# HOW SOCIAL PRESCRIBERS CONCEPTUALISE THEIR ROLE IN REDUCING THE HEALTH INEQUALITIES THAT AFFECT BLACK ADULTS WITH CHRONIC PAIN

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#### ABSTRACT

**Background**: Black people with chronic pain experience a range of health inequalities. Most notably, they are significantly more likely than other ethnic groups to experience chronic pain. The roll-out of social prescribing is a key part of recent UK health policy, with a stated aim of directly targeting health inequalities like these. Little is known about how Social Prescribing Link Workers (SPLWs), the people tasked with delivering social prescribing interventions, think about these specific health inequalities and the role of SPLWs in addressing them.

**Method**: A qualitative methodology was used to explore how SPLWs conceptualise the health inequalities that affect Black people with chronic pain, and how they see their role in reducing these inequalities. Seven SPLWs took part in semi-structured interviews. Data was analysed using reflexive thematic analysis and a critical realist epistemological perspective was adopted.

**Results**: Three superordinate themes were identified. The first theme, 'Social prescribing: "it doesn't fix the undercurrents of society", explored contextualised understandings of health inequalities held by SPLWs. 'Systemic factors affecting the SPLW role' described how the medical setting and socio-political context of social prescribing influence the SPLW role. 'Learning lessons and thinking differently' captured SPLW perspectives on valuing community strengths, rebuilding trust with communities, and thinking critically about race and ethnicity.

**Conclusions and Implications**: The findings indicate that SPLWs are making a valuable contribution to addressing health inequalities for Black people with chronic pain, but they view change at multiple systemic levels as essential to reducing inequalities in the long term. The SPLW approach to rebuilding trust with Black communities should be learned from, harnessed and developed, while health professionals should be supported and trained to work more sensitively around racialised chronic pain inequalities. Wider structural changes that more directly target the social determinants of health, like housing and education, are essential for reducing health inequalities and supporting the work of social prescribing.

## TABLE OF CONTENTS

1.	ΙΝΤΙ	ROD	UCTION	7
	1.1.	Intr	oduction to Chronic Pain	7
	1.1.	1.	Definition of Chronic Pain	7
	1.1.2	2.	Prevalence of Chronic Pain	8
	1.1.:	3.	Impact of Chronic Pain	8
	1.1.4	4.	Theories of Chronic Pain	9
	1.1.	5.	Treatment and Management	10
	1.1.0	6.	NHS Service Context	11
1	I. <b>2</b> .	Неа	alth Inequalities Affecting Black People With Chronic Pain	12
	1.2.	1.	Ethnicity and Chronic Pain Prevalence	12
	1.2.2	2.	Racism and Discrimination in Healthcare	14
	1.2.3	3.	Distrust of Services	14
	1.2.4	4.	Systemic Racism in Research	16
1	1.3.	Soc	cial Prescribing	17
	1.3.	1.	Introduction to Social Prescribing	17
	1.3.2	2.	UK Policy and Practice	17
	1.3.3	3.	Effectiveness	
	1.3.4	4.	Social Prescribing and Health Inequalities	19
1	I.4.	Sco	pping Review	21
	1.4.	1.	Search Strategy	21
	1.4.2	2.	Search Results	22
	1.4.3	3.	Review of Individual Papers	
	1.4.4	4.	Summary and Conclusions	
1	l.5.	Rat	ionale and Aims of the Current Study	29
	1.5.	1.	Research Questions	30
2.	MET	ГНОІ	DS	31
2	2.1.	Epi	stemology	31
2	2.2.	Des	sign	31
2	2.3.	Ref	lexivity	32
2	2.4.	Eth	ics	33
	2.4.	1.	Informed Consent	33
	2.4.2	2.	Potential Distress	33
	2.4.3.		Debrief	33
	2.4.4	4.	Confidentiality and Anonymity	33
2	2.5.	Res	search procedure	34
	2.5.	1.	Recruitment	

	2.5.2.		Inclusion Criteria	. 34			
	2.5.	3.	Sample Demographics	. 34			
	2.5.4. 2.5.5.		Sample Size	. 35			
			Data Collection	. 35			
	2.5.	6.	Transcription	. 35			
	2.6.	Data	a Analysis	. 36			
	2.6.	1.	Data Familiarisation	. 36			
	2.6.2. 2.6.3. 2.6.4.		Data Coding	. 36			
			Generating Initial Themes	. 37			
			Developing and Reviewing Themes	. 37			
	2.6.	5.	Defining Themes	. 37			
	2.6.	6.	Producing the Report	. 37			
	2.6.	7.	Sample Size	. 37			
3.	RES	SULT	S	. 39			
	3.1.		textualising the Analysis				
	3.2.	Sum	nmary of Themes and Subthemes	. 39			
	3.3.	The	me 1: Social Prescribing: "It Doesn't Fix the Undercurrents of Society"	. 40			
	3.3.	1.	Contextualised Understandings of Inequalities	.40			
	3.3.		"Black People are Not Taken Seriously": Whiteness and Racism in Healthcare				
	3.4.	The	me 2: Systemic Factors Affecting the SPLW Role	45			
	3.4.1.		"A Very Doctor-Patient Dynamic": Navigating the Impact of a Medicalised Setting	.46			
	3.4.	2.	Hampered by Deficiencies in Healthcare, Social Care and Civil Society	. 48			
	3.5.	The	me 3: Learning Lessons and Thinking Differently				
	3.5.	1.	"Making it Bottom Up": Centring Community Assets	. 51			
	3.5.	2.	Valuing SPLW Strengths	53			
	3.5.	3.	"We're Here to Mainly Listen": Rebuilding Trust				
	3.5.	4.	Thinking Critically About Race and Ethnicity	. 56			
4.	DIS		SION				
	4.1.		rview				
	4.2.	Sum	imary of Findings	. 59			
4.3. How do SPLWs Conceptualise the Health Inequalities That Affect Black Chronic Pain?							
	4.3.	1.	Contextualised Understandings of Inequalities	. 60			
	4.3.	2.	"Black People are Not Taken Seriously": Whiteness and Racism in Healthcare	61			
	4.4.	Wha	t do SPLWs See as Their Role in Reducing These Inequalities?	62			
	4.4.	1.	"A Very Doctor-Patient Dynamic": Navigating the Impact of a Medicalised Setting	62			
	4.4.	2.	Hampered by Deficiencies in Healthcare, Social Care and Civil Society	.63			
	4.4.	3.	"Making it Bottom Up": Centring Community Assets	. 65			

4.4.	.4. Valuing SPLW Strengths	65
4.4.	.5. "We're Here to Mainly Listen": Rebuilding Trust	66
4.4.	.6. Thinking Critically About Race and Ethnicity	67
4.5.	Critical Review	67
4.5.	.1. Ensuring Quality	67
4.5.	.2. Methodological Considerations	68
4.6.	Implications and Recommendations	70
4.6.	.1. Implications for Practice	70
4.6.	.2. Wider Implications	71
4.6.	.3. Research	72
4.7.	Reflexive Account	73
4.8.	Conclusions	74
5. REI	FERENCES	75
6. API	PENDICES	85
6.1.	Appendix A: Glossary	85
6.2.	Appendix B: Scoping Review Search Terms	86
6.3.	Appendix C: Ethics Application Form	87
6.4.	Appendix D: Evidence of Ethics Approval	
6.5.	Participant Information Sheet	103
6.6.	Appendix F: Consent Form	107
6.7.	Appendix G: Debrief Form	109
6.8.	Appendix H: Interview Schedule	111
6.9.	Appendix I: Example of Annotated Transcript	112
6.10.	Appendix J: Map of Initial Themes	113
6.11.	Appendix K: Final Thematic Map	115

## 1. INTRODUCTION

This research concerns the way that people involved in social prescribing think about the health inequalities that affect Black<sup>1</sup> individuals with chronic pain, such as the higher rates of chronic pain seen amongst Black communities in the UK. At the outset of this thesis it is important to make clear how my own identities and experiences have informed my approach to researching this topic. Through working in mental health and physical health settings, my views have developed to understand pain as something moderated by social forces and much more than a physical symptom. At the same time, my clinical psychology training has pushed me to critically engage with the privileges and power that come with my own identity as a White man. My understanding of the way that *Whiteness* defines norms and can lead to a failure to recognise racism in our institutions and practices, has influenced my thinking throughout this project. My experiences have led me to believe that the burden of challenging the oppressive systems that lead to health inequalities should not lie with those who are subject to oppression. As such, this project attempts to critically engage with the concept of racialised inequalities in chronic pain by locating them in their social context.

