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Remote primary healthcare in the UK: How does marginalisation shape experiences of healthcare?

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Remote primary healthcare in the UK: How does marginalisation shape experiences of healthcare?

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I, Ada Humphrey, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

In response to COVID-19 there has been a shift in the way in which healthcare services are accessed in the UK with most non-acute healthcare service delivery made remote. This is against a background of strong and persistent inequities in health outcomes and healthcare access in the UK. Whilst there are hopes that remote healthcare will remove many barriers to accessing healthcare it is also possible that this form of service delivery will both create new types of inequities as well as replicate and re-embed existing ones. This PhD study explores the experiences of changes to GP care amongst marginalised groups in the UK. The study focuses on the different ways in which healthcare work is being created and reallocated in General Practice and the implications of this for care. The two main focal points are on an increased use of remote consultations, and a reduction in relational continuity of care. The research uses the ideas of responsibilisation, work, and candidacy to explore how processes of marginalisation shape experiences of GP services in the UK.

This study took an ethnographic approach over the course of six months (November 2021-April 2022) involving observation and interviews, conducted across a range of field sites in London. These include a foodbank, an advice centre for refugees and asylum seekers, and a charity offering digital support. The research also includes in-depth interviews with GPs from London's lowest ranking IMD boroughs, members of staff at Digital Health Hubs across the UK, and staff members at the fieldwork site services. The analysis explores the normative expectations being placed on patients and how these work to produce new thresholds for eligibility and types of healthcare work for patients. The way in which this interacts with patients' capacity is a key question of this research, which focuses on how marginalised groups may be uniquely impacted by changes to GP services. The intention of this study is to feed into practice through a recognition of the potential challenges patients from marginalised groups face in engaging with GP services as well as challenging new assumptions about patients being normalised into practice.

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List of acronyms:

BOTT – Burden of Treatment Theory

DOTW – Doctors of The World

eHealth – Electronic Health

GP – General Practice

LMICs – Low-and-Middle-Income Countries

mHealth – Mobile Health

NIHR – National Institute for Health Research

PPI – Patient and Public Involvement

SES – Socioeconomic Status

TA – Thematic Analysis

WHO – World Health Organisation

Chapter 1. Introduction

Chapter 1.

Introduction

This study examines the impact of recent changes in primary care in the UK on the experiences of marginalised groups, specifically focusing on the implementation of remote appointment booking systems and consultations. The primary research question is: What is the relationship between marginalisation and remote service delivery in primary healthcare experiences in the UK? The second order research questions, and research objectives are outlined at the end of this chapter. The COVID-19 pandemic brought about a significant transformation in the delivery of healthcare services in primary care, with a notable increase in the utilisation of digital appointment booking systems and remote consultations through various digital tools such as telephone calls, video calls, and online tools. It is widely acknowledged that there are persistent disparities in healthcare access throughout the UK. However, the implications of increased digital and remote service delivery in primary healthcare on these inequities are not yet fully understood. While there is optimism that digital and remote healthcare may alleviate barriers to access, it is also possible that it could introduce new access disparities and reinforce existing ones.

There is an established body of evidence demonstrating the negative impact of marginalisation on individuals' health and their healthcare experiences. The expansion of remote and digital healthcare was a key objective in the UK healthcare system even prior to the COVID-19 pandemic, and the pandemic has accelerated its implementation. As remote and digital care becomes more prevalent and standard practice, it is crucial to understand the potential implications for marginalised groups (positive, negative and/or neutral), so they can be taken account of and responded to.

This study utilises a qualitative approach, employing in-depth semi-structured interviews and observational techniques. The analysis centres on two main areas: the self-management of healthcare, exploring how individuals are expected to take on the responsibility for their own health and care; and gatekeeping in healthcare, examining how eligibility for healthcare services is evaluated and negotiated. Additionally, the study explores individuals' relationships with public services and the processes of marginalization that may lead to exclusion from primary healthcare services. These analytical focuses provide insights into the experiences and challenges faced by marginalised individuals in accessing and navigating the primary healthcare system in the face of recent changes to provisioning.

This introductory chapter will provide an overview of how my interest in the topic of study has evolved and share the motivations that led me to undertake this research. Additionally, it will outline the structure of the thesis, the flow of the overall argument and organisation of subsequent chapters.

Development of this study

I embarked on this PhD following an undergraduate degree in Anthropology, a Master’s in Digital Anthropology, and a Master’s in Public Health funded by the Wellcome Trust. Throughout all of these I have maintained an interest in health and inequality, with a focus on the role of digital technologies, particularly mobile phones, in healthcare. I first became interested in digital health through an internship at The Population Council (2013) where I was assisting on a project looking at mHealth (mobile phone-based healthcare) for Sexual and Reproductive Healthcare in Sub-Saharan Africa. Starting from a position of enthusiasm for the potentially inclusive role of digital technologies I have over the last decade become more sceptical about their emancipatory role, specifically in healthcare. I completed my MSc in Public Health at LSHTM 2019-2020, and wrote my thesis, a literature review, on the potential use of mobile phones for sexual and reproductive healthcare education for refugees living in refugee camps in LMICs. As a user of the NHS, I have experienced first-hand the changes to primary care, specifically an increase in remote care, and had begun to wonder whether the same inequities I was curious about regarding mHealth in Low and Middle-Income Countries (LMICSs) may be occurring in the UK. When the COVID-19 pandemic hit, it led to a surge in the use of digital and remote health technologies across healthcare systems worldwide. This re-sparked my interest in how remote and digital healthcare systems, and particularly remote consultations, might impact on marginalised groups in high-income settings too. These processes coalesced to lead to me being awarded a National Institute for Health Research (NIHR) School of Public Health Research (SPHR) and Applied Research Collaboration (ARC) North Thames studentship to undertake this PhD study, beginning September 2020. The funding for this research was awarded in order to explore digital healthcare in the post-COVID metropolitan landscape.

Thesis structure

The thesis is structured as a single monograph, each results chapter includes a summary section that directly connects the findings to relevant literature in the field.

This structure facilitates a comprehensive consideration of the research findings while maintaining a coherent and well-supported argument throughout the thesis. The decision to adopt this structure allows for the extraction of key themes within each results chapter that are closely related to specific bodies of literature. By doing so, it provides an opportunity to explore the nuanced details and findings within each chapter. The Discussion chapter serves as a platform to synthesise and analyse the results chapters collectively, providing a broader perspective on the findings. This comprehensive synthesis allows for a deeper exploration of the overall implications and insights derived from the research, while also contextualizing them within the existing literature. This approach ensures a thorough exploration of the research outcomes at both the specific and general levels.

This chapter aims to introduce the study, how it was developed and concludes with a short positionality statement. This is followed by 'Chapter Two. Literature Review' which contextualises the study and identifies gaps in the literature around our understanding of remote and digital primary care and marginalisation. This includes outlining the Primary Care system and key definitions around digital and remote healthcare and the introduction of theoretical frameworks and terms which will be used throughout the study. 'Chapter Three. Methodology' outlines the study design, how key decisions were made, who was included in the study, why, and how. This is proceeded by 'Chapter Four. Context' the aim of which is to introduce the three main fieldwork sites through a narrative account of my experience as a researcher, to situate the reader in relation to the study contexts. This is one of only two chapters, alongside 'Chapter Nine. Reflections on Data Collection and Analysis' which is written in the first person – drawing attention to the highly subjective nature of the content within these chapters. 'Chapter Five. "It is hard work getting an appointment it shouldn't be like that" – making appointments for GP consultations' is the first results chapter and explores appointment booking systems and how patients experiences of making appointments impacts their access to care. ‘Chapter Six. A Room Without Walls – Physical space during the remote consultation’, the second results chapter, focuses on remote telephone consultations, and how the spaces in which patients and GPs consult from remotely impacts on experiences of care. ‘Chapter Seven. “I can’t show them on the phone so it’s what I say, and I’m not saying a lot”– Non-verbal and visual cues during remote consultations’ the third results chapter, looks at how the loss of non-verbal and visual cues during remote telephone consultations can impact on communication between patients and doctors, and the potential impacts of this. Chapter Eight, “Doctor-Patient Relationships and Continuity of Care”, the final results chapter, investigates how remote consultations and changes in the primary care system, including reduced continuity of care, affect patient-doctor relationships with a focus on the disruption of therapeutic alliance building. Throughout each of these results chapters I will focus on how different characteristics associated with marginalisation, for instance health literacy levels, plays a role in experiences of care. Following on from the results chapters is ‘Chapter Nine. Reflections on data collection and analysis’ which offers a reflective analysis of my experiences during fieldwork and emphasises the subjective nature of the data collection and analysis process. Finally, Chapter Ten, “Discussion”, synthesises the findings across the four results chapters, highlighting key insights and their contribution to the existing literature. It addresses gaps in evidence identified in the literature review and provides an overall analysis of the study's findings.

Positionality statement

I am a white British, young woman from a middle-class academic background in the East of England. My own political and social leanings have invariably impacted on how I designed the study, understood and represented the data. I am a left leaning individual who believes in support by The State, I have a strong belief that those who find themselves on the margins of society are almost always there because of socioeconomic and cultural factors mostly beyond their control. For instance, the impact of intergenerational poverty on education levels or the potential for long term psychological and physiological harm of unstable or poor living conditions in childhood. As such, I believe that those who are experiencing marginalisation should have safety nets available to them, following a policy of equity rather than equality. Meaning that those who are in a position of marginalisation deserve additional help to access and use services rather than relying on their power as individuals to make the most of services available to them. The ways in which my positionality may have impacted on my data collection and analysis of the data will be discussed in greater detail in 'Chapter nine. reflections on data collection and analysis'.

Research Questions and Aims

This thesis sets out to address the following research questions and objectives – the background to which will be explored in greater depth in Chapter Two, the literature review.

Research Questions

What is the relationship between marginalisation and remote service delivery in primary healthcare experiences in the UK?

1) What forms of participation does remote and digital primary healthcare expect from users, and how is this experienced by marginalised individuals?

2) What are the beliefs and practices which underlie the delivery and use of remote and digital primary healthcare, and how does this affect service eligibility?

3) How does remote and digital service delivery in primary healthcare affect the use of primary healthcare services by marginalised individuals?

Research Objectives

1) To identify how the use of primary healthcare by socio-economically marginalised individuals in the UK has changed over the course of COVID-19 as a result of the increased use of remote and digital services

2) To characterise the 'work' of accessing and using primary healthcare services in the context of increased use of remote and digital services and how this is experienced by marginalised individuals

3) To explain the opportunities and challenges of remote and digital service delivery in primary healthcare for inclusion of marginalised individuals

Chapter 2. Literature Review

Chapter 2.

Introduction

This study examines the impact of digital healthcare in primary care during a period of significant change and evolving perceptions regarding the role of digital technologies in our society. This presents both challenges and opportunities for the research. The challenge lies in studying a rapidly evolving field and establishing relevant terms and parameters that remain relevant amidst ongoing changes. However, it also provides an opportunity to investigate an emerging phenomenon and gather insights that may not be possible once digital healthcare practices become normalised.

In framing this study, it is crucial to acknowledge that definitions in the field of digital healthcare were actively being negotiated during the research period and are influenced by relational practices. Therefore, it is necessary to define these terms in direct relation to the specific focus of this study. For this study the work of defining terms, contextualising practices, and identifying relevant and useful theoretical frameworks is necessarily cross-disciplinary. This practice of borrowing relevant ideas and insights from across disciplines, whilst perhaps conceptually challenging, will allow for a representation of the topic that represents the field as understood by this study, rather than being constrained by pre-existing frameworks that may limit new insights.

Chapter 2.

The following literature review will begin by outlining the role of primary care in the UK, defining digital and remote healthcare in the context of this study, and examining recent changes to primary care. Subsequently it will look at different ways in which access to healthcare can be understood, before looking at health equity and marginalisation, supported by empirical evidence and theoretical frameworks. This will be followed by a discussion of what we already know about the relationship between marginalisation and digital and remote healthcare in the UK, and a brief outline of the issue of digital exclusion. The final section will unpack some of the wider sociological and Science and Technology Studies (STS) literature on digital and remote healthcare, exploring different theoretical approaches and introducing a theoretical model to comprehend the interplay between patient capacity and healthcare utilisation. The review will synthesise the empirical and theoretical literature discussed, identify gaps in current research and present the research questions that this study seeks to address.

Primary Care in the UK

Primary healthcare is the first point of contact with NHS healthcare services, except for in emergencies. Primary care includes General Practice, community pharmacy, dental, and optometry (eye health) services, walk in clinics and telephone/online 111 services. Primary care not only acts as a service for a range of healthcare needs, but also as triaging point for referral into specialist services. Depending on the health problem, patients may be referred by the GP to hospital or to a specialist. Primary care is especially important for reducing health inequities by acting as a familiar entry point to the wider healthcare system (O'Donnell et al., 2016).

Chapter 2.

General Practitioners (GPs) as defined by the NHS "treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment. They focus on the health of the whole person combining physical, psychological and social aspects of care." (NHS, n.d.). General practices are small to medium-sized businesses, whose services are contracted by NHS commissioners to provide general medical services to a geographical area or population. Every individual or partnership of GPs must hold an NHS GP contract to run an NHS-commissioned General Practice. Whilst some General Practices are run by an individual GP, most are run by a GP partnership involving two or more GPs, sometimes with nurses, practice managers and others, working together. GP partners are jointly responsible for meeting the requirements set out in the NHS contract for their practice and share the income it provides.

According to the British Medical Association (BMA, 2023) In February 2023 there were 36, 511 individual GPs working in the NHS in England. This equates to 27,277 Full Time Equivalent (FTE) GPs. The overall number of GPs has seen little growth since 2015, despite a government announcement in February 2020 to recruit an additional 6,000 GPs by 2024. Despite these promises, as of February 2023 (shortly before time of writing) there are now the equivalent of 2,087 fewer fully qualified FTE GPs compared to September 2015 (when current BMA collection methods began). The number of GP practices is also falling for various reasons including mergers, inability to recruit staff or GP partners, or Care Quality Commission (CQC) closures due to under resourcing. Whilst the number of GPs and practices declines, patient numbers are rising. In February 2023 there were over 62,355,000 patients registered in England, equivalent to 9,722 patients per practice. There are now 0.44 fully qualified GPs per 1,000 patients in England, as compared to 0.52 in 2015.

Having outlined primary care in the UK, the following section will define digital and remote healthcare before turning to look at how digital and remote healthcare has emerged in the context of primary care in the UK.

Digital and remote health – Defining shifting terms

This section will deal with defining the terms ‘Digital’ and ‘Remote’ healthcare, outlining the ways in which these two things will be conceptualised within this study.

As highlighted at the outset, the emergent and shifting nature of digital healthcare has resulted in a fluidity in the ways in which it is defined and spoken about, with the terms digital and remote often conflated. Further, digital innovation is consistently pushing the frontiers of what comes under the scope of ‘digital healthcare’ forward, and in the process, relegating earlier forms of digital healthcare as either less relevant or less obviously ‘digital’. The conceptual challenge of defining digital healthcare necessitates the need for a broad definition, which captures the experiences of patients when using primary care.

Beginning first by unpacking the ways in which Digital Healthcare is currently conceptualised – Digital Healthcare is defined by the World Health Organisation (WHO) as “The field of knowledge and practice associated with the development and use of digital technologies to improve health” (WHO, 2021). According to the U.S. Food and Drug Administration (2022) “The broad scope of digital health includes categories such as mobile health (mHealth), health information technology, wearable devices, telehealth and telemedicine, and personalized medicine. Digital health technologies use computing platforms, connectivity, software, and sensors for health care and related uses. Interactions, both synchronous and asynchronous are performed through electronic intermediaries and these technologies span a wide range of uses, from applications in general wellness to applications as a medical device. They include technologies intended for use as a medical product, in a medical product, as companion diagnostics, or as an adjunct to other medical products (devices, drugs, and biologics). They may also be used to develop or study medical products". As shown by these definitions, 'Digital Health' as a term encapsulates a wide range of practices and devices. Therefore, the definition of digital healthcare is context dependent, and contingent upon who is speaking and where – referring to specific practices within specific systems. In hospital settings for example, digital healthcare may include complex diagnostic devices, for chronic condition management the focus may be on wearables to track health metrics for instance blood sugar levels, on a health system level it may mean integrated electronic health records, within global health work it is often specifically mobile health (m-health) for non-smart ('dumb') mobile phones, and within primary healthcare may be predominantly remote consultations either video or telephone, or online booking systems. As a side note, another commonly used term within this space is 'telehealth' which can be defined as "the delivery and facilitation of health and health-related services (including medical care, provider and patient education, health information services, and self-care) via telecommunications and digital communication technologies." (Butcher & Hussain, 2022, p. 115). The extent and variety of ways in which digital technologies are now integrated into healthcare practices, arguably makes them a tool of healthcare practice, rather than a separate category– we would not for instance delineate "pen and paper healthcare notes". However, in order to study the impacts of increasing digitalisation of primary care in the UK, a working definition of digital healthcare, with clear boundaries is required.

To begin with, the issue of defining remote versus digital healthcare must be contended with. Digital Healthcare in General Practice includes technology-facilitate interactions which may replace face-to-face consultations i.e., video and telephone consultations, digital solutions for organising healthcare e.g., booking appointments or repeat medications, and digital diagnostic technologies which integrate AI systems or sophisticated diagnostic devices. Separately, remote healthcare is healthcare delivered outside of traditional settings, e.g., in the home. This can include remote consultations over video or phone (Jaffe et al., 2020; Miller et al., 2019; Murphy et al., 2021; Rodriguez et al., 2021), as well as the remote monitoring of patients using wearable devices (Humble et al., 2016; Mayberry et al., 2019). Whilst remote healthcare and digital healthcare have often been used to describe different things, the delineation between the two is increasingly blurred with the use of for instance online video consultation platforms. The complexity of defining what we mean when we talk about digital or remote healthcare is reflective of the fluid nature of the current landscape, and the integration of a range of different technology-based practices into society more broadly, and specifically healthcare. To complicate matters further, 'digital exclusion', a concept which is key to this study, includes phones as well as credit, both data and minutes, meaning that 'remote healthcare' use is vulnerable to 'digital exclusion'.

For the purposes of this study, 'Digital Healthcare' will be used to refer to online systems, such as apps or websites, and 'Remote' will be used to refer to activities carried out over the phone, for instance telephone consultations and booking appointments over the phone. This study will focus on remote healthcare, as this is reflective of the forms of healthcare interactions study respondents spoke about which mostly centred on synchronous remote interactions including booking appointments over the phone and having consultations over the phone. However, for the remainder of this literature review both 'remote' and 'digital' healthcare will be used, to both reflect the terminology used in NHS policy documentation which has a tendency to subsume 'remote' into 'digital', as well as the literature base on this topic which includes studies which use a range of different terms including remote, digital, and telehealth/telemedicine. As far as possible these terms will be used selectively to align with terminology being used within the study or policy document referred to.

Digital Care in UK Primary Care

This section will look at digital healthcare in UK primary care, and how this has been represented in policy documentation as well as current practices, to understand the context in which this study took place.

Digital healthcare has been positioned by governments globally as a way of delivering a fair healthcare system, and reducing costs, with promises “to transform health-care systems including strategies of personal risk management, modes of treatment and practices of care” (Petersen & Bertelsen, 2017, p. 22). Both the NHS Five Year Forward View (NHS, 2014) and the NHS Long Term Plan (NHS, 2019) detail a drive towards digitalisation in order to meet these aims. The NHS Long Term Plan, published a year prior to COVID-19, builds on the NHS Five Year Forward View and the fourth of the five elements of the ‘New Service Model for the 21st Century’ is “Digitally enabled primary and outpatient care will go mainstream across the NHS”. Under this plan, “Digital-first primary care will become a new option for every patient improving fast access to convenient primary care” (p.26, emphasis added). The NHS Long Term Plan, published in January 2019, commits to every patient having the right to be offered digital-first primary care by 2023/24. The NHS England website states:

> “Digital technology is transforming how patients and health professionals interact. As a result, NHS England is supporting primary care to move towards a digital first approach, where patients

> can easily access the advice, support and treatment they need using digital and online tools. These tools need to be integrated to provide a streamlined experience for patients, and quickly and easily direct them to the right digital or in person service." (NHS England, n.d., emphasis added)

The NHS website on 'Digital First Primary Care' lists online consultation requests, and video consultations as the two key elements of digital first, indicating that video consultations are categorised as digital care by the NHS, rather than 'remote', pointing back to the challenge of defining these terms. However, NHS Digital data published in March 2023 records that only 0.7% of GP consultations were conducted over video, versus 26.7% on the telephone (NHS Digital, 2023).

In the October 2021 budget, £2.1 billion was allocated to IT upgrades and digital health technology, indicating a further government commitment to digital healthcare within the NHS. Whilst the move towards remote healthcare in the NHS was already underway, the challenge of responding to the COVID-19 pandemic in 2020 provoked a surge in the use of remote consultations and consequently boosting the use of access solutions including video and telephone consultations. To facilitate infection control during lock-down NHS England mandated 'Total Triage' where all consultations required some form of triage and 'Remote-by-Default' consulting where a clinician must consult remotely, over phone or video, unless there was a "clinical exception" (NHS England, 2020). In July 2020, five months into the pandemic, the then Secretary of State for Health and Social Care gave a speech at the Royal College of Physicians about the future of healthcare in which he stated "From now on, all consultations should be teleconsultations unless there's a compelling clinical reason not to" (Hancock, 2020) – here again, the challenge of differentiating between digital, remote, and even 'telecare' is made clear, as these terms are regularly used interchangeably.

Whilst the use of remote consultations in primary care is not novel to the COVID-19 pandemic, what was novel was the blanket way in which remote contact with primary health care services was rolled out, especially in the early days of the pandemic.

According to the Royal College of General Practitioners (RCGP), prior to COVID-19, an estimated 25% of GP appointments were carried out remotely. At the beginning of COVID-19 restrictions in March 2020, approximately 70% of GP appointments were carried out via telephone or video (House of Lords Covid-19 Committee, 2021). By November 2021, when data collection for this study began telephone appointments made up 32.9% of all GP consultations in England (39.4% in London, where data collection took place) (NHS Digital, 2023).

Having defined primary care in the UK, presented a working definition of digital and remote healthcare in the context of this study and outlined the use of digital healthcare in UK primary care, the discussion will now turn to look at how we can understand and theorise issues of healthcare access.

Access to care

Access is often presented in policy as primarily to do with timeliness or number of appointments. Access to GPs has been a key policy focus of NHS England, and the 20234/24 GP contract stipulates that “GP practices must offer patients an assessment or signpost them to an appropriate service on first contact” (NHS England, 2023). This privileges obtaining an appointment or signposting over, measurements related to continuity of care, or modality of consultation for example. Academic scholarship has shown that access is not simply about availability of GPs and appointments but includes a range of concerns, such as whether methods of access are simple and reliable (MacKichan et al., 2017). This has been described as a "depth decision", with "complex, multistage decisions that hold potentially significant implications" (MacKichan et al., 2017, p. 10). Theories of access aim to capture this complexity, for instance Penchansky and Thomas (1981) define access as "a concept representing the degree of fit between clients and the system". More recent theories of access have described access as a "multidimensional concept based on the interaction (or degree of fit) between health care systems and individuals, households, and communities" (McIntyre et al., 2009). What these models of access have in common is that they recognise access is not created simply by availability of services, but by the interaction between services and users which can either obstruct or encourage use of the service. Additionally, when thinking about health equity, and access to healthcare for vulnerable groups 'Candidacy' is a concept which has been used as a way of describing the way in which eligibility for care is 'jointly negotiated between individuals and health services' (Dixon-Woods et al., 2006) and is a useful framework for understanding specifically how thresholds for eligibility for care are constructed and enacted. This framework was initially developed in the context of access to healthcare by marginalised groups and has seven features: identification of candidacy, navigation, permeability of services, appearances at health services, adjudications, offers and resistance, and operating conditions. Candidacy as a framework for understanding remote healthcare specifically has been used to understand how moving from in person to remote services can impact on access to care (Hinton et al., 2023). Hinton et al., (2023) in a study of remote ante-natal care during COVID-19 found that remote care made navigating services more challenging for patients, and required 'considerable digital literacy and sociocultural capital'. This resulted in services becoming less permeable especially for those experiencing material or social disadvantage resulting in barriers including digital exclusion.

The model of access which informed the development of this study most heavily, and particularly interview guides (which explored access issues from recognising a healthcare need through seeking care, reaching care and consultation experiences – see Appendix 1) is Voorhees et al.'s (2021) model of 'Access as Human Fit' which was developed from a study on access to primary care in the UK, and builds on Levesque et al.'s (2013) framework for 'patient-centred access to healthcare' but with an additional emphasis on human interactions. Importantly, Levesque et al.'s model recognises continuity of care as a key element of access, a component which is often side-lined in policies which privilege timeliness and efficiency. This is important when thinking about a move to remote healthcare as continuity of care may be challenged by remote care specifically, as well as access goals which foreground timeliness (Ladds et al., 2023). Further, evidence has shown that relational continuity of care (between a doctor and patient) may be particularly important during remote consultations in order to establish trust and rapport (Ball et al., 2018; Imlach et al., 2020). Vorhees et al.'s model defines access as "the human fit of the needs and abilities of the population with the capacity and abilities of the healthcare workforce" (p. 346) at five key junctures: healthcare needs, perception of needs and desire for care, seeking healthcare, reaching healthcare, healthcare utilisation, and healthcare consequences.

The following section will examine how access to services relates to processes of marginalisation, and how marginalisation will be defined in this study.

Health equity and marginalisation

Health inequalities are systematic differences in health status or in the distribution of health resources between different population groups (Kawachi et al., 2002). There is already a body of evidence which shows that marginalisation can negatively affect people's health and their experience of healthcare delivery (The Kings Fund, 2020). Persistent health inequalities in the UK have been detailed over the past decades by studies including the Black Report (1980); Whitehall I Study (1987); Whitehall Study II (1991); Acheson Report (1998); Fair Society, Health Lives report/ The Marmot review (2010) and; Health Equity in England: The Marmot Review ten years on (2020). Health inequalities are "avoidable, unfair and systematic differences in health between different groups of people." (The Kings Fund, 2020) which lead to differences in quality of life, and life expectancy. The inverse care law (Tudor, 1971) describes an observed perverse relationship between the need for healthcare and its actual utilisation – those who need healthcare the most are least likely to receive it, whilst those with least need of healthcare tend to use health services more (and more effectively). COVID-19 exacerbated the deprivation divide, increasing inequality in life expectancy between most- and least- deprived deciles from 9.3 to 10.2 years in males and 7.9 to 8.4 in females between 2019-2020 (Office for National Statistics, 2021). The Slope Index of Inequality in healthy life expectancy (years of life in good health) at birth was 18.6, years for males and 19.3 years for females (2018-2020) meaning that there was almost two decades less of life in good health among those living in England's most deprived areas, compared to least deprived areas (Office for National Statistics, 2022).

The social determinants of health are "the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life." (WHO). Whilst the social determinants of health are a key factor in lifelong health and inequities, this study will focus on access to healthcare, rather than health more generally, as a mechanism through which health inequalities are produced and maintained.

Understanding who is at risk of healthcare exclusion, and why and how, necessitates a definition of marginalisation which encapsulates the varied ways in which an individual, or groups of individuals, can be marginalised. The following section theorises marginalisation, and how it can be understood in a way which accounts for the diversity inherent within such a term.

The European Network for Social Inclusion and Health defines marginalisation as the "position of individuals, groups or populations outside of mainstream society" (Schiffer & Schatz, 2008, p. 9). Marginalised individuals often experience health inequities which can result in poorer health status and higher premature morbidity compared to the general population (Aldridge et al., 2018; Lecko, 2013; McLeish & Redshaw, 2019; Shulman et al., 2018). Marginalised people can be grouped according to a common feature or outcome (e.g., low access to care) as a result of their marginalisation, or by other characteristics generative of marginalisation (e.g., ethnicity or immigration status). Although 'marginalised' or 'marginalisation' are imperfect terms describing a complex set of interactions between social, economic, and demographic exclusion, they broadly refer to those at risk of exclusion as a result of structural and/or individual characteristics which limit access to and use of public services, as well as access to resources more broadly.

The reasons for this are multi-layered. At the macro-level marginalised persons may have no voice on healthcare policy or resource allocation, they are "systematically excluded from national or international policy making forums" (Schiffer & Schatz, 2008; Siddiqui, 2014). At the meso-level, poor service designs can lead to gaps in service provision for marginalised individuals (Shulman et al., 2018). At the micro-level, marginalised individuals often experience barriers communicating their needs, accessing treatment due to impairment or personal context (van Rosse et al., 2016; Xu & Chen, 2019) or as a consequence of perceived

(Goodman et al., 2017) or enacted stigma (Håkanson & Öhlén, 2016; Shulman et al., 2018).

Marginalisation is both a process in which individuals are systematically excluded and an outcome of those processes. Individuals can become marginalised from healthcare systems through individual or group level characteristics which make it more difficult for them to engage with and use the services on offer. Additionally, the healthcare system itself can marginalise individuals, by being set up in such a way that access for certain individuals or groups is made more challenging. These processes can take place on a systemic level within healthcare systems i.e., macro and meso levels, as well as on an individual level i.e., micro-level. Fundamental to these processes are inequities in power, resources and knowledge which both lead to and result from privileged access to resources and cultural capital by dominant groups (i.e., the Inverse Care Law – see above). Additionally healthcare systems may be set up in a way which benefits those who are already privileged e.g., resource concentration in wealthier areas of the country. This also works through 'softer' mechanisms indicative of system level bias, for instance the ability of individuals who feel empowered to demand better healthcare and assert their candidacy for care (Dixon-Woods et al., 2006).

Characteristics which place individuals at risk of marginalisation are often interlinked and combine to create different modes of discrimination. Intersectionality Theory (Crenshaw, 1989) posits that "an individual's experiences cannot be understood in relation to isolated aspects of their identity but rather experiences are influenced by multiple identities that interconnect and interact" (Heard et al., 2020, p. 868). This emphasises the importance of understanding health inequities through "experiences of disadvantage in relation to social, cultural and political systems which either support or constrain access to social, economic and cultural capital required to sustain health and wellbeing" (p.869). Taking an intersectional view of marginalisation underscores how different characteristics which come about as both a cause and result of marginalisation processes may ‘intersect’ to accentuate or compound the impact of marginalisation on health.

Marginalisation is relational and contingent on context, any one individual or group may be marginalised in some settings and processes, but not others. Although, in practice, characteristics which place individuals at risk of marginalisation often interact with multiple processes in a way which can lead to multi-marginalisation. This is why when studying quantitatively the impact of different factors on health outcomes, certain characteristics, particularly socio-economic status are adjusted for to identify confounders and get a better understanding of the active characteristics productive of health outcomes (Bécares et al., 2012; Nazroo, 1998). Additionally, characteristics such as ethnicity, can lead to processes of discrimination in education or workplace settings which have a socioeconomic impact on an individual and group level, which then further contribute to processes of marginalisation (Jackson et al., 2016). Consequently, cyclical patterns of marginalisation are set up and enacted, in ways which lead to multi-marginalisation. In the context of primary healthcare, it’s important to recognise that marginalisation is happening in relation to changes in service delivery as well as shifting ideas about eligibility for services and care. They may well be replicating existing patterns of marginalisation in healthcare and society more broadly, but nonetheless should be recognised as active processes which create or reproduce marginalisation.

Groups which are known to be vulnerable to healthcare marginalisation in the UK are sometimes referred to as ‘Inclusion Health Groups’. According to NHS England (2021):

> “Inclusion health is an umbrella term used to describe people who are socially excluded, who typically experience multiple overlapping

> risk factors for poor health, such as poverty, violence and complex trauma. This includes people who experience homelessness, drug and alcohol dependence, vulnerable migrants, Gypsy, Roma and Traveller communities, sex workers, people in contact with the justice system and victims of modern slavery."

Other groups which are known to be vulnerable to healthcare marginalisation in the UK include: people with disabilities, who are unemployed, with mental health problems, older people, rural dwellers, people leaving institutions and single parent families (Aspinall, 2014; Latif et al., 2017; O'Donnell et al., 2018). A common characteristic of many of these groups, is socioeconomic deprivation. Socioeconomic deprivation is "a multidimensional concept as it refers to the relative disadvantage an individual or a social group experiences (including a group defined in geographical terms e.g. a community or a neighbourhood) in terms of access and control over economic, material or social resources and opportunities." (Lamnisos et al., 2019, p. 2).

Whilst there are various ways of understanding and theorising marginalisation, Fundamental Cause Theory (Link & Phelan, 1995) helps to explain why a single factor such as socioeconomic status (SES) may have such a profound effect on health outcomes. Link and Phelan define a Fundamental Cause as one which "involves access to resources, resources that help individuals avoid diseases and their negative consequences through a variety of mechanisms. Thus, even if one effectively modifies intervening mechanisms or eradicates some diseases, an association between a fundamental cause and disease will re-emerge" (p.81). A fundamental cause is also identified as a distal cause which puts people "at risk of risks" through a causal association with proximate causes of disease. This theory was built for the field of epidemiology, but rests on a long-time recognition within medical sociology and social epidemiology, of the social causes of disease. Whilst developed to be applied to (and explain) social determinants of health, this theory is relevant in understanding the way in which socioeconomic deprivation may put people at 'risk of risks' when it comes to utilisation of the primary healthcare system, due to an association with factors such as digital access, health literacy etc.

Socioeconomic deprivation, as both a cause of marginalisation as well as a result, captures many forms of overlapping and compounding marginalisation. Further, it accounts for an intersectional lens which looks at how different characteristics interact, result from, and are productive of different types of marginalisation. Socioeconomic deprivation is consistently associated with both health inequity and healthcare exclusion in the UK as well as digital exclusion (Lloyds, 2020), making it a suitable starting point for unpacking the interaction between digital primary healthcare and marginalisation – a point which will be returned to in the sampling section of 'Chapter 4. Methodology'.

Turning now from discussing how to define and identify marginalisation, we will now review what is currently known about the association between marginalisation and digital or remote primary care.

Digital and remote Primary Care and inequality – what we already know

There has been concern about the potential inequities which may arise as a result of digital and remote healthcare for some time (McAuley, 2014). Overwhelmingly, narratives have centred around the digital divide, and the risk of digitally excluding population groups with lower access to digital technologies, and digital literacy. Attention to this issue spiked with the onset of COVID-19, and led to calls for caution by key stakeholders such as the sitting chair of the RCGP London, Martin Marshall (Marshall et al., 2020) and others (Gallegos-Rejas et al., 2023; Nada et al., 2020; Watts, 2020). Marshall et al., argued that any changes from the evidence-based features of General Practice, especially remote consultations which are of “uncertain and untested value” (p.270), should be treated with caution due to the unknown impacts on various elements of care including doctor-patient relationships. In a Healthwatch Report (2021) “GP Access during COVID-19” the NHS was called on to undertake a formal review of the ways people access General Practice to make sure the service works for everyone, and that people understand changes and how these affect the way they can get the care and support they need. Around the same time, in April 2021, addressing concerns around digital exclusion, The House of Lords Select Committee on COVID-19 published their report “Beyond Digital: Planning for a Hybrid World”. In their report they warn that “without government action we risk services being digitalised, sometimes badly, for cost-saving reasons, without understanding the impact on those who use them” (Marston et al., 2021, p. 4).

Crawford and Serhal in their paper on Digital Health Equity and COVID-19 (2020) have argued that without careful attention the innovation curve may reinforce the social gradient of health, through unexamined inequalities in access to and implementation of digital health. They developed a Digital Health Equity Framework from an ecological perspective, with a focus on how digitally mediated healthcare interacts with social determinants of health to produce inequities in both access to and experiences of care. Likewise, Davies et al.’s (2021; see also Salisbury, 2019) Digital Inverse Care Law looks at how social determinants of health (e.g., education, employment, health etc) are becoming tied up with digital access and use, which leads to a reinforcement of underlying inequities in health. They argue that digital exclusion has become concurrent with Dahlgren and Whitehead’s (2006) definition of a social determinant of health as a social and economic factor with the potential to increase or decrease inequities in health. Their model includes digital healthcare as a direct mechanism through which the inverse care law may be reinforced as those with lower digital access struggle to mobilise the resources to engage effectively with digital and remote healthcare.

A commonality across these calls for attention to the potential for inequities to arise as a result of digital and remote healthcare is that they focus heavily on the digital divide as the primary issue of equity. Whilst digital inclusion is a necessary condition to engage with digital healthcare, it is not sufficient for effective engagement. For instance, it doesn't take into account the quality of communication during remote consultations, and the potential impacts of this.

Several literature reviews have been conducted on the topic of digital healthcare and equity. This includes a 2015 review (Huxley et al., 2015) which drew together evidence on barriers to healthcare access for marginalised groups, and the hypothetical role of digital communication in General Practice for exacerbating or alleviating these. They found that digital communication had the potential to overcome several key barriers including practical access issues e.g., travel, negative experiences with healthcare service and staff, and stigmatising and negative reactions from staff and other patients. They also hypothesised that it may reduce patient-related barriers by providing a level of anonymity and offer advantages to patients who require an interpreter to consult. At the time of their review (2015), evidence around use of digital and remote healthcare for marginalised groups was scarce, which resulted in this realist review being built around hypothesis rather than data on actual use patterns and experiences – a key limitation of the paper.

A 2021 literature review of inequalities in General Practice remote consultations globally (Parker et al., 2021) found that telephone consultations are used more by younger working-age people, the very old, and non-immigrants. Socioeconomic factors were found to largely not effect uptake of remote consultations (Beckjord et al., 2007; Newbould et al., 2017; Uscher-Pines & Mehrotra, 2014) other than one study (Ekman et al., 2019) which found that those living in more affluent areas of Sweden were more likely to have digital consultations, and those with higher educational backgrounds were more likely to have used technology to communicate with their GP (Bertelsen & Stub Petersen, 2015). One study, looking specifically at opioid addicted patients found a positive relationship between engagement and telephone appointments, versus face-to-face (Eibl et al., 2017).

One of the few mixed-method studies available on inequalities and use of remote General Practice consultations in the UK, Murphy et al.'s (2021) longitudinal observational quantitative analysis study compared volume and type of consultation in UK primary care April to July 2020 with April to July 2019. Changes in consultation rates and type were consistent across sex, Index of Multiple Deprivation (IMD), and ethnicity groups, but differed by patient age, mental health status, and shielding status, for both GPs and nurse consultations. In contrast to some previous studies, this study found no correlation between use of remote General Practice healthcare and socioeconomic status. However, the study considers only three months of data during COVID-19 limiting the ability to identify longer term trends as remote care continues to be used outside of lockdown contexts. Further, this study does not include the experiential differences in access clearly outlined in the qualitative literature on this topic which will be explored below.

What is missing from these reviews is a discussion of how experiences (rather than access) of digital or remote care intersect with inequity based on primary evidence. Further, in light of the rapid changes to healthcare bought about by COVID-19, the evidence presented above has become outdated more quickly than it otherwise would have done due to the changes which have taken place in primary care and body of work which has emerged over the last few years.

Primary studies which look at the use of digital and remote primary care in relationship to inequities have overwhelmingly found a negative relationship with marginalisation. The following discussion is focused on evidence from 2020 onwards, as this reflects an important juncture in the ways in which healthcare was delivered in the UK as a result of changes bought about by COVID-19 which are more closely reflective of the context in which this study took place. There is also limited evidence on the impact of remote healthcare services on marginalised groups specifically from before this time – as uptake of remote services was low, and rarely, if ever, obligatory as it became during COVID-19.

A qualitative study based in Finland (Kaihlanen et al., 2022) focusing on migrants and older people, found that a lack of digital skills hampers use of remote consultations within both groups, that language is a barrier to remote consultation as people struggle to communicate without non-verbal cues leaving more room for misunderstandings, and that mental health is perceived as particularly difficult to speak about over the phone as it is perceived as too sensitive to speak about without being face-to-face. They also found that amongst migrants there was a strong preference for face-to-face appointments to develop an emotional connection with the doctor and to avoid misunderstandings due to language barriers. The following section deals exclusively with studies within the context of Primary Care in the UK.

A study of vulnerable migrants' access to healthcare in the early stages of COVID-19 in the UK (Fu et al., 2022), with Doctors of The World, found that remote consultations led to a reduction in uptake of consultations by migrants. Another study specifically on migrants' access to primary care during COVID-19 in the UK (Knights et al., 2021) found that remote consultations may exacerbate health inequalities due to digital exclusion (access and literacy) and language barriers when speaking over the phone. They also identified that remote consultations can lead to difficulty building trust, and concerns from GPs that safeguarding cues may be missed (see also Dixon et al., 2022). Similarly, a study by Murphy et al. (2021) also reported concerns by GPs that non-verbal cues which are absent during telephone consultations, are more important in migrant and other marginalised groups, and may lead to outsized safeguarding risks amongst these populations. Safeguarding refers to GPs abilities to recognise risk to patients as either a result of external circumstances or their own behaviours – to protect the patient. This is different from safety netting which is concerned primarily with managing clinical uncertainty until symptoms have been explained, and providing patients with a clear follow-up plan so that they understand the possible causes of their symptoms, how to look after themselves and what to do if symptoms persist. The impact of remote consulting on ethnic minority groups has also been identified by McGreevy et al. (2023) who found that at the beginning of the pandemic, primary care consulting rates fell more steeply amongst this population.

A trial providing phones and data packages to survivors of modern slavery and human trafficking in the UK (Malpass et al., 2022), found that a lack of data/minutes had previously made it challenging for survivors to contact health services during COVID-19, and that provision of phones and credit had helped to encourage independence of healthcare seeking behaviours. This indicates that digital exclusion as a result of poverty can limit healthcare access via remote services for this vulnerable group.

A qualitative study of total-triage[1] and remote-by-default consulting and its impact on vulnerable groups in the UK (Verity et al., 2020) found that remote consultations were hampered by language barriers, difficulty building rapport and trust over the phone, and digital exclusion. Interviews were conducted with people providing health services to vulnerable migrants, people experiencing

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[1] Total triage means that every patient contacting the practice first provides some information on the reasons for contact and is triaged before making an appointment.

homelessness and drug addiction, people working in health inclusion services, and other support services for vulnerable groups. Two forms of digital exclusion were identified: a lack of digital literacy or the ability to navigate remote consulting, and poverty leading to an inability to maintain phone credit, data packages, and IT infrastructures. At time of writing (2023), this is one of the few academic studies which looks specifically at marginalised groups in the UK more broadly rather than a specific inclusion health group. However, whilst of high quality, the data is collected from stakeholders working with vulnerable groups, rather than directly from individuals within these groups.

Some of the strongest evidence around the impact of remote healthcare on health equity comes from third sector organisations working with health inclusion groups. This includes work from Groundswell who focus on homelessness, MedAct who focus on migrant health, and Doctors of The World who work with the following groups: people who sell sex, Refugees, Asylum Seekers, undocumented migrants, people affected by modern slavery, people experiencing homelessness, Gypsy, Roma and Traveller communities, and people recently released from prison.

A 2020 Groundswell report found that people experiencing homelessness faced significant barriers to accessing their GP online or over the phone. The barriers identified included access to a digital device, language and communication, digital literacy, and privacy because of borrowing devices or using public Wi-Fi. They also found that this population group found it difficult to build rapport with their GP over the phone and struggled with having a 'mono-issue'[2] call due to a high propensity for multi morbidity and a need to address multiple health issues in one consultation. Opportunities of remote care included a reduction in the practical barriers of travelling to a GP surgery, a reduction in fear of discrimination by

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[2] Only addressing one healthcare concern

clinicians during face-to-face consultations and by other patients in waiting rooms, and a preference for phone communication by some people.

A report by MedAct (2020) looked at migrant access to healthcare during the COVID-19 pandemic in light of the Hostile Environment. They found that remote consultations exaggerated exclusion due to a lack of digital access, that language barriers became higher over the phone due to a loss of non-verbal cues and a lack of remote interpreters, and that remote consultations led to issues around privacy for those living in temporary accommodation, e.g., Initial Asylum Centres, due to crowded conditions and a tendency for Wi-fi to only be available in commonly held spaces.

Doctors of the World carried out a Rapid Needs Assessment of excluded people in England during COVID-19 (2020). Their assessment, which took place during lockdown, when access to health services was relatively restricted, found that across participant groups, access to primary care was harder due to digital exclusion, and language barriers which were exacerbated by reliance on remote services. They found that interventions to adjust for this, e.g., phone interpreters, were often hard to use and insufficient, leading to greater reliance on informal interpreters, which can limit privacy.

Overall, the current evidence points towards remote primary care exacerbating health inequities, by making services harder to access for marginalised groups. The primary barriers which are raised across studies are digital exclusion, which includes both access to a device and connection; language barriers which become more difficult to manage when reading written information or speaking over the phone; and difficulty building rapport and trust over the phone leading to a lower willingness to disclose information.

Primary studies which more broadly explore the use of remote consultations in Primary Care in the UK have identified several key considerations which affect patients more generally. These include the exaggeration of safeguarding risks due to a loss of observational information during remote telephone consultations (Dixon et al., 2022); a reduction of rapport building and a perceived inappropriateness for very personal conversations (Donaghy et al., 2019); a disruption to patient-doctor relationships (Atherton et al., 2018); and a reduction in number of problems raised with the doctor (Atherton et al., 2018).

A study looking at the unintended consequences of online consultations in primary care in the UK (Turner et al., 2021) reported findings from the DECODE study, which examined the unintended consequences of three types of digital health tool in primary care: online consultation tools; patient online access to health records; and smartphone apps to help patients manage long-term conditions. They found that online consultations make it difficult for some patients to communicate effectively with a GP, and prevent access for digitally excluded patients, as well as limiting continuity of care. Whilst these studies have not directly linked the impacts of digital primary care to healthcare inequity, there are indications from the studies looking specifically at marginalised groups which were presented above, that these impacts may disproportionately affect marginalised groups therefore exacerbating health inequities e.g., communication challenges due to language.

The preceding section has given an overview of what we already know about the relationship between marginalisation and digital healthcare in primary care in the UK. The following sections look at digital exclusion in the UK in more detail, before turning to a discussion of the theoretical literature around remote and digital healthcare practices.

Digital exclusion in the UK

As noted, digital inclusion is only a starting point for digital health inclusion, and may be less acute than previously thought due to the low use of video consultations in UK General Practice in favour of telephone consultation (Greenhalgh et al., 2022). However, given the significance of digital exclusion in the literature on digital health inequity, and the possible implications for online based services e.g., for booking appointments, it is worth briefly outlining the digital equity landscape in the UK. Milner (2015) describes three ways in which people are digitally excluded: lack of access because of an inability to pay for devices and their running costs; lack of skills to use digital technology; and lack of motivation to engage with digital technology.

The digital divide in the UK is well documented – the Lloyds 2020 UK consumer index found that 16% of the UK population cannot undertake foundational digital activities such as switching on a device, connecting to Wi-Fi or opening an app. Although age remains the main indicator of digital exclusion – 77% of over 70s have very low digital engagement (Lloyds Bank, 2020) – it is not just age that matters. People with an annual household income over £50,000 are 40% more likely to have foundational digital skills than those earning less than £17,499. Further, of the eight million people in the UK who do not use the internet, 90% suffer from other kinds of economic or social disadvantages (House of Lords Covid-19 Committee, 2021, p. 11). Lack of digital access and skills represents a clear mechanism through which marginalisation, specifically socioeconomic marginalisation, may limit an individual's ability to access and use digital healthcare and digital engagement is increasingly framed as a social determinant of health (Allison Crawford & Eva Serhal, 2020; Davies et al., 2021; Kickbusch et al., 2021; Serhal & Crawford, 2020; Sieck et al., 2021) and even a "super social determinant of health" (Gibbons, 2018) because of its relationship to all other social determinants of health.

Prior to COVID-19, in recognition of the potential for healthcare exclusion because of digitalisation, in 2017 The Good Things Foundation in partnership with NHS Digital and NHS England established the Widening Digital Participation programme. This involved setting up Digital Health Hubs across the UK through 'pathfinders' – local organisations which hosted this service. These Hubs were a place for people to come to, to receive digital skills training, and to access online services. This programme ran from 2017-2020 and aimed to reduce digital exclusion in the UK by ensuring people have the skills they need to access relevant health information and health services online (The Good Things Foundation, 2021). The Digital Health Hubs are important to mention here as they will be reintroduced in the Methodology as staff members involved in hosting them were interviewed as part of this study.

Digital and remote healthcare theorisation

Moving now from an exploration of the empirical data on inequities, and defining of key terms, to look at the existing academic scholarship on remote and digital healthcare, and the ways in which it has been understood within the sociological, Science and Technology Studies (STS), and other academic disciplines. Here some key theoretical terms and discussions will be introduced, which will be used throughout this thesis, particularly the 'Chapter 10. Discussion'.

Early theorists of digital technology tended to contrast technological determinism with social constructivism. Technological determinists view technologies as agents of change which generate social change based on inherent properties (McLuhan, 1964). Conversely, social constructivists believe that technologies do not determine human behaviour, rather, human actors shape technologies. Much of the literature on digital healthcare tends to take a more deterministic view, seeing digital healthcare technologies as pressing the intentions of policy makers, onto users (Fotopoulou & O'Riordan, 2017; Rich et al., 2019; Rose, 2009). A more nuanced approach to digital healthcare complexifies this relationship, recognising that digital healthcare users both shape and are shaped by their use of these services and tools (Mort et al., 2009; Oudshoorn & Pinch, 2003). The 'truth' likely lies somewhere at the intersection between policy intentions and service users. Key questions arise here around how far end users, imagined within policy documentation, conform to expectations around their behaviours and experiences, responding to the strategic intentions of policy makers, often related to self-management of healthcare.

A link is often made between digital healthcare, neo-liberal individualisation, and the self-management of healthcare (Fotopoulou & O'Riordan, 2017; Fox, 2015; Lupton, 2013a; Rich & Miah, 2014; Van Dijck & Poell, 2016). This is often referred to as 'responsiblisation' – the process by which individuals are increasingly tasked with the responsibility of managing their own health (Lupton, 2013a, 2013b; May et al., 2014; Rose, 2009; Ruckenstein & Schüll, 2017). This might include for instance the responsibility to report symptoms (Pettinari & Jessopp, 2001) to a clinician over the phone, previously referred to as 'patient work' or 'articulation work' (Strauss et al., 1997).

One of the key themes which will be drawn out in this study is this topic of self-management and responsibilisation. 'Responsibilisation' "is a term developed in the governmentality literature to refer to the process whereby subjects are rendered individually responsible for a task which previously would have been the duty of another – usually a state agency – or would not have been recognized as a responsibility at all. The process is strongly associated with neoliberal political discourses, where it takes on the implication that the subject being responsibilised has avoided this duty or the responsibility has been taken away from them in the welfare state era and managed by an expert or government agency" (O'Malley, 2009). The governmentality literature from which this emerges (e.g., Foucault, 1978, 1979, 1982, 1988, 1991; Foucault, 2003; Miller & Rose, 1990; Rose, 1999) looks at the 'conduct of conduct' including the governance of others, self-governance and various technologies of self (Juhila & Raitakari, 2019).

It has been argued that being able to participate in healthcare is increasingly politicised, promoted to make patients active in a way that is "beneficial, first and foremost, for patients themselves, but also for 'the greater good' of the welfare state" (Nielsen & Langstrup, 2018, p. 276). The relationship between digital healthcare and responsibilisation can be seen within the NHS Long Term Plan (2019) which states "people will be helped to stay well, to recognise important symptoms early, and to manage their own health, guided by digital tools" (p. 92, emphasis added) reflecting this assumed relationship between digitalisation and self-management.

The relationship between digital healthcare and self-management of healthcare has been studied in various healthcare settings (Band et al., 2017; Gilbert et al., 2020; Morton et al., 2018; Morton et al., 2017), with a focus on management of chronic diseases. A recent review by Gilbert et al., (2020) found that the additional responsibility of self-management which can come with the implementation of digital healthcare technologies, changes the work and tasks of patients, and may further burden them. In essence, this is about changes in 'patient-hood' and what it means to be a patient in today's healthcare systems, and the level of direct action and responsibility which patients must take on (Erikainen et al., 2019; Lupton, 2013a; Lupton, 2015; Petrakaki et al., 2018). The focus of literature on digital healthcare for self-management of chronic and long-term conditions e.g., diabetes, reflects the known relationship between digital healthcare and more directive self-management practices (Craig & Rhee, 2020; Humble et al., 2016; Mayberry et al., 2019; Monaghan & Marks, 2020; Rovner et al., 2021). However, there is a notable gap in the literature around the self-management practices and responsibilities asked (/demanded) of patients in primary care by the increased use of digital and remote healthcare practices.

