get the data needed. I knew this participant had not had a good time with her health and had a story she wanted to talk about her experiences. *During the interview*, this participant shared willingly and openly and with great clarity taking me on a journey of her own story. Little questions were required, and I discovered the importance of empathy is hugely important. We had some things in common; chronic back pain and experience working in the healthcare sector, so the conversation was natural. However, as the participant was speaking, I started to feel angry and frustrated with her, that she couldn't get the diagnosis and care she needs to manage her symptoms and had to pay privately to help herself as much as possible. A woman so healthy and active and no history of smoking or any excessive and harmful habits, was suffering and no one can help. I became in despair with her, that all the research that happens in the world and there is nothing to help this range of symptoms that are so far inexplicable.

Insights: *During the IPA process* I noticed parts that I could have probed a little more, however, she was reluctant to talk about how it made her feel as this was too upsetting. She couldn't finish some sentences because it was too hard to acknowledge her own pain. I also noticed there was opportunities to bring some experiences back to COVID-19 specific impact. During this process I began to explore; How can it be that this participant cannot get any help? I started to think, is this modern life, stress on the body from so much rapid change over recent decades, as the risk-factors suggest? But she was healthy and active and didn't smoke and rarely drank alcohol. She has worked in healthcare and seen disjointed pathways for non-acute conditions for 40 years. I began to question what has been happening to the NHS in over 40 years, for there to be no answers for a condition that effects 1 in 4 people and is stealing the retirement and health of this woman and many of our population. I walked away quite sad. And, more in agreement with Wes Streeting's declaration of the NHS being broken. I started to feel for NHS workers that are in a system that is not patient-centred when it comes to chronic disease as they are unable to help in a meaningful way and restricted by frameworks that don't fit patient needs and demands. The outcome appears to be that most the responsibility falls

onto the patient to help themselves and the consequences are poorer health. Patients are left managing symptoms between appointments with long waiting lists and in this case, no diagnosis or care plan.

Next Steps: Interview PT02

Date: October 2024

Stage: PT02 interview and analysis

Summary: *Before the interview* I felt more confident as an interviewer and hoped this participant would also talk freely and openly. After a couple of participants had cancelled from this location, I was nervous because my timeline was becoming tighter. Luckily, she attended but was late due to the community bus not turning up and having to wait for a taxi. Situated in a lovely community group in Manchester that I've been visiting on Wednesday mornings for a few weeks but knew from previous employment. The group is extremely welcoming and caring and a lifeline to many local people that suffer from varying health conditions and situations. I met PT02 the week before, in a casual conversation and found her so humble and inspiring, she asked me why I was there and wanted to take part to help me. *During the interview* she started talking so calm, soft and precise in what she was saying. A few questions opened a conversation of facts and feelings that took me on her journey. The strength in her voice was remarkable given her adverse experiences including abuse and, this made me emotional and wanting to champion her. I left feeling a little angry at the world for what had happened to her, how can it be so cruel. In relation to her healthcare access, I was again, angry. How can a system that is supposed to care for people make it harder, mess them about, cause additional worry and negative impacts. How can it be in 2024, a standard knee operation takes several visits and no clear indication where in that system she sits, to give her reassurance and confidence she will get the help she needs. How can one person need so many appointments and be told they cannot speak of all that is of concern; one appointment, one problem – when 1in4 and growing are suffering multiple conditions. Despite her struggles, she shows understandings for NHS workers. I left with a heavy heart yet inspired by the strength I see. Not one tear and so much pain.

Insights: *During the IPA process* whilst listening to and analysing this participants transcript it confirmed a lot that was discovered with PT01. No help for chronic pain, responsibility to cope on the patient, listening is important and a lack of care between appointments including, those taken away during the pandemic. This case highlighted the importance of community and social networks. And, also brought to my attention that there are varying degrees of “vulnerable” that was not recognised in the pandemic to my knowledge and needs further research.

Next Steps: Interview PT03 and PT04

Date: December 2024

Stage: PT03 interview and analysis

Summary: *Before the interview* I was more confident to ask the right questions and learnt that it is acceptable to explicitly ask about the COVID-19 pandemic impacts. On reflection, my interview guide could have been more weighted towards this, rather than expect the personal accounts to unearth it. For PT01 and PT02, I trusted the guide, but to get some answers some direct questions needed to be asked.