I will continue this chapter by defining chronic pain, discussing its prevalence and impact, the major theories of chronic pain, its treatment and management, and the NHS context. I will then cover the specific health inequalities that affect Black individuals with chronic pain before introducing social prescribing, discussing its policy context and setting out its proposed role in targeting health inequalities. The chapter will finish with a scoping review of literature relating to this topic. Appendix A contains a short glossary of some of the more technical and contested language used throughout this research. The first time that these terms are used in this thesis they are shown in italics.

## 1.1. Introduction to Chronic Pain

#### 1.1.1. Definition of Chronic Pain

Chronic pain, also known as long-term pain or persistent pain, is diagnostically defined as pain that persists for at least three months (World Health Organization, 2019). It can be classed as either secondary or primary. Secondary chronic pain is where another condition or injury is regarded as the underlying cause of the pain (for example, rheumatoid arthritis,

<sup>&</sup>lt;sup>1</sup> The social construction of race and ethnicity labels such as "Black" is discussed in more detail below in this chapter.

endometriosis, cancer or surgery) but the pain has become a problem in its own right (World Health Organization, 2019). Often the pain will continue long after the underlying condition has been successfully treated. In such a case, the underlying diagnosis may no longer be relevant but the pain diagnosis will remain. Primary chronic pain is defined as pain that cannot be clearly explained by another condition or injury, or where the pain appears to be out of proportion to an observable injury or disease (World Health Organization, 2019). Examples of primary chronic pain include fibromyalgia, chronic regional pain syndrome, irritable bowel syndrome and chronic primary musculoskeletal pain.

#### 1.1.2. Prevalence of Chronic Pain

Chronic pain is one the most prevalent health conditions in the UK. A large NHS survey estimated that 34% of adults in England have chronic pain (Public Health England, 2020), while a UK-wide systematic review and meta-analysis concluded that between a third and a half of the UK adult population are affected by chronic pain (Fayaz et al., 2016). In England, more women (38%) than men (30%) experience chronic pain, and prevalence increases with age, ranging from 16% among those aged 16 to 24, to 53% among those aged 75 and older (Public Health England, 2020). Notably, the same NHS survey found that 44% of respondents who identified as Black reported being affected by chronic pain, compared to roughly 34% for adults from each of the other race or ethnicity categories included in the survey (Public Health England, 2020). The study also revealed that people living in more deprived areas of England are 11% more likely to report experiencing chronic pain than those living in the least deprived areas. These disparities are key factors in the rationale for this study, and they are discussed in more detail below.

#### 1.1.3. Impact of Chronic Pain

The impact of chronic pain on the individual is widely researched and reported. It can have a profound and disabling impact on daily functioning (Public Health England, 2020) and can understandably lead to psychological distress and reduced quality of life (Kawai et al., 2017). Chronic pain can interfere with an individual's work activities, and their ability to attend work, which in turn can contribute to that person's social and economic problems (Zajacova et al., 2021). Chronic pain can also affect sleep, contribute to fatigue and affect cognitive functioning (Zajacova et al., 2021). In relation to social and family life, chronic pain can affect an individual's ability to carry out social roles, such as parent or partner, which can contribute to feelings of anger, stress or loss. At the same time, family and friends of those

with chronic pain can feel helpless or may feel burdened by caregiving needs (Dueñas et al., 2016; Zajacova et al., 2021).

One of the most difficult aspects of chronic pain is its "invisibility", particularly for those with primary chronic pain, in that often there is no observable cause. This can lead to individuals with chronic pain experiencing stigma and discrimination across multiple contexts. These can include work, social and family environments, and healthcare settings (Holloway et al., 2007). A common experience for people with chronic pain is to feel disrespected, distrusted and not believed by healthcare providers and others (Upshur et al., 2010), often leading to a sense of disempowerment in their care (McGowan et al., 2007).

The 2019 coronavirus pandemic (COVID-19) has made managing chronic pain even harder for those affected, and has been associated with a rise in chronic pain diagnosis rates (Kemp et al., 2020). COVID-19 infection has been shown to cause widespread muscular pain, while more serious cases might exacerbate, or contribute to, chronic pain symptoms through intensive care treatment or deep vein thrombosis (Clauw et al., 2020; Kemp et al., 2020). At the same time, social isolation measures imposed during the pandemic made it difficult for people to manage their pain with active coping strategies or valued social activities.

There is much written about the societal impact of chronic pain and its economic burden. For example, it has been estimated that back pain alone accounts for 40% of all sickness absence within the NHS (NHS Staff Council, 2014), while an estimated 4.6 million GP consultations each year are attributed to chronic pain (Belsey, 2002). Overall, chronic pain has been estimated to cost the UK economy £10 billion each year (Maniadakis & Gray, 2000).

#### 1.1.4. Theories of Chronic Pain

The most widely accepted theory of chronic pain is currently the biopsychosocial model (Engel, 1977; Turk et al., 2011). This theory builds on earlier biomedical models of pain, such as gate control theory (Melzack & Wall, 1965) and neuromatrix theory (Melzack, 1999), which hypothesised the role of the central nervous system in modulating pain signals. The biopsychosocial model incorporated into these theories a range of psychosocial mechanisms that interact with each other, and with physiological factors, to impact the experience of chronic pain. The most commonly researched psychosocial factors include affect (such as anxiety and depression), experiences of physical or psychological trauma, interpersonal factors, such as social support, and cognitive factors, like beliefs, self-efficacy and pain-

related coping (Gatchel et al., 2007; Meints & Edwards, 2018). As is evident from this list, research and literature on the "social" part of the biopsychosocial model tends to be dominated by interpersonal social-psychological factors, rather than wider social forces or determinants, like structural inequalities or government policies. Social determinants of health (Marmot et al., 2008), such as income, education, experiences of discrimination, and housing stability, have been found to influence disparities in a range a health outcomes, both within and between countries (Marmot & Bell, 2019). When these factors are distributed unequally and unfairly within society, they result in health inequalities. The picture seems no different for chronic pain. In England, people living in more deprived areas are 11% more likely to report experiencing chronic pain than those living in the least deprived areas (Public Health England, 2020). Socioeconomic deprivation has not only been linked to greater prevalence of chronic pain, but also to greater pain severity and pain-related disability (Brekke et al., 2002; Eachus et al., 1999; Janevic et al., 2017). For chronic lower back pain alone, one of the most common categories of chronic pain (Public Health England, 2020), UK research has linked increased prevalence and adverse pain outcomes with lower socioeconomic status (Lacey et al., 2013), while global research has found links between chronic lower back pain and socioeconomic deprivation (Carr & Klaber Moffett, 2005; Putrik et al., 2018), low income (Kuntz et al., 2017; Shmagel et al., 2016), low educational attainment (Chou, 2010; Kuntz et al., 2017; Shmagel et al., 2016), poverty (Schofield et al., 2012) and occupational status (Kuntz et al., 2017). At the population level, social inequality itself is also likely to be a factor, as Wilkinson and Pickett (R. G. Wilkinson & Pickett, 2007) have shown that health outcomes are worse in less equal societies.