Whilst this will be returned to in further detail throughout the results chapters in reference to the study findings, the relationship between self-management and patient capacity will be briefly unpacked here to foreground an important concept which is used in this study 'Capacity'. The ability to engage in self-management, is dependent on multiple resources– resources which are not equitably distributed (May et al., 2014; Ross et al., 2019). These resources are linked to structure and power, and marginalised groups are vulnerable to lacking the 'capacity' to mobilise the necessary resources to engage effectively in healthcare systems which demand self-management practices and behaviours. Patients, and their social networks are increasingly expected to perform within a set of externally defined parameters: not just in terms of what they do for themselves, but also in terms of the ways that they make demands on services. Patients are indirectly asked to be more than motivated, but technologically savvy too (May et al., 2014), and able to articulate their needs in order to navigate the healthcare system.

Burden of Treatment Theory (BoTT) sets out a framework for understanding how expectations to self-manage healthcare may increase the 'burden' of care and impact differentially on different groups, using the notion of patient 'capacity'. BoTT is a structural model that focuses on the 'work' that patients and their networks do to engage in healthcare (May et al., 2014). This theory helps to explain how unequal access to resources impacts on individuals' healthcare utilisation and adherence in different healthcare settings. This theory takes 'capacity' as a starting point to understand how individual and relational resources are mobilised in context to participate in healthcare. In sum, those with less material and cognitive resources at their disposal are generally less able to engage with healthcare systems and self-management practices. Crucially, BoTT emphasises the importance of networks as a determinant of an individual's ability to exploit opportunities to utilise healthcare services. High levels of social homophily may mean that networks of resource 'poor' individuals face a compounded challenge of both individual and network resource scarcity, which limits self-management practices. BoTT provides this study with a framework for understanding how digital healthcare within primary care tasks individuals with self-management practices, and their ability to effectively engage with these.

Finishing now with a brief discussion of the assumptions being made about patients' capacity to engage with new forms of care. De Laat utilises the idea of 'fictive scripts' to describe how the design of new technologies relies on the developers and policy makers "making assumptions about its future location in a wider technological ecology" (2000, p. 9). As digital first option becomes part of the NHS default, it comes into contact with a diverse range of individuals, from across socioeconomic and demographic spectrums, making this imagined end user fundamentally 'fictive' (/imagined). Merrild et al.'s concept of "imagined sameness" (2017) unpacks this tension between these imagined and real users. They argue that "imagined sameness"– the assumption that end users are largely homogenous – transitions to "expected sameness" – an expectation in terms of ways of life, the body, and utilisation of the healthcare system. This process of imagined sameness can be applied to here to understand the ways in which users are 'imagined' into the design process and policies, before being 'expected' to use it in the same ways through a process of *responsibilisation.* The ways in which self-management practices may be embedded into digital and remote healthcare systems, and the work produced for patients through healthcare, can be framed through BoTT, and understood in relation to expectations laid out in policy documents which are then re/enacted by healthcare systems.

How theory informed the empirical work

Theory played a key role in shaping the empirical work of this study. It provided anchor points for constructing themes to be explored during data collection, it also provided frameworks within which to interpret the data. These are described in more depth in the Methodology. The interplay between the empirical data and theoretical models was most evident at points where the data challenged assumptions within models or enriched theoretical narratives in unexpected ways.

Theoretical models also served as a means to orient this empirical study to its historical context. Prior research has built theories around ongoing societal changes, for instance a 'neo-liberal' approach to citizens and its role in shaping the UK's welfare system. The changes in primary care examined in this thesis are part of this broader historical transformation in the UK and globally, and necessarily relate to earlier theories of change which examine how citizens and states interact – a topic which will be returned to in the Discussion chapter. Moreover, the historical literature on the development of complex relationships between people and digital technologies remains salient to current changes in terms of process, even if the technologies themselves have changed. This underscores the value of middle-range theories, which provide generalised frameworks for understanding specific empirical data.

Given the breadth of topics explored within this thesis, the relevance of different theoretical models varies at different points. Each analytical results chapter has a unique relationship to the theories introduced within this literature review, and the more specific literature introduced in each analysis chapter. In contrast, the Discussion chapter which synthesises findings across the results chapters, leaned more heavily on broader theoretical models such as 'responsibilisation', to unify different themes into a comprehensive narrative of change.

Conclusion

This review has taken us through various empirical and theoretical evidence and literature relevant to the topic of study – digital healthcare in primary care in the UK and the impact on healthcare for people experiencing marginalisation. Key terms which have been explored are 'Digital Healthcare' 'Remote Healthcare' and 'Marginalisation' and working definitions for use in this study have been established. An overview of the current evidence has shown a known relationship between remote and digital primary care and marginalisation (particularly remote). The main access barriers identified are digital exclusion preventing appointment booking and remote consultations over the phone or online; language barriers which become harder to navigate over the phone or online; and difficulty building trust during remote consultations. Evidence around digital healthcare more generally has also shown potential issues around safeguarding and building of therapeutic relationships during remote consultations.

However, much of the available work on this topic is either speculative or based on outdated quantitative data in trial settings. Outside of grey literature from third sector organisations, the evidence around use of digital primary healthcare by marginalised groups in the UK is scarce. This is despite the recognition from both within e.g., The House of Lord's Covid-19 committee, and without e.g., the Royal College of General Practitioners (RCGP), government about the need to seriously consider the potential impact of recent changes to primary care services on health equity. Whilst there is some evidence on how remote and digital care impacts on specific inclusion health groups, e.g., people experiencing homelessness, a wider conversation about how different factors associated with marginalisation which crosscut inclusion health groups may affect experiences of care is missing.

Further, currently the different bodies of literature available on the topic across Science and Technology Studies (STS), anthropology, sociology, and public health lack coherence in their use of different models of understanding. The empirical work which is available on inequities in digital and remote healthcare, much of which is grey literature or quantitative public health research, often lacks analytical or theoretical depth. An important reason for this is that much qualitative work on this topic tends to focus on trial settings of remote and digital care for chronic condition management, and to focus on a more homogenous population of well-off users. This leads to a gap in the literature when it comes to well theorised qualitative work on inequities in experiences of remote and digital healthcare, especially within the domain of primary care.

There is also a lack of evidence on how wider changes to the primary care system, including changes to continuity of care and remote and digital appointment booking systems are affecting access for marginalised groups. Whilst there is theorised academic literature on the impact of remote consultations more broadly, and the ways in which this ties in with concepts such as 'responsibilisation or 'candidacy' for care, there is an under theorisation of how these concepts relate to marginalisation and the implications for healthcare access. This study sets out to address these acknowledged gaps in the evidence.

Chapter 3. Methodology

Chapter 3.

Introduction

This chapter will outline the methodological choices made for this study. The chapter begins with an overview of the study design, including who was included and why. This is followed by a brief discussion of the impact of COVID-19 on the study design, the actual impacts of COVID-19 on the study will be discussed under the heading 'data collection' further along in this chapter. The chapter then moves on to explaining the study sample, the field sites, and recruitment processes. This section is split into two halves – service users and service providers. The following section handles data collection, followed by a description of the informed consent procedures. The chapter then turns to look at analysis of the study data, before finishing with a presentation of the data management plan, and ethics.

Study design

This study set out to understand how changes to the Primary Care system in the UK – specifically an increased use of remote and digital practices – impacts on marginalised groups' experiences of care. The study took place during COVID-19 (September 2020-September 2023), with data collection occurring between November 2021 and May 2022. This presented a challenge in terms of the practicalities of conducting research during a global pandemic, but also a unique opportunity to study a healthcare system during a time of major change.

The overall design of the study and who was included will now be outlined to give a broad overview, before discussing sampling, recruitment, and data collection in greater detail further down. Because this study included several groups recruited from different settings, it's important to outline why this decision was made and to give a sense of the study as a whole, before going through each group in detail.

The study sought to gain an in-depth understanding of how changes to the primary care system are interacting with processes of marginalisation, experiences of care, and the potential impacts of this. To produce this kind of data, this study took a multi-method qualitative approach comprising in-depth semi-structured interviews in person and online, and participant observation across three fieldwork sites. Qualitative research "celebrates richness, depth, nuance, context, multi-dimensionality and complexity" (Mason, 2013. , p. 1). Qualitative research is particularly valuable for its ability to study experiences, beliefs, and interpretations of phenomena in question, with attention to natural language and settings as well as the privileged access it brings to people's subjective accounts of their life worlds. This final point is particularly relevant to this research which was conducted with populations whose narratives are often absent from predominant discourses, and research studies.

To gain a rounded understanding of the topic several participant groups were included in this study. These groups can be broadly split into two categories: service users and service providers. Service users (n=15) are people experiencing marginalisation who are potential users of the primary healthcare system, service users were recruited from third sector services catering to marginalisation – the way in which marginalisation was understood and sampled for is discussed further along, building on the theorisation presented in the literature review. 'Service users' are referred to as patients throughout this study when referring to their reflections of their experiences as primary healthcare patients. Service providers included

GPs (n=5) who provide healthcare, Digital Health Hub staff (n=4) who provide digital assistance and help accessing healthcare services within local charities around the UK, and members of staff at the fieldwork sites from which service users were recruited (n=3), who provide a range of different forms of advice to their clients including digital assistance.

The decision to include these four groups, was to gain a better understanding of the whole system in which service users are operating. The inclusion of GPs who work with marginalised groups was particularly important in order to better understand and contextualise the experiences of the primary care system recounted by service users. It is common practice within studies of this nature to include respondents from both sides of the healthcare system i.e., patients and doctors, to understand the viewpoints of both parties, and identify any points of alignment or conflict. In this study, service users and service providers were not known to be each other's patients or doctors and therefore the comparison of each groups responses is a more of a general commentary on system level changes and how these might be interpreted by users and providers, rather than a direct comparison of experiences within one practice. The inclusion of staff members from Digital Health Hubs, and fieldwork services was to reflect on issues surrounding use of welfare services and digital tools by marginalised groups more generally, and how this may relate to healthcare experiences.

COVID-19

Before moving onto study details, the impact of COVID-19 on the study design and planning will be briefly outlined. The actual impact of COVID-19 on the study will be discussed under data collection methods – once the structure of the study has been outlined.

The major role of COVID-19 in the design of this study was the uncertainty it bought to what would be possible in terms of in person data collection. Study design began in spring 2021 with the intention of data collection commencing in Autumn 2021. Because a major area of research interest was the impact of digital exclusion on use of healthcare services, it was important that fieldwork interactions with service users should happen in person to recruit and speak to people who may have very low digital engagement. During the study design phase, it was thought possible that by autumn 2021 there would still be government lockdowns which would prevent in person interactions indoors. Although this ended up not being the case, a backup plan was in place to switch the order of data collection and to interview service providers remotely over the autumn/winter 2021-2022, and to do in person data collection with service users outside during warmer weather in spring/summer 2022.

Another key challenge to the conceptualisation of this study was how willing third sector services and health care professionals would be facilitating or taking part in research due to pressures on their respective time and services on top of the pandemic. This was particularly true for third sector services, many of which had shut entirely during COVID-19 lockdowns, which meant that they would not be able to host a researcher on site. The possibility that third sector service users would be especially vulnerable to COVID-19 due to low vaccination uptake, and higher prevalence of comorbidities was also a concern that meant the study design had to be responsive to changes in COVID-19 risks. As the plan was always to recruit and interview GPs online, it was less of a concern whether in person healthcare services would be fully resumed.

Whilst all efforts were made to recruit the most appropriate services and individuals into the study, there needed to be a degree of opportunism and pragmatism in terms of fieldwork site selection and respondent recruitment.

Setting

In person fieldwork was conducted in London, this was the case for four key reasons. The fieldwork was being set up during the COVID-19 pandemic, and it was possible that further lockdowns could be announced over the coming winter when fieldwork would be taking place. This necessitated fieldwork which could be flexible to last minute changes, would require minimal use of public transport, and would be under the same COVID-19 restrictions as the researcher based in London. Secondly, London is a highly diverse area which was likely to reflect the forms of marginalisation relevant to this study. Whilst marginalisation related to for instance rurality would not be observed within the study sample in London, many other characteristics of interest would be observable within London, making it a pragmatic choice. Thirdly, the plan was to visit all three fieldwork sites during the week to approximate something closer to ethnographic immersion, which necessitated sites which were proximate enough to visit throughout the week. Finally, the study was funded by NIHR ARC North Thames, a funding collaborative focused on the wider London area.

Interviews conducted with service providers were conducted online using Zoom. The location of GPS and third sector service providers was within London, the location of Digital Health Hub staff was from around the UK due to the low numbers based in London.

Sampling and recruitment

Service users

The primary aim of this study was to explore the experience of accessing healthcare for individuals experiencing marginalisation. Both defining and conceptualising 'marginalisation' was a key challenge when designing this study as this can be classified in various ways, and is dependent on context as well as topic of study (Aldridge, 2014). As outlined in the literature review: Marginalised people can be grouped according to a common feature or outcome (e.g., low access to care) as a result of their marginalisation, or by other characteristics generative of marginalisation (e.g., ethnicity or immigration status). The specific groups which have been identified as inclusion health groups in the UK due to marginalisation, includes: people who experience homelessness, people with drug and alcohol dependence, vulnerable migrants, Gypsy, Roma and Traveller communities, sex workers, people in contact with the justice system and victims of modern slavery, people with disabilities, people who are unemployed, people with mental health problems, older people, rural dwellers, people leaving institutions and single parent families.

This study set out to understand how the overlapping and compounding nature of characteristics associated with marginalisation interact with the healthcare system – rather than the experiences of any specific group. Therefore, the decision was made to take a fundamental cause theory approach (Link & Phelan, 1995), using socioeconomic status as a multidimensional concept which both reflects processes of marginalisation as well as being productive of marginalisation. As outlined in the literature review, socioeconomic status is a well-recognised determinant of health inequity and has strong associations with access to healthcare and digital access.

Therefore, services catering specifically to individuals experiencing socioeconomic marginalisation e.g., resource scarcity leading to foodbank use, were selected as the fieldwork sites. The intention of this was to allow for the research to capture a range of different individuals who may share group characteristics of marginalisation but were not being defined by group affiliation. However, to adopt a more intersectional lens which also takes into account the role of characteristics such as language and ethnicity, a third fieldwork site catering directly to migrants, asylum seekers and refugees was also included.

Recruiting individuals who are from marginalised groups is known to be challenging for reasons pertaining to trust, as well as access to appropriate field work sites (Murphy & Dingwall, 2001; Tully et al., 2021) – necessitating a degree of opportunism. In the end, the fieldwork sites were selected based on a range of factors including the individuals likely to be recruited on site, the pragmatics of getting there during the pandemic, and the ability to negotiate access. This is a similar approach to that taken by Kaihlanen et al. (2022) whose study looked at challenges experienced by vulnerable groups in using digital health services in Finland at a similar point in time. Kaihlanen et al.'s study took a convenience sampling approach from third sector organisations that provided services for vulnerable groups across Finland.

Having been warned of the difficulty of recruiting what are sometimes referred to as 'hard-to-reach' groups, combined with disruptions to services by COVID-19, outreach to potential fieldwork services began in March 2021, nine months prior to data collection. It ultimately took until November 2021 to secure access to all three sites.

Fieldwork sites

The fieldwork sites which were selected were all based in a diverse area of East London which won't be named for anonymity purposes. The sites were a weekly foodbank based in a church, a community development 'hub', and a weekly drop-in clinic for migrants, refugees and asylum seekers based out of a church.

Community Development Hub

The Community Development Hub was a local community economic development agency ('Community Hub') with membership open to all. They work within their local community in East London to explore ideas and opportunities to create a sustainable environment for the local communities to flourish. The population they serve are local residents, many of whom are Black British of the Windrush generation. They offer a range of services including advice on accessing statutory services and linking and clients to other charities e.g., foodbanks. This site offered the opportunity to speak to a broad range of individuals experiencing different forms of marginalisation including but not limited to homelessness, substance abuse issues, being from an ethnic minority group, being very low income and unemployed.

Foodbank

The foodbank was based in East London and ran one morning a week. Users must be referred in and could attend for a maximum of four weeks in a row, up to three times in a six-month period. This foodbank catered to a wide range of individuals including but not limited to recently arrived asylum seekers, those with learning disabilities and other long term physical and mental health conditions which limited employment, and those living in unstable housing and shelters.

Drop-in advice centre for refugees, asylum seekers and migrants

This drop-in centre for migrants, refugees, and asylum seekers, offered general assistance in the form of legal advice, help registering and accessing local services, and help with contacting the council for issues around housing etc. The service was run out of a church one morning a week. Service users included both newly arrived migrants as well as long-term migrants (over ten years) of all ages from a range of countries. This included people who were victims of forced migration, in various stages of claiming refugee status, as well as undocumented economic migrants.

Sampling

The sampling strategy for this study was convenience, with respondents selected based on use of field site services, and willingness to be involved. Sample sizes of five per fieldwork site (totalling 15 respondents – see table 1 for demographics) was decided as a target number of interviews, with flexibility to allow for data saturation to be reached. Data saturation occurs when continued data collection ceases to yield new insights (Guest et al., 2006). This sample size was chosen based on the likelihood it would allow for a range of different experiences to be discussed, whilst feasible within the set timeframe and predicted challenges around recruitment. A three-stage sampling strategy was used (Strauss & Corbin, 1990, pp. 181-193) with early recruitment indiscriminate other than being a service user at one of the field sites. As data analysis proceeded respondents were deliberately selected who were likely to generate data of more relevance to the concepts emerging as important, e.g., individuals with English as a second language. In the latter stages respondents were sampled discriminately to ensure an equal spread of male to female respondents, as well as age categories and white/non-white ethnicity. By the final two interviews, no new key insights or codes were identified, suggesting data saturation had been reached.

Recruitment

At each fieldwork site the recruitment of respondents worked differently but followed a broadly similar structure which will be outlined below. Each respondent was given a choice of a £25 Sainsburys or Amazon voucher for taking part in an interview, all but one chose Sainsburys. This is in line with NIHR Payment guidance for researchers and professionals (NIHR, 2021).

Community Hub

At the community-hub it was decided from the beginning that the gatekeeper[3] (a member of staff) would manage the recruitment process. The gatekeeper did not want individuals to be approached directly for several reasons, including the need to ensure the individual did not feel coerced and knew their access to the service was not contingent on involvement in the study. It was also to allow for selection of respondents who it would be feasible to speak with, as some service users had trouble communicating clearly, or were regularly coming to the service whilst on substances. The gatekeeper would discuss the study with clients and request that they come back in on a specific day to be interviewed – emphasising the voluntary nature of consent. Interviews took place in a private room in the office.

Foodbank

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[3] An individual who provides access to a fieldwork site

At the Foodbank recruitment took place in the queue. This was set up in the carpark outside the church building in which the foodbank was based – having been moved outside during the COVID-19 pandemic. The recruitment procedure here was to speak with people informally in the queue as they waited to be served, introducing the study and asking whether they would be interested in taking part in an interview in a private room within the church. In general, especially during the first weeks here, people were not interested in taking part. To begin with people's numbers were recorded and it was agreed that they would be contacted during the week to confirm an interview time for their next visit to the foodbank. However, other than in one case, this did not work and resulted in either no response, or repeatedly cancelled interviews or people not showing up. This was in part reflective of the chaotic lives which many of the respondents described during interviews. Due to this challenge of recruitment, it was decided instead to recruit for same day interviews. This came with its own challenges as people often fitted their visit to the foodbank in between childcare responsibilities or had their children with them.

Drop-in centre for migrants, asylum seekers and refugees

At the drop-in centre for migrants, refugees, and asylum seekers respondents were recruited after they had a meeting with a member of staff during which English proficiency could be determined. At the end of these meetings the member of staff introduced the researcher (me) and explained the study, asking individuals if they would consent to take part. If they agreed to be this took place in a private room within the church.

Chapter 3.

Sample population

It is important to protect the anonymity of individual participants and their life histories. This section gives an overview of the sorts of challenges which were faced across the participant group. This is achieved through the creation of two vignettes describing the life circumstances of fictional participants created through the amalgamation of different circumstances across the participant group as a whole.

Vignette 1: Sarah

Sarah is a white-British woman from Scotland in her mid-forties living in Southeast London. She grew up in Glasgow in a single parent home and left school at the age of 16 to enter vocational work. Sarah has dyslexia which made it difficult for her to perform academically and she left school without the English and Maths GCSEs which are often required in the workforce. She also faces challenges to stable employment due to mental health issues which mean she requires time off unpredictably. She had her first child when she was in her late teens, and now has four children and two grandchildren. Sarah has been using the foodbank for the last 2 months as her partner recently lost their job during COVID-19 after developing long covid. Her household consists of her, her partner, one child who still lives at home and her daughter and grandson who are living there temporarily. Sarah and her daughter are responsible for the household income. Her daughter works as a nurse and Sarah runs a nail salon from home, her partner is struggling to negotiate disability allowance after his recent long covid diagnosis. Sarah's children have phones which she bought them, but they are responsible for their own pay-as-you-go credit. Sarah has a house phone but currently it's not working as they've stopped being able to pay the bill after her partner lost his job. She has a mobile phone contract, but it's likely she'll need to cancel this soon as she's currently in debt to the provider having been unable to pay in full the last two months. She has ongoing mental health challenges and has been on anti-depressants for the last few years. She recently decided to take herself off the anti-depressants because of side effects but hasn't yet spoken to her doctor about this and she doesn't want to discuss her mental health with anyone but her regular GP who she hasn't been able to book an appointment with. When she's interviewed as part of this study in the late winter a concern she has is whether she'll be able to afford heating through the winter but explains this is not the first time in her life when she's struggled with finances, and whilst nervous about it feels confident in her ability to 'make do' without, as long as she can keep her kids comfortable.

Vignette 2: Jacob

Jacob is a Black-British man in his 50s who moved over from Jamaica to London with his parents as a child. Jacob has worked his whole life as a manual labourer, although it's more difficult now that he is older and had an accident which hurt his back 5 years ago. He's spent most of his life in East London and has been part of a West Caribbean community since his teens. He spent time in and out of prison in his twenties, before meeting his ex-partner with whom he had a child. However, they are no longer together and in recent years he's been cyclically homeless in part due to a drug addiction which started as pain management for his back injury. Jacob has a phone but currently can't afford credit and relies on staff at a local community hub which help him to organise access to welfare services, including housing services. Currently they are trying to help register him for council housing, although it is proving difficult because he was forcibly removed from a previous tenancy as a result of police complaints which occurred after he was cuckooed. This is a term used to describe a practice whereby people take over a person's home (often an individual with intellectual disabilities) and use the property to facilitate exploitation, in this instance to deal, store, and take drugs. This practice takes the name from cuckoos who take over the nests of other birds. When Jacob takes part in this study he hasn't spoken to a GP in several years, he believed that his GP was closed during COVID-19 lockdowns, and currently is unable to contact the GP independently without a phone. He is aware that there is a local GP clinic for people who are experiencing homelessness, but he knows he is registered somewhere else so doesn't know if he'd also be eligible to attend this clinic.

Participant group – Service users						
Sex	Age bracket	Ethnicity	Country of Origin	Resident in the UK	Recruitment site	Other relevant information
Male	40-50	White British	Eastern Europe	10-20 years	Foodbank	Recently moved from street homeless to hostel
Female	30-40	Black British	UK	NA	Foodbank	
Male	40-50	Asian	South Asia	20+ years	Drop-in centre	English second language
Female	30-40	White British	UK	Na	Foodbank	
Female	60-70	Black	West Africa	20+ years	Drop-in centre	Illiterate
Male	40-50	Asian British	Middle East	20+ years	Drop-in centre	
Female	40-50	White British	UK	NA	Foodbank	
Female	30-40	Black	North Africa	<1 year	Drop-in centre	English second language
Female	60-70	Black British	UK	NA	Community Hub	Cyclically homeless
Male	60-70	Black British	UK	NA	Community Hub	Street homeless at time of interview
Male	40-50	Middle Eastern?	Middle East	<1 year	Drop-in centre	English interpreter in home context
Female	40-50	White British	UK	NA	Foodbank	
Female	60-70	Black British	UK	NA	Community Hub	
Male	60-70	White British	UK	NA	Foodbank	
Male	40-50	Black British	UK	NA	Community-hub	Recently came out of street homelessness

Table 1 Service user sample demographics

Service providers

The following service provider groups were included in this study: Digital Health Hub staff, staff working at fieldwork services, and GPs. The rationale for including these groups was in order to get a better understanding of the context in which service user respondents are operating, including the third sector services they may interact with, and GP services. Whilst the GPs interviewed were not (as far as known) the doctors to service user respondents, they were included in order to understand and situate changes to primary care from a systems level perspective. The other benefit of including these service providers is that they would be able to provide 'shadowed data' (Morse, 2000). Shadowed data is the data produced by respondents discussing the experiences of others, for instance, GPs discussing a range of experiences they've had with patients experiencing marginalisation or Digital Health Hub staff outlining the ways in which marginalised groups may face digital barriers.

Sampling

Digital Health Hub Staff

Digital Health hubs are informational and educational 'hubs' set up within local charities by The GoodThings Foundation. Charities which hosted these hubs were named 'pathfinders' and given funding in order to provide digital training to their service users in order to encourage and facilitate the use of NHS online services. For this research members of staff at Digital Health Hubs around the UK were recruited, to give insight into the specific challenges people face when trying to access NHS services online and the role of the third sector in assisting with this.

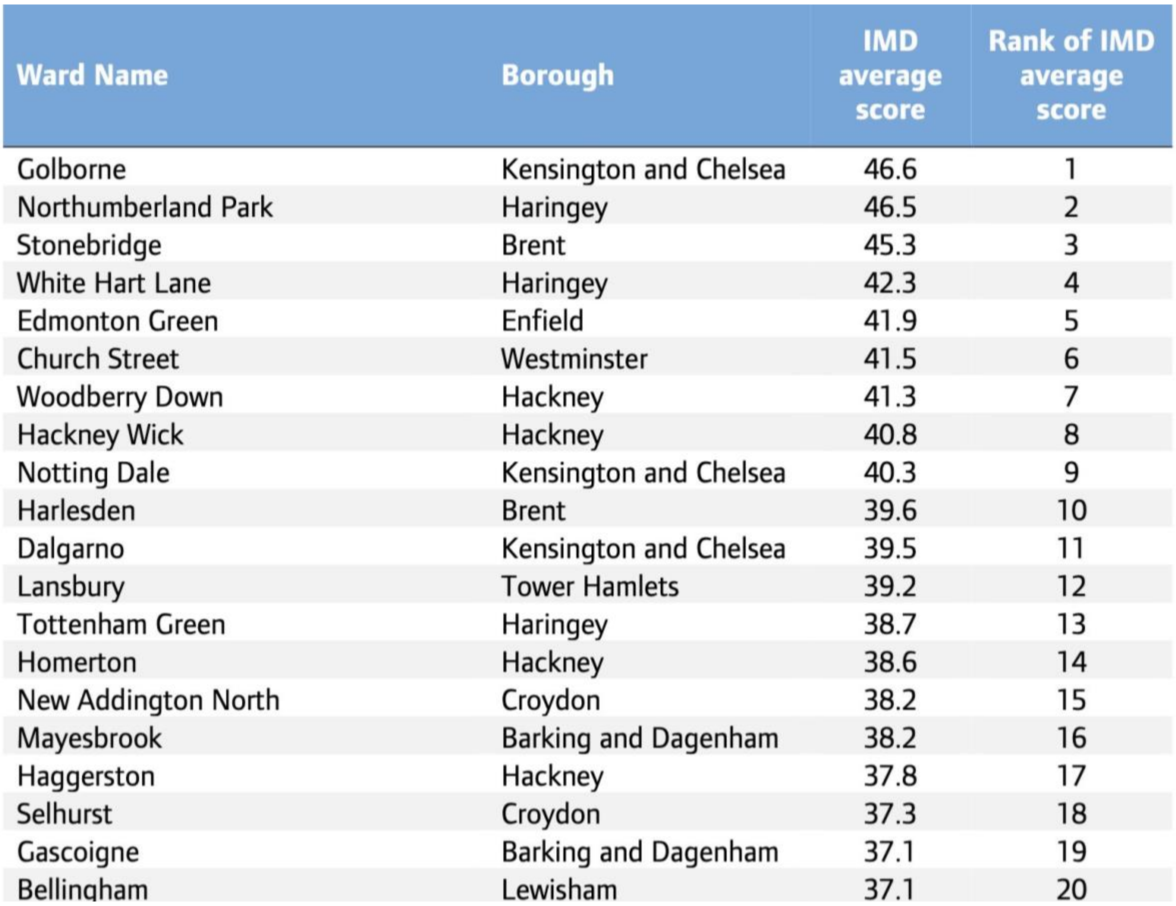
Digital Health Hub staff were selected based on their involvement with running Digital Health Hubs within their services.

Staff working at fieldwork site services

This study included members of staff at the three fieldwork sites from which individuals experiencing marginalisation were recruited (community hub, foodbank and drop-in centre) – outlined in table 2. At each site one member of staff who was involved with running of the service was asked to take part in the study, in order to provide an overview of the sorts of challenges their service users faced, and the ways in which the service catered to their needs, particularly in terms of advice on healthcare access, and digital support. It was anticipated that the staff members, through their interactions with clients would have knowledge on clients' use of healthcare services as well as digital devices. The Community Hub in particular offered extensive assistance to service users, going as far as booking GP appointments on their behalf – indicating that staff at this site would have valuable insights into challenges specifically related to primary care and digitalisation.

GPs

GP sampling was determined based on working at an NHS practice within one of London's 20 lowest ranked IMD boroughs (see Figure 1 below). This was decided based on the need to speak with GPs who had experience consulting with patients experiencing similar challenges to those being interviewed.



Ward Name	Borough	IMD average score	Rank of IMD average score
Golborne	Kensington and Chelsea	46.6	1
Northumberland Park	Haringey	46.5	2
Stonebridge	Brent	45.3	3
White Hart Lane	Haringey	42.3	4
Edmonton Green	Enfield	41.9	5
Church Street	Westminster	41.5	6
Woodberry Down	Hackney	41.3	7
Hackney Wick	Hackney	40.8	8
Notting Dale	Kensington and Chelsea	40.3	9
Harlesden	Brent	39.6	10
Dalgarno	Kensington and Chelsea	39.5	11
Lansbury	Tower Hamlets	39.2	12
Tottenham Green	Haringey	38.7	13
Homerton	Hackney	38.6	14
New Addington North	Croydon	38.2	15
Mayesbrook	Barking and Dagenham	38.2	16
Haggerston	Hackney	37.8	17
Selhurst	Croydon	37.3	18
Gascoigne	Barking and Dagenham	37.1	19
Bellingham	Lewisham	37.1	20

Figure 1 London wards with the highest and lowest average score on IMD 2019 Source: https://data.london.gov.uk/dataset/indicies-of-deprivation

Recruitment of service providers

See Table 2 for breakdown of service provider demographics.

Digital Health Hub Staff

Email addresses for Digital Health Hub staff were obtained through contacting individual 'pathfinder' services which had hosted Digital Health Hubs. These email addresses were available online. Staff members were sent an information sheet on the study, and asked to get back in touch if they were interested in taking part. Once interviews were arranged, soft copies of an informed consent form were sent out to be returned prior to the interview.

Fieldwork site staff

One Service staff member at each of the fieldwork sites was recruited for interview, totalling three staff members. Interviews were conducted as fieldwork drew to a close, so that initial findings from the study could be reflected on during interviews. Interviews were conducted in person (n=1) and over zoom (n=2). Each staff member was provided with an information sheet and informed consent form to return prior to interview.

GPs

GP recruitment during a time of crisis within the NHS, during the ongoing COVID-19 pandemic was a challenge to this study. GPs were recruited through the use of social media. This occurred through Twitter with a tweet outlining the study's recruitment criteria, tagging relevant accounts including NIHR and ARC North Thames. Recruitment criteria included practicing as an NHS GP within the defined list of boroughs shown above. This recruitment method leaves the sample open to obvious forms of bias, selecting for GPs who are active on Twitter, and therefore more likely to either be within academic GP spaces, or already actively involved in inequality work. However, for reasons related to pragmatism, as well as the fact that the GP interviews were in order to get a better understanding of the themes which came through in the service user date, rather than as a thorough exploration of system level changes, this was deemed an appropriate recruitment method.

Once GPs had responded via Twitter, they were asked for their personal email addresses, to set up a convenient time for interview. They were sent an information sheet on the study, and an informed consent form which was returned prior to interview.

Having set out to interview four GPs, five were recruited in the end – one of whom had been interviewed as a pilot study to think about themes to explore within the topic guides for the GP interviews. This GP did not fit the inclusion criteria for the study as they work within London but outside of the list of twenty boroughs identified. However, they have experience working with marginalised groups as the inclusion lead for their Primary Care Network (PCN) and involvement with the DeepEnd project which aims to improve inclusion of marginalised groups within General Practice, and so were included in the study data set due to the valuable insights they provided.

Participant Group	**Relevant Details**
GPs	Location of Practice
	Newham
	Tower Hamlets
	Tower Hamlets
	Tower Hamlets
	Lewisham
Fieldwork Service Staff	Population served
	Immigrants, Refugees, Asylum Seekers
	Low socio-economic status
	Local community including migrants, people experiencing homelessness and addiction issues
Digital Health Hub Staff	Population served
	Older adults with disabilities
	Refugees and Asylum seekers
	Older adults
	Refugees and asylum seekers

Table 2 Service Providers Sample

Data collection methods

Interviews

In-depth semi-structured interviews were conducted with all respondents. These allow for an exploration of respondents' experiences and opinions. This study specifically focuses on *experiences* of healthcare, making interviews as a primary data collection method most appropriate. In a semi-structured interview, the researcher sets the agenda in terms of topics covered, but the interviewee's responses determine the kinds of information produced about those topics and the relative importance of them (Green & Thorogood, 2014). In-depth interviews allow the interviewee enough time to develop their own accounts of the issues important to them. The interview guide (Appendix 1) may be used more or less, depending on the respondent and how willing they are to produce their own narrative.

In-depth interviewing hinges on the ability to 'build rapport' with respondents:

> The in-depth interviewer wants to probe the responses people give. To probe, the interviewer cannot be stonily impersonal: he or she has to give something of [themselves] in order to merit an open response. Yet the conversation lists in one direction; the point is not to talk the way friends do ... The craft consists in calibrating social distances without making the subject feel like an insect under the microscope. (Sennett, 2003, pp. 37-38)

It is through this building of rapport with respondents that warmth is developed within the interaction to elicit an honest conversation. This is particularly important for one-off interviews where rapport must be established quickly, termed by Duncombe and Jessop (2002) as "doing rapport" in order to elicit data. The need to ‘do’ rapport during interviews was especially critical with the main respondent group, service users, as some of the topics covered were sensitive and potentially upsetting. Interviews may however provide benefits in their therapeutic potential (Birch & Miller, 2000; Gale & Newfield, 1992; Ortiz, 2001) so whilst it is important to ensure sensitive topics are approached in a thoughtful way, it is possible to do so in a way which is mutually beneficial to researcher and respondent.

Interviews with GPs, service staff, and DHH staff were more focused on their professional roles, and reflections on the services they provide to service users, and therefore less about their own experiences.

Interview guides were developed based on reading of the literature, and informational calls with gatekeepers to fieldwork sites, staff members at The GoodThings Foundation, and my PhD advisors. Interview guides were designed as a group of topics to cover over the course of the interview, rather than a prescriptive timeline for the interview. It was recognised as important from the beginning to prioritise respondents’ narratives about their experiences, and the factors that *they* viewed as relevant and interrelated, to guide the interviews. The interview guide was a useful tool for drawing attention back to the overall theme of the research if the conversation strayed too far, or as a reminder of topics to ensure all the important themes were covered before ending the interview. However, during interviews the conversation often moved around the interview guide in an organic manner, with the conversation looping back to earlier themes. This flexibility during interviews was important, as it led to the discovery that topics which were predicted to be most relevant to respondents’ experiences, were often subsidiary and vice versa.

The themes covered in interviews with service users were: Accessing primary healthcare, accessing other healthcare services, general health and wellbeing, and using digital devices and the internet. Themes covered with field site service staff were: the impact of COVID-19 on service provision, access to healthcare services for clients, and the impact of digitalisation of public services. Digital Health Hub staff interviews covered the same themes as field site service staff as well as specific questions on the role of the Digital Health Hubs. GPs were asked about: the impact of COVID-19 on General Practice, self-management of healthcare, and working with marginalised populations. All interview guides can be found in Appendix 1.

Interviews were conducted first with the main respondent group – service users. This was in order to gain a better understanding of the experiences of marginalised groups interacting with the primary healthcare system, and digital systems. Insights from this data were then used to inform interview guides for interviews with service providers (GPs, fieldwork service staff and DHH staff).

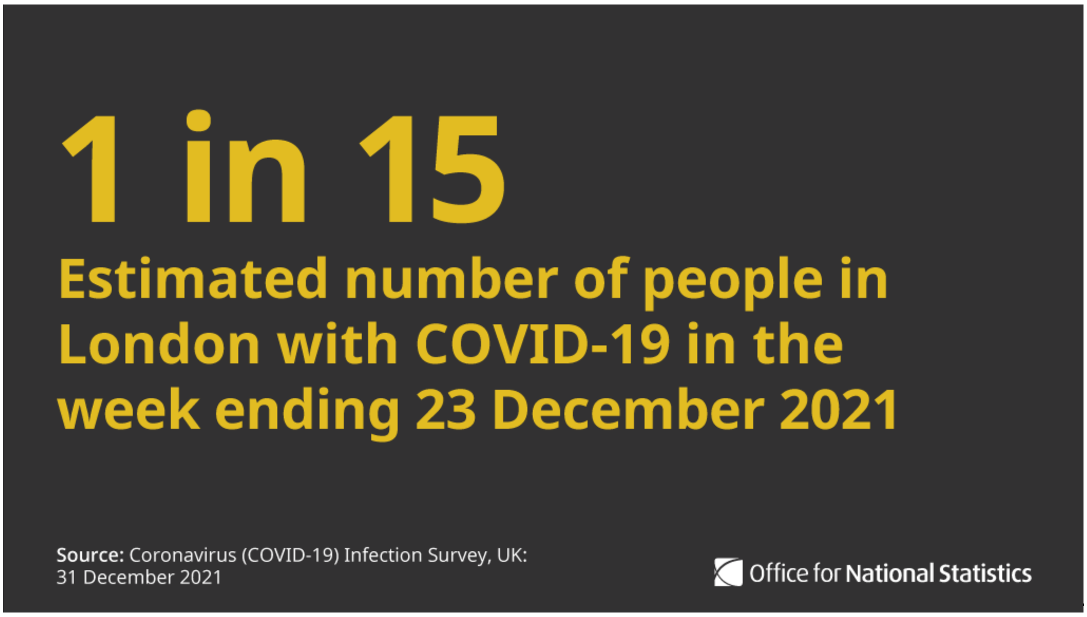
Interviews with service users were conducted in person in a private room within the fieldwork site services. GPs and DHH staff were interviewed over zoom and fieldwork site staff were interviewed on site. Interviews lasted between 30 minutes and 1 hour 15 minutes. In person interviews were recorded using a password protected audio recorder. Online interviews were recorded using the Zoom record function.

Participant observation at fieldwork sites

Participant observation (Green & Thorogood, 2014) of digital assistance was observed at two of the three field sites – the Community Hub and Migrant Drop In Centre. This took the form of sitting with service staff members as they interacted with clients, helping them for instance with applying for welfare assistance online, or booking doctors’ appointments. After observing meetings, staff members who had led the interaction were asked about things of interest which were observed. Data was recorded through fieldnotes written during and after observational periods.

Participant observation was intended to move beyond what people (clients at fieldwork site services and staff) said they did, to observe what happened in practice. It was also an opportunity to observe interactions which could be explored in more detail during interviews – as prompts for speaking about particular behaviours.

The Impact of COVID-19 on data collection



1 in 15

Estimated number of people in London with COVID-19 in the week ending 23 December 2021

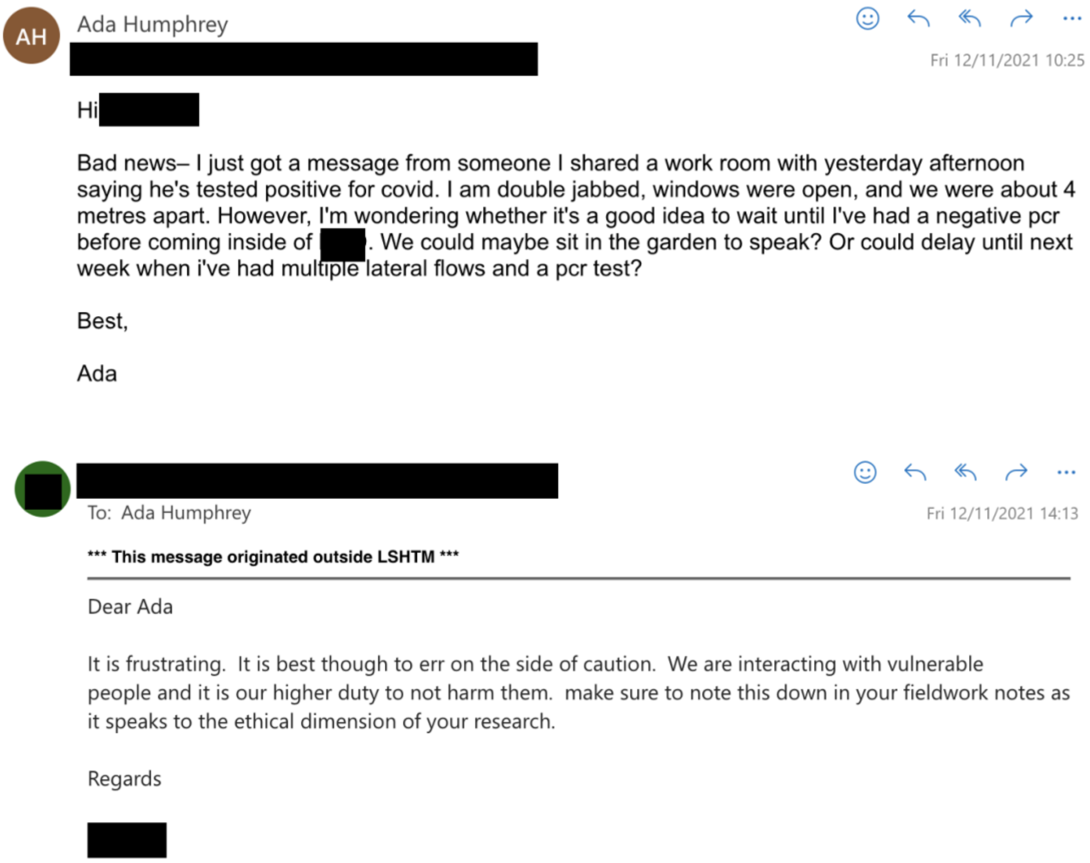
Source: Coronavirus (COVID-19) Infection Survey, UK: 31 December 2021

Office for **National Statistics**

Figure 2 COVID-19 ONS graphic 31.12.2021

The fieldwork period took place during the COVID-19 pandemic. This section gives an overview of the impact of this on the data collection for this study. At the outset of the research, it was recognised through data on vaccination rates and COVID-19 fatality data that the respondent group included in this study may be particularly vulnerable to COVID-19. Figure 2 is a screenshot of an advert being shared online at the time of fieldwork, which was based in London.

Very early into fieldwork, the ethical challenges of conducting in person fieldwork during a pandemic became relevant:



Ada Humphrey
[redacted]
Fri 12/11/2021 10:25

Hi [redacted]

Bad news– I just got a message from someone I shared a work room with yesterday afternoon saying he's tested positive for covid. I am double jabbed, windows were open, and we were about 4 metres apart. However, I'm wondering whether it's a good idea to wait until I've had a negative pcr before coming inside of [redacted]. We could maybe sit in the garden to speak? Or could delay until next week when i've had multiple lateral flows and a pcr test?

Best,

Ada

[redacted]
[redacted]
To: Ada Humphrey
Fri 12/11/2021 14:13

***** This message originated outside LSHTM *****

Dear Ada

It is frustrating. It is best though to err on the side of caution. We are interacting with vulnerable people and it is our higher duty to not harm them. make sure to note this down in your fieldwork notes as it speaks to the ethical dimension of your research.

Regards

[redacted]

Figure 3 Email exchange with staff at Community Hub 12.11.2021

As seen in the email chain above between myself and the gatekeeper to one of the fieldwork sites, the risk to respondents at fieldwork sites was deemed higher than the general public, and the decision was (and continued to be) to err on the side of caution. During the fieldwork it emerged that many respondents had not received any COVID vaccinations.

In late November the Omicron variant developed as a variant of concern. In mid-December 2021 whilst at the foodbank fieldwork site on a Tuesday, the researcher (myself) received a message from someone seen over the weekend:

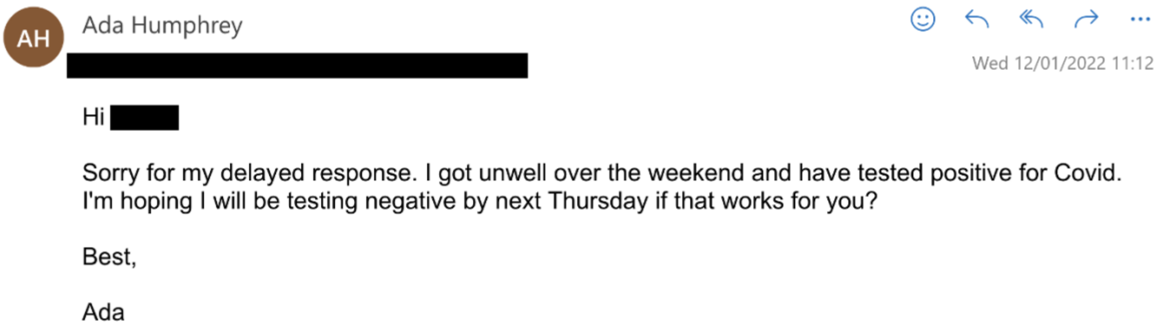
14 Dec 2021

Heya - JFYI I got a positive covid test this morning after a couple of people I saw at the weekend messaged me, so might be worth you taking a lateral flow if you're planning on going home soon
09:46

Sorry for the bad news! 09:46

Figure 4 Message from friend received whilst at foodbank 14.12.2021

Due to the rising case numbers and the chances of either catching at or bringing COVID to fieldwork sites, the decision was made to pause fieldwork for the rest of December. After coming back to London in January the researcher (myself) caught COVID within a week, and fieldwork was paused for another 10 days.



Ada Humphrey
[redacted]
Wed 12/01/2022 11:12

Hi [redacted]

Sorry for my delayed response. I got unwell over the weekend and have tested positive for Covid. I'm hoping I will be testing negative by next Thursday if that works for you?

Best,

Ada

Figure 5 Email to gatekeeper at Community Hub 12.01.2022

There were ongoing ethical dilemmas around conducting fieldwork with vulnerable groups during a pandemic which required attention to ethics in practice. This highlighted the differences between ethics as per a protocol, and the reality of doing fieldwork, which necessitates an ongoing and responsive approach. Whilst this PhD study didn't focus on COVID-19 as a topic of research, it was nonetheless intricately tied in with both the changes to primary care being discussed, as well as respondents' lived experiences with the healthcare system and vulnerability to poor healthcare outcomes.

Informed consent procedures

Service users

Interviews conducted with service users took place in person, and informed consent was taken at time of interview. Research methods that 'rely on reading or writing or abstract reasoning of verbal fluency may effectively exclude [vulnerable respondents] from the role of respondent or informant in ways that mirror their exclusion from wider society' (Tim, 1996, p. 252). Due to an expectation that some respondents may have low literacy levels it was decided that informed consent would be taken verbally by default, removing the need to ask respondents about their literacy. The impacts of this decision are discussed at length in 'Chapter 9. Reflection on Data Collection and Analysis'. Information sheets were sent to gatekeepers at fieldwork services to ensure clarity, as well as being discussed during a PPI meeting organised through NIHR ARC North Thames, in May 2021.

Information sheets were read out to respondents, they were given the option of taking a copy, and they were asked to give verbal consent in front of a witness who co-signed the consent form. At each fieldwork site the staff members acted as a witness to the consent procedure, and then left the room so that the interview could be conducted in private.

At the community hub there were extensive conversations about the consent procedure to ensure it was ethical and comfortable for respondents. The gatekeeper had concerns that service users would feel intimated by being asked to participate in a study and knew that many of them felt deeply distrustful of those they didn't know, especially when they were seen as representative of institutions which could have government affiliation. The consent procedure was practiced multiple times with guidance from the gatekeeper. This is outlined in the fieldwork notes below:

> I had a conversation with [name] about seeking informed consent and the fact that the consent procedure is very intimidating for people and having all the papers out isn't going to work. We did a practice informed consent procedure, and she coached me on using more casual language and framing it as more of a study. We spoke about the reasons why people might take part and the need to frame it as 'improving healthcare for everyone so it's easier to access the doctor'. She thinks that recording on my iPhone would be more acceptable to people rather than the audio recording device. We've agreed for the next informed consent procedure that [name] will do the talking and introduce the study to the person before we say 'the university needs me to tick these boxes with a few questions before we start speaking'. It came up that people may not be happy for the interview to be recorded in which case I need to decide whether it's okay to go ahead and do the interview without recording it. She made the point that if I use a word like 'group' people will think I am talking about them being black, and that I should avoid using language which makes things feel too bureaucratic. The informed consent procedure went really badly today, and I feel sad about it, and [name] was upset about it because it could damage her relationship with her clients- we agreed that we should have discussed the informed consent procedure before doing it.
>
> [Fieldwork notes from Community Hub, 27.01.2022]

The training I received at the community hub was also beneficial for taking informed consent at other fieldwork sites, as it helped to refine the language used and the way in which the study was presented. For instance, instead of "experiences of the primary healthcare system" saying "what it's like talking to your doctor". This training also helped to consider use of language during interview questioning. When interviewing across social and occupational differences between the interviewer and interviewee it is particularly important that the interviewer adapts their language so that it is comfortable for the interviewee and does not extenuate social differences (Mao & Feldman, 2019) – this includes limiting the use of academic jargon and abstract terms.

Service providers

Informed consent for, GPs and fieldwork service staff, and DHH staff was given by sending soft copies of the information sheets and consent forms, and asking that they return digitally signed copies prior to interview. Consent was reconfirmed verbally before pressing record at the beginning of remote interviews.

Analysis

Data from this study was analysed using reflexive thematic analysis (TA) (Braun & Clarke, 2006, 2022). Reflexive TA is a flexible analytical method that enables the researcher to construct themes – meaning based patterns – to report their interpretation of a qualitative data set (Terry & Hayfield, 2021). Braun and Clarke's (2006) seminal paper on TA refers to reflexive TA, which draws attention to the importance of the researcher's interpretation of the data and the researcher's subjectivity. Rather than viewing the researcher's inherent subjectivity as a limitation to the data, reflexive TA is premised on the deep engagement of the researcher with their data, and a recognition of this.

1) Familiarisation with the data

Data familiarisation was carried out at various points, starting with conducting the interviews and listening back to the audio whilst transcribing. Each interview transcript was then re-read and a short abstract written about the key narratives which came through, as well as notes about potential thematic codes. Once all interviews had been transcribed, these were read altogether as a 'set' of data for each respondent group.

2) Generating codes

Each transcript was imported into Nvivo, where the data was coded. The first few interviews which were coded each produced additional codes, which were then applied to the previous ones if applicable. The same coding set was used across all participant groups, with individual codes added for specific participant groups, when needed. Ultimately there were 56 granular level codes. These codes were 'semantic' and descriptive in style, rather than 'latent' codes which are more interpretative and conceptually laden. Codes were not clustered into themes until all interviews from a participant group had been conducted and coded. However, notes about potential themes were made during the coding process.