During the interview I found it easier to listen and circle back. PT03 was very clear about the order of events relating to his long-term conditions. Wanted to tell it chronologically to convey his journey and how this has formed his opinions. He wanted to lead the conversation and told it almost like a story, taking on the character of healthcare professionals. Throughout this conversation I realised the impact of COVID runs deep for the participants. Not only frustration and reduced health waiting for appointments or a correct diagnosis, but the disruption to services has led them to question the system, the government and the treatment they receive. Misdiagnosis causes health harm, e.g. wrong medication effects or mental health and wellbeing. This participant explains this was the case before, but COVID has offered some confirmation that the system just can't help people when they need it and identifies that interventions are outdated. Put simply, the removal of routine appointments puts into question if they were needed in the first place or they there to make money, but they do offer reassurances. This conversation was strongly focused on trust and faith and questioning a system that has not been helpful to him for a sustained period, potentially causing harm to health and resulting in the opinion that it's not fit for purpose. It seems that patients with chronic diseases are left with no information that can help reduce stress, mental health problems and therefore, making it harder to cope on top of conditions that effect daily life. Like no one is listening and they want you to “fit in a box”. I left this conversation thinking there is a real impact COVID has had on the faith and trust of the mainstream Healthcare Services.

Insights: *During the IPA process* This participant was very inquisitive, took responsibility for his health, independent and living alone. It got me thinking that characteristics of a person is vital for patient centred care. Understanding the whole person situation, their views and beliefs all count towards co-creation of a meaningful and impactful individual care plan.

Next Steps: Interview PT04

Date: January 2025

Stage: PT04 interview and analysis

Summary: *Before the interview:* Due to Christmas and various diary clashes this interview was delayed over a month. This caused worry for my deadlines, which was eased when re-scheduling the milestones on the timeline and reassurance from the Supervisors there was enough time.

During the interview PT04 was a surprise. He discussed years of positive and consistent experiences when accessing healthcare. From moving to the UK from Africa in 2005 to the present-day, he explained experiences of connected healthcare. Up to this point, participants experiences were less positive. I was overwhelmed by the memory of this participant as he recalled vividly the timeline and events from 2013 to the present day. COVID had very significant events of needing to travel to see family that he hadn't see for many years. The overall positivity and personal beliefs of this participant drove his experiences of the world. Seeking gratitude and acceptance in every situation. I left feeling like the patient experience is driven by their own view of the world in conjunction with the events themselves. Also, that the healthcare system does get it right sometimes and a recommendation may be to find these specific examples to be used as a blueprint for how we improve our health services.

Insight: *During the IPA process,* it reinforced PT03 conclusion, that characteristics and circumstances are important to patient-centred care. I realised that the NHS does get it right sometime, so what is it that Manchester is doing in this location that makes it work for some and not for others? COVID-19, however, did have some negative impact on a very positive person and healthcare service, driven by an increased vulnerability. This circles me back to PT02 and the need to understand levels of vulnerability and how this can be helpful to individual's circumstances.
Next Steps: Cross-Case analysis to produce Group Experiential Table (GET)

Date: February 2025

Stage: Cross Case Analysis and produce a GET ready to write up the findings

Summary: My attention was back to the framework of the thesis for the first part of February; refining sections has allowed me to maintain a focus on the purpose of the study throughout the data collection process. Data collection has been mentally consuming, in the sense that I'm nervous I want to do the words justice whilst drawing out the answers to the questions. Going back to the aims and context of the study helped remind me the purpose and the importance of answering the question.

During the latter part of February, I focused the rigorous data analysis for each participant, I knew the participants and their experiences inside and out and could

produce the cross-case analysis with relative ease and enjoyment. This took about 3 full days of constant refinement and going back to the data source to verify context. This process developed a clear split of experiences that answered the research questions. First, *what is it like to live with MLTC and access healthcare*, and second, *how did the COVID-19 pandemic impact people with MLTC accessing healthcare*. I used a white board and coloured pens to split out the experiences of pre and post COVID to time stamp the experiences. I really enjoyed this process; it was challenging and sometimes caused me to become data blind. This required me to walk away and come back with the question in mind. I learnt that this part of the process requires blocks of protected, undisturbed time to immerse in the data, but also breaks to reflect and reset and go again. At first, this felt uncomfortable, as it was not a linear process but an iterative one that required constantly going back to the transcripts, the personal experience tables and the research questions to qualify my interpretations and themes.
Next Steps: Post-COVID literature review

Date: February –March 2025

Stage: Post-COVID literature review

Summary: On completion of the data collection and analysis, the next step is to explore the post-COVID-19 literature, with particular attention to answering the research question. I used the same methodology as the pre-COVID literature review to find any literature that exists that has focused on 3 main elements: Multiple long-term conditions, patient perspectives and COVID-19 pandemic. This was difficult. 4 years post-pandemic and there is not much data within the databases, so I extended this search to google scholar and did not find very much.