The relationships between social determinants of health and experiences of chronic pain are complex and often bi-directional. For example, the effect of social disadvantage on chronic pain outcomes is likely to be mediated by health literacy, healthcare availability and experience, mental health problems, behavioural risk factors, such as unhealthy diet or physical inactivity, health issues, such as diabetes or obesity, and exposure to environmental risks (Dionne, 2001; Marmot & Bell, 2019). In turn, the occupational and economic impact of living with chronic pain, as mentioned above, can compound the cyclical relationship between chronic pain and socioeconomic deprivation (Maly & Vallerand, 2018).

#### 1.1.5. Treatment and Management

The National Institute for Health and Care Excellence (NICE) has published recommendations for the management of chronic primary pain (NICE, 2021). This was the first NICE guideline to recognise chronic primary pain as a health condition in its own right. There are no equivalent stand-alone recommendations for managing chronic secondary pain, however, the guidelines for common chronic secondary pain-related conditions, such as endometriosis or osteoarthritis, contain their own treatment and management recommendations.

For the purpose of this introduction to the topic, I will focus primarily on the management of chronic primary pain. The NICE guideline recommends the development of a care and support plan based on the person's preferences, abilities and goals, and on the impact of pain on their day-to-day activities. The guideline also stresses the importance of having honest discussions in healthcare interactions with the person about the challenges and uncertainty of the prognosis. Specifically, it recommends discussing that pain symptoms may fluctuate over time, that an underlying cause or reason for the pain may not be identified, and that even though their pain may not improve there can still be improvements in their quality of life.

In terms of evidence-based pain management recommendations, the guideline endorses exercise programmes, physical activity, acupuncture and psychological therapies, such as acceptance and commitment therapy (ACT) or cognitive behavioural therapy (CBT). Although it is worth noting that evidence for the effectiveness of psychological interventions is not particularly encouraging (A. C. de C. Williams et al., 2020). In a shift away from previous practices for managing for chronic pain, NICE does not currently recommend any pharmacological pain management apart from consideration of antidepressants after discussing their benefits and harms. It stresses that antidepressants "may help with quality of life, pain, sleep and psychological distress, even in the absence of a diagnosis of depression" (NICE, 2021), and that this should be explained to the individual. The absence of other pharmacological interventions, such as opioids, benzodiazepines, non-steroidal anti-inflammatory drugs (NSAIDs), and antiepileptics, is justified by NICE due to limited evidence of their effectiveness contrasted with extensive evidence of long-term harm, such as risk of substance misuse and dependence.

#### 1.1.6. NHS Service Context

NHS support for pain management is most often provided by GPs, mental health services, multidisciplinary pain management services, and other medical speciality teams, such as oncology or rheumatology. Specialist pain management clinics tend to provide a range of interventions and programmes, usually including psychological therapies, physiotherapy and advice around exercise and medication. These services are often seen as the 'gold standard', particularly for supporting people to manage chronic primary pain. Unfortunately, specialist pain services like these have been found to fall below recommended standards of

care in terms of access, waiting times and multidisciplinary staffing (McGhie & Grady, 2016; Price et al., 2019). In addition, for people experiencing more socioeconomic exclusion or deprivation, NICE-favoured interventions such as psychological therapy or exercise are particularly inaccessible. Despite the NICE guidelines explicitly cautioning against the prescription of opioids, these shortcomings in the provision of NHS chronic pain care have arguably contributed to the continued over-prescription of opioids by GPs and hospital teams. This is evidenced by a 2022 survey which found that since the publication of the NICE guidelines, 47% of people with chronic pain still report taking opioids to manage their pain (Zambelli et al., 2022). This may also contribute to the UK having the highest per capita consumption rate of prescription opioids for pain management of anywhere in the world (Jayawardana et al., 2021). It is with this backdrop that the UK government and NHS have turned attention and resources towards social prescribing, as a way of personalising care and support for people with physical and mental health concerns, such as chronic pain. I discuss social prescribing in more detail below.

#### **1.2.** Health Inequalities Affecting Black People With Chronic Pain

In this section I will be particularly focusing on the health inequalities that affect Black individuals with chronic pain. I am aware that the label "Black" (along with all other race and ethnicity labels) is a socially constructed category that has the effect of flattening or homogenising many cultural, historic, linguistic and other identities that vary significantly, including for those who might describe their identity as of mixed Black heritage. Holding this in mind, I have chosen to use the term Black throughout this project because of its use by many researchers, charities, activists, community organisations and public bodies as a way of highlighting and discussing inequalities that should be addressed. When reading this thesis, it is important to remember that this is a potentially harmful way of categorising people unless its socially constructed nature is held in mind throughout.

#### 1.2.1. Ethnicity and Chronic Pain Prevalence

As noted above, a Public Health England survey from 2017 showed that the prevalence of chronic pain varies with people's self-reported ethnicity (Public Health England, 2020). 44% of respondents who described themselves as Black reported experiencing chronic pain, compared to roughly 34% of respondents who described themselves as either White, mixed ethnicity, or Asian, and 26% of those in the Other ethnicity category. The very broad ethnicity categories reported in this study unhelpfully group together people from many different backgrounds. The huge variety of Asian ethnic identities are amalgamated into one, *socially excluded* groups like Gypsy, Roma and Traveller communities are subsumed into other

categories, and the use of 'Black' implies that Black identity in England is one homogeneous group. It is important to highlight that this provides an oversimplified picture of disparities in the prevalence of chronic pain, which can lead to problematic consequences when the results are used to inform influential areas like government policy, service design or media narratives. In spite of these issues, the 2017 survey tells us that there are likely to be racialised disparities in the prevalence of chronic pain. This matches up with other UK-based studies, which have found that people from *racially minoritised* groups are more likely to experience chronic pain (Beasley et al., 2014; Nicholl et al., 2015). In these cases, the differences were found to remain even after some other factors associated with chronic pain had been accounted for, such as social deprivation and having multiple long-term health conditions. This also aligns with disparities in other long-term physical and mental health problems, for example type 2 diabetes, which is more prevalent in South Asian and Black Caribbean communities in the UK (Goff, 2019).

More recent research in parts of South London has found that chronic pain is significantly more prevalent among Black residents (McGreevy et al., 2023), with the rate in some areas estimated to be almost twice as high for Black residents compared to those from other ethnic groups (Lambeth Together, 2023). In these same areas, the disparities in chronic pain prevalence appear to be even greater for Black women, who are significantly more likely to experience chronic pain as well as other long-term conditions (King's College London, 2023; Lambeth Together, 2023).

The reasons why Black people are disproportionately affected by chronic pain are not clear. As discussed above, social disadvantage and psychological distress, factors which are often more common in Black communities, may increase the risk of developing chronic pain (Raleigh & Holmes, 2021). Similarly, in the UK, Black people are more likely to live in deprived areas, are more likely to have multiple long-term health conditions, and are more likely to be unemployed or working in lower paid manual jobs (Hayanga et al., 2023; Runnymede Trust, 2021). There is also evidence that experiences of racism and discrimination are associated with chronic pain symptoms. For example, a US study has found a correlation between experiences of discrimination and pain-related symptoms, with African-American women being the worst affected by this relationship (Edwards, 2008). In the UK, the extent to which *systemic racism* harms Black communities has been widely documented, with, for example, Black people more likely to be in prison, more likely be stopped and searched and more likely to excluded from school than their White counterparts (Runnymede Trust, 2021). In line with the biopsychosocial model of chronic pain, this

specific combination of factors disproportionately affecting Black people in the UK, may explain the disparities in prevalence discussed above.