3) Constructing candidate themes

In order to construct candidate themes a mind map was drawn either clustering codes together into themes, or *promoting* codes to themes, and clustering codes together under them or subsuming them within it. An example of an early mind map can be seen below (figure 6). Once the overall structure of the results had been laid out, the process was repeated again for each results chapter, to create a more detailed map of each theme.

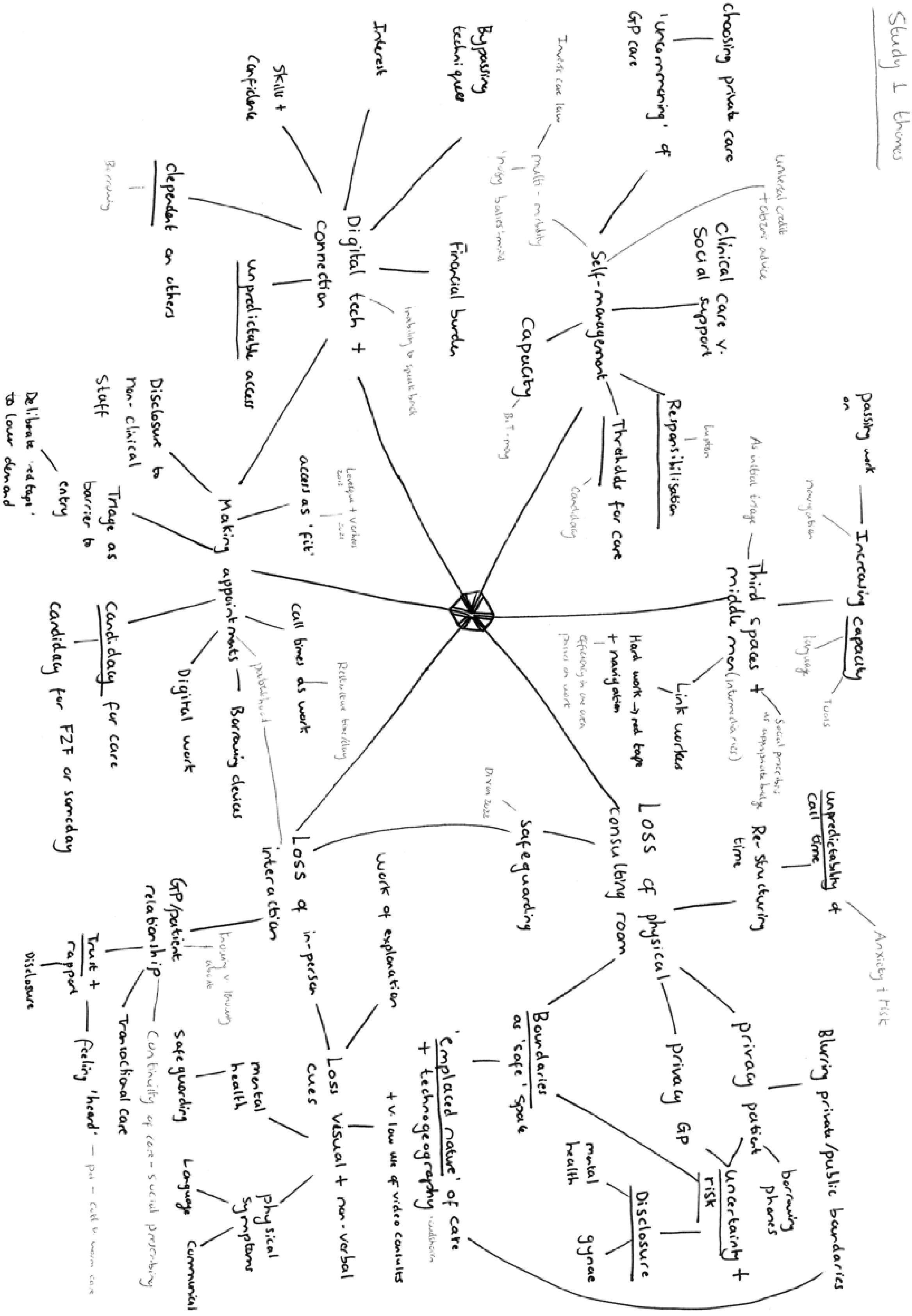


Figure 6 Example analysis mind map

4) Reviewing potential themes

Reviewing potential themes occurred during write up of the results chapters. For each candidate theme, representing a chapter, there was a document into which all the relevant codes were written. All quote segments belonging to these codes within Nvivo were then moved over into a data document for the chapter. At this point it was possible to see whether these sets of data made sense together within a single theme. During this process some codes originally placed into one theme were moved to another. For instance, one theme initially identified as a standalone chapter (third sector service support with accessing the NHS) was split up between two different chapters as it had been wrongly promoted to a theme without having enough data to support it.

5) Defining and naming themes

Defining and naming the themes happened whilst writing the results chapter, and confirming which codes belonged where. It was at this point which chapter titles which summarised the theme were developed. Where possible a quote from the data which reflects the theme, plus a short description, has been used as the chapter title.

6) Producing the report

Writing the results and Discussion chapter of this PhD were both an outcome and a part of the analysis process. Having written all of the results chapters, narratives which ran throughout were identified to consider how these might be bought together in the Discussion chapter. One of the challenges during this process was to move away from a desire to let the data 'speak for themselves'– to recognising the role of researchers in shaping and communicating findings. The signposting, analysis, contextualising information and commentary provided throughout this thesis are part of the co-creation of the research between participants and researcher, and hopefully the 'connective tissue' (Terry & Hayfield, 2021) which brings the PhD together. The role of the researcher (myself) in the analysis is examined in greater detail in Chapter nine.

The role of theory in analysis of the empirical work

Theoretical models from across the different disciplines introduced in the literature review were integral to the analysis of the data at various points.

In the first instance theory was used to inform the design of the interview guides themselves, which in turn produced data on particular topics. Interview guides were created by the researcher towards the end of the first year of the PhD and based on previous empirical work as well as theoretical models which have previously been used to understand issues of access as well as the use of digital and remote technologies. For instance, the concept of 'Burden' of treatment informed a line of questioning within the interview guides around the different tasks involved in the setting up of and participating in a GP consultation. Whilst careful not to mis-, or over-interpret study data, participants' narratives around the demands placed on them whilst engaging with healthcare services was then examined through a Burden of treatment lens, using concepts such as 'work' and 'capacity'. Therefore, whilst reflexive thematic analysis is inductive in nature, the importance of how theory informs data collection itself cannot be overlooked.

The analysis process itself, during which empirical data is analysed as a set of narratives which help to build an overarching story about experiences of care took an iterative approach to theoretical framing. First off empirical data was grouped according to themes, for example 'long hold times when making appointments' or 'difficulty describing symptoms without gestures'. These sub-themes were then clustered together under core themes which described the element of care they related to, for example 'Making an appointment' or 'Remote consultations and communication'. Each core theme had a cluster of sub-themes. As this thematic analysis process progressed theoretical frameworks and concepts were overlaid onto themes to help frame or explain the data, for instance 'candidacy' as a theoretical concept was tagged onto the sub-theme 'negotiation process with receptionist' and 'responsibilisation' (another key theoretical concept) was tagged onto a group of sub-themes which described the difficulties patients have when trying to make secure private space in which to have a remote consultation. This resulted in relevant theoretical concepts being spread out across the different core themes, meaning that some concepts such as 'responsibilisation' were tagged onto sub-themes within each chapter, whilst others such as 'candidacy' sat closely with only one core theme. In this way analysis was conducted so that theoretical concepts and frameworks were mapped onto different elements of the empirical data based on relevancy.

Due to the high degree of overlap between some core themes (which are presented as analytical chapters) there are certain theoretical frameworks which ended up being prioritised as overarching explanatory models when it came to pulling all core themes together in the final Discussion chapter. However other theoretical concepts and frameworks introduced in the literature review became deprioritised as the study progressed and it became clear that they either did not speak to the experiences relayed by study respondents, or were less relevant alternatives to the theoretical models which were ultimately used to understand the data.

Ethics

Ethical approval for this study was granted by the LSHTM ethics committee (number: 26235). Whilst designing the study various people were consulted about how to ensure this study was conducted ethically. This included speaking with PhD advisors who had experience working with marginalised groups in the UK, as well as informational calls including with gatekeepers to services which became the field sites. These calls gave an opportunity to run ideas by individuals with extensive experience working with marginalised populations, for instance around informed consent procedures. However, despite the careful consideration given to ethics during the design of this study, one of the most important lessons learnt during this study was the importance of ethics in practice versus ethics on paper, a topic which is explored in more depth in 'Chapter nine. Reflections on Data Collection and Analysis'.

Data management

Interviews were downloaded onto DSS software associated with the audio recording device. Audio recordings were transcribed manually during which identifiable information such as names were removed, before storage of transcripts. Transcripts were then uploaded to Nvivo software for Macs, where they were coded (see data analysis). Participant data and informed consent forms were kept separate from interview data.

All data was stored on an encrypted, password-protected USB device, and on the LSHTM H:drive. The LSHTM H: drive is a secure network drive operated by LSHTM IT Services, which has been approved for storage of Confidential Data and is backed-up daily. Access to the work the H: drive is restricted to by LSHTM username/password.

Anonymised data (transcripts and fieldnotes) will be stored for 10 years, in the LSHTM secure server area and in and in the LSHTM data repository. The LSHTM data repository administrator will store an archival copy of the files in the repository. This will ensure the files are preserved for 10 years and repository administrators will act as a correspondent for data use by other researchers, if I am not available.

Chapter 4. Context

Chapter 4.

> *"By writing first – and in minute detail – the stone, plastic, wooden-framed, papery, magnolia-painted materiality of the corridors, I could then – only then – return the participants to their proper places in the ethnography, as parts of a spatialized, materialized, mobilized world in process".* (Hurdley, 2010, p. 522)

This chapter aims to give a sense of the spaces I was spending time in during my fieldwork. This is one of two chapters alongside chapter nine that will be written in first person, in deliberate recognition of the highly subjective nature of both site descriptions as experienced by myself, the researcher, and my own reflections on the role my positionality played in this study.

Research is an embodied experience, and the physical spaces and what happens within them have an unpredictable and significant impact on the research findings and analysis. This happens through deliberate means, for instance using fieldwork notes as data, but also in more subtle ways through the interaction between the researcher, spaces, and participants. This is a topic I will discuss in more detail in relation to my own thoughts and feelings about my experiences in chapter 9. The purpose of this chapter however is to build on the more practical elements of the methodology, to give insight into the spaces in which this data was generated, and to share something of the experience of conducting this study so that the reader might orientate themselves into the data through a narrative account.

Chapter 4.

Foodbank

It's November 2021 and London feels almost back to normal, following 1.5 years of lockdowns – normal, but a little bit dulled. It's already become cold, winter coats are on and breath turns to steam. I'm travelling to my first day at my first fieldwork site, a foodbank based out of a church in East London. After a tube journey and 40 minutes sitting on a bus I arrive, having left the domain of artisan coffee roasters, traversed well cared for green spaces, and entered into a residential and slightly run-down area. It doesn't take me long to work out where the foodbank is as I see a line of coral coloured plastic chairs in a church car park, filled with people of all ages stomping their feet and rubbing their hands, each with a sea of bags around their ankles.

First thing I notice– I am going to stick out like a sore thumb. I'm wearing a long wool coat and a pair of Chelsea boots, I'm white, and I've got blonde hair down to my waist. To top it off, I've got a clipboard under my arm.

Grey plastic tables are being unfolded onto grey concrete under a grey sky. Fruit and vegetables are layered above and beneath one table, the other two hold an array of products, from baked beans, tomato soup, Thai curry mixtures, toilet bleach, hand sanitiser, a bunch of goji berry mixed bags and dark cocoa nibs (another sore thumb), through to the end section of sanitary towels and pastel coloured hand knitted children's scarves. Later in the year mince pies and children's' gifts will appear. Behind the table is a box of candy, bagged into smaller plastic bags– allocated out one per adult because (the woman behind the table tells me) "*These people* don't always know what's good for them".

I introduce myself to the main point of contact who welcomes me warmly and shows me through to the back, where the cupboards of food are stored. She shows me the registration system – referrals only, three months of food at a time, allergies and preferences stated. Despite the abundance of soy milk that has been donated, I hear it commented more than once that it doesn't make sense to be vegan when you're using a foodbank – apparently dietary choices are for those who can afford them.

Having been shown around I make my way out to the queue. I receive a mixture of hesitant smiles, deliberate gaze aversion, and unsure stares. As I begin to introduce myself, I see shoulders freeze up and jaws tighten – heads start to shake before I've even indicated what I will be asking.

Fast forward three weeks (three visits and minus another four degrees) and I've made a friend – a participant whose dog I got to know who then agreed to be interviewed. We are on a first name basis, and everyone else is made more comfortable by seeing us interact. The clipboard is long gone, as are the boots. At this point a lot of my interactions are happening within the queue, I am telling people what I am doing ("research into how you talk to your doctor") and there are strong opinions all round "Oh it's a nightmare" "It's rubbish" "What doctor!?" "Oh, I don't bother with that". Moving from this casual conversation to an interview however is even harder than I anticipated. During my time attending this foodbank I have the opportunity to meet the regular users. I stand outside with them, commenting on how red our noses are getting in the cold, and wiggling our toes to keep warm.

My research period coincides roughly with the maximum amount of time people are allowed to attend – meaning that there are some people I see every week, and many who disappear during my stint there. I hear stories of how people ended up using the foodbank, many of which hinge around a single life event which turns vulnerability into marginalisation. A lot of the regulars who I have developed a familiarity with remain unsure about being interviewed, and I learn to not ask again if I see any gaze avoidance as they register my presence. In general, it seems to be the *most* vulnerable (both socially and medically) who are the least willing to speak to me in any formal capacity.

Interviews are taking place up in a room in the church, opposite the priest's office. There's a desk, two chairs, and lots of books. During my four months here, I manage to secure five interviews. Each of these interviews gives me a window into the chronic cycles of marginalisation these individuals are caught in – that it is expensive to be poor, that you must fight for welfare payments, that networks are crucial, and that no one chose to be in the position they are in. Stories of multigenerational deprivation, mental health needs, and systemic exclusion through being born on the wrong side of the social determinants of health. I am reminded of the 'Red Queen' hypothesis, a biological theory that species must constantly adapt, evolve, and proliferate in order to survive while pitted against ever-evolving opposing species. It is named after Lewis Carroll's Red Queen, who tells Alice "The world keeps shifting so quickly under her feet that she has to keep running just to keep her position" (figure 7).

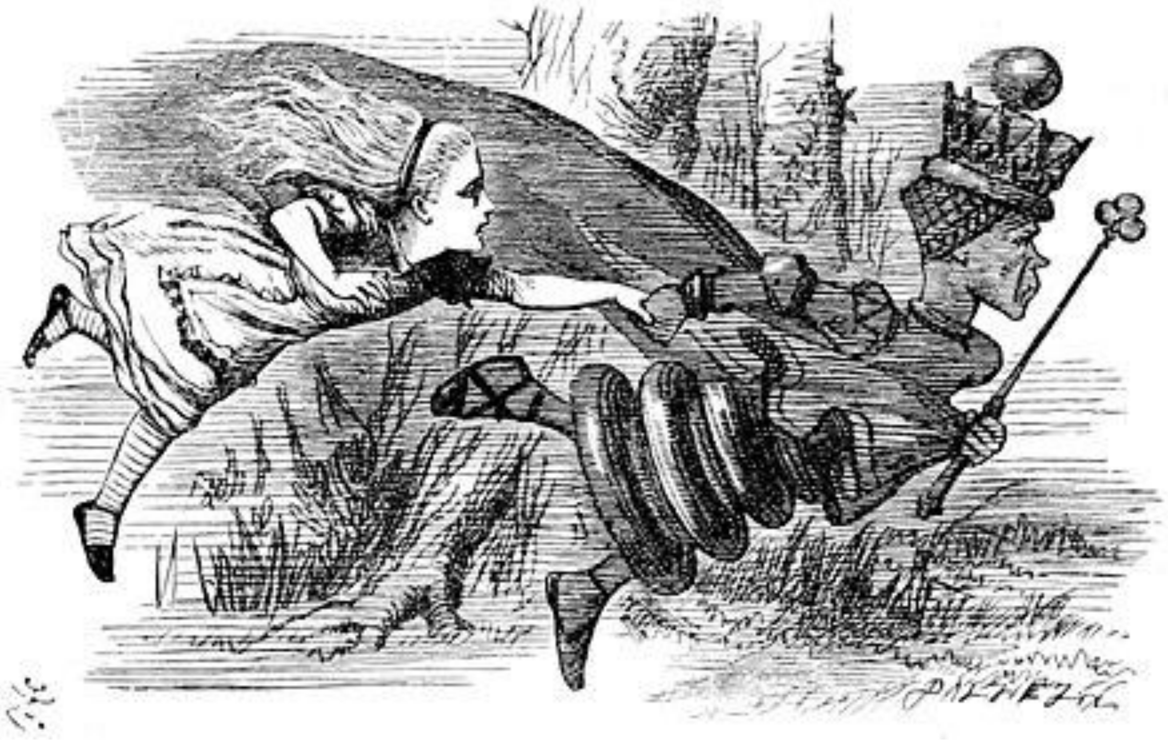


Figure 7 "Now, here, you see, it takes all the running you can do, to keep in the same place." — Lewis Carroll, Illustration by Sir John Tenniel from Lewis Carroll's "Through the Looking-Glass," 1871 (out of copyright)

Travelling home on the bus is like travelling through Carroll's looking glass. I grit my teeth as I try not to think about the person sitting opposite me 20 minutes ago crying because they can't afford a bed for their child, because they can't get the mental health support they need, and because they are reliant on products from a church car park to meet their basic sanitary needs. It feels immensely unjust to return home to my warm house and MacBook Pro, to do thematic analysis of a life story. It also feels very important that I find a way to do justice to the stories shared with me by finding a way to capture the complexity of exclusion faced by those I speak with – a topic worth at least a dozen PhD theses, of which I will only write one.

Community centre

My route into the Community Hub was less direct than my other fieldwork sites. I first contacted the Community Hub as it had previously been a GoodThings

Foundation Digital Health Hub. However, they were no longer going to be running this programme. I spent a lot of time trying to get hold of one particular member of staff, who, until he found out I lived in the local area, was not responsive. After two months of back and forth I managed to arrange an in person meeting. In late autumn, I took myself over to their office. As soon as I got there I was introduced by my initial lead, to another individual, who had a background in social work, and spent a lot of time interacting with service users in the local square where many of them hung out. This individual had a background in the social sciences, and was excited by my research, quizzing me on the anthropological texts I had or hadn't yet read. After having some tea in the enclosed garden at the office he suggested the only way I could do my fieldwork was to get out 'into' the community and meet people where they spend their time – the 'square'.

Not wanting to turn down my first fieldwork lead I agreed to walk around the corner with him to the square. As we approached he told me I needed to get my anthropologist hat on and get into character – 'tough it up a bit' he said, as he slanted his cap on an angle and introduced a saunter to his walk. Rounding a corner we come onto the square, a few people look up to see who's coming, most stay looking at the ground or engaged in their group discussions and games of dominoes. We make a beeline to a tall individual who recognises my guide at a distance, I am introduced to the man using his 'street' name – many of the men in this community go by these names, and often the service staff use these too. The man I'm introduced to runs an informal foodbank in the mornings, serving the local community and in his own words "keeping them out of trouble". We explain that I am hoping to get to know the community, and that volunteering at this foodbank is the best place to start, as it will help me gain some credibility.

Fast forward three days and I turn up 8am, freezing cold (a theme across a lot of my research in services forced outside by the pandemic), to the mini gazebo set up on the square. There are a few tins of food, some pastries, and a large canister of tea. As the morning progresses individuals start to trickle in from the main street onto the square, the regulars approach the gazebo and are greeted ‘Hi Tins’ ‘Hiya Keith’ ‘Hey there Biccy’[4]. Many of those arriving spent the night on the streets, others in accommodation which I am told is “not fit for rats”. As I stand in the tent it becomes clear that the food and hot drinks on offer play only a minor role, and that the social role is key.

Nothing could have prepared me for the amount or types of conversation I would have that morning. A significant proportion of those attending present as having some form of mental health disorder, which affects the way in which they interact. I spend nearly 45 minutes commiserating with a man whose inheritance has been stolen, only to find out that this inheritance is the largest plot of unused land in London, and he is in fact owed several billion dollars by the government. Another individual talks to me in detail about his stays at Stanmore psychiatric unit, the number of people he’s murdered and where he keeps their knuckle bones. At one point a fight breaks out and a man sweetly smiles at me, bringing me into his confidence confessing “Should I kill that woman? I’d like to, you know”, after some discussion we reach an agreement that he probably shouldn’t do any killing during breakfast. The reactions to me being there range from light interest, enthusiasm for a new person to speak to, through to disdain and a refusal to acknowledge my presence. Some of this is uncomfortable, some of it is frightening, and some sad. At one point the organiser of the foodbank decides it’s become too chaotic and insists that no-one must step behind the table to sit down, this is partly to calm the situation, but also, I suspect to make me comfortable. After a long morning, I fabricate an important meeting with my bosses, and make an exit. I return home, exhilarated (finally some fieldwork), but also drained, unsure I can handle that

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[4] Pseudonyms reflective of the nicknames

again and wondering how much to reveal to my supervisors. A week later a man is shot and killed on the square – I agree with my supervisors I won't be going back.

Having ruled out this site, observations, and interview recruitment from within the service's office becomes the goal. Many of the individuals who spend time on the square are users of the service, and come by the office, it feels like a good intermediate and more controlled option. I am passed on again to another member of staff, a woman who is warm and kind, with deep knowledge of the community she works with, and seemingly endless patience for her clients – Sally (pseudonym). Over the next four months I will spend a day or two here a week.

We agree that I won't be doing the recruitment myself, she recognises the population of service users as particularly vulnerable as well as fearful of involvement with anyone that may be seen to represent state services. The majority of those who come are in their fifties and sixties, West Caribbean, and a large proportion are suffering from substance abuse issues and mental health issues, intermittent homelessness is also common. She wants to ensure that I avoid speaking alone to some of the more challenging clients. We spend the first two weeks refining my recruitment process – as detailed in the Methodology. While some interviews are set up for me, many are organised by spending time observing Sally interact with clients and asking them if they'd be okay speaking with me. Most people we ask don't want to take part. Sally is clear with me about the responsibility not to 'over recruit' because of assumptions people won't turn up, as this would then "deprive people of vouchers they've been told they can have", so recruitment is much more iterative, and people are given a few chances to show up before recruiting someone else.

In one instance an individual agrees with Sally to take part but when I begin the informed consent process becomes extremely distressed. I notice this as it happens and pause to check he's okay, as he begins to cry, he gets up from his chair and leaves the building as quickly as possible. As I get up to go find her, Sally notices what's happened and runs out after him, to find him mid-panic attack on the street, she comes back in tears. The paper documentation and audio recorder were too much.

Many of the service users know Sally well, and have a warm relationship with her, turning up to ask for help with an online form or a phone call, interacting with her like a friend they respect. Most interactions I observe are about housing, universal credit payments and disability allowances (PIP). In general, the attitude towards me is gentle confusion as to what I'm doing there. Now and again a client turns up in an elaborate outfit, on substances and shouting – occasionally there is a verbal altercation between clients, which Sally deals with deftly. Many of the men (it's mostly men) using the service are in their sixties and have loosely known each other since their teens. I'm asked to help with work at the service in exchange for my access, which I am happy to do. Often, I am trying to look up information on other services and phone contact numbers which don't exist.

I usually return home exhausted from these hours of observation, especially when I've run an interview. I also return home shocked at some of the things I hear about the conditions people are living in and their treatment by statutory services they rely on. Spending time here is an embodied experience, perhaps more so than in my other fieldwork sites. I feel shame as I breathe through my mouth when clients come in having not been able to wash for several weeks (an impossibility if you have no access to hot water in the dead of winter) or smelling of strong liquor. I am sweaty behind my thick face mask which I wear knowing many of the clients are unvaccinated for covid – vaccine hesitancy is a topic which comes up often here. I often feel jittery after spending the morning around clients who shout and swear, leaping around the office. Most of the time I leave feeling guilty, especially when someone I previously interviewed (who received a voucher) comes by the office and smiles at me before asking if I have any more food vouchers because they "got to eat so much that week".

Migrant, refugee, and asylum seeker drop-in centre

The drop-in centre for refugees and asylum seekers is perhaps the field site in which I felt most at ease. Run by a lovely older couple, and volunteers from the area, it's based out of a church one morning a week. There's a placard up outside indicating the presence of the service, and a sign in desk at the front. There's a permanent crafting table, with two women knitting, and a charming older man who asks every twenty minutes if you'd like a cup of tea or coffee. In my time there I never once see a client use the crafting table – but it adds an air of friendliness to the room. The large church hall is split up by dividers, with tables and chairs behind them. The tables each have a plate of biscuits, some satsumas, and sucking sweets on a plate. There are also two large side rooms which are used to speak with people. Another cold fieldwork site, the windows are open throughout the winter to mitigate for covid risk, and the heaters under the window pour hot air out onto the street. The majority of volunteers at this site are advocates with previous careers in immigration law or large public health NGOs, the couple who runs it are experienced and have ties into local authorities, often contacting MPs directly to discuss a case. The woman who runs the service with the couple is fierce and runs a tight ship ensuring every client is logged into the system and dealt with properly.

My mornings here vary hugely, some days one person drops by, other days there is a constant stream through the door. There's also variation in service users with long term immigrants who may or may not speak English, through to newly arrived refugees and asylum seekers – whole families from Afghanistan, and young mothers from Eritrea. People often come with a friend or arrive on the phone with a friend to interpret for them. There are some staff members with language skills, but usually informal networks of service users are used for interpretation purposes. The staff members here are incredibly welcoming and allow me to observe sessions with clients so that I can get a better idea of what the service offers, and the circumstances of those who use it. When I can I attach myself to the woman in the couple 'Jill', as she explains to me in detail what's happening and why. Whilst sitting in on sessions I am able to ascertain a client's level of English, and whether it is appropriate to consent them into the study. At the end of their session, I introduce myself and my study, and ask if they'd be happy to stay a little longer to speak with me.

The reasons why people came into the centre were diverse, and included asking for help with accommodation and work, but overwhelmingly to ask for assistance with their immigration status. It was uncommon for people to come to get help with accessing the NHS, but it did happen. There is a small box of NHS access cards on the desk, although the stack never seems to get any shorter over the months I am there.

Overview

The intention of these descriptions is not to give a clear idea of exactly who study respondents are, or a reflection on my own positionality within the study – these are dealt with elsewhere. The purpose of this chapter is to orientate the reader towards something more akin to an embodied experience of the research, and therefore the data presented in the results.

Chapter 4.

Chapter 5. "It is hard work getting an appointment it shouldn't be like that" – Making appointments for GP consultations

Introduction

This chapter focuses on GP appointment booking, which serves as the initial point of substantive interaction with primary care services. It also touches upon the broader communication between patients and primary care services. Access to healthcare encompasses more than just the availability of appointments; it encompasses various concerns, including the simplicity and reliability of access methods (MacKichan et al., 2017). Previous research has described the difficulty in making primary care appointments as a form of patient work, wherein patients face the potentially challenging task of navigating their way into the healthcare system. “Making a request of GP receptionists, such as to see a doctor, can involve a ‘burden’ on the patient to drive the interaction – and service – forwards, or push back on premature closings” (Sikveland et al., 2016, p. 5). Long hold times and narrow call windows to make appointments have previously been identified as key barriers to appointment booking (Ball et al., 2018) which can lead to overuse of emergency services as an alternative (MacKichan et al., 2017).

One way in which this negotiation process for a GP appointment has previously been understood is ‘candidacy’ which is a term introduced in the literature review to describe the way in which eligibility for care is jointly negotiated between individuals and health care services (Dixon-Woods et al., 2006). Of the six stages of candidacy: identification of candidacy; navigation; and permeability of services, are the most obviously relevant to appointment booking – themes which will be returned to in the summary section. Recent evidence from remote antenatal care provision during COVID-19, found that moving from in-person to remote service provision can impact on healthcare negotiation practices associated with candidacy requiring patients to possesses greater sociocultural capital to elicit care (Hinton et al., 2023).

During the COVID-19 pandemic, there was a rapid transformation in how patients made appointments, particularly in General Practice settings. In person appointment booking was swiftly replaced by online and telephone booking options in many practices. Although GP practices have started to reintroduce face-to-face interactions, remote booking systems and consultations have remained as the default in many cases. Additionally, there has been a growing reliance on digital communication systems for tasks such as ordering repeat prescriptions or receiving test results.

Chapter 5.

One of the main themes that emerged from the interviews regarding access to GP services was the difficulty individuals faced in obtaining appointments. This challenge arose from various factors, including the way systems operated and individual circumstances. This chapter will explore the obstacles people expressed, which encompassed limited access to digital technologies, particularly phones, for appointment booking; financial and planning difficulties due to long hold times; the need for digital and English literacy to make appointments online; challenging interactions with GP receptionists to gain access to care; and a perceived increase in the threshold of clinical severity required to secure a GP appointment.

Individuals employed various strategies to navigate these barriers, such as strategically tailoring their responses and interactions with receptionists to compel them to grant an appointment. Other approaches included resorting to private options (e.g., online pharmacies) or seeking assistance from third-sector services to secure an appointment. Some respondents shared accounts of being unable to navigate the primary care booking system and ultimately giving up on attempting to make an appointment. While challenges in booking GP appointments are not exclusive to any specific group, this chapter will examine how marginalised individuals, characterised by limited access to resources, interact with structural changes in the appointment booking process and explore the resulting impacts on their access to healthcare.

The subsequent section will present the study findings pertaining to appointment booking, examining the various themes that emerged. These themes will then be synthesised in the summary to provide insights into how changes in appointment booking systems may influence access to primary care for marginalised populations.

Findings

Perceptions of GP appointment booking

Throughout the fieldwork process during interviews and more informal fieldwork interactions, the difficulty of making GP appointments came through as a key concern. This first section looks at respondents' general perceptions of getting GP appointments, before moving on to look at the specifics of why appointment booking is portrayed as a challenge.

During recruitment at the foodbank many people commented on how difficult it was to get through to their GP: "Oh yeah it's been way harder", "you have to call them 85 times", "It's impossible to see my GP" (from foodbank fieldwork notes November 2021). This was often the first comment made by people when the study was introduced, indicating that appointment availability and booking process is a key concern when it comes to use of primary care services and that getting a GP appointment is seen as a key challenge.

This theme also came through strongly during interviews, in which the following comments were made about making GP appointments:

> "I'm trying my hardest to get an appointment but it's beyond my control. I actually can't physically do nothing about it." [2, Female, 30s, black British, foodbank]

> "It is hard work getting an appointment it shouldn't be like that, like fair enough I know the doctors are busy and stuff but it shouldn't be so hard to get an appointment [...] so you just think why should I bother and then you end up getting worse, cos I did I put it off for a month my back and I was literally in agony

> everyday it was awful and then I just thought there’s no point I won’t get an appointment” [9, Female, 40s, white British, foodbank]

These quotes highlight several key concerns and dilemmas, namely that getting an appointment is difficult for patients, and that perceived inaccessibility may lead to despondency around attempting to make an appointment, despite an ongoing need. As respondent 9 questions, why should she continue to bother trying. Further, there is a reflection by respondent 9 that difficulty getting an appointment is related to an issue of high demand with doctors being ‘busy’. This speaks to the development of a narrative around scarcity of GP appointments, which was spoken about repeatedly across all respondent groups, including GPs.

This sentiment was also reflected in contemporaneous media, with headlines such as “It’s not your doctor’s fault you can’t get an appointment” (Bloodworth, 2021,The Newstatesman), “Struggle to see GP tougher for Britons than other westerners” (Hayward, 2022, The Times) or “As patients say they can't get a face-to-face GP appointment, why this could be a glimpse of the future” (Guttridge, 2022, Birmingham Mail) . At the time of data collection there was a strong focus on the NHS by popular media outlets, and health and healthcare remained at the forefront of public discussions due to the ongoing COVID-19 pandemic. During the early stages of the pandemic, the NHS was reified by the press, and public – through discount schemes for staff, public clapping on a Friday night, and praise from the government in daily briefings. By November 2021 the narrative had shifted to one of a service under immense pressure, and a primary care system which was no longer delivering for patients, a narrative which was reflected back in this study through offhand comments as well as more in-depth accounts during interviews.

The reasons behind the perceived difficulty in GP appointment booking specifically, are complex and include long hold times, challenging interactions with receptionists, and digital access problems and literacy. These issues are discussed in the sections that follow which look in depth at a set of challenges which respondents experienced, and the potential implications of this for access.

Appointment booking modality

This section looks at changes to appointment booking modality, from having in person options, to communication primarily taking place over the phone or online. This is followed by an exploration of the challenges which individuals face accessing and using the necessary digital technologies such as mobile phones, and how this impacts on communication with primary care services.

Since the COVID-19 pandemic, GP appointments are mostly made over the phone or online, as in person appointment booking ceased at most practices at the outset of the pandemic. Respondents recounted having previously used in person booking options which are no longer possible which contributed to their challenges around getting an appointment.

> “Even before COVID I was trying to get through once and I phoned about 200 times, and I couldn't get through, it was a nightmare. In the end, you have to just go down there and queue up and nag the reception. Obviously through COVID you couldn’t do that.” [9, Female, 40s, white British, foodbank]

This quote illustrates the challenges around appointment booking which existed prior to COVID-19. The respondent describes a process as frustrating and requiring persistence over an extended period of time. However, the last resort – 'nagging' in person – has now been taken away by COVID-19.

Respondent 8 gave another example of previously booking appointments in person:

> "Because before is this like go past there if I'm in the area I used to just go there, and just say can I book an appointment blah blah blah. But now you have to phone them and you couldn't go when you go if you did pass it when COVID on there they don't let you in innit." [8, Male, 40s, British Pakistani, drop-in centre]

These examples suggest a shift has happened since COVID-19, with the removal of an avenue of contact which leads to greater reliance on remote systems (telephone and online) for access. Whilst this may not fully exclude patients, it can make accessing appointments more challenging, as the systems which are available may be difficult to navigate and use – the focus of the following sections.

Precarious access to devices and connectivity

As outlined above, prior to COVID-19 patients could make appointments with their GP by attending a practice in person. However, during COVID-19 lockdowns, in person access to appointment booking was severely limited or made impossible – obligating the use of remote appointment booking over the phone or online. The following section will argue that increasingly, consistent access to a mobile phone with either unlimited or a high data and minutes limit is becoming a prerequisite for accessing primary care effectively. Those who do not have the resources to pay for and maintain this may find themselves further marginalised and unable to access the primary care system and sometimes be penalised or face an undue financial burden when trying to make appointments. The relationship between resource scarcity and access to digital devices will first be discussed, before looking more closely at how this might impact on access to primary care services.

During fieldwork many examples of limited or unpredictable access to digital technologies because of finances arose. This was also an issue when trying to arrange meeting times with respondents and limited the possibility of arranging interviews in advance. Lack of device access in this context means limited or unpredictable access to a mobile phone, and connectivity (WIFI or data), caused by precarious finances which prevent consistent access to, or replacement of lost or broken devices. As well as device access, a consequence of unstable finances is buying expensive phone 'bundles' of minutes and internet gigabytes rather than having a phone contract with unlimited use, which makes use of a phone more expensive. This is compounded by low use of landline phones, which, like a phone contract allow for reliable ongoing ability to place and receive calls. Solutions people had to access devices included borrowing, relying on third sector services to provide phone and internet access, or alternatively the use of simple devices (i.e., non-smart phones) which aren't always suitable for accessing services.

First, looking to device use and connectivity. Having a phone contract, rather than buying bundles, was framed by respondents as an important steppingstone in device use – allowing for greater access to services through predictable connectivity:

> "Mine is EE I have an iPhone contract, but I'm 100GB data because that helps because now I know I can just make a phone call and everything is accessible but before when I had a non-contract phone it was pay as you go I had to sometimes use someone else's phone to make a phone call that's when it becomes a bit difficult." [11, Female, 60s, Black British, community development charity]

For respondent 11, having a phone contract made 'everything accessible', whereas previously she had relied on borrowing a phone to make calls, making access less predictable. She mentions the borrowing of a device as a way of securing access to services as challenging – which will be discussed further down.

Respondent 14 related her phone contract directly to her access to healthcare, stating:

> “I'll be honest if I never before I had my contract and stuff and I never had a way of calling them I'd go there and make an appointment. That was all fine” [14, Female, 40s, White British, foodbank]

Here she points out the relationship between her access to a mobile phone contract and appointment booking and her previous reliance on in person booking to circumnavigate this. Obtaining a phone contract can be difficult for individuals on low or unstable incomes, or those with unstable housing, as network providers usually require proof of address, income, or a credit check. This obligates those in precarious financial or living situations to use pay as you go phone options which tend to be expensive, but more accessible as they don’t require a monthly payment. However, even if an individual does obtain a mobile phone contract, it isn’t guaranteed that they will be able to maintain it, and it can become a potential source of ongoing stress:

> “Urm my smartphone I think was fortunately I got it because I actually had my own address so I think when I applied for it, [the provider said] well actually you can have it today and I was really dead shocked, but then I have to pay that bill every month” [2, Female, 30s, black British, foodbank]

> “In the last few months, I'm really behind on my [phone] bill, because it's 20 pounds a month. They take from my account, and it's been...since over Christmas and stuff, I’ve not been able to pay my bill. They've been so good. I've spoke to them, and they've, you know, let me pay a little bit off they've been really understanding.” [14, Female, 40s, White British, foodbank]

A phone contract was represented by these respondents as a luxury as well as an added burden. However, when finances get tight, phone connectivity may be one of the first things that people give up as difficult financial decisions are made:

> "I also just moved into a new property and I was homeless before that, I have no bed, still don't have no bed...I was this Christmas...I'm happy to give up my bed but when I lie in my daughter's bedroom and see the breeze and felt that draft, she's having her bed, so that definitely means there's no this month there's actually no phone bill, there'll probably be no rent, and these are my realities" [2, Female, 30s, black British, foodbank]

> "Oh, yeah, no the Wi Fi could just go out the window if it comes to that I just have to suffer. Because the majority time I've got a house phone, but we don't really use it because it's quite expensive. But if it comes to it, when they do cut it off, they normally leave like incoming calls on my house phone[5]. So, people can still contact me that way. Okay. I just can't contact them [...] Because obviously they can still phone me but if it runs out it runs out if I've not got the money, I'd rather put gas and electric on and get food for the kids." [9, Female, 40s, white British, foodbank]

Few respondents gave examples of complete lack of device access, but the narrative of precarity presented above was common, with phone use tied closely to fluctuating financial circumstances. Consequently, economic deprivation forces people to make choices between immediate needs (e.g., heating) and other needs, which includes phone connectivity. This can have knock on effects, including reduced access to healthcare due to a difficulty contacting services to make or change appointments, as detailed in the following quote:

> "Because you don't know if people can afford to travel a lot of the appointments I've missed over the last few years is because I have no money to travel, I don't

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[5] Respondent 9 was the only respondent who reported using a landline phone.

> even have money on my phone to call you to say I can't make it and I'll lose that appointment and then they won't see me ever" [2, Female, 30s, black British, foodbank]

In this excerpt respondent 2 recounts an example of having been unable to access travel or a device due to finances, creating a two-fold barrier to care. She also expresses concern about the potential implications of a missed appointment for future access to care. This account also indicates the potential issues with *in person* appointment booking, if getting to the surgery costs money – showing how resource scarcity has the potential to impact on access to care regardless of whether appointments are made or conducted in person or remotely.

Aside from connectivity, respondents also talked about broken mobile phones which they could not afford to fix, limiting device use. When this happens, access to services may be disrupted, which can lead to patients having to find other ways of accessing technologies such as borrowing, as in the following instance:

> "Respondent (R): My phone broke and I can't actually afford to get it fixed it's 100 pound but I just can't afford to do it otherwise I have to get rid of the internet for that month so you know
>
> Interviewer (I): So, in a situation like you're in now if you needed to contact the doctor what would you?
>
> R: I'd have to go to my mum's house [....] So, I then have to knock on my mum's door, she'd open her bedroom window because no one is allowed in her house since the lockdown and I'd have to ask her to make the phone call for me because I won't be allowed to touch her phone
>
> I: So then how, have you had to do that before?

> R: I have I've had to shout, they put like the doctors and stuff she puts them on loudspeaker and I have to shout like I give permission for her to speak on my behalf" [5, Female, 30s, white British, foodbank]

Respondent 5's account exemplifies the impact of resource precarity on consistent access to devices, with a broken phone leading to device borrowing. Here, she describes choosing to privilege connectivity (WIFI at home to use on a laptop) over having a phone. When asked whether there were any online booking systems for her GP she said she was unaware of them, which had forced her into the situation she outlined above. This is only one of many examples given of relying on borrowing a phone due to unstable access to either a device or connectivity. Not only does borrowing as a way of securing device access necessitate reliance on others to contact the doctor, but it also has implications for privacy, which will be explored in more detail in the following chapter (six).

As outlined, COVID-19 led to a reduction of in person booking options which redirected patients through remote appointment booking systems – necessitating digital access. However, for those with limited or unstable access to devices and connectivity this can present a challenge, as remote systems are not always easily available to use.

Technological thresholds

The ways in which resource scarcity relates to access to digital technologies, and how this can impact on communicating with primary care services has been outlined. This next section looks in more detail at how access to different types of digital devices can impact on how patients communicate with services, and how digitalisation of communication systems might be raising the level of technological access needed.

The problem of digital technology access was spoken about by Digital Health Hub and fieldwork site service staff – either citing clients' total lack of devices, or access to older technology which prevented access to services. Their accounts detail the ramping up of digital access which is expected of patients – with access to a smartphone increasingly necessary to access communication systems or apps in use by the NHS.

Access to a 'dumb phone' (without internet capacities, and generally much cheaper to buy) only may act as a barrier to interacting with healthcare services as the NHS increasingly makes use of both apps as well as links to online services. However, these forms of communication are not compatible with 'dumb phones' as outlined in the quotes below:

> "Booking booster appointments and vaccine appointments because a lot of that is like they send the link to their little Nokia phones, but they can't become links on the Nokia phones" [7, Digital Health Hub Staff, older adults and those with disabilities]

> "You know, there's a lot of people might even have an old style non smartphone well, other than telephone conversations, nothing you can do on that, there's no clicking links or anything on that. And there's still plenty of them around. You know, it's, it is I don't know, it's lovely to think, 'Oh, look at this, we can do it easy, and we can send this link and they can just access the website', and that's lovely, it's really great thinking but actually, there's this whole major group, not a minority, a major group of people in this country of all ages, and ethnicities and disabilities, that can't access this stuff. You know, I see it all the time it's frustrating." [22, staff member, foodbank]

The quotes above about patients being sent links via text message suggest an assumption being made within the NHS that patients will have access to a phone with internet capabilities and can engage with new forms of communication or booking via online services. However, for those on very low income, access to a smartphone may not be possible – given the relative cost when compared to a 'Nokia brick'. This can act as a barrier to engaging with the healthcare service by preventing access to online based services.

Further, given the amount of time that smartphones have been commercially available, it may not even be enough to have access to a smartphone as older versions are no longer compatible with contemporary apps:

> "One is of course poverty, they [refugees] can't afford to have internet and have proper digital equipment, you know, when we detailed it to know how many asylum seekers have a smartphone, we found out that two out of three they do have a core smartphone. But those smartphone the software and the processor are not good enough to download and put a GP application on those phones because that's the phone they can afford." [DHH 15, Refugees and Asylum seekers]

The necessity to have not only a smartphone, but a relatively new smartphone, speaks to the ramping up of digital technology access being asked of patients. Further, it underscores an assumption about what is now considered to be a 'normal' level of digital access.

In the examples above, access to the *right sort* of digital technology is highlighted as a potential barrier to care, as communication systems including appointment booking is increasingly moved online. This relates more to the use of online services than the telephone but is a consideration when thinking about the channels being made available to patients. Whilst the majority of respondents indicated that they made appointments over the phone rather than online, this speaks to the need for ongoing flexibility in service access when it comes to channels of communication.

What emerges from these findings is that exclusion as a result of digital or connectivity access is not clear cut, and simply having access to a phone or connection may not be sufficient for seeking care. Instability underpins device and connectivity access for the respondents– which forces people to either use expensive pay as you go options, or to borrow devices. The borrowing of devices will be returned to in detail in the following chapter (six) when looking at implications for privacy during remote consultations. Moreover, the removal or reduction of in person booking options is pushing patients to book appointments by telephone or online, which exaggerates the impact of resource instability by necessitating device use.

Long hold times

The previous section explored device access as a prerequisite to remote appointment booking, moving now to look at what happens when patients get attempt to make appointments over the phone. Long hold times to get through to GP receptionists was presented as a key characteristic of appointment booking. This was raised by some respondents as a source of frustration when booking an appointment; for others it was presented as a major barrier preventing access altogether as a result of unstable access to digital devices and the financial or social cost of being on hold. This builds on the previous argumentation around the impact of digital exclusion on access to primary care appointment booking systems.

Respondents recounted that call times through to GP receptionists could be anywhere from 15 minutes, up to an hour and a half, and that these had increased since COVID-19:

> "I: before the pandemic how did you access your doctor?
>
> R:Through the telephone and it was quite easy if you missed like I said the 8am appointment you just phoned up at 12 and there was about maybe about 2 people in the phone queue like I said now that's increased to like 7-9 people in front of you and believe it or not that could at least be an hour and a half sometimes ..." [5, Female, 30s, white British, foodbank]
>
> "When you phone up "oh you can go online book appointment online" but it doesn't allow you.... what you meant to do ring them up again spend about 15 mins 30 mins on hold in a queue? What's the point." [8, Male, 40s, British Pakistani, drop-in centre]

In the above example (respondent 8) long hold times are framed as a result of an ineffective online booking system, which redirects demand through the telephone line. For this respondent, this led to despondency around even attempting to get an appointment, due to an anticipated wait time of up to 30 minutes. This indicates the way in which an inability to use online booking systems can force people into relying on telephone booking which is perceived as having a high administrative burden.

Many GP practices have set call times during which patients can make appointments, generally 8am. However, this can have the impact of funnelling all demand through a short call window, which contributes to the long hold times spoken about by respondents. Respondents gave accounts of being *unable* to get through to their GP receptions at all, as phone lines were cut off when demand peaked. This in turn could lead to needing to call back several times to even get through to being put on hold:

> "I: So being on hold is an issue and of itself?
>
> R: Yeah, it's crazy. Yeah. And you just got to keep phoning back, they won't put you on hold they'll just say because there's such a queue yeah its busy phone back, busy phone back. So, you're just like, constantly on the phone going? Ring? No, redial, redial, redial." [9, Female, 40s, white British, foodbank]

Whilst long hold times are not a unique experience to marginalised groups, the burden of access may be disproportionately higher amongst those who pay for or borrow devices because of resource scarcity – discussed below. This directly relates to the issue of digital access instability outlined above, which results in phone borrowing and use of public and/or third sector organisation phones.

Respondent 11, who had previously been homeless recounted the challenges she had faced when trying to make an appointment due to the cost of being on hold:

> "They take long to answer the phone I'm sitting on the phone I'm ringing the phone for about 20 minutes, half an hour, oh they put you on hold and don't seem to realise this is costing you money you could be at a telephone box and don't have the money so they're not really catering for people like financially get it" [11, Female, 60s, Black British, community development charity]

For those who can afford contract phones with unlimited minutes, being on hold does not present an added financial cost. However, for those who rely on alternative means of device access such as using a phone box, being on hold can represent a financial burden. Public phone boxes are increasingly uncommon, however two respondents speaking about their experience of being homeless described renting mobile phones off of other people as a modern alternative – which has the same impact of making being on hold 'expensive'.

Another potential implication of resource scarcity is that people may rely on borrowing devices, which can render long hold times socially expensive. Respondent 5 gave an account of how borrowing a phone could make appointment booking difficult because it physically ties the borrower to the lender.

> "I phoned bang on at 12 and there was already 7 people in front of me on the queue which means obviously, especially if you're using somebody else's phone you've got to stay for a long time on someone else's phone, and if they've got to go somewhere or something that's really hard you know" [5, Female, 30s, white British, foodbank]

The use of network resources to meet needs, e.g., borrowing of phones, is common in resource scarce populations. Whilst borrowing (rather than renting) may not come with financial costs it can create a barrier to access if making an appointment necessitates ongoing use which must be negotiated with the lender. Phone borrowing is a challenge which is often discussed in relation to the use of mHealth in Low-income settings (Mechael et al., 2010). However, this is rarely, if ever, identified as a potential challenge to access in high-income settings.

The challenge of GP appointment booking, and long hold times is not exclusive to marginalised populations and was also spoken about by one of the GPs interviewed. However, whilst having personal experience of this she also recognised the potential for an unequally high impact on marginalised populations:

> "GP phone lines, being impossible to get through to I had personal experience with this, I was on the phone for two hours to my own GP practice to try and get through to them to try and order some medication. So, it's a real problem. And

> that's because of demand. There's so many people, phoning practices, and they're kind of, you know, the infrastructure hasn't expanded in surgery. So, the number of phone lines they have available, the number of people they have available to answer phone. So, all of that has become so much harder. And then obviously, from a marginalised populations point of view, it's become even harder." [26, GP, Lewisham and DOTW]

She frames long hold times in terms of resource scarcity within the NHS, and a mismatch between patient demand and practice capacity to manage this demand – creating a workflow surplus. Neither long hold times or a surplus of demand are unique to COVID-19 and the subsequent changes to primary care. However, the impacts are potentially amplified in a way which disproportionately impacts on marginalised groups by the removal of in person booking systems, redirecting demand through the phone or online. The accounts given by respondents show how resource scarcity which leads to unpredictable device access, might interact with long hold times, to produce a barrier to access either social or financial. This has the potential to exacerbate marginalisation by further marginalising groups who have unstable device access.

Digital literacy

The previous sections have looked at the ways in which access to digital devices and connection impacts on communications with NHS services, and appointment booking. However, whilst digital access is necessary it is not sufficient for appointment booking online or over the phone. Digital literacy and the capacity to engage successfully with digital technologies is also key. This following section focuses on the use of online GP services, rather than telephone – and the different factors which may impact on this.

Although generally the uptake of online appointment booking services by respondents in this study was low (a data point in of itself), people did speak about their online behaviours and digital capacities more generally. For those who used the internet this was predominantly on a smartphone, rather than a computer. However, amongst the older respondents, online use in general was low as a result of digital literacy and feeling uncomfortable online, leading to a choice not to engage.

> "I'm not 100% computer savvy I do understand a little bit don't get me wrong, but I try to explain to them I can't be bothered with all this computer stuff" [11, Female, 60s, Black British, community development charity]

> "I can't do a computer, I can play solitaire on the computer full stop I know how to turn it on I know how to go to where the games are. I don't know anything else. I haven't got a clue of anything else, I've had problems just now because I'm supposed to get a bank account [online]. I don't know how to get a bank account, my pension stopped because the post office account been stopped. So, I've had no pension for four bloody weeks." [18, Male, 60s, White British, foodbank]

> "I've never done that, never ever, ever I never me personally I've never gone online even setting up WiFi I gotta get so called friends to come set it up" [21, Male, 40s, Black British, recently homeless, community development charity]

These examples speak directly to the challenge of low digital literacy, with respondents indicating both limited capacity to use online services but also disinterest. Whilst it's possible this disinterest precedes limited capacity, this is also true in reverse, with a recognition by respondent 18 than being able to use a computer may have tangible benefits for him in terms of service access – in this case, a bank.