Insights: There is a lot of focus on tele-medicine and digital solutions for healthcare provision. This method of healthcare delivery was accelerated because of the pandemic, providing interesting viewpoints to the appropriate use of such approaches. Research focused on maintaining physical activity and the impact of COVID-19 on mental health and emotional wellbeing, with some references to the pre-COVID themes and the themes within this study. One study was aligned to this one and create very similar themes.

Next Steps: Writing up the GET

Date: March 2025

Stage: Writing up the GET

Summary: I spent a further 4 full days immersed in the GET to write up the key themes and sub-themes. Paying particular attention to similarities and difference in participant experience of the same or similar events and what was meaningful to them. It emerged

that individual characteristics of the participants created some convergence and divergence within the data. 4 main themes were identified that reflect what living with multiple long-term conditions is like and the impact of the pandemic. Noting, potential discussion points as I processed each theme and the accompanying supporting quotes.

Insights: It emerged that individual characteristics of the participants created some convergence and divergence within the data. 4 main themes were identified that reflect what living with multiple long-term conditions is like and the impact of the pandemic. Noting, potential discussion points as I processed each theme and the accompanying supporting quotes.

Next Steps: Write the discussion

Date: March 2025

Stage: Write the discussion and submit the draft

Summary:

Date: April 2025

Stage: Preparing for submission

Summary: Revisit each chapter and make amends based on feedback. Ensure references are accurate to Harvard cite them right, check formatting and submit to Turnitin.

Appendix 10: Ethics approval

Submission - 56815: MRes - Impact of COVID-19 on patients living with 2+long term conditions access to healthcare

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06/08/2023

Project Title: MRes - Impact of COVID-19 on patients living with 2+long term conditions access to healthcare

Ethos Reference Number: 56815

Ethical Opinion

Dear Paula Alexandria Moore,

The above application was reviewed by Prof Christopher Hatton and on the 06/08/2023, was given a favourable ethical opinion. The approval is in place until six months after the end date recorded in your application documentation (08/01/2024).

Approved Documents

Document Type	File Name	Date	Version
Information Sheet	PIS Final	03/08/2023	2
Consent Form	Consent form Final	03/08/2023	2
Recruitment Media	paula poster	03/08/2023	1
Project Protocol	MRes Protocol PM Final	06/08/2023	3

Conditions of favourable ethical opinion

The favourable ethical opinion is granted with the following conditions

Approval is in place for your UG/PGT project

This approval is only valid for Undergraduate (UG) and Postgraduate Taught (PGT) projects and does not grant approval for any Staff or PGR projects.

Adherence to Manchester Metropolitan University's Policies and procedures

This ethical approval is conditional on adherence to Manchester Metropolitan University's Policies, Procedures, guidance and Standard Operating procedures. These can be found on the Manchester Metropolitan University Research Ethics and Governance webpages.

Amendments

If you wish to make a change to this approved application, you will be required to submit an amendment. Please visit the Manchester Metropolitan University Research Ethics and Governance webpages or contact your faculty research officer for advice around how to do this.

We wish you every success with your project.

Health and Education Research Ethics and Governance Committee

v1.8.1

Submission - 56815: MRes - Impact of COVID-19 on patients living with 2+long term conditions access to healthcare

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06/09/2024

Project Title: MRes - Impact of COVID-19 on patients living with 2+long term conditions access to healthcare

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Approved Documents

Document Type	File Name	Date	Version
Additional Documentation	Paula Masters - Info poster	08/08/2024	2
Additional Documentation	Patient Consent Form	08/08/2024	2
Additional Documentation	Participant Information Sheet	08/08/2024	2

Conditions of favourable ethical opinion

The favourable ethical opinion is granted with the following conditions

Approval is in place for your UG/PGT project

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We wish you every success with your project.

Health and Education Research Ethics and Governance Committee

v1.11