#### 1.2.2. Racism and Discrimination in Healthcare

In addition to being disproportionately affected by chronic pain, Black people are also more likely to face racism and discrimination throughout their healthcare journey. A widely reported US study found that 50% of medical students endorse false racist beliefs about pain, including that Black people feel less pain and have thicker skin than White people (Hoffman et al., 2016). Similarly, Black women with fibromyalgia in the US describe not being believed by health professionals, and struggle to be recognised as morally deserving of disability benefits claims (Pryma, 2017). There are similar patterns in the US when looking at pain treatment. Both African American adults and children are less likely to be prescribed pain relief medication than their White counterparts (Goyal et al., 2015; Meghani et al., 2012; Todd et al., 2000). This is not to say that people with chronic pain should be prescribed more pain relief medication, but rather that treatment decisions are likely to be influenced by harmful racist beliefs and biases held by health professionals. There are fewer UK-based studies in this specific field, but research on endometriosis (a common chronic pain-related condition) has shown that women from racially minoritised groups are less likely to have their pain believed by health professionals (Denny et al., 2010). At a broader health level, a large UK-based survey found that almost two thirds of Black people have experienced racism and discrimination from healthcare staff (lacobucci, 2022a). Respondents cited feeling like their concerns were not listened to, with Black women participants highlighting that their pain was dismissed by clinicians due to the stereotype of them being "strong Black women". These findings must be seen against a backdrop of a UK health system in which Black and other racially minoritised people are underrepresented in senior NHS roles (NHS, 2022), and underrepresented in disciplines that work with people with chronic pain, such as the clinical psychology workforce (NHS Digital, 2013). These studies and statistics depict a pervasive Whiteness within healthcare which is likely to worsen chronic pain outcomes for Black people in the UK.

#### 1.2.3. Distrust of Services

An important factor impacting Black people's experience of chronic pain is their access to, and engagement with, health services. A comprehensive review by the NHS Race & Health Observatory found that among Black communities (as well as other racially minoritised groups) there is a lack of trust in primary care and mental health services, and a fear of racist treatment, which deters Black people from accessing services to seek help (Kapadia et al., 2022). This includes perceptions that health professionals do not understand racism or how it impacts Black people's experiences and outcomes of healthcare (Linney et al., 2020), that health professionals underestimate the contribution of racism and discrimination to individual distress (Kalathil et al., 2011), and that mental health care is impacted by a lack of understanding of 'the Black experience' (Memon et al., 2016). Again, these findings are likely to be linked to the history of normative Whiteness within UK healthcare, which privileges White service users at the expense of racialised groups. This relationship between distrust, fear of racist treatment, and an understandable reluctance to access or engage with services has been highlighted in various Black communities in the UK, including Somali people living in Bristol (Linney et al., 2020), African, African Caribbean and South Asian women in London (Kalathil et al., 2011), and Black Caribbean older adults across the UK (N. V. Bailey & Tribe, 2021).

The distrust and fear of mental health services that Black people report is most profoundly justified by the evidence of ongoing systemic racism in acute psychiatric care in the UK. Those identifying as Black African, Black Caribbean and mixed Black heritage are overwhelmingly more likely than those from other ethnic groups to be admitted to psychiatric wards (Barnett et al., 2019; Halvorsrud et al., 2018), more likely to receive Community Treatment Orders (Barnett et al., 2019), more likely to be subject to coercive treatment, including seclusion and restraint in the prone position (Halvorsrud et al., 2018), and more likely to receive intrusive treatment, such as injectable anti-psychotic medication, whilst being less likely to receive talking therapy for severe mental health problems (Das-Munshi et al., 2018). Keating et al. (2002) theorised that "circles of fear" exist for Black people in the UK, in which staff in mental health services hold prejudiced attitudes and fear violence from Black people, which leads to them treating Black service-users more coercively, violently and intrusively within acute mental health settings. This fuels distrust and fear among Black communities, which deters and delays them from accessing services, and makes them less likely to engage with, or accept, treatment. As a result, Black people are more likely to access acute mental health services when they are in a state of mental health crisis, or via the criminal justice system, which in turn reinforces the prejudiced views held by staff. Whilst the research above applies more to mental health services in general than specifically to chronic pain care, there is likely to be some degree of understandable distrust of primary and secondary care services for Black people with chronic pain. This may be particularly evident when the recommended interventions for an individual's chronic pain are psychosocial in nature, as is often the case.

Aside from the ongoing evidence of systemic racism described above, it is important to note that the fields of medicine, psychiatry and psychology all have long and shameful histories of

racism. In the early twentieth century, the English scientist Francis Galton popularised his theory of eugenics (Galton, 1883), according to which certain groups of people were genetically inferior to others. He argued that unrestricted procreation by so-called inferior groups would weaken the genetic makeup of the population. Unsurprisingly, his racial hierarchy placed "Anglo-Saxon" groups at the top and Black populations towards the bottom. Similarly, in America, psychiatry was inextricably linked with racism through the coining of "drapetomania", a supposed psychiatric disorder describing a Black slave's desire to run away from their slave owner (Cartwright, 1851). In more recent history, the Tuskegee Syphilis Study conducted between 1932 and 1972 by the US Public Health Service (Baker et al., 2005) saw hundreds of poor African American farmers deceived into taking placebo treatment under the guise of free healthcare, in order to monitor the progression of untreated syphilis in Black men. Many of them died directly from syphilis or from syphilis-related complications, and many passed on the condition to their partners and children. Black women have been subject to particularly violent exploitation throughout the history of medicine. For example, in the nineteenth century the American doctor, J Marion Sims, performed experimental gynaecological surgeries on enslaved Black women, without their consent, and without using anaesthetics, as he believed that Black women had higher pain thresholds than White women (Ojanuga, 1993). This history of racism in medicine and psychiatry affecting Black and other racially minoritised groups further justifies the lack of trust in services providing care and support around chronic pain. Ultimately, this barrier to accessing and engaging with services is likely to worsen individual physical and mental health, and widen the inequalities that already exist for Black people in the UK with chronic pain.

#### 1.2.4. Systemic Racism in Research

In the UK, racially minoritised people with chronic pain also face health inequalities due to ongoing systemic racism in medical research. Black and other racially minoritised groups are consistently underrepresented as participants in UK health research despite having comparatively higher rates of health problems (Powell et al., 2022; Smart & Harrison, 2017). For chronic pain in particular, there is a lack of UK research on pain management for racially minoritised communities (Burton & Shaw, 2015). The acknowledgement by prestigious UK-based academic journals, Nature and The Lancet, of their role in maintaining systemic racism and White bias in medical research is a sign of the deep-rooted nature of this inequality ("Systemic Racism: Science Must Listen, Learn and Change," 2020; The Editors of the Lancet Group, 2019). For Black people with chronic pain, the inequalities in research

compound the disparities described above to create further barriers to receiving equitable, fair and inclusive healthcare.