Respondent 17, spoke directly about accessing GP services online saying:

> “Yeah, you can try [to book an appointment] on the phone. But online is best, really. So, we went online. In fact, the staff [at work] didn't do it that time. *staff member* did it downstairs yesterday she did it for me.” [17, Female, 60s, Black British, community development charity]

Her account indicates the impact that digitalisation of appointment booking can have on peoples’ ability to use services independently, making them reliant on personal networks or third sector services to access healthcare online. She frames online as ‘best’ implying that whilst telephone access might be possible, that there may be a preference for online appointment booking, in order to avoid issues with long hold times or negotiations with receptionists – a theme discussed in the next section. During fieldwork people often came into the community-hub to get help accessing online systems and filling out forms, indicating that when it comes to low digital literacy, third sector services may fill an important role in access and use.

However, moving from assisted use of technologies to independent use is not simple, as outlined by a member of staff at a Digital Health Hub who described the challenges of digital training for low digital literacy groups:

> “I think there’s a lot of people to catch up definitely there's not the resources to catch all these people up I’m not even sure if it's if it's sometimes a tablet or a connectivity issue I think it's an ability to train them all is the biggest issue, we can't physically train the people that we need to train to the level we need to train [...] if you can imagine the time it takes to take somebody from beginner you could be looking at well if they did an hour a week with you could be looking at 20 or 30 weeks” [7, Digital Health Hub staff , older adults and those with disabilities]

The role of the third sector in helping marginalised groups to access online services was spoken about during interviews with Digital Health Hub staff and service staff at fieldwork sites. Digital Health Hubs were set up with the express intent to run digital training to ‘upskill’ local communities to engage with digital services. However, as expressed in the excerpt above, using online systems requires a level of skill that would take weeks or months of training for more some groups to achieve, and there are insufficient resources to do so. This essentially risks some people being ‘left behind’, or made reliant on others, as the need to digitally engage increases.

Respondent 15, who ran a Digital Health Hub in a service for refugees and asylum seekers outlined the various barriers this group faces in accessing services online:

> “COVID-19 came in, of course, all services went online, yeah, and it was very hard and difficult for asylum seekers, refugees, to access online services, as well…they had difficult access to them before they came online. Then become online it became worse because of many reasons. One is first of all, they don't have any access to digital equipment, which are very expensive for them to access. Second, digital skills and access for asylum seekers and refugees is very low compared to white community, and the third they live in accommodation provided by home office and they are not allowed to have like a Wi Fi in the house.” [15, Digital Health Hub staff, Refugees and Asylum seekers]

In this account he describes the layered nature of digital barriers ranging from access to a device, to connection, through to digital skills, indicating a stacking up of barriers preventing online access to services. These barriers relate to various outcomes of marginalisation which lead to precarity, poverty, and uncertainty around social determinants of health such as housing – limiting the ability of individuals to facilitate their own digital access.

The challenges of digital literacy in relation to GP registration were also touched on by a GP working for Doctors of the World:

> "So normally, if a person was trying to find out how they might register, they would have walked into a surgery and asked them like, you know, how do I register with you, but they couldn't do that, because surgeries have closed their doors, you have to call them or you had to look on their website, which you had to be digitally literate to be able to do. So many practices switched to online registration forms. So, you then had to have online access in some way you had to have so many had to have an email address, because obviously had to be able to send your response. And so many people didn't, and this was something where Doctors of The World would step in, we would use our generic email addresses as a way, you know, of somebody gaining access, and then I also the increased use of the E consult system as well. So many practices, now, you can't even make an appointment, you have to use the eConsult. So, it's not even a case of just clicking some buttons to book an appointment online, you have to be able to answer all of the questions they asked you to answer as part of the eConsult, to even to get to that process to then get a call back from your GP. So lots more barriers, really, in the last few years that have made it progressively harder." [26, GP, Lewisham and DOTW]

Here she runs through several issues, including access to digital technologies, having an email address, and answering a set of questions online. She recognises that online systems introduce new barriers to registration which can make access harder for certain population groups. Further she identifies the ramping up of digital skills needed in order to participate in online services 'it's not even a case of just clicking some buttons'. Whilst not related directly to appointment booking, this speaks to the issues which may be introduced by online appointment booking systems which also involve free-form text.

This escalation in digital skills needed to participate was also touched on by a Digital Health Hub staff member who recounted the story of a client who had come in for assistance communicating with their GP:

> "The doctor had sent a form through, I think she wanted some vitamin D or something, but they'd emailed her something through that she had to complete I don't know if it was in the NHS app or she clicked on a link and she had to fill in like a review thing and basically she, put in what she wanted, and there were a whole range of questions she was struggling with at home and she's not too bad actually, she's not too bad with IT, but she couldn't do this, and so she came in and I volunteered and went through all the questions helped her type all the answers, even typing them in on your little phone you know, all these answers to long questions and stuff, and so we went through it all and submitted it" [7, Digital Health Hub staff, older adults and those with disabilities]

As well as requiring more digital literacy, online forms such as eConsult also necessitate more advanced technology with screens and keypads large enough to fill out online forms. This links back to the issue discussed earlier of having the 'right' sort of digital device for access and highlights the fact that digital access is not binary, but stepped, meaning that patients might be expected to have increasingly sophisticated digital skills and devices in order to access online services.

Online appointment booking systems

The last section looked at various barriers related to digital access and skills can make communicating with primary care services difficult. However, even with digital access and skills, online booking systems may be challenging for patients to use for other reasons including English literacy and mental health.

The following section presents one respondent's experiences of trying to access care as an extreme example of the demands which may be placed on patients when making appointments online and over the phone. Whilst this is not necessarily applicable to a wider set of individuals, it highlights how barriers can 'stack up' when demands are made of patients, with limited flexibility to adapt to their circumstances.

She described the challenges she faces when trying to book a GP appointment, starting with being requested to make an appointment online:

> "It's [COVID-19] had a massive ripple effect so having access to the doctors the normal NHS doctors, trying to get on the phone being told we're not doing it like this you have to go on a computer- a computer to do what!? How do I do this? I don't understand what this woman is saying she's not communicating with me, I need to get my medication, no one is listening to me…" [2, Female, 30s, black British, foodbank]

Her interaction with the GP surgery begins with a request for medication. However, the way in which this needs to be done has shifted online, and the communication about what to do is not clear to her. This leads to a feeling of being stymied by the system 'no one is listening to me' as she is redirected to an online system, she already knows that she is going to find challenging to use due to her dyslexia:

> "I find that response [being told to go online to book an appointment] really, really frustrating, I'm dyslexic I hate the fact that I'm dyslexic already, let alone having to say it to the whole world– "I'm dyslexic", and it seems like…it seems like, it makes you feel really less than and it makes you shut down while you're in that conversation and it makes me feel like what's the point? These people really don't care." [2, Female, 30s, black British, foodbank]

This process of automation, whereby she is asked to go online reveals a hidden disability (dyslexia) which may lead to forced disclosure. This in turn results in an emotional reaction as she comes up against an inflexible system. She then describes what happens when she tries to use her GP's online system:

> "It's horrible, because even, you get a thing it will say COVID-19 symptoms, do I click that bit? Where am I meant to put the info, it's confusing, for me it's really, really confusing, it's like who am I meant to be talking to then, because they say to put on the symptoms if you might have a go at typing the symptoms in or whatever and then you realise that was for COVID-19 that has nothing to do with the issue I'm actually on here for and that frustration it builds up, and I'm 38 and dyslexic." [2, Female, 30s, black British, foodbank]

The online system is frustrating to her because of the demands it places on her literacy. On top of this she is contending with mental health issues which can make absorbing and understanding information even more difficult:

> "I have 4 voices in my head, and I can't translate that information in a way that you're going to understand because it's going to look like aggressive blurb of frustration and then it, it is just not going to work, I can't translate the fact, because I'm in…it's a mental health episode so I don't know where my head is at that time, so I might not even make sense let alone to see someone say it's just really frustrating because I can't do it, if I can't do it I feel really embarrassed and I won't ask you for anymore help." [2, Female, 30s, black British, foodbank]

Due to her embarrassment around her dyslexia, combined with her mental health she ends up wanting to withdraw from the system 'I won't ask you for anymore help', a theme throughout the data whereby barriers to access are high enough that people stop trying to access care. Rather than giving up however she tries to navigate the barriers she's up against by coming up with an excuse for not being able to use the online system:

> "Well now I have to lie, which I don't like doing, I have to say- I have no internet to book an appointment, and I have to it's I hate it, it's like unless I shout scream basically break down on the phone" [2, Female, 30s, black British, foodbank]

Her narration around booking a GP appointment outlines a distressing situation, leading to the risk of her self-excluding from the healthcare system. The challenges centre around the difficulties of navigating, sorting and relaying information in a comprehensible way – all tasks which need to be completed in order to successfully use an online booking system. This produces two forms of work: navigating systems and articulating needs, both of which are reliant on individual capacities to engage in these forms of work – and this is a stark example of how this work can fall outside of patients' capacity.

The potential challenge of illiteracy for engaging with the healthcare system was also raised by respondent 6:

> "Last year they say go online, I said I don't go online I don't do it because I don't know how to read and write I don't know how." [6, Female, 60s Nigerian, immigrant resident 20+ years, drop-in centre]

In response to the necessity to go online she relies on others in her community to read for her. As with the need to seek digital assistance, the need for English literacy help forces people into dependence on others to communicate with health care providers:

> "I: So, your partner and your neighbour?
> R: Yes, sometimes they will book a test like the other I do I don't know they book it for me
> I: They book what?
> R: That for what for treatments for the booster, so I don't know how to read so I went and said can you read this for me, and she [neighbour] booked the appointment and I go for my booster
> I: And that was your neighbour or your partner?
> R: Sometimes my neighbour sometimes my partner" [6, Female, 60s Nigerian, immigrant resident 20+ years, drop-in centre]

Respondents 11 and 14 also indicated they would have a hard time with an appointment booking system that required reading and writing, and had therefore avoided seeking it out:

> "I: Does the GP have any kind of online system for getting appointments as well?
>
> R: Not sure if I'm honest because I've dyslexia I have not looked into that, but I wouldn't have thought so. I've never had other messages." [14, Female, 40s, White British, foodbank]

> "I: Have they ever asked you to go on their website?
>
> R: Yeah, they have but I said no I refused, yeah, I refused… you're making things more complicated as well, I need my glasses number one cos I can't see blah blah blah and then I gotta sit down and read it and analyse it cos I got to ask a lot of questions, what does this mean? Go through the dictionary…I said nah I'm not on that." [11, Female, 60s, Black British, community development charity]

These examples suggest the potential barriers which patients may face if booking systems online force patients to use written text, which necessitates reading and writing skills. Whilst most respondents were able to book GP appointments over the phone, there were instances given of when booking online was either represented as the only option, or the strongly encouraged option. Whilst this may not lead to outright exclusion the reliance it can create on others removes the ability to access healthcare independently and privately. The impact of this is a disproportionate burden on those with low literacy skills (often associated with marginalisation), making a system once open to them harder to engage with.

Language

Aside from literacy, English language proficiency may also emerge as a challenge when making appointments online. This was mentioned by a member of staff working at a Digital Health Hub, based in a service for refugees and asylum seekers:

> "But most of older people, they, they come and we help them. Don't forget in terms of for literacy and education among asylum seekers, many people we have here who can't read and write even those who can read and write they might be able to read Arabic, but you know not able to read English." [15, Digital Health Hub staff, Refugees and Asylum seekers]

The challenge around language was also recognised by a GP working with the NHS and for DOTW:

> "Yeah, you've got to type and describe like even if you've got, you know, basic reading and writing of English, you might need, might be able to navigate a tick box system on an online form. But if you've then got to articulate what you're experiencing and type that in English because eConsult is only in English, it's impossible." [26, GP, Lewisham and DOTW]

This example touches on two elements, English proficiency and digital literacy, again pointing towards the ramping up of skills needed to engage with the healthcare system. If practices enforce the use of online booking systems, this produces a possible route towards exclusion for those with low English language skills.

Interactions with receptionists

The previous sections have looked at communication with GP practices, and the ways in which remote communication might hamper access. This next section looks directly at interactions with receptionists once patients are through on the telephone, a key topic of interviews. Two themes which came up during interviews were that patients resented being asked to share details of their healthcare needs with receptionists, and that they perceived receptionists as enacting high and obscure thresholds for care which they often failed to meet.

Receptionists asking patients why they are making an appointment is not a new phenomenon (although it may be increasingly common due to changes in the primary care system related to triaging, which are outlined below as well as in chapter eight), however it was raised by respondents as potentially limiting their access to care:

> "You can only really speak to the receptionist so it's hard to, it's really hard to speak to the be honest they want to know what you want to speak to the doctor about sometimes you're not really... not happy with explaining to a receptionist because they're not a doctor you shouldn't have to tell them why, exactly what is the problem for them to kind of pass it on. But yeah, that is how it is and that's what stops me as well because I don't want to tell them why" [14, Female, 40s, White British, foodbank]

In this excerpt respondent 14 talks about the reasons why she finds it difficult to get through to a GP to discuss her mental health concerns. She frames receptionists questioning her reason for making an appointment as a barrier to care which 'stops' her from even trying to contact her GP. Other respondents detailed reluctantly sharing information with receptionists but feeling uncomfortable about it:

> "I do think you nosy bugger but obviously I suppose they have to sort of gauge the importance of the appointment and but then they really shouldn't because that's what triage job is..." [9, Female, 40s, white British, foodbank]

Similarly, respondent 11 felt that receptionists were crossing a boundary by asking her questions, and pushed back refusing to disclose this information:

> "I'm very offended, what I don't like is when you phone the doctor's they always ask you what is it all about I said to them I said, I want to see my doctor innit it's personal I'm not discussing my personal problems with a receptionist that's not a qualified doctor or nurse" [11, Female, 60s, Black British, community development charity]

In both cases above, the receptionist is presented as crossing a boundary by asking for medical details as this is outside of the remit of what they're expected by to do. Whilst this is not a new occurrence GPs spoke about reception teams taking on increasing levels of triage as their function within the practice changed. This was presented as partly due to the increasing diversity of GP practice teams (discussed in chapter eight) which means that a patient may be triaged to a number of different practitioners other than the GP.

> "We've got a, what we call a PCC [Patient Care Coordinator] which is a patient.... I can't even remember what it stands for. But our reception team, basically who facilitate how people are engaging with us, and they, now their role really is to gather more information from patients to facilitate them going to the right place...to that person in the practice and so, you know, I think there are layers of negotiation." [23, GP, Tower Hamlets]

Similarly, GP 25 presented receptionists as part of a 'layer' between patients and doctors, shifting to a role as a 'patient navigator':

> "So, there are two layers of triage. So one, the first layer is done by our reception team, we actually call them patient assistants. We don't call them receptionists because they they're not there to just book appointments, but they act as patient navigators, and so when a patient comes to us either face-to-face, or they're calling

> us or they're sending an online consultation, they act as the first patient navigators. So, they might signpost the patient to a pharmacy, they might tell them, you need to go to the optician or the minor eye service." [25, GP, Tower Hamlets]

In this description the receptionist, or patient navigator, acts as a buffer between the GP and patient, sending patients to alternative services e.g., the pharmacy or optician. This form of triaging is identified by patients as both 'nosy' as well as necessary, however there is a mismatch between patients identifying receptions as not triage versus GPs recognising their increasingly triage focused roles. Further, GPs' accounts frame the receptionist as more of a protector of the GP service, as they re-direct patients away.

The changing role of reception staff, in direct relation to changes in GP appointment booking systems was also mentioned by respondent GP 20. She spoke about encouraging receptionists to make decisions about who was being labelled as 'CAP' (Communication Alternative Provider), meaning they shouldn't be asked to book appointments online:

> "I don't know, I mean, certainly I work very closely with our reception manager, and I'm always saying to her, you know, if people are calling you...and so a breakthrough this week, for example, was she said, "You know, so and so?" and I was like "yeah", she said, "Can we put her as a as a CAP as an eConsult not first", and I was like "is she not one already?", this person calls all the time, and she's very chaotic, and she's got all these issues. And somehow, she'd slipped through. But I was more impressed that the non-clinicians had felt empowered enough, and I said, you know, "if there's anybody else like that, you need to do that", and, and it was sad that they had to wait until I got there, that they didn't just go right, I'll put it on. That's the next step, I would actively encourage that, because they know as well, I mean, if we're finding these people complex, it's very good chance at reception, our frontline will find them complex as well" [GP 20, Tower Hamlets]

This again indicates an increasingly involved role for GP receptionists, to make decisions about not only where a patient is triaged to but how. This also introduces an extra layer of work for receptionists, who are expected to identify patients who need extra support for contacting the surgery. Further, it puts an important decision-making power in their hands, with the potential to exclude certain groups who struggle with communication over the phone.

Thresholds for care

Having outlined the increasingly triaged focused role of GP receptionists, this next section looks at how negotiation processes during appointment booking might enact high thresholds for care. Respondents in this study identified receptionists triaging as a potential barrier to care, gatekeeping services based on perceived eligibility of needs. This was most strongly expressed by respondent 17:

> "You might as well [look after yourself] because you're [the doctor] not taking care of them. What, what am I supposed to do? I've got a stoma bag. I've had many years and I still got it. So obviously I can look after...Oh, you're alright. That person over there has got cancer. They're not you're alright so I accept it. I suppose really in comparison I'm alright." [17, Female, 60s, Black British, community development charity]

In this quote the respondent frames her access to the GP relative to others' healthcare needs indicating that what feels like a high clinical need to her could be seen as manageable when compared to someone with cancer. She went on to question this threshold for care further, saying:

> "Boy we've all got to die, but it's the way we're gonna die. I don't want to die in a way that's not going to be you know…because I've been let down by the NHS. But it probably will be because how can we wait so long for an appointment? For something you've never looked at. Who, *who* are the people that are in front of me? Who are they? What is it that they've got that I haven't?" [17, Female, 60s, Black British, community development charity]

Respondent 17 positioned her healthcare needs in relation to an unknown more clinically severe set of patients 'in front' of her in the queue for care. She framed her challenge of access as a result of a deliberate allocation of scarce resources excluding her, which could eventually lead to her becoming more unwell as she waits for care. Ultimately, she questions how sick she would have to be in order to meet the threshold for care, pointing towards an opacity around how triaging systems work, and who is allocated care and at what speed.

A perceived severity threshold for care was also commented on by respondent 9, who felt that she often didn't get an appointment because her healthcare needs weren't seen as 'bad' enough:

> "Just literally like you phone them up and you're on the phone for ages in a queue waiting, and then you've got to tell the receptionist what's wrong, and then she'll, you'll maybe get a call from triage. And then sometimes you don't get the call, you're supposed to get the triage call. And then they'll make the decision if you're bad enough to see the doctor which 99% of time they don't." [9, Female, 40s, white British, foodbank]

In this example the respondent speaks more directly about the decision-making process, with the triage call being used to determine care. This is framed negatively as a gatekeeping process which rarely allows access – rather than a system which matches needs with appropriate care. In one sense the triaging system is working as it is designed to, rationing out GP appointments to those who need them, and signposting patients elsewhere if appropriate. However, this may be interpreted by patients as a preclusive gatekeeping process with receptionists increasingly implicated.

This can lead to patients trying to force or 'game' the system by becoming agitated or lying about their needs. Respondent 17 recounted becoming distressed on the phone to the receptionist and becoming angry:

> "Okay, I think I can command the English language not too badly. So I'm an idiot now, but once I open my mouth and show you that I'm not an idiot, then I'm a black aggressive bitch, and that's how I have to act for you to get what I'm saying [...] but now I'm down as I mean even when I ring the reception, I get the feeling that these people are a bit a bit scared of me. But I've had to act like I had to act like that to get my medication." [17, Female, 60s, Black British, community development charity]

When she reaches the end of her negotiation skills with the receptionist, she asserts herself by demanding care. However, she predicts this will lower her access to care in the longer term as she is perceived negatively by staff and frames herself using racial stereotypes. This speaks to the 'negotiation' layers which GPs mentioned and gives some insight into the forms of work which patients may be handed during these interactions. When this work falls outside of their interactional capacity communication may break down or become fraught. A member of staff at the community-hub speaking about interactions with GP receptionists gave the following account of making appointments for clients:

> "I: Why is it that you are able to get through when sometimes they aren't?
>
> R: Very interesting yeah. I have a professional voice when I'm on. I'm sure it's, that, I'm sure it's a prejudice. Okay. Because I've got this professional voice, that, therefore, they have to talk to me.

> I: And you think that people having kind of more colloquial language stops them being seen?
>
> R: Yeah, well, you know, you can tell whether people are West Indian. Immediately, most people can, everyone can" [27, staff member community hub]

In this description she was speaking about her experience of making a GP appointment for a client who was struggling to make his own. He had called the reception team several times and was repeatedly told he needed to go online to book an appointment, he had eventually asked this member of staff to assist him. She interprets her capacity to make an appointment as related to her social position and her ability to use professional language – indicating the potential issues related to discrimination which may emerge during interactions with receptionists. This also alludes to the importance of interactional negotiation skills, which help patients to have their needs met. This contrasts with respondent 17's account of becoming angry with the receptionist when she wasn't listened to and being perceived as a 'black bitch'. The need to negotiate effectively with GP receptionists may therefore have a detrimental impact on patients whose communication skills (including health literacy and English language) are lower, or who are perceived by receptionists as having lower competency to correctly know and therefore prove eligibility for their healthcare needs.

Aside from becoming angry at receptionists, respondents also gave examples of trying to 'game' the system in order to get an appointment:

> "If I want to be seen for my back urm sometimes it's extreme pains I might not be able to go to sleep, it happened a year ago, 6 months ago I couldn't go to sleep because rubbing like , they won't see me and that it's long term treatment and I thought to myself…I lie I can use my blood pressure, I feel dizzy I'm having black

> outs my necks a bit stiff, and as soon as I say that I can feel my heartbeat pounding, they go yeah okay you have to be seen by a doctor, but when I actually go to the doctor physically I said yes my back and I don't mention the blood pressure." [8, Male, 40s, British Pakistani, drop-in centre]

In this instance the respondent has identified high blood pressure symptoms of being 'dizzy' and having 'heartbeat pounding' as a way to elicit care by meeting the threshold needed to be given a GP appointment. They describe 'gaming' the appointment system by using these symptoms as a way to secure a fast appointment for a different concern which they had been struggling to elicit care for.

Becoming angry or trying to game the system are just two examples of the ways in which patients might deal with interactional challenges with GP receptionists in order to receive care. Respondents also gave examples of bypassing systems altogether by using online pharmacies or taking prescription medications from friends. In both instances, the alternative routes chosen were framed as a response to the challenges of making an appointment.

Another possible response to challenges getting a GP appointment is use of A&E services, which was spoken about by both respondents recounting their experiences as patients, and staff members at Digital Health Hubs commenting on their clients' use of the NHS. Respondent 5 spoke about a time when her daughter had tonsilitis, and during the triage process they had requested a photo of her throat. However, this photograph wasn't accepted as clear enough and led to her being denied care and using A&E instead. The following quote goes through a series of different issues this respondent faced when trying to get her daughter seen by the GP.

> "[My daughter] came down with tonsilitis during the lockdown which then became a problem because obviously I contacted the doctor and the doctor said take a photograph of her throat so we took a photograph we emailed it as far

> down the throat as I could get and basically they got back on the phone to them and they said that wasn't any good we need to see further down her throat and I said I can't it's just a phone camera I can't you know I can't I had the light on and everything as well I said I can't get further down her throat so the lady started getting a bit rude to us and saying basically we need a photo of her throat so I said listen I can't get a photograph of her throat so I said I need the appointment I said we've taken the covid test she definitely doesn't have covid [...] I said we need to see a doctor so she said no sorry you can't see one so I said what do you mean we can't see one she said no, not with that we won't see her with a throat infection..... I said no we really need to see somebody it's really bad she can't talk and all her glands had swelled up in her throat so her throat was like twice the size and she was actually having trouble breathing so I said she really needs to see someone so they said no we can't you haven't sent a photo properly and we can't see her so I said listen we definitely haven't got covid it's just a throat infection its tonsilitis she needs some medication, no sorry there's nothing I can do, and put the phone down and we rang back and they didn't answer after that so I ended up having to take her to A and E and dropped her outside [...] she ended up being given extremely strong antibiotics for it really strong they said it had gone completely out of control they said it had just torn her tonsils apart urm yeah and so obviously they gave her them but yeah the doctor literally point blank refused to see her and put the phone down which obviously was quite frightening" [5, Female, 30s, white British, foodbank]

In the vignette above, being asked for an image is used as a legitimising mechanism for care. This situation was framed by the respondent in terms of COVID-19, and the GP's perception that the patient could have active COVID-19 and so shouldn't be allowed into the surgery. However, she was not offered an alternative solution e.g., a prescription to pick up, essentially excluding her from the primary care system – leading to her use of A&E. In effect she was not triaged in but triaged out. Not only does this present a clinical risk, but also signifies the development of a system (in this example at least) which works to bar patients dependent on their ability to fulfil the work they are assigned, in this case, taking a clear photo. This exemplifies how thresholds for care, based on patients' ability to negotiate their way through the system, might be set up. This extends beyond thresholds around severity of healthcare needs which (de)legitimise healthcare seeking, to also include peoples' capacity to perform tasks incorporated into a new model of eligible 'patienthood'.

Appointment booking systems have evolved to prioritise the efficient allocation of resources, making sure that patient needs are matched with services through a triaging process. However, triaging may keep someone out of the primary care system altogether, redirecting them to, for instance, the pharmacist. This is a functioning triage system when it works well. *However*, the various interactional barriers described by respondents show how an inability to communicate and negotiate effectively with receptionists can lead to inappropriate matching by triage, with the potential for patients being incorrectly redirected out of the primary care system.

In the accounts given by respondents, the appointment booking and triaging system was experienced as a strict gatekeeping process, limiting their access to resources they felt they needed. Respondents outlined inflexible systems which they found hard to navigate and gain access to, with elusive thresholds which they often failed to meet.

Summary

This chapter has consolidated data gathered from various respondent groups regarding their experiences with making GP appointments. As emphasized throughout, the focus is not on complete exclusion but rather on the varying burdens placed on patients during the appointment booking process. These findings contribute to our existing knowledge by highlighting how patients with characteristics associated with marginalisation may face disproportionate impacts due to changes in appointment booking systems. The identified barriers include unstable access to digital devices, limited digital literacy, low proficiency in English language, and inadequate English language skills.

The findings of this study align with prior research conducted before the onset of COVID-19, providing further evidence of existing barriers. Moreover, this study extends the conversation by specifically investigating how processes related to marginalisation, such as financial constraints and limited interactional capacity, can interact with appointment booking systems, thereby amplifying the barriers to access.

The barriers to appointment booking can be viewed as either hurdles or walls. Hurdles make securing an appointment more difficult, while walls completely prevent appointment booking. Hurdles can be understood as a patient 'burden', as patients face increased effort in accessing healthcare. Prior research by Ball et al. (2018) identified long hold times and limited call windows as primary barriers in telephone-based triaging systems, making appointment booking cumbersome – a finding supported by this study. However, this data reveals that the burden has varying effects depending on individual circumstances. While it may be an annoyance for some, for others, it can result in financial strain due to costly phone data or reliance on public phone boxes. Additionally, individuals borrowing phones due to limited resources may find long hold times prohibitive. This demonstrates how a seemingly similar situation, such as waiting on hold to speak with a receptionist, can have unequal negative impacts based on individual circumstances. In addition, the elimination or reduction of in person booking systems, which were previously relied upon by many respondents, exacerbates the challenge. This leads to a concentration of demand through a limited number of channels. Furthermore, individuals who require assistance from others for phone access or navigating online systems are placed in a position of dependency, restricting their ability to independently manage healthcare arrangements.

Once patients get through to receptionists, they can experience them as gatekeepers, with respondents linking this gatekeeping process to their ‘candidacy’ for care. The concept of candidacy during appointment booking has been discussed in prior research (MacKichan et al., 2017) and resonates with the experiences of study participants. The requirement to prove candidacy to receptionists in order to meet care thresholds can result in a negotiation process, as receptionists engage in de-facto clinical triaging. Patients experienced this as a potential barrier, as they had to navigate their way through an unclear system. This negotiation process can take various forms, such as being directed to use alternative systems (e.g., online) or being asked for clinical details for triaging purposes. The negotiation process during clinical triage has been identified by Sikveland et al. (2016) as a form of patient burden which expands or contracts depending on an individual’s capacity to negotiate. Among study respondents this led to diverse reactions, including trying to ‘game’ the system, becoming distressed, seeking care in A&E or privately, or in some cases giving up altogether. The final two examples represent instances where patients reach the limits of their ability to negotiate with the receptionist and disengage from primary care in effect excluding themselves as candidates for care. These findings align with the work of Neuwelt et al. (2016), demonstrating that vulnerable patients may disengage from the primary care system before obtaining an appointment due to barriers related to appointment booking. This relates to issues surrounding marginalisation as the capacity to negotiate with receptionists is unevenly distributed. Those with higher health literacy and social capital may be better equipped to advocate for their needs, as illustrated by the staff member at the community hub who could leverage her “professional voice” to ensure she was heard.

Moreover, whilst some respondents described excluding themselves as candidates for care and no longer seeking appointments, others faced challenges in determining their candidacy for care due to perceived shifts in thresholds for getting an appointment. This gave rise to discussions about the severity of illness required to warrant an appointment, as well as an acknowledgment of the possibility that other patients' needs might take precedence and result in them having priority access to the limited available appointments.

While many respondents had some level of access to digital devices and internet connectivity, the skills required to effectively engage with services on these devices are becoming increasingly complex. As noted by multiple respondents, it is no longer simply a matter of checking boxes; it now entails reading detailed information and providing responses in free-form text boxes. This places demands not only on technical skills but also on literacy and language proficiency. Furthermore, the need to identify and articulate healthcare needs during the appointment booking process is growing. Patients may need to describe their needs in detail to the receptionist or input them into an online booking system in order to make themselves candidates for care. This creates an additional layer of work for patients, requiring them to express their healthcare needs in a manner that the system can comprehend before they can receive care. Consequently, there is an escalation in the level of interactional and technical skills that patients must possess to successfully book appointments. It is important to note that this is rarely a binary situation of access versus non-access, although there are instances where such extremes exist. Instead, it is about the varying degrees of ease with which different population groups can access care. In their study on the impact of COVID-19 on migrants' access to primary care, Knights et al. (2021)found that individuals lacking digital literacy, technology access, and facing language barriers may encounter difficulties accessing telephone-only booking services. This study suggests that this challenge may extend more broadly to marginalised groups, as they often encounter issues related to digital exclusion and communication barriers.

Moreover, online booking systems may offer relative advantages compared to telephone services. They provide patients with the opportunity to bypass the challenges mentioned earlier, such as long hold times. This creates a potential experiential difference, where those who can utilise online appointment booking services have a more time-efficient method of scheduling appointments. Additionally, online booking might improve access by giving users priority access to appointments, allowing them to simultaneously use the online system instead of waiting in a first-come, first-served telephone queue.

One respondent described the process of making an appointment as “hard work”, highlighting that the notion of patient burden in appointment scheduling is not solely an academic concept but also a lived experience for patients. Moreover, respondents mentioned previous difficulties in securing appointments as a deterrent for future attempts, leading to pre-emptive self-exclusion as a candidate for care. Previous research indicates that the perceived lack of access to primary care appointments can result in inappropriate utilization of emergency departments (MacKichan et al., 2017; Pinchbeck, 2019; Whittaker et al., 2016). Additionally, Pinchbeck (2019) points to evidence from other contexts suggesting that “inconvenience and hassle can be powerful barriers to participation” (Bertrand et al., 2006; Kahn & Luce, 2006), indicating that barriers in appointment booking, even if they don't completely hinder access, can create a burden and potentially lead to both underutilisation of primary care services and overutilisation of emergency services. This finding was reflected in the study data, which included various examples of individuals either resorting to emergency departments instead of primary care or avoiding seeking NHS healthcare altogether.

This chapter has focused on the communication with primary care services and the process of making GP appointments, with specific attention given to understanding how characteristics associated with marginalisation can influence access. The subsequent chapter (six), delves into remote GP consultations and explores how the shift away from the traditional GP surgery setting affects patients. Importantly, this chapter will also examine the continued impact of marginalisation on healthcare experiences, further expanding on the themes discussed in this chapter, particularly related to resource instability.

Chapter 6. A Room Without Walls – Physical space during the remote consultation

Introduction

Chapter six of the thesis shifts the focus to the remote consultation itself, specifically examining the process of "re-emplacement"[6] of care outside the traditional physical GP consultation room. This chapter explores the experiences of patients in relation to the availability of suitable spaces for conducting remote consultations, with particular attention to privacy. It also explores the introduction of safeguarding and clinical risks stemming from reduced disclosure levels in remote consultations due to a lack of privacy. The concept of healthcare "work" is employed to analyse the potential redistribution of responsibilities between patients and GPs during remote consultations, and how this dynamic interacts with characteristics associated with marginalisation. The final theme discussed is the significance of institutional healthcare spaces and the differences experienced during remote consultations compared to in person encounters.

There are several forms of remote consult which include assessment, triage, treatment and follow-up. While phone consultations have been considered suitable for triage and follow-up purposes even before the COVID-19 pandemic, the necessity of remote healthcare during the pandemic led to all forms of

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[6] A term used here to describe the way in which healthcare is being taken out of physical institutional settings, and emplaced in other spaces

consultations being conducted remotely by default. This shift has persisted, with 33% of GP consultations in London in March 2023 being remote (NHS Digital, 2023). Although telephone consultations were already utilised by many practices prior to the pandemic, the widespread adoption of remote consultations, particularly during the early lockdowns, has significantly transformed the spaces in which healthcare is delivered. A notable change bought about by remote consultations is the displacement of the consultation outside of the physical GP practice. In theory, remote consultations can occur wherever the patient has access to a phone signal, and this flexibility has been highlighted as a potential benefit in policies such as the 2019 NHS Long Term Plan.

The transition to remote consultations has introduced a shift in responsibility, as patients are increasingly expected to find suitable spaces for engaging with the healthcare system. This places the onus on patients to create an effective working environment, contrasting with the traditional model where GPs provide the consultation space. Interestingly, the spaces in which remote consultations occur have received limited attention in literature and policy documents, with a predominant focus on the communication channels themselves, such as the phone or video conferencing platforms.

During the COVID-19 lockdowns, the home became the primary space where many patients conducted their remote consultations. However, as restrictions eased, other spaces, such as offices, are increasingly utilised for consultations. It is important to recognise that these spaces possess distinct physical and social characteristics that can either facilitate or hinder certain forms of interaction during remote consultations. This introduces factors that are beyond the control of the clinician, such as noise, interruptions, and lack of privacy. Understanding the influence of these spaces on the consultation process is crucial for ensuring effective healthcare delivery in the context of remote consultations.

Up until now, the term ‘space’ has been used to refer to a physical location in which interactions are situated. However, spaces are not stable containers of activity, but dynamic contributors to meaning creation, transformed into ‘places’ by ongoing interactions and practices (De Certeau, 1984 ; Langstrup et al., 2013; Tuan, 1991). The displacement of GP consultations from the GP consultation room into places raises “questions as to the implications for place-making – or more specifically how actors manage the relations between self, other and place as virtual clinical encounters unfold in their home.” (Langstrup et al., 2013). ‘Re-emplacement’ builds on earlier work on ‘re-spatialisation’ (Andreassen et al., 2018) which looks at how different forms of remote healthcare move care out of institutions into other locations, predominantly, the home.

The significance of place and its impact on remote healthcare is often overlooked in mainstream discussions. While the literature on telemedicine for chronic conditions has addressed the role of place to some extent (Langstrup et al., 2013; Oudshoorn, 2012), there has been a lack of exploration regarding the re-emplacement of healthcare during remote GP consultations. The displacement of the consultation leads to its ‘emplacement’ elsewhere.

The concept of the ‘emplaced nature of care’ (Milligan, 2001) highlights the importance of physical locations in shaping the meaning and dynamics of healthcare interactions. Building on this idea Oudshoorn (2012) introduces the notion of the ‘technogeography of care’ – outlining the “intertwined processes involved in changing the relationships between people, places, care and technology” (*ibid* p.124). This concept recognises how technologies connect disparate locations, redefining spaces and creating new sites of care. Drawing on Akrich’s (1992) work on the ‘geography of responsibilities’ Oudshoorn explores how technologies generate interdependencies and distribute responsibilities between people, places, and devices. While Donaghy et al. (2019) briefly touch on the re-emplacement of care in their study of primary care video consultations, highlighting the responsibility placed on patients to create suitable conditions for receiving calls, there remains a need for further exploration of this topic within the context of remote GP consultations.

During remote consultations patients' homes, workspaces or commonly held spaces such as streets and public transport, can become sites of healthcare interactions. This chapter aims to examine the impact of remote displacement of GP consultations on experiences of care. Specifically, it will investigate how the characteristics associated with marginalisation intersect with the capacity to create suitable places for remote consultations. By exploring the complex relationship between place, marginalisation, and remote primary healthcare this chapter aims to shed light on the potential barriers faced by marginalised populations in accessing satisfactory care.

Findings

The following results sections will look at five key findings: creating private spaces for care; ascertaining privacy during remote consultations; device use and privacy; healthcare needs and privacy; and spaces appropriate for care.

Creating private spaces for care

The issue of privacy during remote consultations came up as a key concern of respondents. The level to which privacy was a problem was tied to clinical symptomology (e.g., an issues patients don't want to share beyond their GP) as well as the available space and time in which to take a call from the GP. The following section will look at the results of the study relating to privacy.

Patients reported struggling to create private spaces in which to speak with their GPs during remote consultations, a problem created in part by the unpredictability of remote consultation call times. In one of the clearest examples, an individual explained the various challenges she faced when trying to create suitable space for a call with her GP, and how this ultimately affected her willingness to disclose mental health issues to her GP when she ended up taking a call from a shared car.

The first challenge she faces is sharing a house with her children as a single mother, and not wanting them to overhear her consultation:

> "Yeah the kids and stuff you know I mean I'd rather the kids not hear that I'm like going through depression and I've got thyroid problems and my heart goes too fast and I have palpitations. I don't want the kids worried about me, nah it's not fair especially my son he gets really upset he's only just turned 13, the other day... he gets so upset with anything like that, little softie that one" [9, Female, 40s, white British, foodbank]

When asked what would need to happen to enable her to have private space at home for a consultation, she responded that more predictable call times would mean she could plan to have private space:

> "Just to know when to know what sort of time then I can sort of make sure kids go downstairs I can be upstairs waiting for the call, that would be better do you know what I mean I can make sure they are occupied make them do the washing

> up or whatever, just to know what time that's the main thing to know like right your appointment is at this time and then they call at that time" [9, Female, 40s, white British, foodbank]

Here she points out the importance of being able to reliably predict when the GP is going to call, in order to organise her space appropriately. As well as negotiating privacy from her children she also had to make sure she wasn't with a hairdressing client when the GP called. However, the unpredictability of the call times from her GP limited her ability to do this. She explained that sometimes she needs to take a call when a client is there and that she will go into the kitchen to do this but it's a "bit awkward". As a result, she ends up cancelling an entire day of work to make sure that she has privacy when the GP calls – rather than allocating a specific window of time in which she knows she needs to be available to take a call. This is a response to the unpredictability of the call time from her GP which can leave her feeling caught out:

> "Yeah I don't want to take that call at like someone's house or while I'm doing someone's hair or something like that. You feel like can't really doing nothing." [9, Female, 40s, white British, foodbank]

> "Like you know what I mean like why can't I just discuss it when I phone, or if I could go down now, then I can just say, right, I'm going to change your [hairdressing] appointment slightly. I don't know what time they're going to call back. If they gave you a time to call back, it'd be easier. Yeah. Because then I can say, right, can you come in like half an hour later, or come a little bit before? Because I like to have a break between clients. I could just like miss my break, and just get them in quicker or getting a bit later. And it just be easier to be more private." [9, Female, 40s, white British, foodbank]

The crux of the challenge is the unpredictability of call times which differ from in person consultations scheduled for a specific time. Not knowing when the GP is going to call makes daily commitments more of a challenge leaving her feeling like she 'can't really do nothing' altering an entire day to ensure private physical space is readily available.

As a result of this unpredictability, she had received a call from her GP when she was out of the house. She ended up getting the call whilst she was driving to pick up her granddaughter from nursery, and found that this limited her ability to speak honestly with the clinician:

> "And I had to do that call in my car on my way to pick my granddaughter up from school. It was the initial [mental health] assessment, okay. And they said, they'll be phoning me after a certain time. I didn't know what time and I'm like right okay I've got to go and pick my granddaughter up from school because my daughter in law's dad passed away. So, she phoned me and asked me to pick her from school. Yeah, and I've had to do it [consultation] in my car driving like whereas normally obviously they ask you quite personal questions about how you're feeling and I felt like I couldn't quite answer properly because I didn't want people to look at me like a lunatic while I'm driving down and sitting in traffic tears streaming down me eyes, and, you know, I mean, I think I felt like I really couldn't answer properly and honestly" [9, Female, 40s, white British, foodbank]

The narrative she gives of struggling to create privacy to speak with her GP is influenced by a range of different factors. The unpredictability of the call time is what transforms these from factors which can be managed to ones which impact on her consultation, allowing real life to crowd out the clinical encounter. Thus, the interaction between available spaces, and time can enable or prevent privacy. The car example indicates the potential issues which can arise as a result of physical space – whereby disclosure was curtailed due to lack of privacy. This has potential implications for future care, including the GP being able to make a clinical diagnosis and being referred into the right services on an appropriate timeline.

The potential challenges of creating physical spaces for privacy was also picked up on through interviews with staff members at organisations which had hosted Digital Health Hubs. In one interview conducted with the manager of a service for refugee and asylum seekers, the use of the Hub offices as a private space for consultations was discussed:

> "R: Yes, that's [privacy] an issue, not only for multi occupancies, but also having the children next to you. When probably a booking an appointment for sexual health check. Yeah, yeah, and that's an issue. That was a big issue in terms of confidentiality. And another issue, is...
>
> I: That's something you've heard people say?
>
> R: Yes, yes, yes, and that's why some people when they, they said, we prefer coming to the centre than doing it at home, because it's more confidential here at the centre than at the house. Yeah." [15, DHH, Refugees and Asylum seekers]

The need for private spaces can sometimes be fulfilled by third-sector services which have offices and rooms open for use by service users. However, this leads to a reliance on an alternative (to the GP surgery) physical space outside of the home. Further, it can create problems when those spaces are not available as was the case during COVID-19 lockdowns. This was touched on by one GP [26] who was working for Doctors of The World (DOTW) and in an NHS clinic. She gave the example of the difficulty of arranging a private spaces for a call with one of her DOTW patients who lived in a multi-occupancy household.

> "A lot of our service users didn't have private spaces and we would have to be very flexible about when we call people to try and allow that opportunity. I remember we had one particular case of a lady who lived...she was asylum seeker who was living in a shared house. And this was before they moved people into hotels, so she was in a shared house and had paper thin walls. You know, she had

> no privacy in her home at all, and she had lots of very difficult medical issues to talk about. We had to try and coordinate a time when all of her…everyone else in the house was out so that she could take the call and be comfortable to you know, to talk fully" [26, GP, Lewisham and DOTW]

DOTW is not a permanent solution for healthcare access, and they aim to get their patients into NHS services after a first consultation. Thus, whilst this example is from outside of the NHS it is possible that the patient she refers to faces the same challenges around privacy when accessing NHS consultations. In this example the physicality of the space available to the patient was not amenable to privacy and required careful planning. The woman had to coordinate her care with her doctor to make sure she was in a space where she could disclose information. However, not only does the require the patient to identify and share barriers to creating private spaces, but also for the doctor to work flexibly around the patient.

GP respondent GP outlined an experience of working alongside a patient to ensure privacy. In this instance the patient's schedule limited privacy:

> "So, the person I'm thinking of I think she put in an eConsult, and I tried to call back and there was no answer, but it was a mental health condition and I wanted to speak to her. So, I said, I presume you're at work. So, you can do this thing on the text message where they can put a response. And I don't do it for all of them. But I said, I presume you're at work, please tell me a good time, my next working day is Friday, tell me a good time, and I'll call you at that time. And she messaged back and said, yes, I'm a teacher, I can't hold the mobile phone. I will ask permission to hold it during this break time. Can you call me between these 30 minutes" [20, GP, Newham]

In both examples the GP negotiated timing with a patient to ensure privacy, which diverges from the traditional (in person) model of GP care, where privacy is ensured by the consultation room itself. This takes privacy from an implicit element of care to one that is negotiated and relative.

The results of this study demonstrate the work which patients must engage in to co-create private, protected spaces for the GP to consult in effectively. These spaces can be challenging or impossible to create dependent on the time of the call. Patients may be able to work *with* their GP to co-create spaces by agreeing on specific times when their capacity to place-make will be heightened. However, ultimately patients are made responsible for place-making as this task is delegated to them by the assumption that they will have suitable space in which to have a remote consultation.

The examples provided by GPs in the previous section demonstrate the communication that can take place between clinicians and patients to arrange a suitable time for remote consultations. However, it is important to note that this is not always the case, as highlighted in the account of respondent 9 who took a call from her car. Other GP respondents reported instances where patients conducted remote consultations in public spaces, which challenged the implicit assumption that patients have access to private spaces. GPs expressed surprise when this occurred, indicating a need to reconsider assumptions about patients' access to suitable private environments for remote consultations:

> "I'm very surprised about, you know, the number of patients who will just take a call on the tube" [23, GP, Tower Hamlets]
>
> "The number of times I remember doing NHS remote calls and someone's clearly in an office and probably like an open plan office so it sounds very noisy, or they're in a shopping centre or something" [26, GP, Lewisham and DOTW]

Assuming that it is not patients' preference to speak to their GP whilst on public transport or in a shopping centre, the implication is that remote GP consultations may be forced into non-private spaces due to their unpredictability. This highlights the challenge patients may face when place-making for remote consultations.

This tacit assumption that patients would have access to private spaces when they received a call was also reported by GP respondent 26:

> "I think I feel like at Doctors of the World we did quite well. So usually, our service users will have already had a conversation with someone prior to the remote consultation with a GP. And in this conversation, which was usually with someone answering our advice line or a caseworker, they, we had a standard bit of information that we said verbally to the person and then also sent in a text message prior to the consultation, which included to please ensure if you can that you're in a private space when you take the call, as we want you to be able to answer questions as openly and honestly as possible. And we may ask you sensitive questions. So, we primed people for that, in general practice that doesn't often happen it's kind of an assumption that people would do that." [26, GP, Lewisham and DOTW]

In this account there is a clear assumption made about the level of privacy which patients both want and have available to them. During in person consultations patients access to space and ability to carve out private time is made homogenous as the GP surgery itself provides a predictable private container. However, as outlined, during remote consultations patients' personal circumstances can have a large impact on their capacity to have an effective consultation. This makes normative assumptions around access to privacy potentially harmful as it expects similar outcomes from patients with different resources and capacities for action. This assumption means that those who are unable to negotiate access to private space may have remote consultations in settings where they feel unable to disclose private information – potentially limiting clinical or safeguarding information gathering. If relevant information is lost, then clinical and/or safeguarding outcomes may be negatively impacted. The other ways in which information gathering might be affected by remote consultations and a loss of non-verbal and visual cues is discussed in detail in the following chapter (seven).

This next section expands on the previous point regarding the role of unpredictability in remote consultations, specifically exploring the explanations given by GPs. Patients are being given wide call windows of several hours in which to expect a telephone call from their GP. This introduces temporal unpredictability to the consultation, as patients need to be on 'standby' to receive a call, as opposed to visiting a GP surgery for a designated appointment time – which may be delayed, but very rarely for hours.

The increasingly standardised practice of giving patients unpredictable call times was described by GP 25:

> "In my practice, what we do is when we book an appointment for a patient, we send them a text to say, we're going to call you on Thursday, the 21st, between 8 and 12pm. So, there's a four-hour window, and if the patient misses that window, we send a text second text back saying, I'm going to call you within these two hours. Yeah, it's really hard to give an exact time." [25, GP, Tower Hamlet]

Remote consultations were positioned as inherently unpredictable. This diverges from norms around in person appointments where the aim is to see the patient within a certain number of minutes of their scheduled appointment.

However, this unpredictability was framed by GP 20 as necessary result of variable call length leading to back logs:

> "So again, assumption, when we talk about assumptions, you know, we can't presume that people can pick up a phone all the time, just like, I feel that it is

> unfair to say, I'm definitely going to call you at 10 past eight, because actually, the person that you're speaking to before, has a problem that takes longer than the 10 minutes, you have to deal with that." [20, GP, Newham]

She went on to compare NHS remote consultations and the built-in unpredictability with private consultations which have stricter policies around timing:

> "Some of the private providers have GPs, they're ranked on [...] part of the ranking is 'my doctor called me on time'. Now that's not safe, that's not safe. And my friend runs into quite a bit of problems with this, because when she gets a poor star rating, because she called back 10 minutes late, her response back to the senior admin team, who said, can you explain this and she goes, well, would you like to go into the notes for the person before and understand what was going on? At the end of the day, the risk stays with us." [20, GP, Newham]

Here she frames the unpredictability of remote consultation calls as part of clinical risk management, characterising the drive for accurate call times in private remote care as 'not safe'. In the example she gives she outlines a situation in which a call has run over time, resulting in a delay to the next call on the list, the implication being that the first call was prolonged in order to manage a clinical risk. The administrative system, which gives patients call times, is therefore obligated to give wide call windows in order to account for clinical autonomy of the consulting GP. Whilst GPs might experience this as risk mitigation, patients appear to interpret it as producing a more erratic relationship with the healthcare system.

Assumptions made about patients, in terms of their ability to create private space and time is potentially harmful as it leads to increases in the baseline capacities needed to access healthcare effectively. Further, patients are given additional layers of work necessary to enable care. This work may be within the capacity of many patients, but the ease with which the correct conditions for a remote consultation can be set up are not equitable and may disproportionately impact on lower-income groups. Further, there will be some patients who either through individual circumstances, or a coalescence of factors on a particular day end up receiving a poorer level of care due to their limited place-making capacity – for instance by not feeling able to share information remotely with their GP in a public space. This is compounded by the framing of unpredictable call times as a necessity which bakes these challenges into the system.

Ascertaining privacy during remote consultations

Privacy was identified as important by both patients and GPs. During remote telephone consultations both patients and GPs experience a loss of visual and physical cues which confirm privacy e.g., a closed door in a consultation room (physical), and being able to see there is no one else in the room (visual). Patients must undertake the work of creating private spaces in which GPs can consult effectively and GPs work to ascertain whether this goal has been met. GPs outlined various methods they used to do this. These centred around asking patients directly whether they had privacy and looking out for potential verbal signs of a lack of privacy:

> "And I'd have to say to them, can you go somewhere that's a bit private, I would often also ask explicitly, are you somewhere that's private that we can talk confidentially beforehand, but you do have to check that I think it's something that you wouldn't normally have to do if you were seeing them face-to-face." [26, GP, NHS, Doctors of the world, Lewisham and DOTW]

> "Yeah. "Oh, I can't talk right now", or if they've given you someone else's mobile, then that might be a red flag, and saying, "Can you call this", and what we tend to

> do, what I always do is if the patient's husband answers. I always say, "where is she?" unless the patient's there and she's given consent, or I know them both. I would insist that I speak to the woman on her own if not, I say, "okay, I'll book you a face-to-face appointment", and then if he says she doesn't speak English, "that's fine, don't worry, we've got an interpreter who can... so she can come on her own." So, there are ways around ensuring privacy is maintained, and if the appointment isn't suitable for that we tell them to rearrange it with us. But again, as I say, this is where the only points are talked about in terms of what the patient is telling you that intuition really needs to need to kind of pick up on that." [25, GP, Tower Hamlets]

These quotes speak to the difficulty in assuring privacy remotely and the concerns this raises for GPs. This includes both the level of privacy for the patient to be able to disclose sensitive clinical information but also the possibility that the patient is with someone e.g., an abuser, who may actively limit their ability to raise safeguarding issues. This leads to an increased need to pay attention for potential 'red flags' during consultations, as the privacy afforded by a consultation removes space for disclosure. The problem of phone sharing and the implications for privacy were also touched on by GPs and patients, indicating the way in which both access to a private space and a private device (discussed in the following section) can be important for ensuring patient privacy and potentially safety. The role of the doctor's 'intuition' during remote consultations is also raised, with the implication that this is particularly important during remote consultations to ensure safeguarding concerns are dealt with. The topic of intuition and gut instinct is one which will be explored in more depth in the following chapter (seven) regarding non-verbal and visual cues. GP respondent 25 went on to speak about the different techniques which he uses to ascertain privacy of care:

> "And also kind of having some kind of good training for the trainees and the other GPs and other clinicians in terms of, you know, making sure you... the first question should be introduce yourself, ask who you're talking to. Don't just don't

> just, you know, bite into a conversation because there's two types of consultation. One is if a patient expecting a call the other one could be a cold call, because you've seen an abnormal result you're calling the number on the system, to let them know the results. Because you don't know it might be someone else. So, introduce yourself, and then ask who you're talking to and also check their date of birth or address and ID. Yeah, yes, so make sure you are talking to the right person. And then ask them, you know, is this a good time to talk? So that's one of the stock questions I have. So, this is before I even launch into the conversation." [25, GP, Tower Hamlets]

In this excerpt he outlines how routinised use of questions can be used to check privacy, this ties in with the previous examples of GPs working with patients to find appropriate consultation times, and the deliberate work which must go into this process. The absence of a physical consultation space in remote healthcare requires additional effort to ensure and confirm privacy, as well as to address the challenges related to timing. Previously, tasks such as negotiating appointment timing would be handled by the receptionist, and privacy would be assured by the physical boundaries of the GP surgery. However, with the shift to remote consultations, these responsibilities are redistributed and necessitate extra layers of work. This highlights how factors previously taken for granted during GP consultations now require deliberate coordination and effort.