## 1.3. Social Prescribing

## 1.3.1. Introduction to Social Prescribing

Social prescribing, also sometimes known as community referral outside the UK, is a way of connecting or referring people to a range of non-clinical, local services, groups and activities (NHS England, n.d.-b). There are various models of social prescribing, but referrals tend to come from primary care professionals, while "socially prescribed" activities are generally provided by civil society organisations, like community organisations, charities and social enterprises. Activities can range from befriending to sports and fitness, peer support groups, gardening, volunteering, or arts groups. Social prescribing schemes recognise that health and wellbeing are determined by social and environmental factors, and so aim to meet people's emotional, social and practical needs to improve their mental health and physical wellbeing and support them to take greater control of their own health (Buck & Ewbank, 2020). The NHS states that social prescribing can be particularly helpful for people with multiple long-term conditions, "low level mental health issues", "complex social needs", and people who are lonely or isolated (NHS England, n.d.-b).

## 1.3.2. UK Policy and Practice

In the UK, most social prescribing happens through a social prescribing link worker (SPLW), also less commonly known as a community connector or community navigator. In line with this model, health services, social care, charities, or other local agencies, can refer individuals to an SPLW, who will meet with them to co-create a personalised care and support plan, and connect them with the type of community-based resources described above. The SPLW's role also includes an element of "community development", through which SPLWs work with local community members to develop new groups and activities, and support existing groups to be sustainable and accessible (NHS England, n.d.-b). The duration of social prescribing interventions varies by programme, but a typical service-user journey might involve up to six sessions with an SPLW of up to 45 minutes each. SPLWs are employed either by NHS primary care networks (PCNs: groups of GP practices) or by community organisations on behalf of the NHS (NHS Health Careers, n.d.). There are no entry requirements to become an SPLW (NHS Health Careers, n.d.), and SPLWs tend to

come from a range of professional backgrounds. They receive training and development once in their post, on topics such as safeguarding and social welfare.

Whilst social prescribing and similar approaches have existed in the NHS since the 1990s, the current model was introduced into NHS policy first through the NHS Five Year Forward View (NHS England, 2014) and the General Practice Forward View (NHS England, 2016), and then more formally through the NHS Long Term Plan (NHS England, 2019a). The latter publication incorporated social prescribing into the NHS's model of universal personalised care (NHS England, 2019c), aiming to give people more choice and control over their physical and mental health. It aimed to do this by funding increasing numbers of SPLW positions, setting a target of 1,000 new SPLWs being employed in England by 2020/21, and 900,000 people being referred to social prescribing schemes by 2023/24. The UK Department of Health and Social Care also made £5 million available in 2019 for the establishment of the National Academy for Social Prescribing; an independent charity focused on developing the evidence base for social prescribing, raising its profile, and supporting associated civil society organisations (Department of Health and Social Care, 2019).

## 1.3.3. Effectiveness

Whilst UK policy seems to show unequivocal support for social prescribing, the evidence base is less clear. Some isolated studies have claimed that social prescribing via the SPLW model is an effective health and wellbeing approach. For example, a 2017 qualitative study of an SPLW programme in a deprived area in Newcastle found that participants reported improvements in outcomes such as overall mental health, self-confidence, reduced social isolation and health-related behaviours (Moffatt et al., 2017). However, academic reviews of social prescribing research suggest that the evidence is generally mixed, of poor quality, and lacking methodological rigour, despite many of the reviewed studies concluding that social prescribing is an effective health intervention (Bickerdike et al., 2017; Chatterjee et al., 2018). The same is true for studies focusing specifically on SPLW-provided programmes (Kiely et al., 2022). As a result of this apparent gap in the evidence base, Kiely et al.'s review (2022), concludes that policymakers should focus on evaluating current social prescribing programmes before expanding their roll-out across the country. This is particularly pressing considering that social prescribing evaluations have been found to be of poor quality and therefore unfit to support conclusions around impact and effectiveness (Elliott et al., 2022).

There appears to be no research focusing specifically on the effectiveness of social prescribing for people with chronic pain. However, one recent study has found that targeted

pain-management training for health and social care professionals involved in social prescribing increased their confidence in all aspects of supporting people to manage their pain (Corline et al., 2023). It could also be argued that the longer consultation lengths that SPLWs can offer people, compared to GPs, could allow for more thorough conversations about the biopsychosocial factors that impact each individual's experience of chronic pain, and support the development of more trusting patient-professional relationships; both of which have been found to support people's ability to effectively self-manage pain (Bair et al., 2009; Gordon et al., 2017; Slade et al., 2009).

The social prescribing approach also seems to be popular with health professionals working in primary care (Ogden, 2021). This may well be because GPs, faced with increasing workload and workforce pressures (Royal College of General Practitioners, 2023), see social prescribing as a way of cutting down the high numbers of chronic-pain-related consultations they have throughout their week. In line with this, 59% of GPs think that social prescribing can help to reduce their overall workload (Frontier Economics, 2021). This may be particularly appealing to GPs when it comes to chronic pain consultations, which have been found to make some GPs feel hopeless and ineffective in their ability to support people to manage their pain (Breen et al., 2007; Shivji et al., 2022).

#### 1.3.4. Social Prescribing and Health Inequalities

NHS England has touted the roll-out of social prescribing as a way of directly targeting the social determinants of health, and therefore being "effective at targeting the causes of health inequalities" (NHS England, 2019b). This claim has since been repeated by other senior policymakers in the NHS (John, 2022). It is built upon the argument that since many of the determinants of health are social in nature (such as employment, housing security and education) (Marmot et al., 2008), connecting people with social, community-based solutions will improve the health and wellbeing of those who are unfairly deprived of these social advantages. However, commentators have pointed out that this approach does not target the social determinants of health themselves (Buzelli et al., 2022; Mackenzie et al., 2020; Moscrop, 2023). Instead, it focuses on individualised solutions intended to mitigate the inequalities caused by greater social forces, such as government policies and systemic racism. This is an example of a broader critique of health policy and practice, labelled "fantasy paradigms", according to which policy actors and researchers promote less effective "downstream" solutions to health inequalities, instead of macro-level actions (Scott-Samuel & Smith, 2015). Indeed, the World Health Organization Commission on Social Determinants of Health has more explicitly set out that tackling health inequalities requires "major changes in social policies, economic arrangements, and political action" (World

Health Organization, 2008). This differs from the social prescribing approach, which some would argue, aspires to diagnose and treat the causes of inequality at the individual level. In this sense, social prescribing risks medicalising wider social problems, and the medical language of "prescribing" may reinforce this idea. Some critics have gone further to argue that focusing on social prescribing as a solution to health inequalities takes the burden away from the Government, and distracts from the structural reform that is needed to target the social determinants of health (Mackenzie et al., 2020). This is against a political backdrop of over a decade of Conservative austerity policies, which are credited with worsening social conditions for the worst off in UK society, and widening health inequalities as a result (Marmot et al., 2020). In keeping with this, the UK Government has recently scrapped its previously promised white paper on health disparities (Nightingale & Merrifield, 2023), leaving less hope for social policy-level targeting of the social determinants of health under the current Conservative Government.

A more concerning potential outcome of the roll-out of social prescribing in the UK is that it may actually widen inequalities. Brown et al. (2021) point out that those who are disproportionately affected by the social challenges that social prescribing is designed to target, are the most likely to experience barriers to engaging with social prescribing caused by those same social challenges, such as financial difficulties or lack of social support. This is an example of the "inverse care law", according to which people who are most in need of care are the least likely to receive it (Hart, 1971). One particular barrier for racialised communities might well be their distrust of NHS services, as discussed above. Social prescribing's positioning within GP practices and medical pathways may align it with the same services that attract intergenerational distrust from racialised communities, and therefore deter people from engaging. Brown et al. (2021) and McNally (2018) also highlight that social prescribing only works effectively if there are community resources to link people in with. Since socially deprived neighbourhoods often have fewer community resources, like groups and accessible public spaces, people living in those areas are likely to benefit less from social prescribing. This disparity has been made starker thanks to COVID-19 and many years of UK austerity policies that have stripped the public sector and civil society of important funding, which has disproportionately affected racially minoritised communities and more socially deprived areas (Achiume, 2019), resulting in even fewer community-based resources. Many of these concerns have already been noted by a range of civil society organisations as ways in which social prescribing could potentially widen inequalities (Cole et al., 2020). These organisations have also highlighted that SPLWs may not have the required skills or resources to engage with, and support, socially excluded individuals, especially since clients experiencing social deprivation often need more intensive and

practical support than SPLWs are able to provide (Cole et al., 2020). All of these factors are ways in which the roll-out of social prescribing could potentially widen health inequalities for Black adults with chronic pain.

## 1.4. Scoping Review

As described above, there are particular health inequalities that affect Black individuals with chronic pain, and a national health policy which promotes social prescribing as one of the key solutions to these challenges. Bearing in mind the concerns set out above regarding the impact of social prescribing on these health inequalities, the literature in this area has been explored in more depth.

## 1.4.1. Search Strategy

A scoping review was conducted to summarise existing literature on the relationship between social prescribing and the health inequalities affecting Black individuals with chronic pain. A preliminary scoping review revealed that there was no research in this specific area. So to ensure that the scoping review captured related and relevant topics the review was widened to include literature on the relationship between social prescribing in general (i.e. not just for chronic pain) and health inequalities (i.e. not just inequalities affecting Black individuals). This could include social prescribing research that focused on particular racially minoritised groups. Search terms included variations on "social prescribing" combined with terms relating to race and ethnicity or inequality, for example, "Black", "racially minoritised" and "health inequalities". Full details of the search terms are included in Appendix B. The databases searched were Psycinfo, Academic Search Ultimate, CINAHL Complete and Scopus. Additional grey literature was identified through searching websites and organisations.

## 1.4.1.1. Inclusion criteria:

The inclusion criteria were reports published in English language, using any research methodology, where the primary focus of the research is any aspect of the relationship between social prescribing and health inequalities.

## 1.4.1.2. Exclusion criteria:

Reports not written in English and editorials which do not produce new data were excluded from the review.

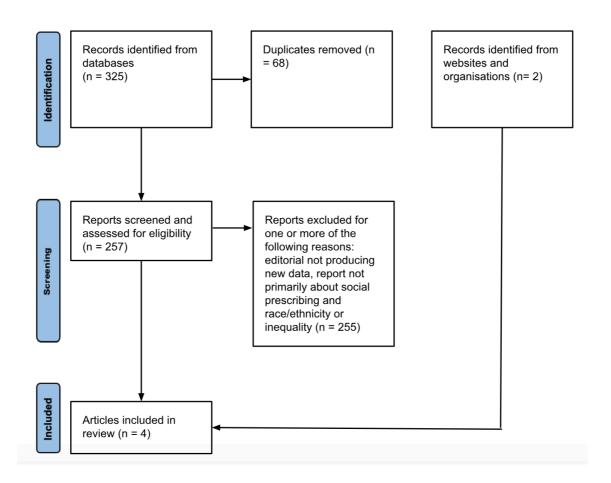
## 1.4.2. Search Results

The search process resulted in a total of four reports which are summarised below. Out of those four, Gibson et al. (2021) and Mackenzie et al. (2020) are both qualitative research studies identified through database searches. The other two, Durrant & Rolston (2022) and Tierney et al. (2022) are grey literature identified through searching websites and relevant

organisation's publications. Figure 1 below is a PRISMA flow diagram setting out the stages and results of the search process.

## Figure 1

PRISMA flow diagram adapted from Page et al. (2021)



## 1.4.3. Review of Individual Papers

## Durrant & Rolston, 2022

# Reimagining Social Prescribing – Perspectives from Black and Racially Minoritised Communities

This is a report produced by The Ubele Initiative, an African diaspora-led community interest company, and London Plus, a charity supporting other charities and community groups in London. It was funded by the National Academy of Social Prescribing. It details a stakeholder engagement process in London involving three virtual roundtable discussions with participants who work in social prescribing and health and wellbeing. The aims of the

project were to explore what social prescribing looks like in Black and racially minoritised (BRM) communities, how it can be effective, and how the sector can best be supported. Participants at the roundtable discussions included social prescribers (including SPLWs), public health professionals and a range of health and wellbeing activity providers who work with BRM communities, including food growers, singing teachers, arts organisations and parenting support services. In total, 19 London-based organisations attended the roundtable discussions. As this was not a formal research project, the method of analysing the data from the roundtable discussions is not explicitly stated, but the authors have summarised the key messages to come out of the discussions. Stakeholders all spoke about the health inequalities that affect BRM communities and how COVID-19 has widened these inequalities. They also discussed the fear and stigma that exists within BRM communities around mental health difficulties, for example, that some cultural traditions understand mental health challenges as a weakness or a spiritual punishment that should be hidden from others. Stakeholders were acutely aware of the distrust of statutory services within some BRM communities, however, it emerged that many community groups with the trust and respect of these communities, providing culturally relevant activities and interventions, were not aware that they fell within the parameters of the social prescribing model. Ultimately, stakeholders agreed that social prescribing was not meeting the needs of BRM communities as well as it could. Some of the key recommendations from the project were:

- social prescribing programmes should engage better with BRM communities by speaking directly to those communities, making their resources more culturally inclusive, and ensuring that their activity provider directories are updated to include BRM activity providers
- BRM-led community groups should have better access to funding opportunities and more support from funders to overcome barriers such as smaller organisations lacking the capacity to apply for funding
- BRM-led community groups should network and share ideas through peer-to-peer support spaces
- guidance for groups and organisations on how to become social prescribing activity providers should be culturally relevant
- Social prescribing activity providers can improve access and cultural relevancy and by appointing more BRM individuals as board members

While this project provides extremely valuable and practical insights on how to improve social prescribing for BRM communities in general, it does not focus specifically on chronic pain or on the unique health inequalities that impact Black people with chronic pain. At the

same time, while the views and experiences of professionals and service-providers offer an important perspective, it is unclear how many SPLWs participated in the discussions, and so the unique perspective of SPLWs is not explored in this project. With national policy holding up social prescribing as one of the solutions to health inequalities, the SPLW perspective on their understanding and role in this process is a key area that is not clearly captured by this project. The methodology of roundtable discussions is also a very useful way of bringing together large groups of stakeholders to encourage engagement and debate, however it is less useful for exploring in-depth and personal understandings of the issue of health inequalities. This leaves a gap in understanding of the nuanced thinking that may impact how SPLWs conceptualise their role in addressing these inequalities.