Patients are not only conscious of their own privacy during remote consultations but may also be curious or concerned about the privacy of their doctor:

> "The doctor could be doing the same thing. Think oh it's just my husband or wife [listening] or whatever, it don't matter... so you feel a bit. Well with face-to-face you know that conversation is just between me and them. Do you know what I mean? Obviously like they wrote down it down and they might discuss it with another doctor. But yeah, if they want to go home and discuss it then fair enough,

> but I'd rather not feel like someone sitting there listening to what I'm saying." [9, Female, 40s, white British, foodbank]

This indicates that the loss of visual confirmation of confidentiality can introduce a sense of risk for patients too – who don't have any way of knowing where their GP is consulting from. This sense of 'risk' is introduced by the loss of the physical boundaries of the consultation room creating and confirming privacy for both the patient and doctor.

The concern about privacy on the GP's side of the call, was also evident in an interview with a GP who discussed instances of patients inquiring about their consultation location:

> "And it's interesting, I've had some patients ask like, "where are you now, where are you? Are you in your GP surgery? Or are you in your home?" from my kind of NHS work, and I would always say, "oh, no, I'm in my GP surgery. I'm consulting from my consulting room" and obviously, they need...they wanted to know where I was so, in their head they could kind of imagine, I don't know, from their perspective, whether it makes a difference whether I'm at home or in the GP surgery, whether that changes how they feel about the consultation, or how comfortable they feel. But it's interesting, I have had people ask that." [26, GP, Lewisham and DOTW]

In this excerpt, the GP recognises the potential for patients to feel uneasy with GPs consulting from home, stressing that she will tell them that she is in her consulting room if asked– it was unclear if this was always the case. Patients' questioning the GP's location may come from a desire for reassurance that their consultation is being conducted in a professional and secure environment. It emphasises the importance of addressing privacy concerns from both sides of the healthcare interaction in order to establish confidence in the remote consultation process.

During the interviews with GPs, respondents were specifically asked about the location from which they conducted their remote consultations. This line of questioning aimed to explore the concerns patients have about the privacy of where their GP is during remote consultations. GP respondent 25 outlined that whilst confidentiality was a 'priority' to them, that it was common practice for GPs to consult remotely from home:

> "In terms of GP side of things, and we most of us will have our own rooms, or we might work in a hub setting with other clinicians. So, there's, there's always kind of confidentiality is always a priority for us. And then at the moment, I'm at home, so what tends to happen is if you've got the right kind of confidential space in your own home, and you're working remotely, that's fine. If not, you come into the practice, and then you work there." [25, GP, Tower Hamlets]

Whilst he stipulates that you must have 'the right kind of confidential space' at home, there is no indication of how, or if, this is regulated, a point inadvertently picked up on by GP respondent 23:

> "I do one remote surgery a week. And so I usually do that, from my breakfast table at home, trying to get my son and my wife to sort of be quiet. You know, I haven't had any sort of negative feedback about that. And I've been, I think, you know, most of the people I know, know that I work here [GP surgery], and I guess they're sort of, you know, in their heads I'm sort of just working from, you know, my office. I'm very surprised about, you know, the number of patients who will just take a call on the tube." [23, GP, Tower Hamlets]

These excerpts highlight the importance of confidentiality during remote consultations and suggest that GPs may conduct remote consultations in settings that could potentially compromise this confidentiality. Interestingly, GP 23 expressed surprise at patients' willingness to have a remote consultation whilst in a public space but seemed unconcerned about potential privacy breaches on their side of the call. The observed discrepancy in concern about privacy during remote consultations raises questions about the differing expectations of patients and doctors regarding the remote consultation environment. This suggests a power imbalance where the preferences and wishes of clinicians may be privileged over those of patients. The unpredictability of call times can make private spaces harder to secure for patients, whereas clinicians have more agency and control in choosing when and where to make their calls making it easier to choose settings that ensure confidentiality.

This section has explored the genuine concerns that both patients and GPs have about each other's privacy during remote consultations. Real life examples were given by both patients and GPs of instances in which privacy was compromised. This builds on the previous section by showing how both patients and GPs are compelled to take on new responsibilities to establish and confirm privacy – a responsibility which may be harder for those with limited resources to take on.

Phone borrowing and privacy

Turning now to the issue of device borrowing and the implications for privacy. Whilst phones are not physical spaces like rooms, they can play a crucial role in maintaining or breaching privacy. The issue of device privacy and phone sharing was discussed in the previous chapter (five) looking at the impact on making appointments. This section will explore this in relation to remote consultations.

Respondent 5 explained the challenges she faced around privacy because she did not have her own phone. She previously had a working phone, but this had broken several months ago and she couldn't afford to have it fixed. When she first became interested in being part of this research, she had provided her number and email address and said that whilst she couldn't send texts or make calls, she could receive them. However, contact could not be established through the number or email address she provided. In the end she turned up in person to the field site to be interviewed at an unscheduled time. The difficulty of contacting this respondent through the specified communication channels, despite her willingness to participate in the study highlights the communication challenges that can arise with unpredictable phone access.

As her phone access was limited, she reported using her ex-partners, or mother's phone to speak with her GP:

> "My ex-partners phone I borrow, my like the father of my child, urm yeah I use his phone a lot because obviously he's got credit and I don't so yeah I use his phone a lot to access the doctors" [5, Female, 30s, white British, foodbank]

This respondent's experiences emphasise the different levels of privacy achieved when using different phones for remote consultations. When using her ex-partners phone to call the doctor she could achieve privacy by taking it into another room. However, when using her mother's phone she encountered barriers in maintaining privacy.

The quote below was used in the previous chapter (five) to show the impact of borrowing phones on appointment booking. Here it is used again to represent the impact that phone borrowing can have on physical space and privacy – forcing interactions into semi-public settings:

> "I have [had to borrow my mum's phone to contact the doctor] I've had to shout, they put like the doctors and stuff, she puts them on loud speaker and I have to shout like I give permission for her to speak on my behalf" [5, Female, 30s, white British, foodbank]

Not only is privacy compromised in the situation outlined by respondent 5, but borrowing a phone also forces her into reliance on someone else to speak on her behalf – removing agency. As a result of the challenges she faced, respondent 5 recounted how she had instead used an online private pharmacy, which she could access using Wifi at home. She justified her use of this online service as a response to the lack of privacy she faced when speaking on a borrowed phone:

> "You can just delete the history you know you know it's [medication] on the way and its very discrete rather than having to say to someone can I phone the doctor, and immediately when I say to my mum and obviously she's my mum so she's worried and first thing she says is 'what's wrong' ...and you know I have to disclose my medical history to her you know and I know she's only worried so obviously I do because she's my mum you know but urm yeah like I don't really want to disclose things like that to her you know so yeah I'd rather pay and sort of save the embarrassment for the doctor." [5, Female, 30s, white British, foodbank]

In this quote she outlines the difference between using an online pharmacy which can be done privately, versus speaking over a borrowed phone in a shared space. She reported spending £15 to use an online pharmacy – the same amount as a phone contract would be per month. However, the one-off nature of this payment was more feasible for her than an ongoing contract which necessitates a stable income as well as a permanent address and credit history (as outlined in chapter five). This is an example of how resource precarity can force people into 'short termism', as longer-term decision making is thwarted by unpredictability of finances.

The member of staff who facilitated fieldwork at the community hub who is a key support worker for several cyclically homeless[7] individuals in the community spoke at length about the culture of phone borrowing amongst people experiencing homelessness. Two of the respondents from this service also spoke about this. Respondent 11 was a black British woman in her 60s and 12 a black British man in his 60s. At the time of interview respondent 12 who was homeless did not have a phone as this had been stolen off him, and he was currently 'renting' a phone off of peers. Respondent 11 had a phone with a contract but spoke about previously relying on either borrowing phones or using a phone box. The experiences described of the challenges of maintaining privacy when borrowing phones, suggest that people experiencing homelessness may be particularly vulnerable in terms of maintaining privacy during remote consultations.

During observational work at the community hub there were numerous examples of individuals coming in to get assistance with benefit payments and PIP (Personal Independence Payment). During these interactions individuals often discussed very private physical and mental healthcare details on the office phone in the communal setting and left copies of medical records with a member of staff to follow up on their behalf. There were also several anecdotal reports from staff at this service of people coming into the office to use the phone to call their GP. This highlights the reliance on others which remote consultations can create, a point also raised in the previous chapter when considering appointment booking.

Phone borrowing was also an issue mentioned by GP respondent 26, who highlighted the problems this can create around follow up:

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[7] Individuals who have unstable living situations and move in and out of sheltered accommodation and council housing, often spending periods of time living on the streets.

> "We did see that [phone sharing] a lot. Which often ...so we always we from early on as part of our sort of protocol of when you took information at the beginning, we did ask people to kind of check this mobile, the mobile you're calling us from is this yours? Is this your number? Or is it someone else? But even when we did that, people often didn't divulge that, and we follow up all of our cases. And we'd often have the difficult situation of trying to follow people up and then realising that the number they've given us was not actually theirs." [26, GP, Lewisham and DOTW]

Sharing of devices is commonly cited as a key challenge to mHealth interventions in Low and Middle-income countries in terms of privacy (Chang et al., 2011; Haberer et al., 2010; Odigie et al., 2012) but is rarely spoken about in relation to NHS users. The normalisation of remote contact with GPs necessitates an acknowledgment of the possibility of device sharing amongst certain population groups and a consideration of the potential consequences of this. Building on the previous discussion of privacy during consultations, and the role of private spaces, it is crucial to recognise that both access to a private space and to a personal phone can be influenced by financial security. When these two factors co-occur, they can generate a dual barrier to privacy, particularly affecting marginalised groups who may therefore struggle to establish privacy during remote consultations.

Healthcare needs and privacy

Different healthcare needs may necessitate different levels of privacy, with mental health and gynaecological issues mentioned as two of the main examples by both GPs and patients. Respondent 9 was presented earlier as struggling to have a remote consultation about her mental health from her car, when asked whether this would have been the case during any consultation she responded:

> "Oh yeah, yeah, yeah my back all day I talk about that but mental health no one really wants to talk about anyway and when you have to you don't want to do it in your car sat next to someone else staring at you like two lanes of traffic" [9, Female, 40s, white British, foodbank]

Here she contrasts seeking care for her back which she is happy to discuss openly, versus her mental health. This is similar to the account given by respondent 5 who used an online pharmacy to access gynaecological care, highlighting the importance of it being more 'discrete'.

The link between the reason for the consultation and the level of privacy needed was also touched on by GP respondent 26:

> "But certainly, yeah, definitely, for women talking about gynaecological issues, they're not going to feel comfortable. I mean, some people just talking about bowels and urinary symptoms, they feel uncomfortable talking about that with, you know, obviously with somebody else, potentially within earshot. And then certainly people talking about their mental health, the way that they're feeling, because they're worried about, if it's another person that's in their family, the impact it's going to have, or for a lot of the people we were speaking to, you know, their employer who you know, watches over them very carefully, and who was often next to them when they're taking any phone calls, they have to be very careful, because they don't want that person to know about that how they're feeling or any, any ill health that might have an impact on their work." [26, GP, Lewisham and DOTW]

She brings together a discussion of the health concern and the setting, indicating that it is the interaction between these which can create problems. The combination of unpredictability of call times, limited access to private rooms and personal devices can create significant barriers to care – which may be exaggerated when accessing care for sensitive and private health needs which require more privacy.

With any one of these factors adjusted for the situation can be made tenable i.e., a sensitive topic discussed in a private space, or a less sensitive topic discussed with less privacy. However, the accounts given by study respondents indicate that for those with limited resources who struggle to establish private spaces, accessing remote consultations for sensitive matters may be particularly challenging, leading to both clinical and safeguarding concerns.

Spaces for care

Turning now from privacy during remote consultations, to a discussion of the impact of the loss of the traditional consulting room. The physical consulting room has traditionally served as an important emotional container for healthcare interactions, and the physical environment of the GP surgery often plays a role in creating a sense of confidentiality. However, during remote consultations, this physical container is lost. This section explores the loss of this space and the potential implications this has.

Whilst the majority of respondents didn't speak about the loss of the consultation room directly, beyond a loss in privacy, it was touched on by a few, whose accounts will now be discussed. Respondent 2, a woman in her 40s who suffered with poor mental health spoke about the importance that physical space and eye contact had for her during GP consultations:

> "Connecting and communicating with the NHS if it's for myself and I'm having a mental health episode and duh, duh, duh, eyes facial features, are what are keeping me in the room and keeping me out of the head yeah" [2, Female, 30s, black British, foodbank]

For her, physical spaces offered a point of stability and her experience of being '[kept] in the room' was linked to her ability to stay focused during the consultation. Thus, the physical consulting room can offer more than just a point of ordered time and space in terms of privacy but can also frame a certain quality of interaction. However, she also noted the potential counter benefits of having a video consultation from home, as potentially more 'comfortable':

> "I must say that if someone is struggling with mental health they are more likely to talk to you if they are comfortable in their own surroundings, I know I would, I know that when I'm in my own home, and I haven't got the pressure of, I have to leave the house I have to be with people even if I'm having anxiety it might come out really loud and blah blah I don't know if I leave somebody safe, it they knew I need to come and see me they can because I'm already at home, it's I don't have to be put in a position where I have to travel, because if I have to travel I don't know what is…[tails off]" [2, Female, 30s, black British, foodbank]

Here she offers an alternative narrative, of remote consultations presenting a safer space for care, in the comfort of home. However, it is worth noting that when asked about times when she had a video consultation with her GP she explained this had only happened once, and it was a video call arranged for her daughter via 111. So, whilst she outlines the theoretical benefits of a video, this is not something she'd experienced, and she spoke at length about the challenges of telephone consultations with her GP for her mental health (discussed in chapter seven).

GP respondent 24 also mentioned the potential advantages of home-based remote consultations for patients with severe mental health difficulties:

> "There may be some things where you know, that talking again, we go back to those areas where when phone consultations may be slightly, slightly more advantageous than face-to-face. If there are some sorts of suspicion or suspicious delusions, then talking over the phone might be a better way of getting a history than actually being face-to-face in a in a small room." [24, GP, Tower Hamlets]

This aligns with respondent 2's description of the home environment feeling safe and this being an advantage during consultations. However, as will be discussed in chapter seven, the predominant narrative from patients who wanted to discuss their mental health was an increased desire to see their GP in person. Therefore, whilst theoretically remote consults create flexibility for patients to consult from home which may be perceived as a safer space, the loss of in person GP contact was not experienced as an acceptable loss for most respondents. Further, the idea of safe spaces for care can vary depending on the spaces someone has available to them and their ability to create a safe private space for consultations.

In one interview the idea of the GP surgery as a physical space of care with social implications was discussed. Respondent 17, a woman in her 60s, felt that the traditional model of GP care she relied on was gone, and that this included the loss of physical places of care:

> "You can't go to the doctor. I mean, how are they [kids] gonna learn what doctor is? Someone on the phone? Someone that mummy Face Times? It's not going to be a place where we go to anymore. A kind of social thing really, that you go, and you sit in the surgery." [17, Female, 60s, Black British, community development charity]

For respondent 17 the physical setting of the GP surgery as 'a place where we go to' as a 'social thing' was framed as integral to the experience. Towards the end of the interview, she became distressed hitting the table and swearing as she spoke about the 'loss' of the healthcare system, and feelings of rejection by the NHS, specifically her GP surgery. In the excerpt above she ties the desire for care from her GP to the physicality of the space. The act of 'sitting in the waiting room' is part of the model of care she wants and involves a space with affordances beyond healthcare. This will be discussed again in chapter eight which looks at alterations to doctor-patient relationships during remote consultations and the potential loss of social care during the remote consultation experience.

This role of the physical consultation space was discussed by GP 26 in terms of both the actual privacy it provides, as well as the associations with being a private space of care:

> "I think there is something very special about the physical healthcare space, it's, for so long it has been recognised as this confidential space, which, you know, allows people not just to talk about health, but to talk about things that they feel that they can't talk to anyone else about, because they don't have anywhere else that's confidential. So, and I think people still associate that very much with the physical space of, you know, being in a doctor's surgery, being in a hospital consulting room, being behind the curtain, even in A&E, you know, even though it's not really a confidential space, because everyone can hear you outside. But there is a feeling that this is a safe space, I feel safe, and I feel calm and so, I feel able to talk about things that I otherwise wouldn't anywhere else. I think there is something that's beneficial, so I think almost before you start talking to someone, them coming into that space, they can feel that safety, that confidentiality, straight away that I think makes them more likely to divulge things that they wouldn't otherwise." [26, GP, Lewisham and DOTW]

The importance of the physical space for care is outlined clearly, referring not only to GP consulting spaces, but healthcare spaces in general. The consulting space is described as setting up a certain *type* of interaction through its physicality and associations, shaping the healthcare interaction. This sense of safety is centred around privacy or 'confidentiality'. She refers to a hospital bed curtain as giving a sense of privacy, even though it is not soundproof, indicating that the symbolic meaning of a space can be as important as the physical reality. Thus, not only is the physical privacy of the consulting room removed during remote consultations, but the associations which come alongside it are missing too. However, she went on to describe how the felt sense of being in a consultation room could be replicated verbally by the GP during remote consultations:

> "But definitely, there's something about that environment itself, that physical environment. But I think if you're a skilled practitioner, you can still create that space in the way that you are, and the way that you ask questions, you can still create that in that space. And therefore, that's what I hope, virtually, with a really skilled practitioner, you can do the same thing over the phone. But that takes a lot of time and experience to do that." [26, GP, Lewisham and DOTW]

In this account, the capacity of GPs to replicate a sense of confidentiality for disclosure can be achieved by performativity – 'the way that you are' – but is dependent on the GP being a skilled practitioner. Skill in this context appears to refer to both willingness to deliberately manage the interactional tone, and experience doing so. Whilst this may in some instances help patients to feel at ease, it does not remove the physical realities of the spaces in which they're receiving calls – creating a disjuncture between the sort of interactional space the GP is aiming to create and patients' physical realities. This may work to fuel the 'surprise' GPs have when patients take calls in public spaces, as it juxtaposes with the interactional space the GP is attempting to create verbally.

This section has highlighted the loss of the physical consulting room during remote consultations – and the implications this has in terms of associations with privacy and a container for potentially emotional healthcare interactions.

Summary

The accounts given in this study indicate that the displacement of the GP consultation outside of the institutional healthcare setting of the GP surgery has wide implications and diverse impacts on patients and GPs.

This results section has outlined themes which emerged from interviews in relation to physical spaces for care and privacy. These can be divided into two groups: the impact of the places into which care is re-emplaced, and the impact of the loss of the GP consultation room. Both themes are characterised by uncertainty, and the shifting of responsibility from GPs onto patients. Remote consultations introduce a layer of uncertainty into the healthcare interaction– as call times can be unpredictable. This in turn can limit the capacity of patients to carve out private spaces in their home/work settings to speak to the GP. This then produces inequities in where care is *re*-emplaced as patients' access to private spaces is not equal. Further, the lack of visible cues about where the GP is situated introduces an added layer of uncertainty around whether the GP's setting is confidential.

Research on 'place-making' during remote healthcare interactions has so far focused on chronic condition management, and the use of at-home medical devices (Langstrup et al., 2013; López & Sánchez-Criado, 2009; Oudshoorn, 2012; Piras & Miele, 2019). There has been limited discussion about patients' access to space in relation to GP remote consultations. Unlike the ongoing nature of remote interventions for chronic conditions, GP consultations are discrete events. This presents less opportunities for habituation of practices by patients and practitioners through iterative learning processes like that seen in chronic condition management (May et al., 2003; Morton et al., 2017). This study highlights the challenges patients face in adapting their environments or schedules for remote GP consultations. This lack of habituation, and the need for quick adjustments to unpredictable call times, makes it challenging for patients to establish private spaces for care, especially for those with limited access to private spaces or personal phones.

Remote consultations shift the onus of place-making onto the patient – who must create spaces in which the doctor can work effectively. During face-to-face consultations it is the GP's responsibility for their consultation room to be confidential and quiet – this work is reallocated to patients during remote consultations. The capacity to undertake this work is related to the material, and network resources available to patients (May et al., 2014). The challenges associated with this have also been picked up on by Hinton et al. (2023) in their study of remote antenatal care which found that access to a private space at home where women felt able to speak freely was an important consideration when organising care. As reflected in this data, patients from marginalised groups may find their capacity to place-make constrained by various factors related to their living circumstances, for instance thin walls in multi-occupancy houses or the need to use a borrowed phone in a shared space. This inability to place-make is compounded by the lack of predictability around call times, which further constricts the capacity of patients to organise limited resources, including time. Less flexible working hours have previously been acknowledged as a barrier for those from disadvantaged groups to access in person primary care services (Field & Briggs, 2001). Whilst remote consultations potentially have the ability to overcome this barrier – unpredictable call times appear to limit this from happening, instead, obligating patients to keep wide windows of time open to receive a call from their GP.

The reliance on patients to construct appropriate spaces for care connotes an increasingly individualistic approach to healthcare through the removal of the shared common space of the GP surgery which acts as a leveller. During in person consultations individuals are in the same physical spaces even if they may perceive these differently (Carruthers, 2019). During remote consultations individual are reliant on their own circumstances to determine consultation space, which can vary significantly and impact on the quality of the interaction. Unlike the traditional GP consultation room, which provides a relatively standardised experience, remote consultations have the ability to expose the inequities and variations in patients' living circumstances. If a lack of suitable space leads to lower levels of disclosure, this can produce inequitable clinical and safeguarding risks. This study builds on Dixon et al. (2022) research and Jokinen et al. (2021) who suggest that remote consultations may increase safeguarding risks for patients by making risks harder for GPs to establish. This study indicates that this may be more of a risk in some groups than others due to variable capacities to establish private spaces for care.

Whilst remote consultations are often framed as 'convenient' or 'efficient' for patients, it appears that the unpredictability of call times can in fact be more disruptive than a scheduled trip to the GP surgery. The unavoidability of unpredictable call times was presented by GPs as a necessity of safe practice allowing for longer consultation times if required. The recognition of unpredictable call times conflicted with GPs' 'surprise' at having patients pick up calls in non-private settings, which speaks to the implicit assumptions being made that patients will have the capacity to create effective working conditions for the GP. This finding builds on previous work by Oudshoorn (2012) which found that home-based telemonitoring devices came with a 'script' that patients are homebound, this script appears to be replicated by expectations of patients during remote GP consultations. These normative assumptions about patients are not only inaccurate but potentially harmful when they contribute to narratives of deviancy around patients who take calls in spaces deemed inappropriate by GPs. Further, as discussed, the capacity to create private spaces is closely tied to characteristics associated with marginalisation, suggesting that marginalised groups may be particularly likely to 'fall short' of the new expectations being placed on them. In

Langstrup's (2013) paper she asserts that in "trying to find its place in the home the virtual encounter is faced with the unruly actors and multiple agendas of everyday life that may have been kept out of a physical visit at the clinic – though rarely out of treatment as such" (p.56). This study expands on Langstrup's work, exposing how the GP virtual encounter meets the unruly nature of not only everyday life in the home, but any space in which the patient is at the time of the call.

Embedded within discussions of place is the issue of privacy and the blurring of private/public boundaries as healthcare is moved out of institutional healthcare settings into patients' personal spaces (López & Sánchez-Criado, 2009). Digital technologies are often presented as bringing the public into private spaces, e.g., large Facebook communities in a family living room. There has been discussion in telemedicine literature of the home becoming a medicalised space as the quasi-public medical gaze enters into the private arena of the home through systems such as telemonitoring (Macmillan, 2014; Oudshoorn, 2009, 2012). However, what this study suggests is that remote GP consultations may also work in the other direction as patients struggle to place-make private space emplacing private healthcare discussions into the public realm. Patients tended to frame this as a stressful experience which limited their ability to engage effectively with their GP. However, this was framed by several GPs as either a cultural shift (becoming normalised) or a surprising, and inappropriate, response to remote consultations. In light of unpredictable call times, it seems likely that the re-emplacement of care into public spaces will remain a common occurrence moving forwards. The risks bought about by the loss of precise appointment times for remote GP consultations, which lead to patients being called whilst in workplaces, on public transport or at home surrounded by other people has also been discussed by Rosen et al. (2022). They found that that this can lead to patients withholding or distorting clinical or personal information provided, as well as potentially leading to safeguarding risks due to the possibility of abusive partners or family members being present with the patient whilst they spoke on the phone with their doctor. This issue of withholding information during a remote consultation as a result of being a public space was reflected within this study data as well, indicating the need to take this risk seriously as a potentially common occurrence.

The final section of this results chapter focused on healthcare spaces creating a particular type of experience. Healthcare spaces offer a set way of being and interacting. The removal of these institutionalised spaces also removes a set of practices and relations. The GP consulting room acts as more than just a physical container for a consultation, but also plays a role in creating an environment which encourages disclosure from patients. The re-emplacement of care during remote consultations is affected not only by the spaces in which these consultations occur for patients, but also by the absence of the specific associations associated with the physical GP consulting room. This also relates strongly to the theme of privacy discussed throughout this chapter, and patients' experiences of a loss of certainty around the confidentiality previously provided by the consultation room. It also raises questions around the potential loss of the therapeutic effect of healthcare spaces during remote consultations, and what this might mean for experiences of care, discussed in chapter eight.

In summary, remote consultations disrupt the ordered nature of General Practice surgeries, including the receptionist, waiting room, and consultation room, leading to temporal and spatial unpredictability. The neglect of the issue of 'place' in discussions of remote consultations fails to acknowledge the impact of socio-cultural and socioeconomic constraints on the capacity to create suitable spaces for remote healthcare interactions. Additionally, the introduction of new working practices in primary care assumes that patients have access to personal phones and appropriate spaces for conducting remote consultations. However, these assumptions come up against complex and often chaotic reality faced by many individuals. A lack of access and control of material resources, which are integral to the process of place-making, can have particularly harmful effects on socioeconomically disadvantaged groups.

This chapter has looked at the implications of changes to the physical spaces in which care is taking place, and the way in which remote consultations may lead to a loss of privacy as well as passing on work to patients to create suitable spaces for care. The following chapter will look at communication during remote consultations, and how a loss of nonverbal and visual cues impacts on experiences of care.

Chapter 7: "I can't show them on the phone so it's what I say, and I'm not saying a lot"– Nonverbal and visual cues during remote consultations

Chapter 7.

Introduction

As covered in chapter six, the loss of the consulting room brings with it challenges around privacy, creating possible clinical and safeguarding risks. This chapter examines specifically how the lack of visual and non-verbal cues impacts upon remote telephone consultations. The subsequent chapter (eight) looks at the overall impact of telephone consultations on patient-doctor relationships. Chapters six, seven and, eight tie in closely to each other as patients and GPs experience the various characteristics of remote consultations presented in each chapter at once i.e., a loss of visual cues whilst physically separated with the resulting impacts on relationships. However, for the purposes of this study these have been divided into three distinct but overlapping chapters, as a way of dealing with complex accounts of the simultaneous impacts of remote consultations. The overlaps and interrelations between these findings will be drawn together in the Discussion chapter (ten).

Nonverbal communication has been shown to be an important component of the GP consultation not only to express symptoms but also for patients to escalate when they feel they have not been listened to (Heath, 1984; Larsen & Smith, 1981; Little et al., 2015). However, remote consultations rely primarily on verbal communication, as telephone consultations are much more common than video[8]. Verbal communication refers to the use of words to convey information. Nonverbal cues include gestures such as pointing, expressions and, tone of voice indicating emotional state, as well as body language. Visual cues include visible symptomology e.g., appearance of a rash, and visual indicators of health such as weight loss. Together nonverbal and visual cues can make up a significant part of

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[8] 31.3% of consultations are conducted via telephone versus only 0.5% by video call (NHS Digital, Appointments Made in General Practice June 2022)

communication, allowing GPs to gain an understanding of a patient's health and wellbeing.

Forms of patient work produced by a loss of nonverbal and visual cues, previously been identified within the remote healthcare literature include noticing and monitoring (Pettinari & Jessopp, 2001), and articulation (Strauss et al., 1997). 'Noticing and monitoring work' is the obligation for patients to identify symptoms before reporting them to their doctor through 'articulation work'. These terms will be used throughout this results chapter to speak about the different tasks being asked of patients. The need to engage in these forms of work during remote consultations is a form of 'responsibilisation' – whereby work is redistributed or re-directed to the patient. 'Responsibilisation' (Miller & Rose, 1990; Nikolas & Miller, 2008; O'Malley, 2009) is a term introduced in the literature review, which comes out of the governmentality literature (Foucault, 1978, 1979, 1982, 1988, 1991, 2003; Miller & Rose, 1990; Rose, 1999) and broadly refers to the way in which tasks are shifted from one actor – usually a state or agency – to individuals.

This chapter will look at the challenges which arise with a loss of nonverbal and visual cues during remote consultations. This is explored in relationship to processes of marginalisation and how patients' capacities for communication in the absence of non-verbal and visual cues impacts on their experience of care. The chapter is split broadly into two sections, the first looks at interactional challenges faced by patients during remote consultations. The second half focuses on risk-mitigation techniques used by GPs to account for the potential clinical and safeguarding risks created by a loss of nonverbal and visual cues during remote consultations.

Findings

The following sections deal with language and communication during remote consultations, and the loss of visual cues and gesturing. These were themes consistently bought up during interviews and spoken about at length – being at the forefront of both patient and GP narratives of experiences of remote consultations.

Language barriers

Many respondents spoke about challenges they had faced when trying to explain symptoms to their GPs remotely. For some, the loss of nonverbal cues, such as being able to point at their body, meant that they felt unable to properly communicate their concerns and needs to their GP. This was because of both language as well as confidence communicating over the phone more generally.

Amongst refugees, migrants, and asylum seekers included in this study, language as a barrier during remote consultation success was a key theme. One woman, a North African refugee in her early 30s, who had been in the UK for a year, felt that although she could communicate well face-to-face, it was much more challenging to try and do so over the phone:

> "R: I think by phone very difficult to tell my problem because I not speak English well I don't know my problem by English how can I say, so a little bit difficult for me
>
> I: And when its face-to-face?
>
> R: When its face-to-face I can say her by (*gestures by pointing)
>
> I: You can point at your body?

> R: I have problem this (*points to body) and that (*points to body) but by phone I can't explain what I have a problem I think a little bit difficult." [10, Female, 30s, Eritrean, refugee resident <1 year, drop-in centre]

In this instance the combined effect of language barriers and loss of nonverbal cues had impacted on her ability to communicate effectively with her GP. Not only did she struggle with understanding and being understood in English over the phone, but the normal compensatory methods such as pointing, were removed. Similarly, a recently arrived Afghan refugee who spoke very good English, reflected on the difficulty for his peers during remote consultations who did not speak English well:

> "Especially for the Afghans, I know, there's a lot of Afghan people now in the UK. So, as you can see, there are a lot of childrens there are problems, most of them there have some sicknesses. So, it's, it's really, really, hard for them. And besides, they don't know, a good language, I mean, their English is not really good and even when I talk on the phone, sometimes it's a little bit harder than you talk face-to-face and you talk on the phone. So, it'll be, it will be really hard for the for the patient to express what they want to say, to openly talk to the doctor, what's their problem, unless they see the doctor and show them how and where exactly they have the pain." [13, Male, 40s, Afghan, Refugee <1-year, drop-in centre]

Here he contrasts remote consultations to seeing the doctor in person when non-verbal communication techniques are available. He went on to explain that even for people who do speak good English, having a heavy accent makes communication over the telephone difficult:

> "Yes. I don't know why but yeah, because their accent is not really good, and you if you don't have a really good accent you can't talk on the phone. Yeah, it'll be really bad" [13, Male, 40s, Afghan, Refugee <1-year, drop-in centre]

As a result of the challenges outlined, he had ended up working as a de facto translator for others within his community, including at the drop-in advice centre he was recruited from. He had even been called up by Afghan families that he did not know, outside of London to help them communicate with healthcare professionals. The use of informal interpreters for healthcare is common and comes with both benefits in terms of familiarity as well as challenges in terms of confidentiality (Doctors of the World, 2020) . Consequently, an individual's ability to communicate with their GP can become tied to their network capacity, and the possibility of enrolling someone else to help them communicate.

This reallocation of articulation work to patients during remote consultations disproportionately disadvantages those who do not speak fluent English. By removing nonverbal and visual cues these individuals may become increasingly reliant on their networks to help them access healthcare. This has the potential to limit privacy as people may have to disclose medical information to those they have social or familial ties with in order to interpret. Further, the responsibilisation of patients for articulation work over the phone may transform healthcare interactions from challenging but manageable interactions i.e., verbal communication substituted by a mixture of gestures and visual cues, into unmanageable ones – effectively lowering their access to healthcare.

Language related barriers even with the presence of remote translation services which are available over the phone were also raised by GPs. The impact of a loss of nonverbal cues on patients who are not fluent in English was spoken about by GP respondent 24:

> "So, our area is quite, it's quite common that English is not the first spoken language. So, we're used to working with translators and advocates, and in a similar way, on the phone, translators and advocates have now gone, we used to

> have them face-to-face, they've now gone completely to distance, telephone translation and advocacy. I think there is…I think it is slightly different. I think it is, again, being a sort of pale white male, there are things that I don't pick up on that I think that I'm not sure whether I would pick up on them if I was face-to-face compared with if I was on the phone. But, if I had an advocate with me or a translator with me, I might ask them, "what do you think is going on here?" Or "is there anything I'm missing?" Or those sorts of questions, you can ask those questions on the phone, too. But I think, personally, I think, you know, face-to-face consultations are often more revealing in terms of some of those nonverbal activities." [24 GP, Tower Hamlets]

Here, the issue of comprehensibility is framed as not only a result of language barriers but also cultural differences, with a suggestion that these differences may be easier to overcome in person. Further, this GP intimates that his ability to ask the interpreter additional questions to help him understand the patient's situation is reduced when working over the phone. Therefore, the work of making themselves comprehensible to the GP may be heightened for patients through the use of remote consultations, even when using interpreters.

The benefits of face-to-face consultations for non-English speakers was also touched on by GP respondent 25:

> "One of our Bengali ladies who doesn't speak a word of English. Yeah, so for those patients, face-to-face with an advocate sitting down and exploring now, I might not do that might be one of my nurses doing that for the contraception, but, but it needs to be face-to-face" [25 GP, Tower Hamlets]

The importance of 'exploring' again indicates the need for cultural bridging as well as language interpretation. This suggests that remote consultations may be experienced by GPs as inappropriate substitutes for in person consultations for non-English speaking populations. Further, this response indicates that if language barriers are anticipated GPs may have a default preference for in person consultations, to ensure joint understanding between the patient and doctor.

Patients' fears that they won't be able to communicate properly with their GPs over the phone due to a lack of remote translation services, may also lead to underuse of healthcare services due to avoidance – a point raised by GP respondent 26:

> "And once people also realised kind of word of mouth that we used, a lot of people were kind of concerned about ringing us because of translation, they felt that in a face-to-face setting, we'd have a translator, but for some reason on the phone, we might not have a translator, if they didn't speak English, that was going to be a problem." [26 GP, Lewisham and DOTW]

DOTW is a service specifically set up for marginalised groups including refugees and asylum seekers. They receive referrals through word of mouth as well as charities working with marginalised groups, meaning they are more likely than other services to be expected or known to have interpretation services. If people are avoiding remote consultations with DOTW due to language concerns, this raises questions around whether populations who do not speak English will also be avoiding or unable to contact their NHS GPs remotely, due to similar fears of a lack of interpretation services.

Whilst language as a barrier to healthcare access is not unique to remote healthcare, it seems likely that remote interactions exacerbate language barriers and may even prevent patients from contacting their GPs in the first place. Respondents' accounts indicate that a loss of nonverbal and visual cues which facilitate communication between GPs and patients with limited English proficiency further risks excluding certain population groups. Additionally, even if not fully excluded, they may be unfairly disadvantaged by limited interactional capacity leading to less effective consultations. This comes with potential clinical risks in terms of GPs being able to garner sufficient information to make a clinical diagnosis, an issue addressed further on.

Communication capacity

Whilst the above examples have detailed communication problems due to language barriers, native English-speaking respondents also gave examples of challenges communicating remotely. The issue of communicating without nonverbal and visual cues for English speakers is qualitatively different from language barriers. However, it hinges on the same fundamental issue which is that a reliance on verbal communication during remote consultations has a disproportionate impact on people less able to communicate verbally.

Patients with specific communication needs may particularly struggle with remote consultations. Respondent 9 expressed the difficulty her son, who has autism and doesn't like speaking over the telephone, has communicating with the GP during remote consultations:

> "It's just been impossible [...] my son's autistic, and him trying to explain to them how he feels is quite hard. And obviously, it would be easy if he could go there they could check him over and stuff. But him having to explain to them it's really hard down the phone [...] he physically can answer but he just he's not good at getting things out...and he's just, I don't know, it's just really awkward" [9, Female, 40s, white British, foodbank]

As a solution to his communication challenges, she acts as a go-between for him and the GP, however this is not always an effective solution:

> "It's still hard though, to explain things over a phone. And I can't even see and I'm trying explain this stuff, and my son's trying to explain it to me, which is hard for him to do and I'm trying to explain it to them. And I'm like, or when to be honest I just get to the point I don't bother phoning up." [9, Female, 40s, white British, foodbank]

As a result of the difficulties she faces trying to communicate on her son's behalf to the GP, she indicates that she's stopped seeking healthcare for him. This is similar in some ways to the informal interpretation carried out within non-native English-speaking communities outlined above, during which a social or familial contact will assist with communication. It carries with it the same challenges around privacy, and removal of agency as individuals who are unable to communicate over the phone are forced into situations of dependency. Difficulty communicating over the phone leading to informal interpretation was also reported by a Digital Health Hub staff member, who had experienced this with clients:

> "Yeah, so soon as the telephone happened, she became really slightly mute, really struggled with it. So I obviously then could have she give permission for me to speak, and then we'd kind of have a three-way conversation. She would get flustered very quickly and get quite emotional, so lots of tears on the phone, if someone is not quite understanding what's going on, or she thinks she's being told something really negative. So yeah, lots of different reactions on the phone. And it was quite interesting to see, I've got another lady who's got borderline personality disorder, and she's the same soon as something on that telephone call goes wrong, she just loses it, it's just gone, everything's gone, she goes mute. Sometimes she just can't speak, so yeah, why can't it just be in person." [16, DHH, Bristol, Older adults and those with disabilities]

In these two examples (respondents 9 and 16), the mode of communication itself, rather than the effects of it i.e., losing visual cues, appear to act as a barrier to communication. This highlights an additional challenge which might emerge during remote consultations, which is discomfort with the modality of communication itself – in this case a telephone.

However, communication challenges for native-English speakers can also be introduced by the obligation of verbal communication during telephone consultations, and the removal of nonverbal and visual cues. Respondent 12, a black British man in his 60s who was rough sleeping at the time of interview spoke about the challenges he faced speaking with his doctor over the phone, and how his difficulties being able to articulate himself verbally limited the care he received:

> "When they want a reply that's what I'm thinking I haven't got enough time to say what I can say and if it's not enough I lose out and that's it and that's what I've been doing, losing out so many… I don't know how to explain it that's what I mean yeah" [12, Male, 60s, Black British, Experiencing homelessness and alcohol dependency, community development charity]

When asked what would need to change to improve communication with his GP he answered:

> "I got to learn my… go back to school I suppose and learn all them big words and all them conditions and then I could put that across to them but I think I'm too old for that." [12, Male, 60s, Black British, Experiencing homelessness and alcohol dependency, community development charity]

Here he presents his education levels as directly relevant to his ability to communicate with his GP, indicating health literacy as a key component of communication. This perceived link between education and healthcare communication was also raised by respondent 11, a Black British woman in her 60s:

> "I phone and I ask friends who are a bit more savvier and they will tell me look at this look at that type this in and see what it says so that's how I do my read up on, you search you search but that's only because like I said I've been studying for so long that I know that you have to research the word and the meaning and things then you get more broader information"[11, Female, 60s, Black British, community development charity]

Education, or studying, can be seen as a euphemism for health literacy, and the capacity to communicate in a comprehensible way with the GP. This highlights how power and social class inequalities can impact on communication between patients and doctors and signifies the additional 'articulation work' patients are tasked with during remote consultations. Notably, in the case of respondent 12 the absence of nonverbal cues emphasised the need for effective verbal communication, making this element of patient work increasingly necessary during GP consultations. A lack of interactional resources for native English speakers reflects disparities in educational opportunities and communication skills, influenced by social and cultural capital. These factors can unfairly disadvantage individuals, who unlike non-native English speakers, don't have the option of using an interpreter (and the recognition of interactional challenges which comes with this) to adjust for this.

A loss of visual communication techniques

The impact of having to manage remote consultations without visual cues came up in several interviews as related to but distinct from communication/language issues. The previous section looked at difficulty communicating remotely due to disrupted verbal communication and the loss of gestures. This section focuses on the challenges of trying to communicate without visual cues i.e., showing symptoms. The cases presented below outline the potential importance of visual communication during GP consultations, and how the removal of this may negatively impact on communication.

Respondent 12 spoke at length about how he'd struggled during remote consultations without being able to communicate with his doctor visually:

> "Urrrmm I'm not…when its face-to-face explaining certain things I don't have to do a lot of talking I just show them you know so they get the full scenario then you know on the phone I can't do that I can't show them on the phone so it's what I say and I'm not saying a lot I won't be saying a lot to them to know exactly what I'm going through." [12, Male, 60s, Black British, Experiencing homelessness and alcohol dependency, community development charity]

Here he explains how during in person consultations he can use visual communication in lieu of verbal, but this option is removed by remote consultations. He went on to explain how his visual symptoms helped to validate his needs:

> "Nah, nah, being there face-to-face I could take it [shoe] off and show them you know what I mean and that's when they're more interested in what I'm talking about because I can't explain certain things properly you know what I mean in detail." [12, Male, 60s, Black British, Experiencing homelessness and alcohol dependency, community development charity]

He framed visual communication as not only important for diagnosis, but also for eliciting the doctor's attention – indicating that he finds it hard to construct a narrative over the phone which makes the doctor 'interested'. A week after the interview, it transpired this individual had gone to the GP with the help of a staff member at the community hub who had booked the appointment and given him a bus pass to attend. Once he arrived at his GP, he had various measurements taken and was immediately sent in an ambulance to the hospital to have an emergency heart stent fitted. This occurred because of symptoms unknown to this man, which the GP recognised and tested for upon meeting in person. This is a clear example of how remote consultations may lead to a lack of clinical information for doctors, which can be compounded by interactional challenges. The removal of corporeal communication, through visual signs and vital metrics rendered this individual's healthcare needs invisible until he was seen in person – an example of how clinical risk may be produced by telephone consultations. Further, it speaks to the need for patients to engage in noticing and monitoring work to ensure they are communicating with their doctors all relevant clinical information needed to refer them for tests or bring the in face-to-face.

Respondent 4, a Bangladeshi man at the drop-in centre who had recently had knee surgery, also struggled with a lack of visual cues during remote consultations. He described that he felt the GP would not be able to properly assess him without seeing him:

> "My right leg is small, the left leg is quite big and very strong, they can't, they can't, if they're not see me face-to-face they can't they can't tell me like how good I am how bad I am then obviously the face-to-face appointment I can explain much better." [4, Male, 40s, Bangladesh, immigrant resident 10+ years, drop in centre]

He questions the doctor's ability to diagnose him correctly over the phone, indicating that they are unable to ascertain how good or bad his condition is without seeing him face-to-face. This suggests that in person care may be seen as a signifier of quality of care due to a perception that the doctor will be better able to diagnose, potentially an underpinning reason for patient preferences for in person consultations.

Finally, respondent 6 who was from Nigeria, and spoke good but often difficult to understand heavily accented English, expressed a sense of being tasked with work she felt unable to do during remote consultations:

> "I don't know like the way I put come and check me I'm not a doctor I'm not come and check me." [6, Female, 60s Nigerian, immigrant resident 20+ years, drop in centre]

Here she frames the work she is being asked to complete during remote consultations as the doctor's work. This speaks to the notion of 'responsibilisation' of patients as they are asked to report their symptoms in a way that is comprehensible to the doctor. Importantly, it also recognises a shifting of work from GPs to patients.

Respondent 14 framed a lack of visual cues as impacting on her treatment, describing remote consultations as being 'treated blind':

> "Treated blind in the way they're not seeing you not speaking to you face-to-face and finding out exactly." [14, Female, 40s, White British, foodbank]

Interestingly the concept of being 'treated blind' indicates a sensorial loss for the GP rather than a communicative loss for the patient, again signifying a perception that the doctor will be better able to make a diagnosis in person leading to better quality of care. This suggests a perception that the GP is forgoing important data when consulting remotely. This perception was also spoken about by GP respondent 26 who commented on patients' expectations that GPs required visual and hands on cues to do their work:

> "So, there is something about this expectation that the way a doctor works is hands on and to examine and, and that can only be done face-to-face. I don't think there's a general understanding in a general patient population that there's a nuance within health care assessment and that the asking of questions and the analysing of the answers is actually the most important bit." [26 GP, Lewisham and DOTW]

This indicates the expectation for a cultural shift to occur alongside remote healthcare, whereby verbal communication becomes recognised as an increasingly important diagnostic tool. However, the idea that a GP gets the 'most important' information from speaking with patients highlights the challenges which may emerge for patients who are less able to communicate verbally over the phone.

Whilst GP 26 argued that verbal communication should be taken seriously as an appropriate diagnostic tool, at other times she spoke about the challenges of losing nonverbal cues, for instance how this impacted on disclosure levels. This was touched on by all the GPs interviewed:

> "I think clearly, you're picking up a lot less. Not visual, you don't get any visual cues. You know, it's not as subtle as face-to-face consultations. But there is no prospect I think at the moment of going back to an open access sort of model, our waiting rooms are empty." [23 GP, Tower Hamlets]

> "So from a doctor's point of view, I think what we miss out in the telephone, and unless you know the patient well, what you miss out for some of those nonverbal cues." [24 GP, Tower Hamlets]

In both quotes, remote consultations are framed as producing a loss of nonverbal and visual cues and the subtlety which comes with these. This aligns with the accounts given by patients. Further, GP 24 mentions knowing the patient well making it easier to gather all necessary information over the telephone – a topic which is returned to in chapter eight on patient-doctor relationships and continuity of care.

However, whilst GPs may be increasingly reliant on verbal communication from patients during remote consultations, it's not a given that they will accept the narratives which patients present. Respondent 9 spoke about a time when she had communicated a physical symptom with her GP, but this had required visual confirmation before it was acted upon:

> "I've tried to talk to them over the phone about my back and they're going 'alright you've got a sore back it's on your records'. I go 'this is not sciatica it's different' and they just wouldn't listen until I went down there and, actually they actually felt where it hurt like yeah, the doctor actually felt all the way along thinking its gonna hurt here because its sciatica, and it didn't, it hurt middle of my spine up my back, whereas sciatica is like here round there and down your legs and stuff electric" [9, Female, 40s, white British, foodbank]

In this example, the account given by her to her GP was not seen as credible, and her attempts to get additional care were blocked repeatedly until her needs were validated during a physical examination. This aligns with the example given by respondent 12 of feeling the GP isn't "interested" in the symptoms he describes. Whilst patients may be tasked with both noticing and articulation work, the accounts they produce are not always accepted or taken seriously, and this may particularly be the case for patients who find verbal communication challenging. This sets up a paradox whereby those least able to verbally describe their symptoms may also be least likely to have these descriptions accepted and then be offered a face-to-face appointment to follow up, further limiting their opportunities for visual communication which could act as validation of their needs.

Whilst it is now common practice for GPs to ask patients to send in photographs of certain symptoms e.g., skin rashes, in order to remotely collect visual information, this is not a phenomenon which was reflected in the study data. The only instance of photos being used was that of respondent 5, discussed in chapter four, in which she was asked to send a photograph of her daughter's throat in order to book an appointment with the GP. This lack of the use of photos in the study data may be the case for several reasons, including that respondents have experience of it and didn't report it. However, it may also point towards the relatively low uptake of online or app-based GP services by study respondents whose narratives overwhelmingly focused on speaking over the phone. This in of itself indicates a further mechanism through which those with lower digital access may be excluded within primary care, as they lose out on the opportunity for remote visual communication with the GP via online or app-based services which require high digital access and literacy.

This section has provided examples of how the absence of visual and nonverbal cues are experienced during remote consultations. Study respondents expressed concerns that GPs not being able to see them could potentially affect the accuracy of clinical diagnosis. This goes beyond the challenges of communication resulting from a loss of nonverbal cues and extends to include the absence of visual cues that convey information on behalf of the patient, eliminating the need for verbal descriptions. Due to the inability for the doctor to physically see the patient's body during telephone consultations, patients are forced to do verbal interpretation and articulation work. As a result, work is redistributed from GPs to patients, who must possess the necessary skills to assess what information is important to share and how to effectively convey this verbally in a way that ensures their concerns are understood.

Mental health and safeguarding

One of the more concerning examples of the potential implications of remote consultations and loss of nonverbal cues is in relation to mental health. As discussed in chapter six, there are some potential barriers to disclosure introduced by remote healthcare and a lack of privacy. However, respondents indicated that a loss of nonverbal and visual cues may also play a role in preventing effective remote healthcare for mental health concerns.

Respondent 2 outlined the challenges she had faced communicating her mental health needs over the telephone. She described how important visual cues could be to making a correct diagnosis, and understanding the severity of her mental health crisis:

> "You could see me you would know…she's not she's probably struggling or whatever, she needs to talk, whatever is going on she needs to say it out loud and you would know because I feel like when I'm having an episode my speech is faster a lot faster, I think my eyes are…can look quite angry I think my face looks quite tense, even just simply things hair clothes how I conduct myself you could make a great urm diagnosis….wouldn't say diagnosis but you could see how big a problem actually is, if I'm overreacting if I'm not overreacting you could see that if you saw me physically." [2, Female, 30s, black British, foodbank]

In this excerpt she describes how the loss of visual cues including self-presentation such as hair and clothing which could indicate that she was not able to look after herself are lost during remote consultations. These visual cues indicating overall wellbeing differ from the use of nonverbal cues such as gestures which are used to communicate a specific symptom. They are also less likely to be verbally communicated with the GP as the patient themselves may not recognise them as symptoms at the time. She went on to describe how remote contact with the GP could also potentially lower the likelihood of honest disclosure, thus putting people with severe mental health difficulties at risk:

> "Yeah, I think it's a risk to a lot of people because if someone wants to kill themselves they're not going to phone and say I feel like killing myself today,

> that's depression that's anxiety, that's feeling less than, someone has actually got that on their mind and actually contemplating to do that, you're not gonna see it via phone call or via typing in the computer because that person is not going to say I'm going to kill myself today, at this moment this is the reason why I feel so bad, they're not going to do it." [2, Female, 30s, black British, foodbank]

The respondent expressed that the times when she most needed to speak with her GP were also the times when she was in crisis, which coincided with when she found it most challenging to speak over the phone. Her account of struggling to communicate indicates that remote consultations could pose additional obstacles to care for individuals experiencing severe mental health disorders, potentially leading to greater safeguarding risks.