#### Mackenzie et al., 2020

## "The state They're in": Unpicking fantasy paradigms of health improvement interventions as tools for addressing health inequalities

The context of this study was a social prescribing programme located in socially deprived areas of Glasgow. The aims of the study were to explore how professionals involved in the social prescribing programme discussed health inequalities, social determinants of health, and the connections between them. The authors particularly wanted to explore, from a practitioner perspective, the "fantasy paradigm hypothesis" (Scott-Samuel & Smith, 2015), according to which interventions focused on individual behaviour are flawed when they are deemed to be the best solution to health inequalities. In total, 47 professionals from 15 GP practices involved in delivering the social prescribing programme participated in the study. Participants included GPs, link workers, practice managers, practice nurses and representatives from local community organisations. Qualitative data were collected from 12 individual interviews and 15 group interviews made up of between two to six participants each. Interviews were focused on their experiences and views on delivering the social prescribing programme, with particular attention given to topics like the scope of the programme and the link worker role in relation to health inequalities. Interview transcripts were analysed thematically. The authors identified three themes on how participants explained the social prescribing intervention's relationship to health inequalities:

- "Dedication to individualised problems", representing the dominant discourse among "believers" that poor health is caused by individual behaviour, poor lifestyle, and negative dispositions, and should therefore be addressing through individualised solutions
- "Intervention as part of a bigger, hazy solution", consisting of "hopeful pessimists" who hoped that the social prescribing intervention would mitigate health inequalities

against the odds, those who saw the social determinants of health as a backdrop to poor health rather than being politicised and causally linked, and those who seemed to be unclear on the difference between individual level intervention and the population level intervention that targets the correlation between socioeconomic disadvantage and poor health ("social gradient")

• "Disrupted narratives", representing the inconsistencies within and between participants' views on how social, economic and political factors impact health.

The main implications of the study are the identification of opportunities to improve practitioners' understanding of the social determinants of health in order to offer better primary healthcare, and the recommendation to "de-couple" the policy aim of reducing health inequalities from the provision of public services focusing on equality.

This study provides extremely valuable insights on social prescribing and health inequalities from the perspective of professionals involved in social prescribing. However, as with the report discussed above, it does not provide insights into their views on the inequalities affecting people with chronic pain. Nor does it focus on racialised inequalities, choosing instead to explore inequality in terms of socioeconomic factors without exploring their intersection with racialised inequalities. It also aggregates the views of practitioners involved in the programme, so the voice of the SPLW, the practitioner who has the most contact with residents and community organisations, is not clearly distinguished.

#### Gibson et al., 2021

#### Social prescribing and classed inequality: A journey of upward health mobility?

This study was carried out in the context of an SPLW-delivered social prescribing programme for people in an ethnically and socially diverse urban area in the North of England. The programme accepted referrals for people aged between 40 and 74 with long-term health conditions. The aim of the study was to explore how processes of classed inequality relate to how people engaged with the social prescribing intervention as well as the impact it had on their lives. The authors used an ethnographic approach, involving interviews with social prescribing clients and their family members, and extensive participant observation, including accompanying participants to SPLW appointments and community activities. For this article, the authors focused on four case studies covering the period from November 2019 to July 2020; each one a social prescribing client with a diagnosis of type 2 diabetes. Two participants were men and two were woman. Their ethnicity is not detailed, however one of the women is described as having moved to the UK from the Indian

subcontinent after finishing university. Socioeconomic status seemed to vary significantly between the four participants.

The authors argue that the social prescribing intervention "worked" for all four participants in varying ways, in that it helped them to "negotiate" the social determinants of health (for example, one participant used social prescribing to access a food bank), however it was unable to "remove" those social determinants themselves. The results showed how motivation and capacity to engage in the social prescribing intervention was shaped by an individual's context and their possession of capital (social, cultural, symbolic and economic). In this sense, while all participants seemed to recognise the health merits of the intervention, inequalities influenced their capacity to engage. The authors conclude that individualised solutions like social prescribing cannot tackle health inequalities because they wrongly presume that everyone has equal capacity and disposition to engage in their future health.

This study addresses the relationship between social prescribing and health inequalities from the perspective of service-users. However, it focuses on type 2 diabetes rather than chronic pain and therefore does not allow the authors to make targeted recommendations to address the inequalities affecting people with chronic pain. As the ethnicity of the participants is not clearly stated, we are also unable to learn how race and ethnicity might have shaped their engagement with the social prescribing programme, and this is not a topic that the authors have discussed. As with the study above, their focus is on broader socioeconomic inequalities and social class. The lack of SPLW perspective in this study also means that the ways that SPLWs think about these issues cannot inform recommendations on how to improve social prescribing for minoritised groups.

#### Tierney et al., 2022

## What does the evidence tell us about accessibility of social prescribing schemes in England to people from black and ethnic minority backgrounds?

This report details the results of a review of peer-reviewed and grey literature relating to social prescribing and ethnicity. The report is described as an "evidence summary", commissioned by the National Academy for Social Prescribing, and produced by their Academic Partners. To conduct this study, the authors reviewed research conducted in

England in or after 2017. The main aim of the research was to understand more about the accessibility of social prescribing in England for people from "ethnic minority" groups.

After searches and screening the authors were left with three relevant studies, all of which were grey literature reports focusing on specific social prescribing services. Due to the lack of available evidence on the barriers and enablers to accessing social prescribing for people from racially minoritised groups, the authors felt unable to make general claims on how best to increase access. However, the review highlights a number of best practice indicators drawn from the three reports. These include building awareness about social prescribing by working with and through communities (for example by working with local faith groups), building trust with community representatives and leaders, increasing inclusivity and trust by working to identify and develop community groups and projects that reflect the needs and expectations of the local community, and having ethnically diverse staff and volunteers. The authors conclude that further research on this topic is needed to ensure that access to social prescribing is equitable.

As with the other studies in this scoping review, the findings in this report are broadly applied to all physical and mental health needs, and not specific to chronic pain. The report does provide useful suggestions on how to ensure that racially minoritised individuals are not excluded from social prescribing services, however this discussion is limited to the topic of access and does not cover other issues such as how people might engage with services when they do access them. The report also does not focus on the specific inequalities that affect Black communities. Overall, the lack of studies identified the authors in their review is a strong indicator that further research is needed on the topic of social prescribing and ethnicity.

#### 1.4.4. Summary and Conclusions

The review identified that, in general, professionals involved in the delivery of social prescribing programmes have a good awareness of the existence of health inequalities, but their views on the relationship between those inequalities and the social determinants of health vary considerably. Some professionals were wedded to the idea of individualised solutions to health inequalities, while others held more pessimistic or disjointed views on social prescribing's role in reducing inequalities. Differences between different groups of professionals were not explored. From the perspective of service-users, their possession of capital, whether social, economic or cultural, seemed to shape their capacity to engage with social prescribing interventions. When looking, in particular, at social prescribing for people from racially minoritised groups, stakeholders seem to have clearer views on how distrust of

services might affect access to, and engagement with, social prescribing, and how lack of civil society funding and lack of culturally diverse and relevant social prescribing interventions may disadvantage racially minoritised communities.

What is notable from the review is that there is no research exploring the topics of chronic pain and social prescribing, let alone the relationship between social prescribing and the specific health inequalities affecting Black people with chronic pain. There is also a lack of research exploring the area of heath inequalities from the perspective of SPLWs. The two studies that did include SPLWs as participants (Durrant & Rolston, 2022; Mackenzie et al., 2020) also included other social prescribing professionals and stakeholders without drawing out any particular views or experiences that were specific to SPLWs. In addition, the roundtable discussion method in the Durrant et al. report (2022), while useful for its purpose, did not allow for a rich, in-depth exploration and analysis of how those professionals might understand or make sense of the issues being researched.

#### 1.5. Rationale and Aims of the Current Study

There are well-established health inequalities affecting Black individuals with chronic pain. Current UK health policy is hailing the roll-out of social prescribing as an important way of reducing health inequalities in general. The scoping review has demonstrated that professionals and other stakeholders involved in the provision of social prescribing are aware of the risk that that this strategy may not work, and may even widen inequalities, including for people from racially minoritised groups. Research is also starting to show that socially excluded communities may face more barriers to engaging with social prescribing. The picture for specific health inequalities is less clear, with a lack of research on social prescribing and chronic pain, a condition that seems to impact Black communities significantly more than others.