In another example related to mental health, respondent 14, who suffered from depression explained how she struggled to feel heard by her GP during remote consultations:

> "It just feels good to be able not to be alone and you're going crazy, because I'm, I'm letting something out. And yeah, and I notice I get angry at myself, and I don't have anyone to talk to…the doctors, I don't feel like they really listen." [14, Female, 40s, White British, foodbank]

In this instance the concern was not about the loss of visual cues, but about the loss of in person connection established through nonverbal communication, a topic which is discussed in more detail in chapter eight. This concern about being listened to was also expressed by respondent 9 whose healthcare narrative mainly focused on mental health:

> "Because you can tell like when, someone's listening to you, you can sort of tell that they're listening and then they respond to whatever, on the phone you don't

> really get that and you can't tell if someone's listening." [9, Female, 40s, white British, foodbank]

As outlined in chapter six, remote consultations may lead to concerns about whether the doctor is in a private setting. It can also lead to uncertainty about the doctor's level of attention (/listening) – due to a loss of nonverbal and visual cues such as eye contact. Participant 9 also related talking over the phone back to the issue of validity, and being 'believed' by the doctor:

> "No it just feels strange [on the phone]. I dunno, because it's feels like you know when you're saying it over the phone it feels like they don't believe you, yeah. Like, I don't know, like you don't…they're not taking you seriously or something, and it's like well I'm being honest." [9, Female, 40s, white British, foodbank]

The absence of visual cues that confirm shared attention associated with listening can induce anxiety among patients. This absence may also contribute to a diminished sense of being heard and understood, which can lead to a reduction in patients' willingness to disclose. Further, it highlights the issue of patients not being able to visually perceive their doctor and the impacts of this, indicating that patients are not only concerned about the doctor's inability to see them during remote consultations, but also their ability to see the doctor.

The challenge of carrying out effective safeguarding work during remote consultations was spoken about by several GP respondents. One concern was around the opportunities for safeguarding needs to be recognised without face-to-face contact:

> "I think they're going back to that lack of visual cues. I think that's been a real issue within lockdown and I think certainly local safeguarding teams have been worried that we've been missing the opportunities to identify safeguarding issues

> because of a lack of face-to-face contact. I think that's across the board." [24 GP, Tower Hamlets]

The loss of nonverbal cues during remote consultations can also restrict the ability to perceive signs of distress or hesitation around disclosure:

> "Yeah, so there's a difference between safety netting and safeguarding, first of all, and sort of, again, I think that it comes from that sort of, you know, the training that you have before when to become a general practitioner to pick up those nonverbal cues, which you can lose both in the phone and digital." [20 GP, Newham]

Additionally, the verbal responses which might be given by patients over the phone may be limited, making it challenging to safeguard, leading to GPs bringing people in for a face-to-face risk assessment:

> "So, I had a patient who was living at home with his parents, and I think had a very difficult relationship with the parents that was contributing to his mental health. And everyone had been, I had had several colleagues tried to do telephone consultations with him, which were very brief and very short. And he didn't really give very much away or give a sense of having a problem. And even during the pandemic, I invited him to come into the practice, because I just didn't feel that he had a safe space to talk. And as a young man, I felt he was high risk for his mental health escalating, and we didn't know when the pandemic was ending, I thought I can't just wait for a time when it's going to be safe for this man to come in. I think actually, I do need to do a risk assessment in person. So, I had the luxury there in general practice to do that." [26 GP, Lewisham and DOTW]

GPs' accounts of safeguarding align with patient's accounts – wherein both groups recognise that relevant safeguarding information may be lost due to the absence of nonverbal and visual cues during remote consultations. Patients report feeling unable to properly communicate their needs to GPs, and GPs report not being able to ascertain sufficient information from patients. As outlined in the previous sections, patients with communication challenges may be predisposed to finding remote consultations difficult, indicating that safeguarding risks may be particularly high for them because of a loss of nonverbal and visual cues.

Risk mitigation techniques for remote consultations

Turning now to look at the ways in which GPs deal with a loss of nonverbal and visual cues during remote consultations. The ability to diagnose a patient remotely was a concern of several GPs, who discussed the challenges of a loss of nonverbal cues. This was often presented in terms of the risk mitigation work which they do to manage the risk of potential medical negligence.

GP respondent 26 framed the loss of nonverbal and visual cues as a matter of safety, stating that remote consultations come with a higher level of risk which can be managed through increased use of questioning or bringing the patient in for a face-to-face examination:

> "I feel like you would get more if you were there face-to-face with the person and you end up having to ask more and more questions and try asking questions in different ways to try and elicit more of a response from the person. And then safety netting becomes more of an issue as well, because generally, it is higher risk to do a clinical assessment over the phone. You're not, you know, for certain cases, you're not going to be able to assess them fully without doing an examination, and therefore you will have to safety net." [26 GP, Lewisham and DOTW]

Questioning as a form of risk mitigation to elicit more information relies on the patients' communication skills. Whilst this may work for some patients there are instances described above in which patients feel unable to express themselves verbally, suggesting that this may not always be possible and this is exacerbated through remote consults. Further, it places more of an onus onto the patient to be comprehensible to the GP and provide them with the forms of information they're asking for, at the same time as increasing the work of the GP by making them ask more probing questions. Increased questioning around sensitive topics may also be seen as inappropriate when conducted during remote consultations – a finding discussed in chapter eight in relation to patient-doctor relationships.

Converting to face-to-face appointments was also mentioned as a risk management strategy, suggesting that in person consultations are seen as inherently safer. Reasons why GPs may convert to face-to-face consultations included clinical symptomology that is difficult to assess remotely e.g., abdomen pain, and concerns over mental health issues which require sensitive conversations:

> "It's probably going to be much more efficient and safe for myself and the patient, to bring them in and examine them. So, it's especially…so if there are certain things like abdominal pain, you're not going to be able to examine the abdomen remotely." [25 GP, Tower Hamlets]

Whilst the most clear-cut reason to convert to a face-to-face is to do a physical examination, another reason why a GP might convert is because they've picked up on nonverbal cues related to tone of voice which have made them concerned about the patient's mental health:

> "Nonverbal cues, you can still get nonverbal cues on the phone. If somebody's sounding a bit depressed, somebody's talking a bit fast, they're crying, and that's a cue for you to bring them in see them face-to-face." [25 GP, Tower Hamlets]

GP 26 reported that patients who she already knew, or who were consulting about an ongoing problem could usually be handled remotely. However, if they had a new healthcare concern or something acute then she preferred to bring them in face-to-face:

> "Actually, a majority of patients, if you knew them, and it was for a repeat problem, majority of them we could deal with on the phone, it's just going to be a small proportion of them that are a new and acute problems that it's going to be harder for you to make that risk assessment and decision purely based on your remote consultation. And therefore, you're going to, you're likely to need to bring them in for an examination." [26 GP, Lewisham and DOTW]

Having a prior relationship with patients may help doctors to understand their needs better based on a remote consultation alone. However, for unknown problems i.e., ones which haven't already been diagnosed, converting to face-to-face can be used as a risk mitigation strategy to ensure nothing is missed. This also introduces the idea of eligibility for a face-to-face consultation, and the setting of thresholds within remote healthcare practices, which are used to make judgements around risk and therefore mode of consultation. GP participant 26 contrasted the capacity to bring in patients face-to-face in her NHS practice, versus her work with DOTW where this wasn't possible.

> "I was fortunate our [NHS] practice only I think did that [fully remote] for about a month or two. And then we had leeway to be able to bring patients we wanted to bring in in. So that felt a much safer environment to be working in. I felt like I didn't have to make so many risky decisions." [26 GP, Lewisham and DOTW]

Converting to face-to-face consultations is framed in these accounts as a way of dealing with risk and creating safer practice, with decisions made over the phone presented as carrying a certain amount of inherent risk due to the possibility of unknown unknowns.

An alternative risk mitigation strategy to bringing in patients for face-to-face consultations is sending them for in person investigations. GP respondent 23 referred to this as 'investigation inflation':

> "[The sonographer] was overwhelmed by sort of mediocre referrals from general practice of, you know, which, for me sounded like these sort of risk mitigation type tests, you know, so I think there's general sort of, you know, investigation inflation, that's sort of gone on." [23 GP, Tower Hamlets]

This account depicts an overuse of investigations as a way of reducing the risk which individual GPs take on during remote consultations. This risk mitigation technique may be seen as a way of compensating for the deficiencies in information gathering of remote consultations, which then has unintended consequences on the rest of the system forcing work into another service. The decision-making process that can go into sending a patient for investigation was described by GP respondent 26, who framed it in terms of the wider context of NHS services:

> "Breast lumps are a really good example, because I think I had colleagues who in the early part of pandemic, who managed it very differently. So, one of my colleagues just referred everybody who described a breast lump on their first consultation. Even for young women, didn't give it time or anything, she would just automatically refer them. Whereas others of us would ask a few more questions. And then depending on duration, I would then invite the person, say two weeks later to come in for the examination in two weeks, and then decide. And yet again, it's going to be personal choice. It's personal kind of risk management. She was thinking about, I'm worried about risk to the patients so, I'm going to make sure they all get to see a specialist. I was also trying to juggle poor hospitals are like trying to manage patients from a COVID risk point of

> view, as well as from their other health care problem. I want to try and help them and therefore I want to try and triage carefully who I end up sending in. So yeah, different practitioners are going to think in different ways. "[26 GP, Lewisham and DOTW]

In this example, respondent 26 describes a risk balancing act considering both a lack of physical examination during the consultation combined with a recognition of strained resources within the NHS. This is an example of the tensions arising within the NHS as clinicians juggle new ways of working which present novel forms of risk, alongside pressures to increase efficiency and limit the use of scarce resources.

The degree to which GPs either converted to face-to-face consultations or sent patients for investigations was framed by several GPs as a matter of individual comfort with risk, and a result of clinical experience:

> "I think that's very dependent on the clinician as well, that the problem the clinician, and terms of their seniority, though, so you, you tend to find juniors tend to convert more and investigate more, where more experienced GPs and I would probably put myself in that, that group now are more comfortable handling risk and uncertainty." [20 GP, Newham]

The challenge of how to build up those intuitive clinical skills whilst consulting remotely was raised by GP 25. He questioned whether GP training needed to adapt in order to include training for this form of consultation:

> "You know that there's that saying, you got to put in 10,000 hours to become an expert at something. And so if you're experienced you've done that, you kind of know whether it's face-to-face or telephone, within a minute or so about where this conversation is going where this consultation is going. But for the younger GPs, that's a skill they need to acquire. And that can take probably about five

> years from the time you qualified. So, this is a real concern about how do we alter our training to this new way of working" [25 GP, Tower Hamlets]

These accounts frame risk mitigation as inversely related to level of clinical experience. This links into the discussion in the previous chapter around the use of gut instinct as a way of determining risk when consulting remotely. This raises important questions around standardisation of risk assessment and how GPs' experience levels, as well as softer interactional skills may affect clinical practice and risk-taking behaviours in remote consultations. The increase in remote GP consultations may also lead to a change in the skillset required from junior doctors in order to develop the skills needed to consult remotely without having years of prior experience consulting in person. Further, it indicates assumptions being produced around the increased risk of remote consultations relative to in person, as well as added layers of work for both patients and GPs to create effective conditions for clinical decision making and risk assessment.

Summary

This results chapter has examined the consequences of a loss of nonverbal and visual cues during remote consultations. It has shed light on the various forms of work that patients and GPs engage in, as well as the potential implications of this. Notably, it has highlighted how marginalised groups may be disproportionately affected by the loss of these cues due to communication barriers. The subsequent discussion will synthesis the data presented in this results chapter, identifying overarching themes and how this builds on the current evidence base.

The results of this study have drawn out several key insights around the impact of the loss of nonverbal and visual cues during remote consultations. These include: a reallocation of noticing, monitoring and articulation work to patients which may fall outside of their communication and language capabilities; a loss of nonverbal communication which may change what information patients feel able to give to their doctors leading to reduced emotional disclosure, which can result in safeguarding and clinical risks; the absence of nonverbal and visual cues confirming shared attention can lead to fears of not being listened to further reducing disclosure; and GPs adaptation of their practice to risk mitigate during remote consultations.

Notably, respondents indicated that remote consultations may introduce communication barriers for them as their ability to communicate using gestures or showing symptoms is removed. This can be a result of language barriers which are accentuated over the phone, or more general communication challenges which are no longer adjusted for by nonverbal and visual communication. A common thread throughout respondents' narratives is the re-allocation of work from GPs to patients.

Nonverbal communication has previously been shown as an important interactional tool during GP consultations. Heath's (1984) study of the co-ordination of verbal and nonverbal behaviour between GPs and patients highlights the important role of nonverbal cues during consultations. He frames patients' nonverbal communication as a "resource" which is "frequently used by patients to encourage doctors to attend to what [they're] saying". He cites work which uses conversational analysis (see for example Jefferson, 1988) which has shown that a speaker's talk is bound up with the behaviour of the recipient of the talk. Conversational analysis looks beyond what is said to understand how talk is constructed. For example, pauses and the importance of being able to see what is happening to understand what is said i.e., a silence due to an interactional issue or the doctor typing or preparing equipment for an examination – which is only mutually understandable if both parties can observe. Heath argues that the ways in which the doctor nonverbally attends to the patient's talk may have consequences for what the patient says and subsequently their diagnosis and treatment (see also, Beck et al., 2002; Larsen & Smith, 1981). The loss of these forms of communication during remote consultations tasks patients with the work of making themselves fully understood through verbal communication alone. The ability to do this is bound up with patients' interactional capacities which relate to language, health literacy and comfort speaking over the phone. If verbal communication does not make up for the loss of nonverbal cues then relevant clinical information may be lost.

This responsibility for patients to articulate themselves to their doctors remotely has previously been termed 'articulation work' or alternatively 'patient work' (Strauss et al., 1997). Langstrup et al.'s (2013) research into the use of home care for chronic heart-failure patients looked at the forms of articulation work patients are tasked with in this setting. She found that patients were trained by nurses to recognise and describe relevant clinical symptoms e.g., oedema in the legs. She concludes that "the introduction of telemedicine involves a division and sharing of work and moreover demands the development of new skills from both patients and professionals" (p.53). Notably, unlike in Langstrup's study, during remote GP consultations, patients are unlikely to have received any prior training in order to describe their symptoms. Alongside the responsibility to articulate themselves to the doctor, patients are also tasked with noticing and monitoring work in order to report their symptoms and build a picture of the cause and severity of the problem (Pettinari & Jessopp, 2001). Patients may need to do this prior to the consultation as a reason for consulting, as well as during. As a result of the tasks patients are given, remote consultations lead to adequate oral and visual communication skills becoming "obligatory points of passage [for patients] and important allies for a successful cooperation and treatment" in order to complete this work (Langstrup et al., 2013, p. 51) (See also,Oudshoorn, 2009; Roberts et al., 2012). The accounts respondents gave were of being tasked with this work without the necessary skills to make themselves comprehensible to their GPs. This can lead to a reduction in the amount of information that patients share with their GPs which has potential knock-on effects for the sort of care they receive. This aligns with previous work which identifies a loss of nonverbal cues as a risk factor during telephone consultations leading to a decrease in the amount of information GPs have to make a diagnosis (Holt et al., 2016; McKinstry et al., 2009). Further, as pointed out unlike remote management of chronic conditions, remote GP care does not offer up an opportunity for healthcare professionals to actively train patients in the recognition and description of specific symptoms – as these vary between patients and over time.

The links between health literacy and healthcare access have been widely drawn upon in the literature (Hunter & Franken, 2012). The data gathered in this study points towards remote consultations exaggerating this effect, by the removal of an important communication technique – nonverbal cues. This builds on previous research by indicating that for marginalised groups, with lower health literacy, remote consultations may disproportionately effect communication (Amoah et al., 2021; Hunter & Franken, 2012; Smith & Magnani, 2019)

Noticing and monitoring work which precedes articulation work is also reliant on individual circumstances. Merrild's work on multimorbidity ' Noisy lives, Noisy bodies' (2017) signifies the potential challenges which socioeconomically marginalised groups may face in symptom identification. She argues that a propensity for multi morbidity in lower SES groups can make it more difficult to identify and track symptoms. The increased expectation for patients to do these forms of noticing and monitoring work normalises a form of self-management of healthcare, with assumptions made about what it's like to 'be' in a body. This can discriminate against individuals who are facing a more chaotic embodied reality – the ability to notice new or persistent individual symptoms is more demanding if you have a lot of concurrent symptoms. Many of the respondents of this study described long-term multi morbidity suggesting that this could be a factor in their symptom identification capacity. This represents a further mechanism through which remote healthcare may act to disadvantage already disadvantaged groups, by tasking patients with work which assumes their ability to recognise and articulate symptoms.

As a result of the potential lost information during remote GP consultations, clinical and safeguarding risks may be raised. Both GP and patient respondents spoke about the concerns they had around what information wasn't conveyed and the consequences of this for care. GPs spoke about the loss of subtly which happens during remote consultations and the potential for this to create unknown unknowns. Patients spoke about not having the knowledge to recognise what information to give to doctors or how describe their symptoms. Atherton and Ziebland's (2016) work on video consultations has emphasised the importance of a loss of physical diagnostic cues during remote consultations, including smelling patients skin and breath, noticing how they walk and using casual contact e.g. shaking hands, to assess skin temperature and tone (see also, Foster et al., 1999 ; Scharff, 2012). During telephone consultations even more information is lost due to a lack of visual cues. The clinical risks of remote consultations are also discussed by Rosen et al. (2022) who found that clinicians in their study were concerned about missed diagnoses owing to a loss of non-verbal cues. GPs in this study also identified the potential for clinical risks as a result of remote consultations, which necessitates risk mitigation techniques to safety net. These risk mitigation techniques include converting to face-to-face consultations, sending patients for investigations, and the increased use of questioning.

In order to make decisions around risk mitigation GPs also reported increased attention to auditory cues available during remote consultations such as tone of voice, pauses etc. as well as increased attentiveness to gut instinct. The ability to risk mitigate using these techniques was presented as related to the experience level of the GP. In Pettinari and Jessopp's (2001) work with NHS direct nurses they outline the interactional tools nurses use to visualise patients to make clinical judgements – "your ears become your eyes". One way in which nurses did this was by asking more detailed questions. Increased use of questioning of patients in order to build a visual picture was also reported by GPs. However, this relies on patients' capacity to verbally communicate as well as notice symptoms, and comes back to the challenge of varying levels of capacity for articulation, noticing and monitoring work. Further, it may require GPs to alter their communication styles to deal with remote consultations, indicating there may be a need for different skills training, a point also made in recent studies on remote consultations (Jiménez-Rodríguez et al., 2020; Murphy et al., 2021; Portnoy et al.)

As well as not being able to get information across, respondents reported not feeling that their GPs took their needs as seriously when communicated over the phone. The issue of patient credibility during remote healthcare has been picked up on in previous studies. Jessop and Pettinari (2001) list the different ways nurses remotely assess patients' 'credibility', including knowledge level and 'perceived intelligence'. The issue with discrimination by healthcare professionals during remote consultations has also been reported by Atherton et al., (2013,2018) whose studies showed that GPs suggested that it is easier to conduct telephone consultations with patients that they consider 'sensible'. Patients who are assessed as less credible by their GP may be deemed unable to take on the noticing and articulation work being asked of them during remote consultations. This can lead to situations in which they are not considered reliable witnesses to their own bodies without the visual symptoms to validate their claims. This suggests an additional barrier which may affect marginalised groups because of their interactional capacities during consultations, with potential impacts on clinical care.

As well as feeling they weren't believed, respondents also reported feeling not listened resulting from the absence of nonverbal cues indicating shared attention. Heath's (1984) work on the role of nonverbal cues during GP consultations found that the GP's display of attention or inattention is a key driver of the interaction and that verbal and nonverbal communication elaborate each other. He shows how during face-to-face consultations patients may pause speaking until they have confirmed they have the attention of their GPs, using various nonverbal communication techniques to recapture attention. Imlach et al. (2020) have found that demonstration of active listening during remote consultations using verbal cues, is particularly important in the absence of visual cues. Patients' accounts of not feeling listened to, or 'heard' indicate that the loss of these cues can be perceived as lost attention. This in turn can impact on patients willingness to disclose which has implications for both clinical and safeguarding outcomes.

The safeguarding risks of remote consultations were discussed by both patient and GP respondents, with one respondent stating that you'd be unlikely to tell the doctor you want to kill yourself over the phone. The ability to observe subtle visual cues may be particularly important in assessing mental health, a finding which has been reported elsewhere (Mann et al., 2021). Concerns over remote safeguarding has also previously been discussed by Dixon et al., (2022), Kilvert et al. (2020) and, Rosen et al. (2022) who argue that a loss of nonverbal and visual cues can lead to lower disclosure levels as well as opportunities to pick up on red flags or signs of distress. Dixon et al.'s (2022) study focuses on GPs and identifies key risk factors related to opportunistic safeguarding care, loss of visual and nonverbal cues, and loss of safe space for consulting. The results of this study suggest that because of a loss of nonverbal and visual cues, patients may deliberately withhold or feel unable to share relevant safeguarding information during remote consultations which may compound the issues presented in chapter six on the potential for loss of privacy during remote consultations.

One lens we might use to draw together the findings from this chapter and understand the interaction between the loss of nonverbal and visual cues, remote consultations and marginalisation is ‘Burden of Treatment Theory’ (BoTT) (May et al., 2014). BoTT, introduced in the literature review, examines the ways in which healthcare work is handed to patients, and the different elements which may expand or contract patients’ capacity to meet these demands. Patient capacity is dependent on a variety of physiological, psychological, personal, environmental, and social factors including health literacy, frailty, status, location, social support, and cognitive functioning (Kyle et al., 2020). The results of this study point towards the need for patients’ capacity to expand in order to take on the new forms of interactional work given to them during remote consultations. The use of this framing to understand patient work during remote consults will be returned to in the Discussion chapter.

This chapter has explored the various impacts of a loss of non-verbal and visual cues during remote consultations. The following chapter looks at the impact of both remote consultations and a loss of continuity of care on patient-doctor relationships.

Chapter 8. “You’re like an Object for them” – Doctor-patient relationships and continuity of care

Introduction

This results chapter focuses on the impact of remote consultations and a loss of relational continuity of care on patient-doctor relationships. The previous two chapters have examined how elements of care including physical space, and non-verbal cues are disrupted, and experiences of this. This chapter serves to integrate and expand upon these prior themes, investigating how the dynamics between patients and doctors are being transformed and redefined. The focal points of this chapter are the therapeutic relationship, the establishment of rapport, and the maintenance of continuity of care, and the interconnectedness of these elements.

A therapeutic relationship can be defined as “a positive and collaborative relationship between patient and therapist” (Cape, 2000; Horvath & Luborsky, 1993; Horvath & Symonds, 1991). There is a distinction between therapeutic relationships in general, specific doctor-patient relationships that are built up over time and involve mutual knowledge, and the primary care consultation as a particular kind of therapeutic relational space. These are not the same kinds of social relations but built around different core interactional processes. These include empathetic listening and engagement by a doctor, leading to a discrete instance of therapeutic relationship building; continuity of care as a longer-term process of ongoing therapeutic relationship maintenance; and the GP as a trusted professional holding therapeutic space.

The role of patient-doctor relationships, and therapeutic alliance has been shown to have various positive outcomes (Balint, 1968; Bazzano et al., 2018; Feldman, 1974; Funderskov et al., 2019; Hinman et al., 2017; Imlach et al., 2020; Kairy et al., 2013; Lawford et al., 2019; Walthall et al., 2022). These include: increased patient satisfaction; higher patient disclosure and thus information collection by doctors (van Dulmen & van den Brink-Muinen, 2004); better treatment adherence (Buszewicz et al., 2006; Mercer & Reynolds, 2002); and ultimately better clinical outcomes (Derksen et al., 2013; Hojat et al., 2011; Kim et al., 2004; Lelorain et al., 2012; Mercer & Reynolds, 2002; Neumann et al., 2007; Reynolds, 2000; Shapiro, 2008).

Remote consultations have been shown to potentially have a detrimental impact on the building of therapeutic relationships between doctors and patients (Bazzano et al., 2018; Funderskov et al., 2019; Hinman et al., 2017; Imlach et al., 2020; Kairy et al., 2013; Lawford et al., 2019; Walthall et al., 2022). However, there is still a relative lack of research on patient and clinician experiences of remote consultations when it comes to relationship formation and maintenance.

The second key theme of this chapter is on continuity of care. This has been included in this results chapter because of the association between continuity of care and patient-doctor relationships. Continuity of care can take two forms, either continuity with a named clinician – relationship continuity (Penny et al., 2014), or coordinated clinical care as an individual moves between different parts of the healthcare system – management continuity (Levene et al., 2018). As with therapeutic alliance, continuity of care has been found to have a strong positive correlation with clinical outcomes (Roland, 2012). Relationship continuity in particular has been shown to be associated by both patients and doctors with good quality of care (Guthrie & Wyke, 2006; Ridd et al., 2006). Further, relationship continuity has been shown to interact with remote consultations by making shared decision-making and support planning easier in the absence of in person consultation (Donaghy et al., 2019; Hammersley et al., 2019).

This chapter builds on the previous chapters which focused on processes, and ties some of the data together through an explanation of outcomes – through an examination of the impact of remote consultations on patient-doctor relationships.

Findings

A significant finding of this study is the transformation of doctor-patient relationships as care becomes more 'de-personalised' due to remote consultations and a decrease in relational continuity. This results chapter centres on the data relating to this finding, starting with an examination of the reasons behind this shift. The chapter concludes by exploring the perceptions by both patients and doctors regarding the changes in doctor-patient relationships, before bringing together these findings in the summary to offer a comprehensive overview of the topic.

Remote Rapport building

Both patients and GPs spoke about the challenges they faced building relationships during remote consultations. GPs compared the ability to use non-verbal cues during in person consultations, with the interactionally light experience of having a remote consultation on the telephone, which relies on verbal communication alone. GP respondent 26 contrasted the difference between seeing a patient in person and the immediate relationship formation which begins, versus the work of doing this over the phone:

> "Relationship building is very, very difficult without the person in front of you. You've lost all the body language that allows you to build a relationship which

> happens as soon as a patient walks through the door, you're able to kind of get a sense of what that person is like or what mood they're in, they get a sense of what you're like, and so the relationship starts straight away. And so on the telephone or by video you're having to work a lot harder, video helps, because you can obviously see the person, but a lot of the time we were doing telephone, so you really had to work." [26 GP, Lewisham and DOTW]

The relationship with the patient is physicalised in this account, with the relationship beginning as soon as the patient 'walks through the door', suggesting the importance of non-verbal cues for relationship formation. This in turn creates interactional work for the GP which would previously happen automatically through the use of non-verbal cues.

Rapport building was seen as particularly challenging with new patients, who the GP had not previously met in person and had a chance to develop a relationship with:

> "Often when patients see you, particularly if they're new patients, they're sizing you up, and seeing whether you're the sort of person who they want to have a chat with, about their, you know, whatever it might be. And, you know, I don't know how easy that is to do remotely on the telephone." [23 GP, Tower Hamlets]

This account indicates that in person contact is not only important for the GP's impression of the patient, but that patients too will use non-verbal cues to make assessments about their doctors which can impact on their willingness to disclose information. The loss of non-verbal and visual cues is referred to as a reason why remote rapport building is challenging, and the difficulties this introduces in terms of getting to know new patients. As discussed in chapter seven, remote consultations may introduce various forms of interactional work for GPs, to make up for a loss of in person cues for understanding symptoms. The accounts given here indicate that the challenge of relationship building remotely also amplifies the need for deliberate rapport building to establish effective therapeutic relationships.

GP respondent 26 went on to discuss the potential implications of a loss of rapport building with patients, and how this could impact on their safeguarding abilities:

> "We usually have a screening questionnaire where we ask people to try and pick up their experience of violence and other risk factors that we may want to pick up. And we normally do that in quite a direct way, because we find that that is usually the best way, once you've established a rapport with a patient, that's usually the best way to elicit a response as to whether they they've had any issues. And speaking to my other kind of fellow volunteer clinicians who are doing the same thing, we found it very difficult to do this Screening Questionnaire [on the phone]. If you're talking to the person about the medical problem they wanted to talk about that's very easy to do, because they're very well engaged to do that. But then as a sort of anonymous voice on the end of the phone suddenly asking you about, have you ever experienced domestic abuse? Have you ever experienced rape? Have you ever felt unsafe at home? Suddenly, certainly, from our point of view feels harder to elicit. I mean, very often, patients would still, if you did it in a gradual, slow way, and you've done everything you could to try and establish rapport, patients did still respond. But a lot would say I'm not happy to talk about that, and you would then just move on, we wouldn't push for that person to talk about it. But it was certainly much more challenging to do that. And the temptation was to not do that Screening Questionnaire. And I think a lot of our volunteer clinicians felt that they couldn't do it at all on the phone, because it felt inappropriate to them. It felt like it would be triggering, it was a non-trauma informed way of dealing with somebody's trauma or kind of trying to elicit if someone's dealt with trauma." [26 GP, Lewisham and DOTW]

This excerpt indicates the challenges that can arise due to a lack of therapeutic relationship building via remote consultations, and the role which relationship building may have in creating ‘space’ for disclosure. The switch from in person to remote consultations has the potential to remove the safety created by an in person interpersonal connection which prepares the patient to be asked about potentially traumatic experiences. A distinction is drawn between an ‘anonymous voice on the phone’ and in person contact, suggesting that being in person may help to produce familiarity even if the doctor is unknown to the patient. As a result of depersonalisation on a remote consultation, safeguarding questions may be seen by both patients and clinicians as inappropriate to ask, leading to a preference for not collecting the information over trying to collect it in a way that could be re-traumatising for the patient. The shutting down of such safeguarding questions can happen when patients push back by refusing to answer, or clinicians deliberately avoiding asking these sorts of questions. This may further contribute to the safeguarding risks raised in earlier chapters, produced by lower disclosure levels. The difference in this account however is of clinicians instigating the lowered disclosure by hesitating to ask sensitive questions, suggesting that remote consultations may make both clinicians and patients more hesitant to discuss certain topics.

GP 25 also identified the potential for lost safeguarding opportunities unless patients were seen in person. He points to a potential increased need to see patients from marginalised groups in person for a ‘chat’ suggesting the softer skills of consulting may have greater importance for individuals who are experiencing difficult living situations which might impact on their health:

> “But what we must ensure is the ones who are marginalised, who don’t speak English, homeless, or in poverty so that we kind of do what we can, this is where they sometimes need a face-to-face chat. I think there’s a really sad story of one of my patients, the other day, and he came to see me for an appointment. I hadn’t seen him for a year and a half. So, as he called me, I said, why don’t you come

> and see me face-to-face, it's been a while since I saw you. So, he came, and he hadn't eaten for 24 hours. So, we just happened to buy some pizza for the team, so I gave him a box of pizza. And then I had to signpost him to the relevant services." [GP 25, Tower Hamlets]

In this account, an in-person consultation is presented as having opened the door for the patient to disclose a personal challenge which was relevant for his GP to know and offer assistance for. The counterfactual, of him having a remote consultation is impossible to know. However, the implication made by the respondent is that the patient was facing socioeconomic hardship which could impact on his health, but this was only shared as a result of being seen in person. This indicates that both patients and doctors recognise that more personal or potentially stigmatising topics may be more easily raised and discussed when consulting in person.

This section has examined how remote consultations can reduce rapport building which can limit the extent to which doctors and patients establish a relationship or therapeutic alliance during a consultation. Further, it has suggested how this can lead to potential safeguarding and clinical risks, as disclosure around sensitive topics is lowered. This may be caused by doctors' hesitance to ask questions about possibly traumatic events, as well as patients' unwillingness to disclose information to a doctor they have not developed rapport with. As highlighted by GPs, this may be particularly challenging for individuals experiencing marginalisation who are at greater risk of experiencing contextual circumstances which may require psychosocial care and/or safeguarding by their GP. This may also be the case for patients who want to speak about potentially sensitive or stigmatising health concerns.

Continuity of care

One of the changes regularly spoken about by respondents was a reduction in continuity of relationship with one doctor. This was presented as a negative change, leading to perceived lower quality of care due to the loss of contextual personal information built up by the doctor over months or years. Further, respondents indicated a lower willingness to disclose information in the absence of a trusting relationship with a doctor and a feeling of being 'known'.

For several respondents, a good relationship with their doctor underpinned their use of primary healthcare services – and one of the major criticisms of the healthcare system in recent times was the inability to speak to their regular GP, as was the case for respondent 21:

> "R: You don't always get the same doctor innit so you get different doctor so that's a bit....I'd rather keep one doctor innit [...]
>
> I: why would you rather see one doctor?
>
> R: Because you get to know people innit they know you, your things. I prefer to see the one on one person and then at least he knows your background in some some respects and is familiar with you and that" [21, Male, 40s, Black British, previously homeless, community development charity]

The preference for continuity expressed by respondent 21 was linked to the feeling of *being* known, with a focus on the doctor's knowledge of him, rather than his comfortability with the doctor. This indicates the importance which patients may place on their doctor's long-term knowledge of them, which they feel to be relevant to their care. Participant 11 also mentioned the importance of feeling known by her GP, presenting her medical history as relevant information which might be ignored if she sees an unfamiliar GP:

> "All the other doctors which was before or if she can't see me, they try to get urm they try to do their job…like it doesn't make a difference you haven't seen me you don't know my case history" [11, Female, 60s, Black British, community development charity]

In both examples respondents refer to contextual information – 'background' and 'case history' – as reasons why seeing their regular GP is preferrable, pointing towards the importance of their GP knowing them, rather than the relationship itself. The implication in both of these cases is that without the background longer term knowledge on them, their doctor may omit potentially important clinical information when making their diagnoses.

However, other respondents placed a focus on the relationship *with* the doctor, with continuity of relationship helping to create a safe space for disclosure. Respondent 14 spoke about the difficulties she faced with communicating honestly with new doctors over the phone, and how this could lead to lowered levels of disclosure:

> "And then you wait for doctor to call and it will be a completely different doctor, and then I won't really talk as much as I feel I need to, I hold a lot back because I don't know this person and my doctor understands me I feel like this person doesn't know me, you know, so I don't feel confident to actually express how I'm feeling so yeah, that's really hard with my depression, mental health, you know" [14, Female, 40s, White British, foodbank]

In this account both being known by the doctor and knowing the doctor are presented as necessary prerequisites for disclosure – as this helps to build a trusting relationship. In one instance a respondent contrasted his current healthcare experience of seeing unknown GPs with his previous experiences of having an ongoing relationship with one GP:

> "I: Do you have like a particular GP that you're you know and like at your GP surgery?
>
> R: No I don't usually they pass me on to whoever is there…a student
>
> I: And how do you feel about that?
>
> R: I'm not happy with that I'm not happy no
>
> I: And why are you not happy with that?
>
> R: When I first my first GP when I was with my son's mother, I knew the doctor you know we got on you know I could talk to him I could explain I could say anything to him you know what I mean with this lot now you know they don't really take in what you're saying and you know…can't really put across what I want to put across." [12, Male, 60s, Black British, Experiencing homelessness and alcohol dependency, community development charity]

Here he suggests that the GP having prior knowledge about him was important in terms of being able to properly explain what he needs, as well as feeling comfortable disclosing information. In this account an established relationship – 'we got on' – suggests that a feeling of interpersonal connection may underlie the importance of an ongoing patient-doctor relationship for some patients. Further, as in chapter seven where respondents spoke about their fears around not being listened to over the phone, respondent 12 links not being listened to with being seen by new, unknown doctors. This signifies the interlinked nature of continuity of care and remote consultations contributing to patients' experiences of feeling heard and validated.

The particular importance of continuity of care during remote consultations was spoken about by participant 14, who felt that remote consultations with a known GP were acceptable, but that having an unknown GP was disruptive to care:

> "I wouldn't mind speaking to him on the phone. In person will be great, but it has to be on the phone. Yeah, it's the same thing, but I know it's him. And I know he knows a lot about me, and I can tell him how I feel. And it's not I know, trust him he's confidential. Whereas I don't feel that that with new doctors because I don't know, I've built this bond over the years with my doctor and now it's just he's nowhere to be seen and just feel alone. Like Where? Who do I talk to?"
> [14, Female, 40s, White British, foodbank]

In this example the respondent interprets the doctor's prior knowledge of her as enabling him to understand her properly when speaking over the phone in particular, as well the importance of a pre-established trusting relationship. Importantly, she makes it clear that for her relational continuity is more important than consultation modality, and that the potentially depersonalising impact of having a remote consultation is negated by relational continuity.

The importance of, and disruptions to, continuity of care were also spoken about by GPs, who presented continuity of care as a key tenet of General Practice, particularly for patients with high psychosocial needs:

> "Yeah, well, part of it is, but part of it is also, you know, the cornerstone of general practice, which is continuity, which is why, again, one of the great concerns of I think GPs of my generation, and maybe a bit younger, feel that some of the options that are being put out there for over the last sort of five or ten years about

> walk-in centres A & E consults and, you know, private providers like, Babylon and the like, miss out that sort of knowledge, really the knowledge that you gain over a relationship that's built up over either many weeks, months, years, decades, and which allows you some insight into how the patient's background and their family setup or the trauma that they've experienced over, over the years, will play into their physical as well as psychosocial presentation. So, I think that's, yeah, that's, that's something that we will lose at our collective peril." [24 GP, Tower Hamlets]

Here the respondent draws a link between continuity of care, relationships with patients, and clinical diagnoses. The fears about loss of continuity of care based on alternative models (walk-in centres, and private digital health solutions such as Babylon) suggest concerns that this is the direction in which the NHS is also moving. The dislocation of GPs from their patients, and patients' contexts is framed as critically important as it allows for contextual information on the patient as well as a relationship – which might help the doctor to understand the patient's needs. This account aligns closely with those given by patients which similarly point towards the importance of both contextual information and the establishment of trust which are created through relational continuity.

This data indicates both a short- and long-term effect of a loss of continuity of care in General Practice. In the shorter-term patients may be less likely to disclose sensitive information over the phone to their GPs if they do not have an established relationship with them. In the longer-term, knowledge on a patient developed over time provides the GP with potentially useful information about the patient which can help with clinical diagnosis, as well as helping to build a trusting relationship which allows for more successful remote consultations.

GP respondent 20 framed continuity of care as especially important for patients with high psychosocial needs or those who have experienced trauma:

> "But psychologically, again, there's a trauma and they need holding, they need to have continuity, they need to trust the clinician is listening to them. There's something happened before and that they need that and that's the trauma informed principles approach." [20 GP, Newham]

Here she also points out the importance of patients feeling that they are being heard by their doctor – drawing a link with the development of a trusting relationship. This mirrors the data presented earlier in which patients expressed that relational continuity with their GP made them feel they were being listened to properly during consultations.

Further, continuity of care may have added benefits for patients in terms of correctly assessing patients' abilities to partake in remote consultations:

> "So, one of the cornerstones of general practice is continuity of care. So that means seeing the clinician that you know well, on a regular basis, I bring in a lot of my regulars because I know, I know them well. I know how they will respond."
> [25 GP, Tower Hamlets]

Whilst this indicates a positive attitude towards maintaining in person consultations for patients who want or need them, it also suggests that this could be more likely with patients where there is an established relationship, with unknown consequences for patients who do not have a regular GP. This is paradoxical, as an established relationship has been shown both in the literature, and within this study to make remote consultations easier, and vice versa. This helps to build a picture of the complex relationship between continuity of care and remote consultations and how these two factors interlink to influence patient-doctor relationships.

Bringing together the comments from GPs with those of respondents reporting their experiences as patients, it seems there is a widely recognised concern around disruptions to continuity of care. This is tied up with remote consultations which may be more difficult to carry out with new patients, creating a dual barrier to therapeutic alliance building. Both patients and GPs spoke about this in terms of a loss of long-term knowledge and familiarity, which could encourage disclosure, but also provide important contextual knowledge on the patient which may be relevant to their clinical care. This indicates a mechanism through which those experiencing marginalisation may be impacted more by a lowered level of continuity. If an individual's life circumstance are difficult, for instance with unstable housing, or addiction issues, then this sort of contextual information is potentially quite important to understand their healthcare needs. Further, because of the stigma around these sorts of topics, patients may be less willing to disclose issues related to their personal circumstances to an unknown doctor who they have not yet developed a trusting relationship with, especially over the phone. This compounds the practical and interactional challenges during remote consultations particularly for marginalised groups, outlined in chapters five and six.

Modularisation of care

A reduction in continuity of care was explained by GPs as the result of spreading care over larger teams within primary care. This was framed as a necessary response to GP shortages leading to a modularisation of care. Modularisation of care happens as different elements of primary care are increasingly split between different practitioners.

A difference was drawn between continuity of a relationship with a named GP and continuity of care within a practice, with recognition that primary care might be shifting focus from relational to management continuity as teams expand:

> "Continuity of care in General Practice is very multidisciplinary. So, in my practice, we've got five nurse practitioners, we've got four pharmacists, pharmacy, technicians, physiotherapists, we're about to get a mental health practitioner. We're about to recruit a physicians associate we've got lots of GP trainees, and nursing trainees. Healthcare assistants so it's a large team, and nurses of course, and continuity of care doesn't need to be just provided by GPs. Yeah, often, often our healthcare assistants who do the check-ups on diabetics, patients with hypertension, tend to see them a lot more regularly than the GPs do." [25 GP, Tower Hamlets]

An increasingly large primary care team is presented as a reason why practices may be moving away from relationship continuity with a GP. This also entails less interaction with GPs in general, as patients are sent to a wider set of practitioners. Social prescribers (link workers within primary care who refer patients to local community-based services and work directly with patients to develop a personalised support plan) were presented as one way of maintaining continuity of patient management to deal with patients' non-clinical needs:

> "It's balancing up with the resources that we have at a time when there's you know, GPs falling left, right and centre and for numerous reasons, so social prescribers are seen as the person that can provide continuity. You know, they are seen as somebody who can do that, because a lot of these patients, they need the continuity, but they don't necessarily need a medical eye on them all the time

> when we did have a social prescriber, and a lot of these patients, I got her to see them.” [20 GP, Newham]

In this account, a separation is made between clinical needs which necessitate a ‘medical eye’ versus other needs (not specified) which can be managed by a social prescriber. This suggests the shifting of non-medical care from the GP to other members of the primary care team – a point picked up on in more detail below. This account also indicates the potential for relational continuity to be maintained with a member of the primary care team, but not with the GP.

A need for patients to adjust to this new way of working was also discussed, with patients needing to become accustomed to not having their GP as the main point of contact within primary care:

> “I think also that the complexity of our team is increasing all the time. So, you know, you’re, you’re you may, people have to sort of get used to speaking to a clinical pharmacist or a physician’s assistant, or, you know, we’ve got a very diverse, an increasingly diverse team. So again, the traditional model of, you know, talking to your GP is, you know, is breaking down, really.” [23 GP, Tower Hamlets]

Notably, the ways in which General Practice is changing are presented in this account as breaking down, rather than for instance evolving, suggesting a loss. One GP compared the role of a GP to the more specialised role of a hospital consultant, indicating that primary care was moving closer towards a hospital model where consultants only see the more complex cases:

> "If you go to the hospital, you're not gonna see a consultant for every complaint you might see them if your complaint is very complex, but more simple ones, like a cough or cold might be dealt with by a nurse practitioner or a pharmacist, or physicians associate. And then GP is dealing with much more complex issues. So that's what's happening at the moment, and that is a shift for patients. I can certainly understand why patients are being concerned, they might think my GP doesn't want to see me for a cough and a cold. It's not that my GP doesn't want to see me because I was...because it will be easy, I can deal with it in five minutes, rather than having to do the complex patient in 20 minutes, I think is how you use the expertise of someone, a clinician." [25 GP, Tower Hamlets]

This description of changes to primary care also points towards the need for patients to adapt to new ways of working, with a recognition that this may be perceived negatively. These accounts by GPs describe the changing nature of the delivery of primary care, as it moves away from being centred on GPs to include more interaction with other health care professionals. This also suggests the introduction of new thresholds around eligibility for GP care, with a deliberate move towards less clinically complex cases being handled by non-GPs, moving to a model more akin to secondary care. The comment by GP 25 that this might be interpreted as a rejection by patients, who think their GP doesn't want to see them for minor complaints indicates the interpersonal tensions which may arise between patients and the primary care services. This tension is present in accounts given by patients when they spoke during interviews about feelings of rejection by services, and questioned how sick they needed to be in order to elicit care – discussed in chapter five on appointment booking as well as the topic of the following section 'eligibility for care'.

Whilst framed as a *necessary* way of dealing with a lack of resources, GP respondent 23 interpreted the spreading of care across teams as a negative form of modularisation:

> "I see very negative things on the horizon actually, and I think the way that things have been sort of compartmentalised into sort of modular sort of units [...] Yeah, and, you know, that was going on before the pandemic, but everyone is in, like, a silo now. So, there's a big health facility somewhere in a block, you know." [23 GP, Tower Hamlets]

This description of modularisation or siloing of care is an alternative interpretation of the spreading of care over larger teams to match needs with care. This ties back to the challenges of making appointments outlined in chapter five with patients having to become more able to articulate their needs effectively prior to consultation to be matched with the correct form of care. This next section looks at a concurrent outcome of this – increasing thresholds for eligibility of care.

Eligibility for care

This section starts with a discussion of the increased use of tests prior to consultation, before briefly recapping the discussion in chapter five on making appointments and eligibility for care. One way in which new forms of eligibility for care are being created is by sending patients for tests before being seen in person. Several GPs spoke about how they used to see patients in person and then send them for tests, and now send them for tests prior to seeing them in person. For some respondents this was interpreted as an eligibility assessment of sorts, which acted as a confirmation of ill health as well as a barrier to entry.

Looking first at this change as reported by GPs. GP respondent 26 spoke about the triaging process into face-to-face care:

> "So, for example, if somebody is saying I've got abdominal pain, I've had it for about five years, I might say, Okay, let me organise some blood tests for you, and a urine test, and maybe a scan depending on where it is, and then with the results, I'll see you face-to-face." [26, GP, Lewisham and DOTW]

Here she presents an ordering of activities, with test results being used as a validating mechanism for receiving care, by giving the doctor more information to work with at the time of consultation. Asking patients to get tests before being seen was presented by GP 23 as putting the GP in control of the interaction:

> "I mean, I think it's just sort of doctor saying, you know, really being in charge, or clinicians being in charge of how somebody engages, you know, and really often, you know, what, what would happen is, you come and see me about a problem, I say, well, you need to have these tests, and then you go away, and then you come back, now I don't see you at all, I say you need these tests first, and then you can see me, so I don't know if it saves time, it seems more logical, I think that, you know getting tests beforehand." [23 GP, Tower Hamlets]

This account details the setting up of additional eligibility criteria for patients as they are asked to articulate their needs and have tests performed before becoming eligible to see the GP. Whilst this may increase efficiencies by giving the GP the information they need before the consultation, it also represents a process of keeping patients at arm's length until eligibility has been established. An important assumption made here is that patients are seeking care for the symptoms/problem they outline initially, with less room for hidden agendas to emerge which may be raised during a consultation.

Moving now to look at how this change in process may affect patients. An account of the use of tests prior to an in-person consultation as a way of producing eligibility for care was given by respondent 17:

> "Do you know something? I must say for once I've felt a certain kind of empathy from her when I went that day and, you know, I felt like she cared and, and when she got the blood results, "why didn't you ring me? Why don't you ring me?" I've got to ring you! Okay, so you got it now. So, we'll make an appointment now, so you could ring me tell me about it, when she rang she told me again and said, what's what more and I felt that she was being quite nice. I suppose that my, my story is valid" [17, Female, 60s, Black British, community development charity]

Here she frames her blood tests as clinically validating, interpreting her GP's care as a reaction to her needs being evidenced. She links her GP's kindness or empathy, to her blood test results – interpreting her clinical needs as underpinning this positive interpersonal encounter. What this account indicates is that whilst GPs may send patients for tests prior to a consultation in order to have more information with which to make a clinical diagnosis, this may be interpreted by patients as a gatekeeping process, and a test of their clinical validity. This builds on the theme of candidacy introduced in chapter five in relation to appointment booking. Another component which comes through in this narrative is around confusion of the patient role, and whose job it is to follow up on results. This potentially leads to an additional layer of responsibility for patients, building on the discussion in results chapter five on making appointments.

Patients' perceptions of high clinical thresholds for eligibility in order to see a GP were discussed in chapter five when thinking about making appointments. This will be briefly recapped here in order to highlight the link between difficult experiences of making a GP appointment, and changes to eligibility criteria as outlined by GPs earlier. The following two quotes were presented in chapter five, and are repeated here in shortened form in order to evidence patients' experiences of higher clinical thresholds for care being set up in primary care:

> "How can we wait so long for an appointment? For something you've never looked at. Who, *who* are the people that are in front of me? Who are they? What is it that they've got that I haven't?" [17, Female, 60s, Black British, community development charity]

> "You're supposed to get the triage call. And then they'll make the decision if you're bad enough to see the doctor which 99% of time they don't." [9, Female, 40s, white British, foodbank]

These two examples lay out the ways in which patients might perceive changes in thresholds to receive care. Both respondents point out that often they no longer feel they meet the necessary clinical thresholds to be seen by a GP. Respondent 17 in particular indicates that she lacks clarity around how sick she needs to be before she can elicit care.

As a result of the increased use of tests prior to consultation, as well as a widening of the primary healthcare team which means patients are less likely to see GPs for less complex needs – patients may be up against increasingly high eligibility criteria to see a GP. Whilst this was presented as a rationalisation of resources by GPs, it is understood by some patients as a distancing process, making the barriers for being seen by a GP increasingly high.

‘Transactional’ care

So far, this chapter has outlined the various factors which may impact on patient-doctor relationships as a result of changes to the primary care system. This section looks at the potential outcome of these changes, and how these are interpreted by both patients and doctors, starting with the former.

Respondents repeatedly spoke about a lack of personal, or psychosocial care during consultations:

> “I’m talking to this woman, and I can’t be personal. It can’t go beyond what we’re discussing. I want to discuss this, this, this, and this, and you want me to discuss that. And you’re saying we haven’t got time to discuss all the things that I want to discuss.” [17 Female, 60s, Black British, community development charity]

> “If you don’t have a bond with them kind of doctors, they are quite cold if I’m honest, most of them, it is just a quick call they don’t wanna you know, they don’t want to hear, get to the point that’s it and deal with it that’s how you feel so no, I’m not confident with speaking.” [14, Female, 40s, White British, foodbank]

In both of these accounts, the consultation is portrayed as highly focused on clinical care, with no space to discuss the context, or develop an interpersonal relationship. This is perceived by respondent 14 as ‘cold’ care – because of an absence of social bond and short appointment times. She interprets these two factors as a result of the doctor not wanting to listen to her. Respondent 1 also spoke about the lack of interpersonal relationship during consultations:

> “There is no personal interaction if you know what I’m saying there is no sympathy there is no you know happiness for you, it’s just a fact which needs to be sorted that’s all– simply professional?” [1, Male, 40s, white Estonian, immigrant, resident 10+ years, foodbank]

Here he contrasts professional care with personal interaction, suggesting that a lack of social bonding indicates a lack of emotional care on the part of the doctor and moreover, a lack of empathy. Similarly, respondent 12 reported that he felt his doctor was not interested in him, only his clinical healthcare needs:

> “I would of think it’s the doctor but if they’re not really interested in you, you’re not gonna get specific healthcare you need you’re just a one of the cattle or sheep like you know what I mean like patients” [12, Male, 60s, Black British, Experiencing homelessness and alcohol dependency, community development charity]

These accounts all centre on the clinical focus of the consultation – which is portrayed by GPs in this study as increasingly the main and only function of their role. A contrast between warm care which includes social engagement, versus professional care indicates a disjuncture between what patients expect or want during healthcare interactions versus the form of care they receive. This was outlined clearly in an account given by respondent 17 who spoke at length about the gap between the care she wanted from her GP, which included a high level of emotional support and psychosocial care, versus the care she received which was more focused on clinical diagnosis:

> “In theory, your doctor is the next, is your counsellor. You’re supposed to, you’re encouraged to go and discuss stuff, you know, as to why I’m feeling the way that I’m feeling. This is what’s happening. That’s what’s happened. And it’s just so

> impersonal. It's just like cut another slice of bread, you know?" [17, Female, 60s, Black British, community development charity]

Here respondent 17 points towards the de-personalisation of care, leading to feelings of objectification. Interpretation of a lack of personal care as objectifying was also spoken about by respondents 1 and 4:

> "Yeah, you're like an object for them" [1, Male, 40s, white Estonian, immigrant, resident 10+ years, foodbank]

> "It's not good I don't feel good yeah like a human you know when you are sick, you need something" [4, Male, 40s, Bangladesh, immigrant resident 10+ years, drop-in centre]

In these examples respondents give accounts of feeling de-humanised during consultations, suggesting that highly (or overly) clinically focused care which prevents patients from speaking about the broader psychosocial and emotional context of their situations, may lead to poor experiences of care.

Moreover there is a discrepancy between people's expectations of GPs delivering personalised emotional care versus the more diagnostic functional care they received which led to them feeling disregarded or objectified. What might be termed 'de-personalised' care was interpreted by respondents as lower quality. This relates to patient satisfaction in terms of expectations, as well as experiences of how people felt about what happens during consultations. Respondents did not relate their feelings of being dismissed to specific situations or processes but tended to frame them as a more generalised sense of being passed through the system without developing a personal relationship with their GP.

A reduction in warmth in doctor- patient relationships was also spoken about by GPs, who tended to frame this as a move towards more transactional models of care. 'Transactional', a term which will be critically examined in the summary, refers to a de-personalised, and business-like model of interaction during remote consultations.

> "I think, you know, one of the big profound changes over the last two years has been the sort of transactional nature of a lot of work. So, you know, people have to sort of declare that they want something, and then there's a negotiation around that. Whereas I think, you know, work prior to the pandemic was, was a more sort of a looser border, you know, it wasn't so transactional." [23 GP, Tower Hamlets]

GP respondent 23's account outlines one of the key themes presented in chapter five, which is an increasing need for patients to negotiate their eligibility for care, and to be able to articulate their needs clearly. This negotiation may limit the scope for exploration with patients during consultations – a 'looser border' – instead, tying the conversation to a pre-stated problem. This aligns with the accounts given by patients discussed above, which focused on the increasingly narrow scope of the consultation.

The potential for a reduction in emotional caregiving because of remote consultations was also spoken about by GPs:

> "But getting back to your other point, I think that, you know, you know, often people [GPs] just want to finish , this is the transactional nature of contact, you know, if you have a sort of contact that is demanding something, you know, what,

> you know, people are wanting is to close that contact, you know, so if they can do something, you know, that sort of finishes that sort of contact, then they may do that now, you knew the decision, if somebody's sitting next to you, and you're able to sort of do a proper examination or have a thoughtful discussion about what may be best, you know, you'll, I think, will be more imaginative or sort of do a bit more sophisticated, rich, risk sharing, if you're seeing somebody remotely, you know, you'll send them for an ultrasound, you know" [23 GP, Tower Hamlets]

Here the respondent indicates that not only are GP consultations becoming increasingly discrete, but that the remote consultation itself may limit in-depth conversation with patients due to lower interest levels or engagement from the GP. His contrasting between 'transactional' care on the phone versus 'thoughtful discussion' in person points towards the degradation of interpersonal rapport building over the phone, as outlined earlier in this chapter. Further, the potential for reduced clinical attention or 'sophistication' is considered an outcome of this. The possibility of reduced emotional connection with patients leading to reduced clinical observation and creativity indicates that the removal of this form of care may have direct implications for clinical care. This adds weight to the accounts given by patients which perceive less exploratory or holistic consultations as lower quality.

Just as patients are unhappy with changes in care, leading to de-personalisation, GPs also expressed discontent. A disjuncture between reasons for going into General Practice, and the new model of care which is emerging were spoken about by GPs 20 and 23:

> "We all went into GP because we love people. So, we don't want these transactional online relationships, some people do, not the sort of traditional GPs that we went through, you know, went into it." [20 GP, Newham]

> "I'm not optimistic that the idea of personal care is going to survive, basically that. And of course, you know, for people like me on a purely selfish basis, you know, that's why I do the job. I like having, you know, relationships with people, and not episodic sort of encounters with, you know, just somebody who, you know, who could speak to an AI bot or, you know, anyway, you know, that's, that's, you know, why I went into it." [23 GP, Tower Hamlets]

These responses indicate a change over time within primary care, and importantly, tie together the reduction in continuity of care with an increased use of remote consultations, producing a more transactional form of care. Further, they suggest that system level changes may be forcing both patients and doctors into forms of care which are perceived as less fulfilling both functionally and emotionally.

This final section of this results chapter in many ways sums up the outcome of the changes discussed throughout the results chapters. Both patients and doctors are noticing a distancing with each other, with patients interpreting this as 'cold' care and doctors as 'transactional'. This outcome is the result of a variety of factors, but ultimately indicates a step change in the way in which doctors and patients relate to each other within NHS primary care, driven by systemic changes which have accelerated over recent years. The final section of this chapter 'summary' brings together the themes discussed within this chapter, before moving onto the Discussion chapter which draws together findings from across all the results chapters and their theoretical and practical implications.

Summary

This chapter has explored the ways in which changes to primary care have impacted on doctor-patient relationships. There are several key takeaways from this chapter including: Patients and GPs are experiencing disruptions to therapeutic relationship building due remote consultations and reduced relational continuity of care; interactions between patients and doctors are becoming more discrete and interactionally light; and these two processes interact and compound to produce 'colder' and de-personalised experiences of care with a consequent disruption to patient-doctor relationships. This in turn has potential implications for clinical outcomes as well as safeguarding because of lowered disclosure levels and the loss of contextual information on the patient.

Whilst the preceding results chapters drew clear links between changes to the primary care system, and processes of marginalisation throughout – this results chapter has not. This is in large part because respondents themselves did not present it in this way, unlike for instance the data presented in chapter seven where respondents commented on their levels of education impacting their ability to engage in remote consultations, or in chapter five where the relationship between economic resources and access to appointment booking systems was discussed. However, this does not mean that there is no relationship between marginalisation and changes to the doctor-patient relationship, an argument this summary will seek to draw out.

Firstly, taking into consideration the discussions of the previous chapters, especially chapter seven on the loss of nonverbal cues during remote consultations and the interactional issues which result, the findings of this chapter can be seen as an exacerbating factor for challenges which predominantly affect those experiencing marginalisation. For instance, an ongoing relationship between a patient and doctor may allow the doctor to understand a patient's additional communication needs, and to pre-emptively identify that they will find a telephone conversation challenging and thus bring them in face-to-face – as mentioned by one of the GP respondents. In the absence of continuity of care this is not possible, and so this potential 'buffer' is removed.

Further, the importance of 'knowing' a patient in order to be able to deal with their needs in a trauma-informed way may also interact with marginalisation if we consider that those from marginalised groups are at higher risk than the general population of requiring safeguarding. This ranges from experiences tied up with having become marginalised, such as a dangerous journey into the UK as an asylum seeker, as well as a known association between, for instance, domestic violence and socioeconomic status. The Office of National Statistics (ONS) 2015-2017 (Alexa Bradley & Angela Potter, 2018) data has shown that women living in social housing were nearly three times as likely to experience partner abuse than those who are owner occupier, and those living in households with an income less than £10,000 were more than four times as likely to have experienced partner abuse than women in households with an income over £50,000. GPs gave accounts of the challenges of building rapport during remote consultations, which in turn limited their willingness to ask safeguarding questions related to issues such as domestic violence. They also reported that patients may refuse to answer such questions over the phone. So, whilst remote consultations may produce safeguarding risks for every patient – the actual *risk* of this will be higher for patients who are more likely to have safeguarding needs.

Respondents placed more emphasis on the need for a good relationship with their doctor when speaking about mental health concerns, and the importance of feeling 'known' by and trusting their GP in order to disclose sensitive information. As with domestic violence, there is also evidence for a strong socioeconomic gradient in mental health, with people of lower SES having a higher likelihood of developing and experiencing mental health problems (*Poverty: statistics*) – those on housing benefit are more than twice as likely to have a common mental health problem than those not receiving it (35.1% vs 14.9%) (Jones-Rounds et al., 2014). Other marginalised groups have also been shown to have much higher rates of mental health issues than the general population, in 2014 80% of homeless people in England reported having a mental health issue (UNHCR, 2015), and research has found that asylum seekers are five times more likely than the general population to have mental health needs (Eaton et al., 2011). Thus, as with safeguarding concerns, whilst many patients may feel less willing to disclose mental health related issues to either an unknown GP, or over the phone – this will disproportionately impact on groups with higher levels of mental health needs.

Having drawn out the possible relationship between changes to patient-doctor relationships and marginalisation this next section looks more generally at rapport building during remote consultations, and continuity of care. Many respondents reported their experiences of care as being cold and discrete, not allowing for discussion of wellbeing beyond the concern the consultation was booked for, leaving little room for personal relationship building. Patients also spoke about feeling rushed during consultations, relating this directly to their inability to share psychosocial information with their GP. Whilst patients did not frame this as directly related to the modality of the consultation, GPs clearly linked remote consultations with challenges building rapport and relationship formation. Further, patients alluded to the impact of consultation modality through comments such as 'just a quick call'. The responses given by both patients and GPs point towards the development of more 'de-personalised' care, with a strong focus on functional clinical information only.

The importance of a good patient- doctor relationship, and therapeutic alliance has been long recognised in General Practice (Balint, 1968; Bazzano et al., 2018; Feldman, 1974; Funderskov et al., 2019; Hinman et al., 2017; Imlach et al., 2020; Kairy et al., 2013; Lawford et al., 2019; Walthall et al., 2022). Previous research has highlighted the importance of perceived GP empathy as part of a therapeutic relationship for both patient satisfaction as well as clinical outcomes (Derksen et al., 2013; Hojat et al., 2011; Kim et al., 2004; Lelorain et al., 2012; Mercer & Reynolds, 2002; Neumann et al., 2007; Reynolds, 2000; Shapiro, 2008). Therapeutic relationships between doctors and patients have been linked with various positive outcomes including shared decision-making, treatment planning, and treatment adherence (Buszewicz et al., 2006; Hojat et al., 2011; Mercer & Reynolds, 2002). This occurs through several mechanisms, including increased levels of disclosure which allows the doctor to gather sufficient information (Dixon et al., 2022; van Dulmen & van den Brink-Muinen, 2004). Therefore, a reported reduction in therapeutic alliances between doctors and patients may have tangible healthcare outcomes for patients.

The accounts of difficulty developing rapport during remote consultations aligns with previous research which has shown that therapeutic relationship building during remote consultations is more challenging (Bazzano et al., 2018; Funderskov et al., 2019; Hinman et al., 2017; Imlach et al., 2020; Kairy et al., 2013; Lawford et al., 2019; Walthall et al., 2022). Respondents spoke about this leading to them feeling treated like an 'object' and interpreting their GP as uncaring. Work by Bernsten (in Mann et al., 2021) has indicated that remote consultations can lead to lower levels of personalised care and patients feeling less heard and seen as a person, a finding strongly supported by these data. Further, respondents' accounts of feeling like their GP does not care about them points towards a dilution of the therapeutic relationship over the phone, which has also been outlined in previous studies (Bazzano et al., 2018; Funderskov et al., 2019; Hinman et al., 2017; Imlach et al., 2020; Kairy et al., 2013; Lawford et al., 2019; Walthall et al., 2022).

One of the impacts of reduced therapeutic alliance, especially when speaking to an unknown GP is that patients may feel uncomfortable disclosing private information. This was discussed by GPs who commented on it feeling inappropriate to ask very personal and emotional questions over the phone. However, this lies in direct contrast with evidence presented in chapter seven showing GPs may use increased questioning in order to gather sufficient clinical and/or safeguarding information. This indicates that there may be certain sensitive topics of conversation which are experienced as too inappropriate to discuss over the phone by both GPs and patients which can lead to an informationally sparse consultation. Previous research has shown that remote consultations are less rich in information and harder to establish trust during (Car et al., 2020; Hammersley et al., 2019). A comparison of face-to-face and telephone consultations found that on average telephone consultations are shorter, deal with fewer health concerns, lead to less data gathering and less counselling and rapport building (Hammersley et al., 2019). This echoes findings from other studies, for instance Groundswells's study of remote primary care use during COVID-19 by people experiencing homelessness (Groundswell., 2020). They found that remote consultations were perceived as more likely to be 'mono-issue' which was a particular challenge for this population group who often suffer from multi-morbidities and tend to consult less, meaning there's a strong preference for each consultation to cover a range of issues. The results of this study support this evidence as well as indicating that this may be interpreted by patients as less ‘caring’ care.

Further, previous work has shown that patients often come to GP consultations with ‘hidden agendas’ (Barsky, 1981) – meaning that the reason they are seeking time with their doctor may not be that which is initially stated when making an appointment. This can lead to patients uncovering their ‘true’ motive at the end of a consultation, what is sometimes called a ‘doorknob’ diagnosis or phenomenon (Kowalski et al., 2018). Remote consultations, through their reduction in exploratory conversation, and shorter times have the potential to prevent hidden agendas from coming out during consultations, with potential implications for clinical information gathering. This is a concern also picked up on in Greenhalgh et al.’s (2021) analysis of data on remote consultations during the first COVID-19 lockdown in the UK.

Additionally, the importance of empathy for patient disclosure about psychosocial and social issues has also been documented (van Dulmen & van den Brink-Muinen, 2004). Given the vulnerable circumstances many of the study respondents found themselves in, including sleeping rough; being unable to afford heating or food; experiencing coercive relationships; and chronic precarity, the need for psychosocial care may be heightened when compared to the general population. This was suggested within the data by the recurring comments made by respondents about the lack of psychosocial care they receive from their GP, and their interpretation of this as low-quality care. The role of the GP in psychosocial care can be critical, as they make referrals to foodbanks, and social prescribers who may help with housing, and other link services. In the absence of a space in which to discuss psychosocial issues related to living conditions, it may be more challenging for marginalised individuals to make their way into services which can offer assistance.

Whilst remote consultations contribute to these effects, the most cited disruption to therapeutic relationship building was the reduction in continuity of care. This is a continuation of a longer term trend in decreased continuity of care in General Practice. Personal lists, where GPs have their own list of patients for whom they are accountable and deliver the majority of their care are considered the gold standard of continuity. Estimates now suggest that fewer than 10% of practices have this system in place, despite once being the norm (*The Future of General Practice*, 2022). As of 2015–2016, all patients were required to have a named GP to take 'lead responsibility for the coordination of all services required under the contract' (Freeman & Hughes, 2010). However, respondents' accounts of rarely seeing the same GP indicate that whilst patients may theoretically have a named GP, they may often see other GPs or other members of the primary care team.

Disruptions to continuity of care were presented by GPs as a result of strained resources, a key theme throughout this study, necessitating sending patients to primary care team members for less clinically complex needs. This development is supported by accounts given by patients of experiences of having to 'prove' clinical validity in order to be seen by a GP. Further, the increased use of tests prior to consultation, as discussed within this results chapter, contributes to increasingly high eligibility thresholds. Proving medical validity has long been an element of seeking primary care – with terms such as 'doctorability' (Heritage, 2009) or 'candidacy' (Tookey et al., 2018) used to describe this process. This study indicates that widening primary of care teams may exaggerate this process. Notably, Hinton et al.'s (2023) study of remote antenatal care found that continuity of care may be more challenging to achieve remotely – indicating that the decrease in relational continuity of care might be a result of both changes to the structure of primary care teams as well as a shift to remote care.

Patients and GPs reported that consultations were becoming more discrete, as a result of a general move from relationship continuity to management continuity. This led to patients experiencing distress as they're unable to speak with a GP they knew and felt known *by*. This in turn can lead to lower levels of disclosure by patients, as well as removing potentially relevant longer term contextual knowledge about patients' history and living conditions. The importance of both short-term and long-term implications of continuity of care was also discussed. In the short-term, having contact with a named GP may lead to higher levels of disclosure, in the long-term GPs can build up important contextual information on patients which helps them in their ability to diagnose and safeguard. Further, respondents indicated that remote consultations were easier if there was already an established doctor-patient relationship, indicating that continuity rather than modality is the key factor.

Previous research has shown that successful remote consultations require mutual trust between patients and doctors, and an established relationship between a GP and patient can mitigate some of the negative effects of remote consultations on relationships (Donaghy et al., 2019; Imlach et al., 2020; Larson & Yao, 2005). However, Imlach's (2020) study of telehealth consultations in General Practice during pandemic lockdowns showed that even with an established relationship, if GPs did not focus on rapport building remotely the positive benefits of a prior relationship were nullified, indicating the ongoing nature of therapeutic relationship building.

The changes to patient-doctor relationships were described by GPs as a move towards transactionality, a word also used in Mann et al.'s (2021) assessment of digital first primary care. When compared with patient respondents the term 'transaction' appears misrepresentative, as it entails an exchange. Patients are not experiencing NHS remote consultations as a transactional exchange with their GP, but as an interactional *loss*. GPs also discussed these changes as a loss, both in terms of the type of care they can provide as well as their job satisfaction. This suggests that remote healthcare may be removing important interactional elements of care resulting in an interactionally light, modular primary care system which comes at a cost for both patients and doctors.

In conclusion, recently the concept of 'personalised care' has become a guiding principle within the NHS as a central part of the NHS Long Term Plan (2019). "Personalised care is a process of negotiation between a patient and their clinician which is defined by empathy, trust and respect leading to a patient feeling heard and seen as a person" (Mann et al., 2021, p. 13). The results of this study indicate that whilst personalised care may be a goal of primary care, that it is being undermined by changes to the system which combine to reduce therapeutic alliance and relationship building between patients and doctors, resulting in 'de-personalised' care.

The following chapter will reflect on the process of data collection and analysis, before proceeding onto chapter ten the Discussion chapter.

Chapter 9. Reflections on Data Collection and Analysis

Introduction

The previous chapter was the final results chapter of this thesis. This chapter sits between the results chapters (five, six, seven and eight) and the Discussion chapter in which the overall findings of this study are discussed. This chapter looks at my experiences as a researcher of conducting this study, and how this experience as well as my own positionality may have influenced the data collection and analysis process. Research is a subjective, embodied experience. The researcher influences the research process at every stage and interaction, from the design through data collection, analysis, and write-up. As outlined in the introduction, in order to reflect the subjective nature of the content discussed, this chapter is written in first person.

Embodied research

This first section will look directly at my experiences as a researcher doing data collection – focusing on what it was like to work at the chosen fieldwork sites. My fieldwork took place between early November 2021 and April 2022. During this period, I spent time at the three fieldwork sites I have described: a Foodbank, a

Community Hub, and a Drop-in Centre for migrants, refugees, and asylum seekers.

Data collection can be an intense experience, especially if the research topic includes hearing about stressful human experiences and/or working with vulnerable groups. Qualitative fieldwork is, in many ways, like any form of social interaction and subject to the same forms of complexities, ambiguities, and unpredictability (Mann, 1976). The stories the researcher hears about may be of suffering, social injustices, or other upsetting experiences (Morse & Field, 1995). Qualitative research seeks to uncover and explore, but also to bear witness, and give voice to experiences which may otherwise go unheard. Whilst this can be viewed as a transformative research process, or a gateway to advocacy work, the researcher is not simply a translator but is intimately implicated in the research process itself. The following account details how this played out during my experience of data collection.

During my in-depth interviews with participants, I heard various stories of social injustice and distress. This ranged from detailed descriptions of mental health issues, often accompanied by crying during the interview, as well as accounts of suicidal ideation. I also heard descriptions of extreme poverty – sleeping on the streets without blankets, living in mould and rat-infested tenancies, and not being able to afford to feed children. Bearing witness to these instances had several effects, two of which I will discuss – firstly the impact on me as the researcher and how this may have affected my data collection, secondly, the way in which the data was interpreted and presented in this study.

Hearing about distressing experiences during research has been termed by Alty and Rodham (1998) the 'Ouch! Factor', referring to "certain experiences encountered in the process of conducting qualitative research: which may include "a short sharp shock to the researcher to those situations and experiences that can develop into a chronic ache if not addressed early" (p.275). Throughout my fieldwork period I experienced 'Ouch! Factor' interactions, which over time began to lead to a chronic sense of unease and exhaustion.

As a researcher we are taught to in some senses keep ourselves outside of the research itself, not developing personal bonds with participants. However, we are also encouraged to engage in conversations with participants, in a bid to 'build rapport' (Duncombe & Jessop, 2002). In the case of this research, that meant holding therapeutic space for participants to speak during interviews. It also meant holding therapeutic space for staff members as they discussed their challenges with me, which became less comfortable as time went on.

Birch and Miller (2000) have written on the therapeutic possibilities of interviews, which may yet be uncomfortable for the interviewer. Holding therapeutic space and witnessing distress can lead to what (Morse & Mitcham, 1997) term 'compathy'– "the acquisition of the distress and/or physiological symptoms (including pain) of others by an apparently healthy individual following contact with the physical distress of another"(p.650). I experienced this on multiple occasions during fieldwork, specifically after interviews in which participants wept, shouted, or were physically volatile e.g., banging the table. I would come away from them on edge. Whilst it has been argued that qualitative research may be cathartic for study participants (Gale & Newfield, 1992; Ortiz, 2001) and this was reflected to me by participants who told me at the end of the interview that it had felt like 'therapy', the impact of this on the researcher themselves is often unrecognised. I am not a trained healthcare professional, or therapist, and taking on this sometimes-therapeutic role was a challenge. This took various forms as either guilt, strong empathy, or occasionally a sense of personal boundary violation. There were several occasions whilst observing in the field that I felt unsafe due to erratic behaviour of service users who were either on substances or had more severe untreated mental health problems. These instances led to a guardedness on my part, and ultimately led to feelings of anxiety before going to fieldwork sites particularly the Community Hub.

This 'data' on my own experience of doing the work reflects what it can be like doing work with individuals with high psychosocial needs. Emotional and physical burnout by those working with marginalised groups in the third sector, as well as healthcare professionals is a well-known phenomenon. O'Dowd (1988) coined the term 'Heartsink' patients to describe patients who "evoke an overwhelming mixture of exasperation, defeat, and sometimes plain dislike that causes the heart to sink when they consult" (p.528). 'Heartsink patients' often have many chronic medical and psychological problems, yet are not easily definable by a set of characteristics. Lee (2006) advocated for terminology to move towards heartsink 'reactions' rather than 'patients', shifting responsibility to doctors rather than inherent characteristics of any patient. Moscrop (2011) suggests instead the term 'heartsink relationships'. This final term seems most closely reflective of my own experiences of doing research whereby the interactional dynamic with participants was co-created as I asked them to disclose personal information to me. The reasons why the populations I worked with experience discrimination from services is complex and related to many larger structural factors. However, there is also an interpersonal element to it, which may be played out between individuals, and I interpret some of my experiences during fieldwork of an expression of this 'heartsink relationship' discussed within clinical care.

Various techniques for managing the sorts of experiences outlined above have been discussed by other researchers, including peer discussion, debriefing, and the consideration of boundary management strategies as self-care strategies for qualitative researchers (Dickson-Swift et al., 2007; Pickett et al., 1994). However, conducting this fieldwork during a time when my university was almost entirely empty of staff and students because of COVID-19, the more informal debriefing of fieldwork did not happen. By the fourth month of my fieldwork, I was experiencing signs of burnout, which in the end played a role in the termination of the fieldwork period once the scheduled number of interviews had been completed.

Ultimately, whilst I believe that I had collected sufficient information to write my study, my decision to finish fieldwork was also a personal one. “Researcher saturation” (Wray et al., 2008) is a term used to describe when a researcher has reached their capacity within the field and can be described as:

> Researchers who are involved in all phases of emotionally demanding research; that is, data collection (recruiting, observing, expanding field notes, and interviewing), transcription, and data analysis repeatedly relive difficult events, which might potentially compromise the researchers’ well-being and, in turn, the research process and data validity. (Wray et al., 2008, p. 1)

The research period was an eye-opening experience, which I was lucky to have the opportunity to do. However, it was also a time which felt chaotic, and became more challenging over months of fieldwork. It is recognised that “observing frequent intense emotional responses of others, [and] very personal activities or violent behaviours can be psychologically and emotionally wrenching for investigators regardless of how experienced they are in conducting research” (Wray et al., 2008, p. 173). Further, it is acknowledged that the emotional response of the interviewer may be repeated upon transcription and analysis of the data (Gregory et al., 1997; Morrell-Bellai et al., 1997). Due to the limited time available to me, I was simultaneously recruiting, observing, writing-up field notes, interviewing, and transcribing. Towards the end of my fieldwork, I had reached what I now recognise as researcher saturation which, alongside having collected enough evidence to write the study, contributed to the cessation of the fieldwork period.

Moving on now to the second point I want to make about the impact of hearing about distressing experiences during fieldwork. Having gone into this research already with the perspective of wanting to write a thesis which advocates for health equity, and inclusive access to primary care – the experience of doing fieldwork strengthened this resolve many times over. Straddling the line between being a social researcher and a social presence in my fieldwork sites meant that I got to be on friendly terms with some respondents who were regular attendees at the service I was collecting data at. Having borne witness to respondents' often distressing accounts I felt an important sense of duty to produce work which was reflective of the ways in which people are being constantly re-marginalised within our society, specifically in primary care, with the hope that this may lead to change in the system.

This meant that writing up the data, I have been keen to draw out as clearly as possible the barriers to care people are experiencing and at times struggled to problematise the accounts given by service users or question the complex interactions between people and systems which are less straight forward than the system actively marginalising patients. I hope through constant reflection, feedback and re-iteration of each chapter that I have been able to strike a balance which takes both an advocacy stance as well as being reflective of several realities inherent within the situation.

Researcher positionality

Moving now to reflect on my own position within the research context and how this may have influenced the study. Conducting research close to home comes with benefits and challenges. On a practical level it makes it easier, the commuting times are shorter, and the researcher is not required to relocate. Further, for this research an interpreter was not necessary meaning I could conduct interviews myself without assistance. However, this sort of close proximity research also comes with challenges which includes boundary blurring, due to a lack of temporal and spatial dislocation from the fieldwork site and experiences. The shared cultural signifiers (Bourdieu, 1977, 1984) between researcher and participant can throw into relief the social differences, for instance relative access to resources – the topic of the following account of my experience.

Social differences between participants and researcher can exist in relation to a range of demographic and other factors. These include race, class, socio-economic status, age, and gender (Green & Thorogood, 2014). The effects of these differences are complex and enters into the research process itself … and importantly influences the relationship with those we are researching (Edwards, 1990). There were a range of social differences between myself and my participants, including age, gender, ethnicity, and class, as well as professional role. However, class was the most cross cutting of these and in all three services there was a noticeable split between white middle-class staff members, and a more diverse and working-class client group. Previous literature (e.g., Mao & Feldman, 2019; Mellor et al., 2014) on class differences during interviews has called for sustained and considered reflection about the impact of this on researcher-participant interactions. Drawing on Bourdieu's (1977, 1984) conceptualisation, class can be seen as the cultural and social resources, or 'capital', which produce a character structure, or 'habitus', that generates particular sorts of behaviour in given contexts, or 'fields'.

Relative to more visible forms of social difference such as skin colour, class differences are grounded in social differences related to resource distribution. Belonging to a certain class may be communicated through observable cues such as clothing, accents, and speech, as well as more subtly through taken-for-granted values, beliefs, and expectations (Mao & Feldman, 2019). Whilst I tried to limit observable class signifiers whilst at fieldwork sites to avoid accentuating distance, for instance through my clothing, there are elements of class identity which are less mutable such as accent (Hey, 1996) and my accent was occasionally commented on by participants as well as staff members. During fieldwork I was aware of the potential for class differences to enact 'symbolic violence' (Bourdieu, 1984, 1991) whereby the relative differences between my position and that of participants at fieldwork sites might throw into relief the difference in our social position and access to resources. This was especially the case at the foodbank, where there was a quite visible split between older white women on the serving side of the table, and a younger, much more diverse customer base. Whilst there were many white customers, there were no non-white staff members. At this site I felt that my position, as one of someone with resources was accentuated by my association with the staff members, and after my first few visits I tried not to spend any time serving behind the tables, instead aligning myself with those in the queue.

Whilst it is difficult to determine how exactly these differences may have influenced the research process, I believe there are two ways in which it was felt. Firstly, during recruitment, particularly at the foodbank I experienced a lot of suspicion about my presence at the site, as well deliberate avoidance speaking to me. This may have been for various reasons including that this was the only field site where I was making my own introduction to service users. However, I sensed that the difference between me and the participants, may have contributed to this. This came through in subtle ways, for instance a pattern of men introducing themselves to me by what they used to do before they'd been in financial hardship, positioning themselves as someone who didn't expect to find themselves here. Interestingly I never experienced this with the women I met. Another way in which it was signified was by people commenting on my clothing and that it looked smart, or warm – suggesting a visible difference in what I was able to wear versus what they had access to, despite efforts I made to wear clothing which limited any visible differences. In general, I noticed that the more confident, and articulate users of the foodbank were most willing to speak with me, and that those who I was told by staff were on the very edges of marginalisation and had been long-term recurrent users of the foodbank regarded me with a higher degree of suspicion. When trying to recruit people I had to be very careful about the power dynamics and was quick to switch the conversation back to chatting if I felt that people were looking nervous of me or upset. This may have led to a bias in the sample recruited, as those who perhaps would have been able to speak most strongly to the experience of accessing healthcare whilst marginalised, were also the least likely to agree to participate.

The other way in which this social difference between myself and participants may have played out was during interviews themselves. Since social class entails enduring differences in perceptions, attitudes, and access to resources (Argyle, 1994 ; Bobo & Lamont, 2002; Bowman et al., 2009 in Mao & Feldman, 2019), class differences between researchers and participants can shape the style of conversation, degree of trust, amount of disclosure, and inferred meanings. (Mao & Feldman, 2019, p. 127). Overall, I felt that I was able to develop good rapport with most respondents. However, whilst conversations were rich enough to help me to understand my research topic it is impossible to know what participants *didn't* tell me about.

Another characteristic which is known to impact on the collection of qualitative data, is the position of the researcher as a 'professional' (Hoddinott & Pill, 1997; Richards & Emslie, 2000). In my case this was as a PhD researcher from The

London School of Hygiene and Tropical Medicine. Having begun data collection introducing myself in these terms, I quickly realised that this could be an alienating introduction for several reasons which includes 'PhD' is not a familiar term to everyone; using the word 'researcher' implies that those I was talking to were to be 'researched' which has pejorative associations; and finally that the name of my university was long and formal sounding and was interpreted by most people to mean that I was a clinical doctor. The introduction I shifted to using was that I was a student from a university doing some work on access to the doctor. Interestingly, this often led to people assuming that I was younger than I was and offering to 'help out with my project' much more readily. Further, by distancing myself from the medical profession I believe I was perhaps more able to elicit more honest responses around respondents' experiences of healthcare, as I was also on the 'outside looking in'. This is a phenomenon which was picked up on in a study by Richards and Emslie (2000) which compared qualitative interviewing between a researcher who told respondents she was a GP, and her colleague who introduced herself as a researcher. Their paper concludes that for the interviewer identifying as a researcher her professional background became more muted to respondents and other characteristics such as her gender and age came to the fore as she was referred to as 'the girl from the University'. I believe that this was also the case for me.

The ethical implications of power differences during research were highlighted by the offer of vouchers for participation. The ethics of this were discussed in detail with my supervisors during the research design, as well as with gatekeepers to the fieldwork sites and a PPI panel I discussed my methodology with. It was decided based on these discussions as well as NIHR guidance that payment in-kind through £25 vouchers (Sainsbury's or Amazon) was appropriate to reimburse participants for their time. Whilst for some participants this appeared to have little bearing on their willingness to take part, for the majority this was a strong driver for participation. This was particularly the case in the Community Hub, where recruitment was very challenging. The potential coerciveness of this process in which I could provide a needed resource in exchange for participation was uncomfortable – and as far as possible I tried to frame it as a ‘thank you’ for their time, rather than an incentive to take part. There were several occasions in which I met respondents again after having interviewed them and was asked if I had any more food vouchers. This again, highlighted the very tangible difference in both power and access to resources between myself as the researcher and respondents – and was something I struggled to feel comfortable with.

Being a young woman doing fieldwork also had an impact on data collection. Whilst overall I felt safe at my fieldwork sites, my identity as a woman sometimes placed me in uncomfortable positions. There were times when participants spoke about how I looked in front of me or made inappropriate comments or physical touch. In some instances, behaviour like this prevented me from interviewing male participants I may otherwise have done.

On the other hand, I felt that being a woman was beneficial to my research, although the counterfactual of my being a man in the same settings is of course unknowable. Being a woman enabled me to speak openly and honestly with women who revealed to me intimate details of their lives including access to sexual health and gynaecological issues. It’s also possible that being a woman had this effect when interviewing men, as women may traditionally be seen as caretakers (Horn, 1997) and as an interviewer you are “required to take on an acquiescent, attentive, and assenting role very close to the traditional notions of femininity” (Green et al., 1993 p. 630) therefore accentuating this characteristic. Schwalbe and Wolkomir (2001) argue that we should move beyond ‘who is asking whom?’ to ‘who is asking whom about what?’. In this instance, asking about healthcare, I believe that my role as a woman was advantageous to my study in eliciting intimate details and building rapport around sensitive topics. I think it may also have played a role in my fitting in with staff at fieldwork sites which were overwhelmingly staffed by white female volunteers.

This is an example of how my own intersectional identity came to bare on my research, with different elements of my character e.g., being a white, middle-class, professional, female, affecting power dynamics in different ways depending on who I was interacting with. As has been noted by other researchers this is one of the reasons why trying to 'match' researchers and participants is not always advised, as it assumes that there is only one 'truth' about identity, foregrounding this characteristic (Mellor et al., 2014; Thwaites, 2017). This very matter of intersectionality, and how it works to produce shifting power dynamics is key to my research and has been interesting to reflect on as both a process within the research as well as an insight within the data.

Ethics in Action

This section 'Ethics in Action' differs slightly from the preceding and following ones, as it is less about the subjective experience of doing this research. Instead, it is a short commentary on one of the challenges which emerged during data collection – which speaks to some of the themes I have spoken about in this chapter to do with power dynamics when working with marginalised populations.

When designing this study, it was raised by gatekeepers to the field sites, the PPI panel I sat with, and my academic advisors, that some of the individuals I would try to recruit into this study would have low literacy levels. This necessitated an informed consent procedure which was designed to accommodate this. I initially made the decision to have two options for taking informed consent: written and verbal. The written consent procedure required the signature of myself and the respondent, the verbal required the signature of myself, the respondent, and a witness. The feedback I received from the ethics committee included a concern that I would be unable to differentiate who was or was not literate and therefore could potentially stigmatise respondents by having to ask them to declare this. Off the back of this feedback, I made the decision to make the informed consent procedure verbal by default. However, when I began data collection this threw up several challenges, which are detailed below in an excerpt from a letter which I sent to the ethics committee to seek an amendment to the study design:

"Dear [ethics committee]

I recently received ethical approval for my study looking at the impact of digitalisation of General Practice in the UK on marginalised groups. I have since started fieldwork and have been going to a foodbank in London to recruit participants into my study. Despite all of our efforts to create an ethical process for informed consent and recording consent, a new ethical dilemma has emerged on the ground, which is not workable. Below I will present the challenges to you and the amendment I would like to make to my study.

I have ethics approval to take verbal informed consent from individuals which is audio recorded, however the approval I have requires an impartial witness. In practice this has meant data collection is tied to the fieldwork site (a foodbank in a church hall), in order to also have an impartial witness present. In practice this does not work for people as it does not allow for the flexibility of meeting them at a time and place which is appropriate for them – for instance a local café or park, or a private room at the church (which the reverend has agreed for me to use) on a day other than the one morning a week that the foodbank runs[9]. Having met the people using the foodbank, many of whom are keen to take part in my study, the strict time constrictions imposed by the need for an impartial witness on site, do not align with the way in which their lives are set up and run, which includes pressures to attend services related to their welfare needs, or childcare. This limits their ability to take part, thus potentially excluding their voices from the study. Further, it adds a layer of formality to the process which makes the participants into 'objects' of study,

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[9] In practice, interviews did not move into these spaces, and remained situated at fieldwork sites

rather than individuals with valuable experiences and stories which they can share with me in a more informal interview set up. The need for an impartial witness contributes to a sense of lack of agency, as not only are they recipients of charity at the foodbank they attend, but their ability to independently consent to taking part in the study is challenged by the need for a gatekeeper to stand witness. As such, it forms a microaggression against participants, and replicates the very oppression which I am seeking to understand and address through my research.

Further, the ethics committee had previously asked me how I intended to identify those with low literacy levels in order to take informed consent. My response to this was to make the entire consent procedure verbal as a default, in order that no individual had to disclose low literacy levels to me, which can be potentially stigmatising. Whilst conducting fieldwork it has become clear to me that I will be able to get a sense of people's literacy levels when I introduce myself to them, tell them about the study and offer them an information sheet- for instance I have had people say to me "oh I can't read this, because I am dyslexic", "I don't have my glasses" or "my English isn't so good" as a response to being shown a written information sheet. Staff members were able to later inform me that the man presenting as dyslexic was illiterate. However other participants have taken the information sheet and had a look over it whilst at the queue for the foodbank and asked me further questions. I have in each instance offered to people that I read out the information sheet to them and go through it with them– at which point participants have either waived this option, or indicated that they would like it read out to them.

In light of this I would like to request an amendment to my informed consent procedure. I would like to be able to take written consent from individuals who are able to give written consent, after having been given several opportunities to either have the information sheet read out to them, or to give verbal consent. This will contribute to a sense of co-creation in the research and avoid the unnecessary set up of a power hierarchy at the opening of conversations, thus giving dignity to my participants. This will lead to two informed consent procedures 1) written consent for those who choose this 2) verbal consent for those who choose this or indicate to me through other means that literacy may be an issue. Secondly, for those who do give verbal consent, I think it is more appropriate and ethical to audio record in full this consent procedure, and not require the additional burden of an impartial witness which ties the interview procedure to a very strict time and place, and also adds a layer of formality to the study which is oppressive for participants. Further, this group of participants may be particularly sensitive to power hierarchies, something I have spoken about in length with my gatekeepers, and I feel that the need for an impartial witness

will add to a sense of being an 'object' of study, rather than a consenting adult who is able to independently make a choice to take part."
[18/11/2021]

This letter lays out the gap which can emerge between an ethically designed study and ethics in practice – which often requires a greater degree of flexibility to act in accordance with the reality of the situation on the ground. This draws attention to one of the challenges which can emerge during data collection with any population, but particularly when working with populations with whom there are already sensitivities to power dynamics between the researcher and the researched. This relates to the earlier discussion of how my positionality during data collection potentially impacted on the data collected, and how interactions between researchers and study respondents necessarily exists within a wider context which impacts on how data is collected. It also highlights the importance for considering the potential for ethics as per a protocol and ethical decision making during a study to diverge.

Analysis

For the analysis of this study data I have used Braun and Clark's Reflexive Thematic Analysis (TA) (Braun & Clarke, 2006, 2022) – as outlined in the methodology chapter. A key aspect of this method of analysis is the deliberate recognition of researcher subjectivity as a "tool" for reflexive analysis, not a problem to be managed or controlled, but a resource of analysis (Gough & Madill, 2012). The notion of 'research bias', a commonly discussed flaw in public health research, which implies the possibility of unbiased or objective knowledge generation is incompatible with reflexive TA, which recognises all knowledge generation as inherently subjective and situated (Braun & Clarke, 2022). As part of this process it is critical to reflexive TA that the researcher articulates and reflects on their generative role in the analysis, striving to "own their perspectives" (Elliott et al., 1999).

There are several key areas in which I believe my own subjectivity came into play when conducting data analysis. My research questions and interest were key drivers in how the interview guides (appendix 1) were developed and the questions I concentrated on whilst conducting data collection. This was also guided by the input of previously published materials which are also biased in their interpretations, and largely from the fields of public health and sociology. Sociology in particular places focus on inequalities and the tensions between systems and users of the system.

This may have led to a skewing of the interview data towards a discussion of inequities with a focus on what the challenges were with accessing the GP, and how changes to the primary care system may be contributing to these. That is to say, I have scant data on the potential improvements to the primary care system, or positive framings of access to care. In general, I believe this reflected the direction of travel of the interviews as led by participants. However, it is also the case that during data analysis I was less attuned to positive messages around the healthcare system than I may have been if I'd asked different questions of the data.

Conclusions

This chapter has outlined my reflections of doing data collection and analysis for this study. I have tried my best to strike a balance between reflective academic practice, and personal reflections – to give the reader a better idea of who I am as the researcher and what impact this had on my study. The next chapter 'Discussion' brings together all of the study findings to reflect on the key themes, to explore how this study has built on our current knowledge, and to identify the implications for practice and policy.

Chapter 10. Discussion

Introduction

This discussion draws together the various themes presented across the results chapters (five to eight), commenting on how changes to the primary care system coalesce to create increasingly de-personalised experiences of care, and a passing on of work to patients. This is considered in relation to marginal identities, and how changes to the primary care system may reproduce, exaggerate, and create structural barriers to care which are actively marginalising. This discussion will conclude by arguing that a shift towards greater levels of remote consultations, combined with lower levels of relational continuity are creating both clinical and safeguarding risks, which are skewed towards marginalised groups, and risk amplifying health inequalities.

The specific characteristics of marginalisation which may exclude patients from primary care which will be discussed in this chapter are as follows:

- Unstable access to digital devices and connectivity which makes it difficult to make appointments over the phone or online or to have telephone or video consultations.
- Challenges with health literacy which makes it difficult to explain healthcare needs, a challenge which is exacerbated by a loss of non-verbal and visual cues during remote consultations.
- Low English proficiency which makes it difficult to explain healthcare needs, a challenge which is exacerbated by a loss of non-verbal and visual cues during remote consultation.
- Complex psychosocial needs which require more attention to therapeutic alliance building and may require more exploratory consultations both of which are disrupted during telephone consultations and by reduced relational continuity of care.
- Multimorbidity which requires more attention to therapeutic alliance building and may require more exploratory consultations both of which are disrupted during telephone consultations and by reduced relational continuity of care.
- Poor mental health which requires more attention to therapeutic alliance building which is disrupted during telephone consultations and by reduced relational continuity of care.

The primary research question guiding this study was, “What is the relationship between marginalisation and remote service delivery in primary healthcare experiences in the UK?” The analytical results chapters explored various aspects of primary care, including appointment scheduling (Chapter 5), remote consultations (Chapters 6 and 7), and changes in doctor-patient relationships resulting from remote care and wider shifts in the primary care system (Chapter 8). Each chapter explored the relationship between marginalisation and healthcare from a different angle. This exploration included issues such as limited access to material resources blocking engagement with services and the specific challenges posed by remote consultations, particularly in addressing mental health or high psychosocial needs. While the focus of the study centred on remote service delivery, in line with the primary research question, the empirical data necessitated a broader examination of changes to the healthcare system occurring concurrently with the shift toward remote service delivery.

Chapters 6 and 7, which focused on remote consultations, are most closely related to the original research question. In addressing this primary research question, the study has revealed that remote service delivery introduces barriers to effective care, which can impede access for marginalised individuals. These barriers arise from the demands placed on patients during remote consultations, as outlined throughout the study. These demands include the need to create private spaces for care, articulate healthcare needs verbally, communicate specific symptoms verbally, and adapt to changes in patient-doctor relationships that can lead to a decrease in psychosocial care. Furthermore, these barriers tend to compound, as a patient facing limitations in one domain is more likely to encounter limitations in another, due to the multifaceted nature of marginalisation.

This study has highlighted however that remote service delivery represents only one facet of broader changes in the healthcare system. These changes include the restructuring of the primary care team and the evolving role of GPs as more specialised clinicians. Therefore, while the primary research question served as an essential starting point for this study, it does not offer a comprehensive understanding of how marginalisation interacts with experiences of primary care – the focus of this Discussion chapter.

This Discussion will begin by placing the findings of this study in relation to the contemporary NHS policy intentions of 'digitalisation' and 'personalisation', as well as the study context of COVID-19. Here, the term 'digital' will be unpacked to understand how this might be understood in relation to the study findings and how respondents interact with the healthcare system, making an argument that 'remote' rather than digital may be a more accurate term within the study context. The discussion will then turn to a broader analysis of study findings, presenting the argument that recent and ongoing changes to the primary care system are producing distance between patients and doctors, physically, interpersonally, and emotionally. The subsequent section will look at how work is produced and redistributed by the distance which is created, and how these different forms of work interact with the cognitive, material and network resources available to patients. This will be considered in terms of responsibilisation, and how patients are, or are not, able to rise to the demands being placed on them, using a Burden of Treatment Theory lens as a way of understanding how capacity interacts with demands. It is in this section that the association between marginalisation and the changes to the primary care system are drawn out most clearly.

The discussion will then turn to look at how responsibilisation comes with assumptions about patients' capacities to perform different forms of work, and in turn, how this creates both clinical and safeguarding risks, when patients are unable to fulfil these expectations. This is followed by a deeper examination of how distancing within the primary care system is happening on an interpersonal level due to remote consultations and a reduction in relational continuity, and the resulting changes to the patient-doctor relationship. The ways in which these various processes interrelate are then considered in relation to how we might understand marginalisation in primary care, and how the changes examined might be productive of marginalisation through the creation of structural barriers to care. Throughout, the findings of this study will be contextualised in reference to policy documentation as well as other literature within the field. This discussion concludes with a commentary on what this study adds to our current understanding of the primary care system and issues of access for marginalised groups, and the potential implications of this study both for practice and research.

Context

This chapter will begin by placing the findings of this study in relation to the contemporary NHS policy intentions of digitalisation and personalisation, as well as the study context of COVID-19, recapping some of the material introduced at the outset within the Literature Review.

The context in which this study has taken place is critically important in understanding the findings – both in terms of policy intentions and the influence of COVID-19 on the way in which healthcare was and will be delivered going forwards. Data collection for this study took place November 2021- May 2022, a time at which the UK was facing the emergence of a new variant of concern – Omicron – whilst also beginning to move out of pandemic protocols, other than those bought back in for the winter. The responses given by people interviewed are unique to their time and reflect a period in which society was emerging 'out' of the pandemic with high levels of heterogeneity between how both healthcare services and individuals approached the virus and levels of in person contact.

All of these changes are also underpinned by NHS policy intentions which had been set prior to the pandemic. Most relevant to this study is the drive towards increased digitalisation of services across the NHS, and especially primary care, alongside an increased focus on 'personalisation' of care. The NHS Long Term Plan (2019), called for a digital-first approach in which "people will be empowered, and their experience of health and care will be transformed, by the ability to access, manage and contribute to digital tools, information and services" (p.93). Crucially, the Long-Term Plan committed to every patient having the right to be offered digital-first primary care by 2023/24, including remote consultations. Additionally, personalised care is one of the five major changes laid out in the NHS Long Term Plan which states "the NHS also needs a more fundamental shift in how we work alongside patients and individuals to deliver more person-centred care, recognising – as National Voices has championed – the importance of 'what matters to someone' is not just 'what's the matter with someone" (NHS, 2019, p. 24).

As outlined in the literature review the term 'digital care' may be used by the NHS to refer to online and telephone booking systems as well as video and telephone consultations. However, due to the low use of online and video services by study respondents, the focus of the findings has been on telephone appointment booking and telephone consultations – making the focus of the study 'remote' rather than 'digital'. Whilst online booking systems such as e-consult may have been available to respondents, these were not in use by the majority, and only mentioned through comments on how to avoid using them. Digital devices in this context therefore refers to the more 'basic' forms of digital technologies – mobile phones being used to make telephone calls, rather than, for instance, smartphones being used to fill out e-consults. A determinant of the themes discussed in this study, as well as a theme in of itself, is this low use of online services by respondents. Many respondents had smart phones, a small number made use of a 'dumb phone' without internet capacity. *However*, these smartphones when in use were not being used to engage with NHS online services but being used as a telephone only for service interactions. This suggests that the meaning of a digital NHS may itself be a fluid term, as marginalised groups may make use of the most basic form of digital NHS only, which can be defined as 'remote'.

Prior to COVID-19 much of the research on remote consultations took place within trial settings, with the intention of showing the efficacy of remote care as an alternative to in person. Further, the focus of research has primarily been on the management of long-term conditions and the integration of remote consultations into longer term healthcare management (Band et al., 2017; Craig & Rhee, 2020; Gilbert et al., 2020; Humble et al., 2016; Langstrup et al., 2013; López & Sánchez-Criado, 2009; Mayberry et al., 2019; Monaghan & Marks, 2020; Morton et al., 2018; Morton et al., 2017; Oudshoorn, 2012; Piras & Miele, 2019; Rovner et al., 2021). Populations included in these studies tended to be fairly heterogenous, and sparse attention was paid to more vulnerable patients, who were not expected to want or need to pioneer remote primary care. However, the emergence of COVID-19 necessitated the uptake of remote services by all patients, overnight, leading to a windfall of studies on digital and remote primary care. This study contributes to this relatively new evidence base as a 'real time' snapshot of patients interacting with primary care services as they went through the transition to remote care.

Distancing

One of the major findings of this study is that there is a distancing occurring between patients and the primary healthcare system. This is happening on the physical, emotional and, interpersonal level – discussed in turn. The implications of this are touched on briefly in this section but will be discussed in more depth in the following section on the creation and redistribution of work. Whilst the distancing between patients and the healthcare systems is not a new phenomenon, and has previously been discussed by others (Mort & Smith, 2009; Oudshoorn, 2008), and labelled as the creation of a 'distal patient' (May, 2014), this study indicates an acceleration and embedment of this distance.

Physical distance

On the physical level, patients are being encouraged to limit their in-person interactions with the healthcare service by booking appointments and consulting remotely. This was enforced during COVID-19, during which time patients were strongly discouraged from entering GP surgeries, and the practice of making appointments over the phone has remained common place. Whilst this may have already been common for many patients, respondents in this study indicated that prior to COVID-19 they often relied on in-person booking. The use of telephone consultations has also become much more common, and respondents reported feeling unable to access in person care when they wanted to. This physical distancing has consequences for both patients and practitioners, as both must deal with the *new* physical conditions created i.e., where patients take their remote consultations calls from, and how they manage interactions at a distance, the subject of chapter six. As discussed in results chapters six and seven this has implications, both for privacy of care, as well as the ability to communicate healthcare needs without the use of non-verbal and visual cues. Paradoxically, digital interactions do not abolish spatial relations (as they're often thought to do) but in many ways exaggerate them.

The reduced tie between care and traditional spaces of care also removes the affordances which go with those spaces, from assured privacy, through to associations with confidentiality which can encourage patients to disclose information to their doctor. Whilst GPs may attempt to adjust for the loss of these affordances, for instance through the use of deliberate tone of voice to portray listening and safety, the actual physical spaces patients are in, which may not be private, can contradict these attempts.

Emotional and interpersonal distancing

This physical distancing appears to also lead to emotional distancing, as patients and doctors struggle to maintain therapeutic alliance during remote consultations. The importance of seeing the doctor and being seen *by* the doctor was mentioned often by respondents, who used these visual cues to confirm their doctor's interest in them, and thus the validity of their health concerns. Feeling listened to was presented as a key factor in patients' ability to disclose information, especially if it was of a sensitive nature such as around mental health. Further, GPs spoke about the challenges they faced when asking sensitive questions, in the absence of physical interactions which helped them to establish a therapeutic alliance and approach sensitive topics in a way that felt appropriate for trauma-informed care. As a result, physical distancing may lead to interpersonal distancing as the ability for patients and doctors to build a therapeutic alliance is disrupted.

However, physical distance alone does not explain the emotional and interpersonal distancing described by respondents – and is the result of the combined effect of remote telephone consultations and a reduction in continuity of care. Remote consultations were often portrayed by respondents as both quick and 'cold' with little space for emotional care or relationship building. This was often framed in terms of a lack of psychosocial care being offered during consultations, compounded by the loss of relational continuity with a GP, leading to a de-personalised interaction. GPs also spoke about a loss of interpersonal connection with their patients due to the challenges of building rapport over the phone, as well as reduced continuity of care. However, whilst patients framed reduced continuity of care as a sign of a lack of care from their GP, GPs framed it as a necessary shift from relational continuity to management continuity in order to rationalise scarce resources i.e., the clinical skills of the GP. Interestingly, although GPs recognised an underlying rationale, they also framed the outcome – reduced relationship building – as a negative outcome which lay counter to their reasons for going into General Practice. This suggests the imposition of emotional distancing by macro-level actors, which is negatively received by both patients and doctors.

Further, emotional distancing is also produced by an increasingly narrow focus of GP consultations on clinical care only. Patients interpreted this as a lack of empathy from their doctor, and a lack of interest in the wider contextual factors they felt impacted on their health. However, GPs tended to present the clinical focus of consultations as a reaction to the spreading of care over a wider primary care team – with GPs increasingly only seeing patients for complex clinical needs. The impact of this is compounded by both the reduced ability to build rapport during remote consultations, as well as a reduction in relational continuity of care which allows for longer term contextual knowledge on a patient to emerge. The combination of remote consultations and reduced continuity of care combine to produce an experience of primary care that can feel highly de-personalised for patients. This is in direct contrast to NHS policy priorities of personalised care laid out in the NHS Long Term Plan (2019) which states that "People will get more control over their own health and more personalised care when they need it" and a focus on "what matters to someone" rather than "what's the matter with someone". This indicates that whilst personalised care may be the intention, that wider changes to primary care are actively working against this by disrupting the factors which underpin it, or alternatively, that 'personal' does not refer to 'interpersonal', which, based on the findings of this study is often "what matters to someone". The contrast between policy intentions for personalised care and what is happening in practice has also been written about by Mann et al. (2021) within an evidence briefing commissioned by the Personalised Care Institute.

Underlying this is an interesting paradox, the *collapsing* of physical space – whereby a physically separated patient and doctor can be in contact actually leads to an increased experience of distance due to the emotional and interpersonal distance it creates. This distancing, as discussed in each of the individual results chapters can lead to the introduction of clinical and safeguarding risks as a result of interactional difficulties which lead to disrupted information sharing and reduced disclosure as a result of difficulties communicating and establishing an interpersonal relationship. These outcomes will be discussed in depth in the following section which looks at the work which is redistributed, created, and exaggerated as a result of the distance created.

Work creation and redistribution and access to resources

The preceding section looked at the creation of distance as a result of changes being made to the primary healthcare system, and functioned as a summary of themes which cut across all four results chapters.

This section looks at the redistribution of work throughout the system as a result of remote consultations and reduced relational continuity of care. It examines various forms of work that patients and doctors engage in to bridge the distance created by these changes. Specifically, it explores the negotiation work involved in appointment booking, as well as place-making, noticing and monitoring, and articulation work. The argument made is that remote consultations and reduced relational continuity of care leads to a responsibilisation of patients as they are required to take on additional forms of work to navigate and engage with the healthcare system. This section also examines the increasingly high level of practical resources patients are expected to mobilise in order to book appointments and engage in remote consultations, underscoring the challenges patients face in accessing and utilising these resources. To provide a theoretical framework for understanding the interaction between patients' ability to perform the requited work and access resources, Burden of Treatment Theory is introduced. This theory helps to understand how patients' 'capacity' interacts with demands, facilitating or obstructing their access to care. The subsequent section examines the assumptions made about patients' capacities to undertake the redistributed work and the potential for exclusion of those who do not meet these expectations, shedding light on how certain individuals may be marginalised or disadvantaged by these processes.

The redistribution of work

Negotiation during appointment booking - The first form of work for patients that has become more burdensome is that of booking an appointment and the increasing need to negotiate with reception staff – outlined in results chapter five. The need for practical resources i.e., a phone will be discussed separately below when thinking about the access to resources needed to make an appointment. The comments made by respondents about appointment booking being ‘hard work’ indicate that the use of the term ‘work’ from an academic standpoint aligns with lived experiences. Increasing levels of negotiation are occurring as reception staff are tasked with more informal triaging work which requires patients to articulate either verbally or in text, their healthcare needs to a greater degree to be correctly assigned to a service. While defining healthcare needs to book an appointment is not a new phenomenon, it is increasingly important as receptionists become a larger part of the triaging process. Seeking healthcare involves people ascertaining a claim to candidacy for medical attention. Candidacy “describes the ways in which people’s eligibility for medical attention and intervention is jointly negotiated between individuals and health services” (Dixon-Woods et al., 2006, p. 7). Making candidacy demands involves work that requires a set of competencies, including the need to formulate and articulate the issue for which help is being sought (Dixon-Woods et al., 2006). Previous research has indicated that more deprived individuals face a higher risk in these situations as “they may be less used to or less able to provide coherent abstracted explanations of need” (*ibid* p.8). Both Dixon et al. (2007) and Cooper and Roter (2003) have suggested that socioeconomically deprived people may find it more challenging to use their “voice” to demand services, and struggle with the articulation, confidence, and persistence required of them. Respondents in this study reported that they found the negotiation to make an appointment with receptionists difficult, and they talked about instances of becoming frustrated and either lying in order to secure an appointment or disengaging from the primary care system as a result of perceived ineligibility. Respondents often framed their access to appointments in terms of eligibility and whether they were sick enough to reach an invisible threshold beyond which they could see their GP in person, in essence a need to negotiate candidacy. This relates to ‘distance’ being created in the primary care system, whereby patients have to increasingly ‘prove’ their healthcare validity before being allowed closer to the service by making an appointment with a GP. Moreover, this study demonstrates that the actual opportunities for negotiation around candidacy between individuals and the health service are often absent. This is especially true when it comes to online appointment booking systems, which offer no opportunities for 'live' (synchronous) discussion.

Place-making – 'Place-making' is the process of organising resources and time to ensure the correct conditions for a consultation are met. Place-making work, discussed in detail in chapter six, occurs as patients are tasked with producing effective working conditions for GPs during remote consultations, ensuring they are in a place where they can be heard clearly and have enough privacy to be able to disclose clinically relevant information. Respondents in this study reported on the potential difficulty of creating private spaces for care in the context of unpredictable remote consultation times, which limited capacity to plan. As a result of this, respondents spoke about instances in which they were unable to secure private space and how this had affected their ability to speak openly and honestly with their doctor. The capacity to place-make is reliant on both access to a physical space and a digital device – and lack of access to either of these may limit patients' capacity to secure an appropriate space, discussed below in relation to resource access.

Whilst GPs gave accounts of working *with* patients to produce effective working conditions, for instance negotiating a suitable call time, GPs also reported that unpredictable call times were baked into the system as a way of ensuring clinical safety i.e., a phone call may run over if a patient needs urgent support. The reason why this differs to in person appointment time systems remains unclear. Further, GPs expressed surprise at patients taking phone calls from work or on public transport, which indicates an expectation that patients will carve out private spaces which are not impacted by unpredictable call times – an issue which will be discussed in more detail when thinking about expectations of patients.

Noticing and monitoring – Noticing and monitoring work, discussed in chapter seven, are produced at various stages of making and completing a GP appointment. Firstly, patients must be able to define their health concerns to the GP receptionist when booking an appointment, secondly patients must be able to identify relevant clinical information to share with their GP during a remote consultation. Whilst noticing and monitoring work is not novel, and patients have always had to perform an element of this to support healthcare seeking behaviour, what has changed is the level of specificity required from patients. During remote consultations, patients need to be able to notice relevant clinical information to share with their GP without the support of visual or non-verbal cues which may enable the GP to make more complete diagnoses. Further, the responsibility to notice and report healthcare concerns is also exaggerated prior to consultations, due to the increasing requirement to specify healthcare needs when booking an appointment, in order to get triaged to the correct member of the primary care team.

This self-surveillance expected of patients is particularly striking in that it shifts responsibility from the healthcare system to the individual, without a corresponding shift of skills or training. This expectation on patients, to notice and monitor, requires the medical gaze to turn inwards and to take on a form of biological reductionism to locate and explain symptoms in detail (Foucault, 2003). The accounts given by patients of feeling like they were being asked to do their GP's work over the phone indicates a recognition that they may be asked to conduct forms of work previously fulfilled by their doctor. However, as discussed in results chapter seven, the ability to take on this work is not equitably distributed and individuals experiencing marginalisation may experience barriers to their capacity to self-survey their symptoms either as a result of multi-morbidity which makes pinpointing new symptoms harder (Merrild et al., 2017), or low health literacy (Jansen et al., 2018; Svendsen et al., 2020).

A Foucauldian lens of surveillance and biopower has previously been applied to the digital healthcare space – for telemedicine of chronic conditions as well as mobile phone based self-tracking tools (Fotopoulou & O'Riordan, 2017; Fox, 2015; Lupton, 2013b, 2017; Rich & Miah, 2014). What this study shows is that changes to the primary care system which produce or exaggerate forms of noticing and monitoring work may also lead to an increased need to self-survey as patients are expected to report on their bodies in more tangible ways, which bridge the physical distance created by the shift to remote consultations. This redistributes work from clinicians to patients and heightens the need for patients to have the necessary skills to be able to both notice and convey healthcare information.

The increasing responsibility for patients to notice and monitor is shown within the NHS Long Term Plan (2019) , through statements such as "People will be helped to stay well, to recognise important symptoms early, and to manage their own health, guided by digital tools" (p.92, emphasis added). Not only does this indicate a push towards greater patient involvement in their own symptom management, but also an expectation that this will be helped by digital tools, which this research found no evidence of within this study population.

Articulation- Following directly on from this and closely related is articulation work, described in chapter seven. Articulation work arises as patients are tasked with verbally describing their healthcare symptoms to the GP without the use of non-verbal or visual cues. This is the next step on from noticing and monitoring work, as patients must convey the symptoms they've identified to their doctor. As mentioned earlier, there is a recognised relationship between the ability to complete this sort of verbal articulation work and marginalisation (Cooper & Roter, 2003; Dixon et al., 2007; Dixon-Woods et al., 2006) as well as the social and cultural capital involved in health literacy (Lastrucci et al., 2019; Svendsen et al., 2020). Respondents reported that not being able to gesture and/or not being able to show the doctor a symptom may obstruct their ability to communicate effectively. The language demands placed on patients in order to communicate over the phone, in terms of English, but also specific language about the body, are increasingly high. For patients who don't speak English, telephone-based interpreters are made available through systems such as 'Language Line'. However, for those who speak some English but struggle to understand and be understood over the phone, or for people who face more general communication challenges – remote consultations which necessitate verbal *only* communication may be exclusionary. This is an interesting example of how some characteristics which are more absolute e.g., speaking no English might actually be less exclusionary than more hidden forms of marginalisation such as low health literacy, for which specialist services are not available in the same way.

Without non-verbal and visual cues, GPs' ability to pick up on symptoms which have not been noticed and described is severely limited. As a result of this, the GP's ability to gather information may be restricted, with a potential for poorer clinical outcomes if symptoms are missed. This may be especially true for healthcare of a sensitive nature including mental health, a concern identified elsewhere (Liberati et al., 2021). GPs reported trying to adjust for this risk by increased questioning, increased attention to tone of voice and pauses, sending patients for more tests ("investigation inflation"), or bringing in patients for face-to-face consultations. Consequently, work is also produced for GPs, who must adjust for remote working conditions to mitigate risk. GPs who do not adjust for the risks introduced by remote consultations may inadvertently contribute to the production of poorer clinical outcomes for patients who struggle with noticing and monitoring, and articulation work.

The changing nature of demands placed on patients are in essence a redistribution of work to patients, which is part of a broader narrative of the 'self-actualising' patient (May et al., 2014). Patients are being responsibilised for their own healthcare as they are tasked with greater levels of self-surveillance (noticing and monitoring), articulation, place-making, and negotiation work. The following sections will examine how inherent within these expectations are assumptions about patients' capacities for action. These expectations are normative in that they presuppose a certain level of cognitive, material, and network resources readily available to patients. Risk – clinical and safeguarding – emerges when patients do not meet these normative expectations, and thus 'fall short' of the tasks handed to them, for instance, being unable to describe their clinical symptoms in a comprehensible way over the phone.

Access to material resources

The previous section looked at the different forms of work created for patients within the primary care system and the skills these demand of patients. We now turn to the issue of material resource access and how these impact on patients' ability to carry out the work of engaging with the healthcare system, specifically remote consultations. The two main material resources which impact on use of primary care services are digital devices and private space.

Access to digital technologies is often presented as all-or-none, in terms of both devices and connection (WIFI/data). Because the majority of respondents spoke about use of mobile phones only, and not computers, 'digital device' here is taken to mean a mobile phone of varying levels of sophistication.

This study has shown how digital access works along a continuum and access to both devices and connection can be experienced unstably or partially. Whilst unstable or partial device access is unlikely to lead to full exclusion from services, it can make accessing services more difficult. Unstable refers to the instability of digital access which can occur as a result of resource scarcity – many of the respondents in this study reported buying ‘bundles’ of phone credit when finances allowed, meaning that sometimes they did not have a working phone because they could not afford credit. Further, for those with low resource availability, either losing or breaking a phone can lead to a substantial period without access to a device. Partial digital access refers to access to devices which are not advanced enough to use online services, or device access mediated through borrowing from family and friends. Unstable access often leads to partial access because during periods without devices people may borrow from others. Both unstable and partial device access can impact on use of healthcare services as it makes booking an appointment over the phone/online, and having a remote consultation, more difficult. As argued in chapter five, borrowing of phones is being made increasingly challenging due to increasingly long hold times when booking appointments over the phone, the need to call a surgery *at* 8am to make an appointment, and wide, unpredictable call windows for remote consultation appointment times. Further, borrowing phones can also lead to issues around privacy if the borrower is required to be physically proximate to the phone owner as well as making it challenging for patients to get re-contacted by the doctor unless pre-arranged.

Although reported infrequently, some patients were told they have to book appointments online. If this happens, access to a ‘smart’ device is necessary which makes the threshold for resource access higher, given the relative cost of a smartphone or computer. This means that in order to engage with this form of service, patients must have access to both a ‘smart device’, and the necessary skills to use it. Moreover, even if telephone appointment booking is available, online appointment booking may offer some advantages in terms of efficiency such as not needing to wait on hold to the receptionist, choosing slots and being able to do this at any time. This can produce a tiered service rather than a hybrid service, in which those able to make appointments online through a smart device have access to appointments more quickly, and therefore potentially better access.

Another form of practical resource which patients require access to is private space – touched on above in relation to place-making, and discussed in depth in chapter six. As with device access this is rarely all or nothing and may also be both unstable and partial. The ways in which place-making interacts with access to physical space is tied up with unpredictability of call times, and whether patients' access to physical space is secure enough to be flexible. For instance, in the vignette given by a GP of an asylum seeker in temporary accommodation needing to arrange a call time during which the other residents in her multi-occupancy house were out, her access to physical space was not amenable to unpredictable call times. This differs from for someone who can work from home and is certain of a private space within which to take a call regardless of timing. More rigid patterns of working life have been recognised as a barrier to the ability of disadvantaged groups to negotiate access to in person primary care health services (Field & Briggs, 2001). The increasingly wide windows for remote appointment times may exaggerate this effect. Further, as outlined above, device access and private space access can become tied together in cases where people are borrowing phones – leading to potential issues around privacy. Therefore, it is not enough to have access to a private space, but patients must have flexible access to privacy in order to account for the unpredictability of call times, and rigidity of a system which has limited scope for flexibility around patients.

The way in which inflexibility in a healthcare system relates to marginalisation can be understood through the lens of 'porosity'. Dixon-Woods et al. (2006) in their literature review of access to healthcare for vulnerable groups have used the term 'porous' to describe the degree to which health services are permeable to patients. The porosity of services can impact on the ability of marginalised groups to access and use them. Porous services require the mobilisation of relatively fewer resources (Dixon-Woods et al., 2006), meaning that unstable access to the necessary practical resources i.e., a phone, will have a lower impact on access. This is because for those who have unstable or incomplete access to practical resources, a system which facilitates access in the absence of these resources will be more consistently accessible. However, services which are inflexible to patients' varying needs and resources, for instance, by insisting on online appointment booking, or access to a phone and private space within a relatively wide window of a few hours, can lead to exclusion because of an inability to mobilise the correct practical resources when required. This in turn makes precarity (often a defining characteristic of marginalisation, specifically socioeconomic) a higher potential threat to healthcare access – as resource mobilisation becomes more closely tied to making appointments and having remote consultations. Primary care services that are less porous are already known to have high levels of avoidance by socio-economically disadvantaged people (George & Rubin, 2003; Macleod et al., 2000; McClure et al., 1996). What this study indicates is that changes to appointment booking systems as well as an increase in the use of remote consultations may contribute to an increasingly impermeable primary healthcare system, which limits access for certain groups.

Understanding work and access to resources as patient capacity

This next section draws together the topics of 'work' and access to resources, through a Burden of Treatment Theory lens, to understand how patient capacity interacts with the increasing demands placed upon them.

As outlined in the Literature Review, we can understand the relationship between the various forms of work being produced by changes to the primary care system, and patients' capacity to meet them, through the Burden of Treatment Theory (BoTT) framework (May et al., 2014). BoTT outlines how patients' capacities interact with the demands placed on them by healthcare systems, and how this impacts on their capacity to organise and coordinate care. Capacity is created through a combination of practical and cognitive resources (what could be referred to as skills), such as language, health literacy, and device access. BoTT argues that healthcare systems may structurally produce non-compliance and/or over or under use of healthcare services because of the interaction between demands and patients' capacity. It builds on a cumulative complexity model (Shippee et al., 2012) to argue that healthcare systems may produce complex demands out of what seems to be simple interactions and rules. The ways in which demands have a habit of 'building up' was exemplified through the study data which outlines how structural changes such as a shift towards remote consultations can lead to compounding demands – access to a private room, a flexible schedule, and a device all at once – which may lay outside of an individual's capacity. In this way what might be seen as a 'simple' solution, a remote consultation, becomes complex for the patient to organise and carry out effectively. Further, the assumptions made about patients and their capacities to meet what may be viewed as simple demands – such as being in a private space to take a call or describing a symptom verbally – may limit the flexibility of the system to account for differences in patients' capacities for action. However, rather than Burden of *Treatment*, it may be more apt to think about Burden of *Healthcare* in this case, as the study findings focus on the process of making appointments and carrying out remote consultations, rather than individual management of a condition.

Capacity for action, is recognised as an 'unstable situational accomplishment' (May et al., 2014). This speaks to the 'unstable and 'partial' nature of resources outlined above, for instance, access to a mobile phone with data only when finances permit, or access to a private room only during certain hours. For socioeconomically marginalised individuals resources are more likely to be unstable due to precarity of financial situations, with any unexpected costs having a larger impact, making agency for action more unstable. May et al. (2003) argue that the nature of the demands placed on the patients and the resources available to them may combine to limit the extent to which patients can act independently. In order to account for a lack of access to resources, patients may recruit others to assist them, creating ‘prosthetic agency’ (May et al., 2014). Respondents gave accounts of being reliant on either their personal network, or third sector services to effectively engage with the healthcare service. This included getting others to read out text messages they’d been sent by their GP surgery, to book appointments for them online or over the phone, to translate informally during remote consultations, or to provide private spaces for remote consultations. Whilst being able to recruit others for assistance is a form of network resource, it comes with drawbacks in that it can make access to healthcare reliant on others and limit privacy. Further, BoTT recognises that reliance on network resources is also inherently unstable due to everyday commitments and competing priorities, meaning that access to network resources does not adjust for an individual’s precarious access to personal resources.

As well as the practical challenges to mobilising network resources, a need to call in ‘prosthetic agency’ leads to what Zehng and Walsham (2008) term ‘capability deprivation’. As the healthcare system becomes more geared towards ‘self-provision’ which “involves active welfare subjects taking their own initiative to engage the welfare state” (Henman, 2010, p. 216) there is a consequential shift from rights-based to obligations-based provisioning of welfare (Brown & Baker, 2013). This can force people into a position of dependence on others (third sector or interpersonal networks) in order to fulfil these obligations, which fundamentally deprives them of the capability to access care independently – capability deprivation.

An alternative framing of capability deprivation, is one of forced interdependencies. Andreassen et al. (2018) argue that “sociotechnical systems that aim to empower patients to act autonomously may actually lead to new dependencies, by creating expectations of new relationships or compensating for the loss of old ones” (p.41). This is an apt description of what appears to be happening in the primary care system for patients who no longer have the required capacity to book appointments and have remote consultations. The need to enact ‘prosthetic agency’ through networks or third sector organisations e.g., to secure access to a phone or private space, disproportionately impacts on marginalised groups who have lower access to material resources and therefore leads to a higher likelihood of forced dependencies (/capability deprivation) for these groups.

Risk in the clinical encounter and the relationship to patient capacity

The previous sections looked at the creation and redistribution of work, and increased need for access to practical resources, before drawing these two themes together through a Burden of Treatment Theory Lens. This next section examines how patients’ capacities (both material and cognitive) can lead to clinical and safeguarding risks if patients are unable to fulfil the demands being placed on them. Clinical risk may emerge due to patients’ disrupted ability to share sufficient clinical information during remote consultations. Safeguarding risks may emerge due to patients’ inability to mobilise private spaces in which to have remote consultations, limiting their willingness to disclose information. The topic of disclosure will be returned to again later on when looking at changes to doctor-patient relationships.

If patients are unable to carry out the noticing and monitoring, and articulation work being demanded of them during remote consultations, then their ability to adequately share information with their doctor can be hampered. This means that the doctor is less able to gather information on the patient's clinical needs, creating the potential for missed diagnoses – a concern cited elsewhere in the literature on remote consultations (Rosen et al., 2022). This was spoken about by patients who feared their doctors couldn't understand them well enough over the phone to make a diagnosis, as well as by GPs who spoke about the increased levels of clinical risk they perceived during remote consultations due to a loss of non-verbal and visual cues.

Based on this study's findings, the characteristics most closely associated with the ability to notice, monitor and articulate, are health literacy, and language. Health literacy has previously been shown as strongly correlated with socioeconomic status (Svendsen et al., 2020), and a potential mediating factor by which socioeconomic status relates to poor health outcomes (Lastrucci et al., 2019). Respondents' comments about a need to gain more education in order to be able to speak with their doctor over the phone reflects a known relationship between health literacy and education levels (Jansen et al., 2018) and is one way in which socioeconomic status becomes tied to health literacy levels. What this study indicates is that this relationship between health literacy and healthcare outcomes may be exaggerated as the pressures to perform health literacy during remote consultations is heightened because of the need convey clinically relevant information in the absence of nonverbal and visual cues. This can produce clinical risks if the doctor is unable to pick up on health symptoms patients themselves may not have noticed, or to gain sufficient information on symptoms if patients are unable, or less able, to articulate these. In sum, patients who are less able to do the noticing and monitoring, and articulation work being handed to them during remote consultations, may be at higher clinical risk as a result of reduced clinical information sharing and gathering.

Language, as opposed to communication skills, is also a potential barrier to sufficient information gathering during remote consultations. This was reflected in the study data when speaking with refugees and immigrants who had low levels of English proficiency. Although these individuals spoke enough English to participate in an interview without the need for an interpreter, they talked about struggling to understand and be understood over the phone when unable to see the other speaker, or to use gestures to accentuate their points. Whilst interpretation lines are available to use during remote GP consultations, this places in an added barrier to care for patients who would otherwise be able to communicate sufficiently with their doctor in person – another example of capability deprivation (Zheng & Walsham, 2008).

The other risk which might be created by remote consultations is safeguarding, as patients can struggle to find private spaces in which to speak with their doctors. Further, during remote consultations GPs also lose the non-verbal and visual cues which might alert them to a potential need to safeguard. This is a concern which has previously been picked up on in the literature (Dixon et al., 2022), and this study confirms these concerns as well as showing how safeguarding risks may disproportionately affect marginalised groups.

Disruptions to privacy were found to limit patients' ability to disclose information to their doctor, for instance speaking about depression or suicidality when taking a call from a car. This was also a concern for GPs who cited the difficulty they had in establishing whether a patient was in a private space in which it was appropriate to ask them sensitive questions. Privacy is largely related to access to physical private space, and a personal phone. If a patient does not have flexible access to a private space and their own device, their ability to disclose sensitive information to a GP during a remote consultation can become disrupted. This may not be an issue for some health concerns, but for those which are considered sensitive e.g., mental health, or information related to safeguarding risks, it can quickly become both a clinical and safeguarding risk. Given the known association between mental health (*Poverty: statistics*) and socioeconomic status, as well as safeguarding risks such as domestic abuse (Alexa. Bradley & Angela. Potter, 2018) – the need for privacy in which to take remote consultations may be higher for those experiencing socioeconomic marginalisation. Socioeconomic marginalisation is also a reason why people may find it harder to create the private conditions necessary to disclose information during remote consultations.

A recent review of qualitative data on primary care during COVID-19 (Rosen et al., 2022) highlights many of the same risks identified in this study. Notably, the potential for clinical care to be disrupted through missed or delayed diagnoses because of remote consultations. There is particular anxiety within the medical community over cancer diagnoses (Rigney, 2022) with concerns that those with English as a second language may be particularly at risk. What this study shows is that these risks are related to both skills (e.g., interactional) as well as resources (e.g., a phone), which produce a mediating factor by which clinical and safeguarding risks may become disproportionately higher for individuals from marginalised groups.

Patient doctor relationships

The production of different forms of work and need for access to resources described above is happening within the context of changes to the role of the GP within primary care more generally, and disruptions to patient-doctor relationships.

The key findings of this study vis-à-vis relationships were that there is an ongoing shift from relational continuity to management continuity, alongside a dilution of personalised therapeutic relationship building as a result of remote consultations, contributing to an interpersonal distancing between patients and doctors – depersonalisation.

Voorhees et al. (2021) building on Levesque's model of access (Levesque et al., 2013), characterise continuity as an important component of access, rather than in opposition to efficiency. Policy measurements often prioritise efficiency and access e.g., timeliness, over, or even in opposition to experiences of care. However, Vorhees et al., emphasise continuity as a key element of access, highlighting the importance of feeling known and understood by the doctor as a central concern for patients. This study builds on this previous research to suggest that a reduction in continuity combined with remote consultations may limit some patients' abilities to openly discuss their needs with a doctor leading to potential clinical and safeguarding risks *on top* of those already outlined.

The loss of relational continuity was framed by GP respondents as a direct result of a widening of primary care teams and specialisation of the role of the GP. For patients this was perceived as distancing by their doctors. Several respondents criticised the lack of psychosocial care they got from their GP, indicating that they see alternative primary care providers as inadequate substitutes. Meanwhile, GPs framed psychosocial care as increasingly coming under the remit of other professionals including social prescribers, to free up their time for more complex clinical cases.

The NHS Long Term plan (2019) states:

> In ten years' time, we expect the existing model of care to look markedly different. The NHS will offer a 'digital first' option for most, allowing for longer and richer face-to-face consultations with clinicians where patients want or need it. Primary care and outpatient services will have changed to a model of escalation depending on need. (p.92, emphasis added)

This excerpt outlines changes to primary care which will fundamentally alter the role of the GP as they become the 'top' of a tiered primary care team. So, whilst patients may have a named GP on their record, they may only see them in cases of more acute clinical need, fundamentally changing the model of GP care which centres on ongoing interaction between patients and 'their' doctor. This links back to the earlier discussion of patients needing to negotiate with receptionists in order to see a GP, as candidacy thresholds are increasing. The move to a tiered model was reflected in the experiences of both patients and GPs – with a recognised shift from relational continuity to management continuity.

This process of increasingly high clinical thresholds to see the GP may be further exaggerated by the Prime Ministers Primary Care Recovery Plan announced May 2023. The plan sets out to "get rid of the 8am rush for GP appointments" (Gov.uk, 2023) by "making sure patients are either given an appointment immediately when they call, or signposted to a more appropriate service such as NHS 111 or their local pharmacy". This signals a reaffirmation of the 2023/24 GP contract which stipulated that GP practices must offer patients and assessment or signpost them to an appropriate service on first contact (NHS England, 2023). However, what this new plan adds to the current contract is that patients will be able to get medications directly from the pharmacy without a GP appointment, for things like earache, sore throat, or urinary tract infections, as well as the oral contraceptive pill. The rationale behind this move is to free up more GP appointments (an estimated 15 million over two years). This signals a further distancing of patients from GP practices, and GPs, moving care into the community through local pharmacies. This has the potential to exaggerate the already increasingly high clinical thresholds needed to see a GP, as well as removing opportunities for opportunistic safeguarding and psychosocial care by the GP.

The spreading of care amongst larger primary care teams has two concurrent outcomes. Firstly, it represents what Mort et al. (2003) term ‘clinical Fordism’, secondly it characterises a form of biological reductionism in the management of patients. ‘Clinical Fordism’ was used by Mort et al., to describe the way in which teledermatology leads to a breaking down of nurses’ and doctors’ skills as they viewed parts of a patient through photographs. This term could be repurposed to describe the way in which patients’ needs are being split up within the primary care system. As outlined by both GPs and patients, management of chronic conditions as well as psychosocial care are being distributed to non-GP team members. This leads to a more fractured or ‘modular’ system with increasingly narrow ways of knowing patients, and a de-personalisation of the doctor-patient relationship.

The NHS definition of General Practitioner, first introduced in the literature review is that they “treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment. They focus on the health of the <u>whole</u> person combining physical, <u>psychological</u> and <u>social</u> aspects of care” (NHS, n.d. emphasis added). This study indicates that the more holistic elements of this care i.e., whole, psychological, and social, are at risk of falling to the wayside through a combination of remote consultations and reduced continuity.

Further, a reduction in ‘whole person’ care may produce biological reductionism in interactions with GPs as they increasingly focus on more complex clinical needs whilst sending patients elsewhere for needs related to other elements of their care. This is being rationalised as a time saving measure within policy documentation (NHS Long Term Plan, 2019), but may also have the effect of essentially changing the nature of the doctor-patient relationship as the GP shifts from being positioned as an 'all-rounder' to a more specialist member of primary care teams. The result of this is that GPs may have less contextual knowledge on patients which may have implications for clinical and psychological care. Further, a splitting up of care between practitioners, whether different GPs or other members of the primary care team might represent what Balint (1968) refers to as the 'collusion of anonymity' through the scattering of responsible agents so that no single person has responsibility for a patient's holistic needs. Coulter and Oldham (2016) in their paper on patient-centred care, start with the following statement by Hippocrates two and half thousand years ago: 'it is more important to know what sort of person has a disease than to know what sort of disease a person has'. All these years on, this nicely sums up what patients report that they are losing – to be known as a person, in order to feel cared for properly. This research suggests that primary care may be edging in the reverse direction: disease first, person second (if at all).

Not only does this have important implications for care, but is a departure from the basis on which primary care within the NHS was founded, and perhaps more remarkably, a step change in how we *do* healthcare. Through much of human history, healthcare, or more essentially 'healing', has been performed through a combination of ritual, belief in the healing powers of one or a set of individuals, and sometimes (if lucky) the use of medicinal plants with active properties. The role of the GP as a 'healer' has been discussed widely, and referred to variously as the "physician healer" (Dixon et al., 1999) or the doctor as a "drug" (Balint, 1968). Balint's seminal book "The Doctor, His patient, and The Illness" (1968) argues that a great deal of the GP's work is psychotherapy, whether they like it or not – which refers back to the points made in results chapter eight about the clinically important role of therapeutic alliance between patients and doctors. Further, it speaks to the earlier point made around the shifting definition of what it means to be a GP. Importantly, Balint makes the point that this 'doctor drug' may be particularly important for patients for whom the wider circumstances of their lives are challenging – "some of the people, who for some reason or other, find it difficult to cope with the problems of their lives resort to becoming ill" (Balint, 1968). This may help to explain the aggrieved accounts respondents gave of feeling that their life circumstances, and psychosocial needs were not being taken into consideration, as the role of the doctor as a 'drug' is disappeared.

This reduction in relational continuity within primary care and psychosocial care by the GP cannot be separated from the modality shift to remote consultations. Evidence from this study, as well as previous work (Bazzano et al., 2018; Funderskov et al., 2019; Hinman et al., 2017; Hinton et al., 2023; Imlach et al., 2020; Kairy et al., 2013; Lawford et al., 2019; Walthall et al., 2022) has shown that remote consultations have the effect of reducing rapport building and therapeutic alliance between patients and doctors, although this can be somewhat adjusted for through relational continuity (Donaghy et al., 2019; Hammersley et al., 2019). However, what we are seeing in NHS primary care now, is a shift to remote care alongside a reduction in relational continuity of care. The outcome of this is a double-blow to patient-doctor relationships, which was reflected in this study through a unanimous representation of care becoming de-personalised and experienced as less 'caring'. This is particularly concerning when it comes to mental health care, as respondents gave accounts of feeling unable to disclose or explain their symptoms to a clinician when they found themselves speaking to an unknown, disembodied voice on the other end of the phone who had limited contextual knowledge on them beyond what they could see on their records (separate or on top of the issues around privacy). This builds on prior research which highlights the clinical and safeguarding risks of remote healthcare for mental health (Dixon et al., 2022; Liberati et al., 2021), and adds to the argument presented above around the exaggeration of clinical and safeguarding risks which is occurring.

The following section brings together the discussion by coming back to the chief question of this study, of how these changes impact specifically on marginalised groups, and how we might conceptualise marginalisation in relation to the findings of the research.

Understanding marginalisation

The findings of this study show that marginalisation may be structurally produced and reinforced as the cost of compliance in the primary healthcare system becomes progressively higher, meaning that the ability to rise to the demands of inclusion becomes possible for a smaller and smaller group of people. However, this process is far from clear cut, and rather than patients becoming fully excluded, a more likely scenario is the development of a tiered service, with easier access to appointments, and better remote consultation experiences, for those with more resources at their disposal. This risks reinforcing health inequalities for those with lower 'capacity' to meet the inclusion criteria for using primary care. A lot of the conversation within the analysis of study findings, has been around the creation or exaggeration of 'risk' for patients. Link and Phelan's theory of fundamental causes of inequality, called for a consideration of the macro-level contexts that "put people at risk of risk" (Link and Phelan 1995 in Reynolds, 2021). This study indicates that remote consultations in particular are putting individuals who are less able to mobilise the capacity to meet the demands of a remote consultation at *risk* of both clinical and safeguarding risks.

Additionally, the way in which the passing on of work to patients is being dealt with and framed in NHS Policy Documentation is deceptive as it masks it as freedom, or empowerment. The redistribution of responsibility through the system and distancing between patients and doctors can be seen through the lens of neoliberalism as the responsibilisation of citizens for their own healthcare management. The NHS Long Term Plan (2019) states "People will be empowered, their experience of health and care will be transformed, by [...] digital tools, information and services (p.93, emphasis added)" and as already quoted "People will be helped to stay well, to recognise important symptoms early, and to manage their own health, guided by digital tools (p.92, emphasis added)". In both of these statements a neoliberal appeal to freedom and autonomous agency (Pyysiäinen et al., 2017; Rose, 1999) is made, using the terminology of empowerment rather than responsibility. However, as outlined, the ability to meet these demands of empowerment (or responsibility) relies on patients' capacity, which is not equitably distributed. Not only this, but it also places the production of patient burden into a framing which does not necessarily align with patients' experiences – a removal of freedom as they become reliant on others through the use of 'prosthetic agency' (Callon, 2008)to complete the tasks being handed to them. The potential for 'responsibilisation' in remote care to put vulnerable groups at risk by handing them 'digital work' that they are not equally able to undertake was also picked up on in Hinton et al.'s (2023) study of remote care, further substantiating the findings of this study around the risks of responsibilisation for disadvantaged groups.

Within public health discourse it is acknowledged that in order to address the root causes of health inequalities we must understand how social systems interact with multiple and simultaneous identities for diverse individuals within populations (E. Heard et al., 2020). This necessitates moving away from a single axis framing which privileges a singular underlying factor as a determinant of outcomes. Until recently much of the literature on digital booking systems and remote healthcare has focused on the issue of digital exclusion, with an embedded assumption that access to the right sorts of digital technologies and digital skills will account for most if not all issues of access. This overlooks a range of other factors which have been shown within this study to affect patient's experiences of accessing primary healthcare, such as health literacy and its relationship to articulation abilities. A cumulative complexity model (Shippee et al., 2012), as discussed earlier, can help to understand how these different characteristics, or factors, end up reinforcing and compounding each other as the demands placed on patients layer. This results in an impermeable service, which does not take in account the different capacities between different population segments or leave room for instability of resource access.

Benefits of remote and digital healthcare for marginalised groups

This thesis primarily focuses on the negative and sometimes neutral consequences of remote and digital healthcare on the experiences of care for marginalised groups. However, it's important to acknowledge, that even though respondents didn't directly discuss the benefits of remote care in terms of their own experiences, occasional references were made to potential advantages.

Two positive consequences of remote healthcare were highlighted. Firstly, one service user respondent mentioned the reduction in time and cost required to see a doctor due to the elimination of a commute to the GP surgery. Secondly, both a service user and a GP respondent emphasised the positive mental health benefits of being able to have a remote consultation from the safety of one's own home, particularly for those with more severe mental health issues.

However, the drawbacks of remote care spoken about by respondents seem to directly outweigh these theoretical benefits. To begin with, the long call windows of remote consultations often result in the actual time needed to be set aside for a remote consultation being longer than the time required for a commute to and from a GP surgery for an in-person appointment. Moreover, the potential cost savings from not having to commute to a GP surgery are often outweighed, particularly for resource poor individuals, by the financial burden of ensuring stable access to a phone and connection.

Furthermore, regarding the theoretical emotional safety of having a consultation from one's home, the prevailing narrative among respondents in terms of mental health and remote consultations was negative. Patients expressed a strong preference for in-person conversations with a known GP to ensure what felt like safe care. Additionally, GPs expressed hesitancy about conducting remote consultations for mental health concerns regardless of severity, due to concerns about their ability to effectively safeguard without an in-person evaluation.

Notably, the theoretical benefits mentioned correspond with those frequently outlined in policy documentation such as the NHS Long Term Plan (2019) emphasising efficiency and convenience as the primary benefits of remote care. However, based on data from this study, it becomes evident that these advantages are overshadowed by the inflexible nature of the system, imposing challenging hurdles for individuals with limited or unstable access to the essential resources required to effectively engage in remote consultations.

Strengths and Limitations

One of the main strengths of this research is that it was conducted with respondents recruited from outside of the healthcare service. This has enabled a broader selection of voices to be heard, including people who are low users of the healthcare service and would be unlikely to be recruited into a study in this way. The recruitment of participants from a range of different services also led to diversity in the sample, which means that this study was able to look at overlapping and more specific challenges which different marginalised groups may face when accessing primary healthcare services. Secondly, the unique timing of this study during COVID-19 was both a limitation and a strength. It was a strength in that it allowed for an opportunity to study the potential implications of a 'remote by default' healthcare system, even if this is no longer the case. It was a limitation because it was disruptive to the research process and limited which services and respondents were reached by this study. Further, whilst it gives insights into a snapshot in time which may be reflective of the direction of travel of General Practice in the UK, it makes transferability of some of the findings more of a challenge in the immediate future. This study was conducted primarily in London, for reasons which were laid out in the methodology, including practical ones related to COVID-19. However, this limits the generalisability of the study findings, as individuals from marginalised populations outside of London may have substantially different experiences of interacting with General Practice surgeries – for instance, the opportunity to have a phone consultation may be seen in a more positive light for people living in remote areas who would otherwise need to travel long distances to seek care. Further, London has more specialist services available, as well as community charities which are able to offer assistance to marginalised communities, meaning that there may be more safety netting available to help with accessing healthcare. On the other hand, London is a large capital city and so it is potentially easier for people to slip through the net if they are unknown within their local community. Another limitation of this study is that it did not explore in depth one of the main characteristics known to be associated with health inequality, which is race. Whilst commentary on the impact of racism was included in the data and write up, this was not a focus due to the relative lack of data on it which made it hard to isolate from the other factors affecting experiences of using the healthcare service. A group which was also missing from this data is those with physical and learning disabilities. The impact of remote consultations on people who are blind and deaf is something that was raised during the initial PPI panel run for this study – as one member of the panel was hard of hearing. People with limited mobility or learning disabilities may also experience remote consultations in substantially different ways. This is an avenue of research which is important to ensuring equity in service provisioning, however it was not covered by this study.

Policy and Practice Implications

As introduced in the literature review the NHS has progressively been moving towards a policy of digitalisation, with unclear boundaries around what might be defined as digital or remote. However, statements such as those by Hancock (2020) pushing for a remote by default primary care system – indicate that many of the changes put in place during COVID-19, specifically a shift towards greater levels of remote care, may be here to stay. What this study shows is that this process should be approached with extreme caution, as there is strong evidence from this research that remote care may be actively exclusionary for marginalised groups who have less capacity to mobilise the necessary cognitive and material resources necessary to engage.

The findings of this study have several key policy and practice implications. The main policy implication, is that a drive towards digitalisation, and remote delivery of services must not become the 'default' offering, and patients should always have other avenues of access made flexibly open to them. There are several key implications for practice. The main suggestion is that patients should be not be obligated to use remote appointment booking systems or to have remote consultations, inclusive practice would be to give patients an option for their preference without asking for a reason. Secondly, practices should aim to maintain greater relational continuity of care for patients who are known to have complex needs or to struggle with communication. Additionally, during remote consultations, clinicians may need to be deliberately more attuned to patients verbal cues which suggest that there is a possibility of safeguarding concerns – a skill which could be included in the training of junior doctors who are starting their careers with high levels of remote consultations. Finally, if unpredictable call times cannot be avoided for remote consultations, then clinicians may need to identify patients for whom this is going to be particularly difficult, and put in place systems which enable for more exact call times for these patients. Most of these suggestions are on the assumption that remote consultations are going to continue being in high use, however it seems likely that there are segments of the population for whom this is going to remain a challenge, making the first suggestion of choice of appointment booking and consultation modality particularly important.

William Gibson, the science fiction author who termed the term 'cyberspace', said "The future is already here, it is just not very evenly distributed" – a phrase which sums up a lot of what this study has found and argued. Gibson wrote extensively of a dystopic future in which technology replicates and exacerbates many of the current inequalities in society. Whilst the emancipatory potential for remote and digital services in healthcare may well yet bare out to be true, what this study has shown is that the journey there is likely to be staggered, with a high risk of those who are already vulnerable being left behind.

Conclusions

The current evidence base around the impact of changes to the primary care system in the UK, specifically a move to remote healthcare, was presented in the Literature Review. As noted, much of the strongest evidence comes from Third Sector reports, including Doctors of The World (2020), MedAct (2020) , and Groundswell (2020). This study has built on this existing evidence, to both confirm many previous findings and concerns, as well providing evidence around a range of other challenges which must be taken into consideration.

This study has provided further evidence around the following challenges of remote consultations in primary care for marginalised groups: an exaggeration of language barriers (Groundswell., 2020; Kaihlanen et al., 2022; Knights et al., 2021; MedAct et al., 2020; Verity et al., 2020) and communication (Groundswell., 2020); healthcare exclusion due to issues of digital access (Groundswell., 2020; Knights et al., 2021; Malpass et al., 2022; Verity et al., 2020); the introduction of increased safeguarding risks and difficulty building rapport and trust between patients and doctors (Dixon et al., 2022; Groundswell., 2020; Hinton et al., 2023; Murphy et al., 2021; Verity et al., 2020) and finally; the predisposition of remote consultations to be particularly mono-issue which is less suited to some populations' needs (Groundswell., 2020). Further, this study has added weight to the concerns that have been raised about the potential exclusionary impact of changes to the primary care system – providing evidence supporting models including the Digital Health Equity Framework (Allison Crawford & Eva Serhal, 2020) and Digital Inverse Care Law (Davies et al., 2021). Novel findings of this study include insights into the inequities in care which can be created when patients do not have suitable spaces available to them in which to take remote consultations – an issue which is exaggerated by unpredictable call times.

APPENDICES

Appendix 1 – Interview guides

INTERVIEW GUIDE- SERVICE USERS

What is the relationship between marginalisation and digital service delivery in primary healthcare experiences in the UK?

The Interview topic guide is meant as a guide to the themes that should be covered with research participants. It includes a set of questions that serve as conversation starters and suggestions for what I will ask in the field.

The goal is not to ask every respondent every question, rather, the guide is a tool to help me address the key themes of my study. In general, I will seek to let my curiosity, along with the respondents' focus, guide the conversation, rather than following the guide question by question.

Introduction:

- Introduction of the researcher (me)
- Overview of the study and time for questions
- Ensure written informed consent
- Reaffirm consent verbally
- Participant introduction

Accessing primary healthcare

How has the way you make an appointment with your doctor changed over the past 18 months?
- What was your experience of this?
- What resources did you need in order to make an appointment?
- Did you require assistance making an appointment?

How has the way in which you speak with your doctor changed (GP appointment)?
- How did this consultation take place?
- Can you tell me about your experience of this consultation?
- What resources did you require in order to have this consultation?
- Did you require any assistance?
- If different, how did this compare with how you used to speak to your doctor?

When COVID-19 first emerged and the UK went into lockdown do you know if your GP was still open?
- How did you get information about your GP practice during lockdown?
- Can you tell me about the changes to your GP practice during COVID-19?

Who makes decisions about the level of care that you need?
- Is anyone else involved in the decision making process?
- How are you involved in this decision making?

Who decides whether you are seen face-to-face or remotely?
- Which do you prefer and why?
- Are you involved in this decision making?

Accessing other healthcare services

Other than your GP which other NHS services have you used in the last 18 months?
- If you want access to an NHS service other than your GP how do you arrange this?

Have you ever used the NHS 111 service?
- Why did you decide to use 111?
- What was the result of your contact with 111?

Have you ever used A&E services?
- Why did you decide to use A&E?
- What was the result of your A&E trip?

Health and wellbeing

Do you consider yourself healthy?
- What things do you do to help keep yourself healthy?

If you needed more information on your health where would you go for information?
- Is this easily accessible to you?
- What resources do you need to be able to do this?

If you were worried about your health who would you speak to first?

If you need advice on how to access healthcare who do you speak to?
- What advice did they give you last time you asked them for advice?
- Do you have any other sources of advice if you need them, and if so who?

Exercise:

Ask participant to draw on paper a timeline of their last healthcare encounter with their doctor, marking points of contact with healthcare services and activities in between.

Using digital devices and the internet

Can you tell me what digital technology devices (e.g., phones, tablets, computers) you have access to?

- What do you use each device for?
- Do you ever receive help from anyone using these devices?
- Are there any other devices you don't have access to which you would like to?

Can you tell me about how you access the internet and what you use it for?

- Do you ever have any issues trying to access the internet?
- Do you feel like you have as much access to the internet as you would like?
- Can you tell me about a time you used the internet for a health-related question?
- Are there any public services e.g., the council or the doctor which you use the internet to find information on or contact?
  - If so, can you tell me about how you use the internet to do this?

Finishing remarks

Is there anything important which I've missed which you'd like to share with me about your opinions about changes in the ways in which healthcare is delivered?

INTERVIEW GUIDE- GPS

What is the relationship between marginalisation and digital service delivery in primary healthcare experiences in the UK?

The Interview topic guide is meant as a guide to the themes that should be covered with research participants. It includes a set of questions that serve as conversation starters and suggestions for what I will ask in the field.

The goal is not to ask every respondent every question, rather, the guide is a tool to help me address the key themes of my study. In general, I will seek to let my curiosity, along with the respondents' focus, guide the conversation, rather than following the guide question by question.

Introduction:

- Introduction of the researcher (me)
- Overview of the study and time for questions
- Ensure written informed consent
- Reaffirm consent verbally
- Participant introduction

Appendices

General practice during COVID-19

Can you tell me a little bit about the area you work in and the patient population?

Can you tell me about how your practice has changed during COVID-19?
- How was change communicated to you?
- Who was responsible for implementing change?
- What resources were necessary for implementation of change?
    - Who provided these resources?
    - Were there any resources you required which you didn't have access to?

Did your practice stay physically open over the course of the last 18 months?
- Were patients able to attend the practice without booking?
- If not how was this communicated to them?

How do patients book a consultation through your practice?

What modes of consultation are offered in your practice?
- Which are used for which purposes?

What is the role of digital technology in primary healthcare in the NHS?
- Who decides?
- How is this communicated to GPs?

What has your practice done over the last 18 months to contact individuals who may have limited access to digital technologies and the internet?
- How were these patients identified?
- How were these patients contacted?

Under what circumstances might you see a patient face to face instead of remotely?

Who is responsible for deciding whether patients get face to face or remote consultations?
- How do they make this decision?

As we emerge from this latest stage of COVID-19 what changes to your practice brought about by COVID-19 are staying?

Self-management of healthcare

Can you tell me what "self-management" of healthcare means?
- To what degree do you expect your patients to engage with self-management practices?
- Are you aware of any resources available to them to support this?
- Who do you think may be less able to engage in self-management?

How if at all has COVID-19 affected self-management healthcare practices?

Working with marginalised populations

Which groups would you see as most at risk of marginalisation within your GP practice population?
- What is your experience of providing care to these groups?
- What are the main challenges?
- How do you think care for these groups has been over the past 18 months?

What if any do you think the impact of an increase in digital healthcare service delivery has been on marginalised groups?

Who is responsible for ensuring marginalised groups can access primary healthcare?

Final remarks

Is there anything important which I've missed which you'd like to share with me about your opinions about changes in the ways in which healthcare is delivered?

INTERVIEW GUIDE- SERVICE STAFF AND DIGITAL HEALTH HUB STAFF

What is the relationship between marginalisation and digital service delivery in primary healthcare experiences in the UK?

The Interview topic guide is meant as a guide to the themes that should be covered with research participants. It includes a set of questions that serve as conversation starters and suggestions for what I will ask in the field.

Introduction:

- Introduction of the researcher (me)
- Overview of the study and time for questions
- Ensure written informed consent
- Reaffirm consent verbally
- Participant introduction

The impact of COVID-19

Can you tell me a bit about your role?
  - Which population groups do you work with?
  - How long have you been working in this role?

How has the service you work for been affected by COVID-19?

How has COVID-19 impacted on the populations you work with?
  - What have the main challenges been?

Access to healthcare services

Amongst the populations you work with can you comment on their access to healthcare services?

Amongst the population groups you work with are there any common challenges to accessing healthcare?
  - Why is this?
  - Where can they go to for advice?

- What resources are necessary for them to access healthcare effectively?

Do you know of any local services which help marginalised groups accessing healthcare services? E.g., digital training centres?

- What support do they give?

Digitalisation of public services

One thing I am interested in learning more about is how the digitalisation of public services may enable or prevent certain groups from accessing them– I'd like to know what you think?

- Is this something you've seen happening with the groups you work with?
    - Which services in particular?
    - What are the main barriers and enablers?
    - Who can they go to for advice?

Amongst the populations you work with, have you seen any changes in levels of access to public services during the course of COVID-19?

- Why is this?
- What impact has/could this have?

Digital health hub staff only

Can you tell me what the role of a digital health hub is?

- What resources were necessary to run them?
- Were there any other resources you would have liked to have had but didn't?

What types of activities did/does the digital health hub run?

- How were these activities selected?

Who is/was accessing your digital health hub?

- For what reason were they coming to it?

What are some of the main challenges those using the digital health hub face/faced?

- Why was this?
- What was done to assist them?
- Did this assistance lead to sustained change?

Amongst the population groups who attend the digital health hubs work with are there any common challenges to accessing healthcare?

- Why is this?
- Where can they go to for advice?
- What resources are necessary for them to access healthcare effectively?

Does/did your digital health hub have contact with local health services?

- How were these contacts set up?
- What was the nature of the communication?

Is there anything important which I've missed which you'd like to share with me about your opinions about changes in the ways in which healthcare is delivered?

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