SPLWs have been tasked with delivering social prescribing interventions and are therefore key figures in achieving the policy goal of reducing health inequalities. SPLWs also occupy a unique position at the intersection of health services, community organisations and individual community members. For these reasons, understanding how SPLWs conceptualise the specific inequalities affecting Black people with chronic pain, along with their role in tackling them, is valuable information to help inform policy and practice in this area. As such the aim of this study is to make a novel contribution to the literature by hearing the views and experiences of SPLWs on the relationship between social prescribing and the health inequalities that affect Black people with chronic pain. The aim is for the findings to influence

policy and practice that will ultimately lead to reductions in these inequalities, and possibly also to other related areas of health inequality.

## 1.5.1. Research Questions

This study will employ a qualitative design to answer the following research questions:

- 1. How do SPLWs conceptualise the health inequalities that affect Black people with chronic pain?
- 2. What do SPLWs see as their role in reducing these inequalities?

#### 2. METHODS

This chapter will set out details of the study's epistemology and design, reflections on positionality in relation to the research, ethical considerations, the research procedure, and an outline of the data analysis process.

#### 2.1. Epistemology

This study adopted a critical realist epistemology. Critical realism acknowledges the existence of an objective reality. It suggests that our observations of the world may allow us to come close to 'knowing' this reality, but it accepts that knowledge is constructed socially and subjectively, making our observations fallible (Bhaskar, 1975; Danermark et al., 2019). In this sense it distinguishes itself from both positivist and constructivist epistemologies (Bhaskar, 1975). It allows for research to provide us with important knowledge about what exists, without our observations being a direct reflection of objective reality. Positivist approaches are common in healthcare research, with advocates claiming that it is possible to 'know' reality through scientific observation. The 'gold standard' for such research is the randomised control trial, which claims to establish 'scientific truths' through objectivity (Clark et al., 2007). For the purpose of the present study, the problem with this type of approach is that it disregards the context in which healthcare staff exist. SPLWs are situated in complex systems of personal connections, healthcare services and wider sociocultural and historic contexts, which interact with each other and influence SPLWs as individuals (Byrne, 2005). Recognising this, a critical realist approach to this study allowed for an exploration of multiple individual meanings shaped by these contextual connections, in relation to the research aims.

## 2.2. Design

In line with this epistemological position, the study adopted a qualitative methodology to generate detailed individual accounts of the views and experiences of SPLWs on the relationship between social prescribing and the health inequalities that affect Black people with chronic pain. This approach was chosen because it was best suited to exploring research questions that focused on SPLW's personal understandings and meaning-making (Taylor & Francis, 2013). Qualitative methodologies are also useful in areas such as this that are not well researched (Kimble, 1984), providing opportunities for unanticipated insights and important contextual details from SPLW's accounts (S. Wilkinson et al., 2004). Individual

semi-structured interviews were chosen as the qualitative method of data collection in order to gather data which captured detailed individual perspectives whilst also directing interviews towards important areas of focus. Focus groups were deemed to be a less appropriate method for the present study because the research questions were less concerned with group processes or norms.

This study did not claim to adopt a participatory methodology, but the aim was to involve stakeholders where possible to ensure that the research was relevant and meaningful for Black individuals with chronic pain and for the people and systems that support them. Accordingly, in the early stages of the project I made contact with an employee of an integrated care partnership (ICP) in London whose work focused on chronic pain and health inequalities. I worked closely with this stakeholder to discuss and refine the study aims and research questions, and again to refine the interview schedule, as discussed further below. The draft interview schedule was also discussed and refined in a meeting with a service-user. Further details are set out below.

#### 2.3. Reflexivity

Qualitative researchers should reflect on how their personal "experiences, values and positions privilege" impact their approach to research (Harrison et al., 2001) in order to highlight how these aspects may have influenced the research outcomes. Throughout this project I reflected on my prior clinical experience as an assistant psychologist working in an NHS chronic pain service. Through this work I witnessed the impact of chronic pain on people's lives, and saw, first-hand, how Black communities were disproportionately affected by health inequalities in this area. Whilst this was both observable and empirically evidenced, I did not feel that health services were doing enough to explore and challenge these issues. I also reflected on my other clinical experiences, particularly in physical health on certain communities, and the relationship to physical and mental health. These experiences have developed my interested in approaches to physical and mental health, such as social prescribing, that take an individual's social context into account.

I also reflected on how my own identity as a White, British, middle-class man may have influenced the study, including the interview process, and particularly when speaking to participants who differed from me across multiple demographics. As I do not have chronic pain, I reflected that there are blind spots in my knowledge of the experience of chronic pain, and of the intersectional experience of chronic pain and racial minoritisation. In light of this, I

tried to ensure that the research was ethical and meaningful for racially minoritised people with chronic pain by involving racially minoritised service-users and other stakeholders at various points in the project.

## 2.4. Ethics

Ethics approval for the project was sought (Appendix C) and granted by UEL School of Psychology Ethics Committee (Appendix D).

## 2.4.1. Informed Consent

An information sheet was given to potential participants (Appendix E) containing details of the aims and relevance of the study, the study design, their right to withdraw, and information on how their data will be used and protected. During recruitment, participants had opportunities to ask questions about any aspect of the research before agreeing to participate, and they had further opportunities to ask questions immediately prior to their interview. All participants signed a consent form before participating (Appendix F) and were asked to confirm their consent verbally before their interview.

## 2.4.2. Potential Distress

I was aware that discussing sensitive topics like racism, Whiteness, inequality, and difficult aspects of their jobs could potentially cause distress to participants (Alty & Rodham (née Gadd), 1998). With this in mind I reiterated prior to the interview that participants could choose not to answer questions and were able to withdraw from the study. I also conducted the interviews sensitively and tried to build rapport early on, for example by starting the interview with a simple question about their day-to-day work. When sensitive topics came up in interviews I gave time for thought and discussion, and I went at each participant's pace.

## 2.4.3. Debrief

After each interview I made space for participants to ask questions or raise concerns. A debrief form was then sent to each person (Appendix G) with info on how the data will be managed, what will happen with the results of the study, and how they can seek support if needed.

## 2.4.4. Confidentiality and Anonymity

Transcripts were anonymised by removing or making pseudonyms for participant and organisation identifiable information. All research data and personal information was kept confidential and a data management plan approved by UEL and followed to ensure that data

were stored securely and ethically. Transcripts, consent forms and any other documents containing personally identifiable information were saved on a secure and encrypted UEL drive. Anonymised data will be stored on the UEL drive for three years before being destroyed to allow time for dissemination.

## 2.5. Research procedure

## 2.5.1. Recruitment

Recruitment followed a purposive sampling technique (Ritchie et al., 2003). I established contact with an employee from an Integrated Care Partnership (ICP) in a London borough with relatively high levels of health inequalities and a relatively high population of Black and racially minoritised people. Part of the employee's role was focused on chronic pain and racialised health inequalities in the borough. I was then invited to make a short presentation about my study at a meeting attended by employees from the ICP and SPLWs who work in the borough, who were employed either by a charity of by the NHS. My contact at the ICP then introduced me via email to particular SPLWs who he thought might be interested in participating in my research. I then followed up with emails to SPLWs attaching the study's information sheet (Appendix E).

## 2.5.2. Inclusion Criteria

The inclusion criteria for participation in the study were:

- Aged 18 or over
- Living in the UK

- Working or volunteering as an SPLW or similar role primarily involving social prescribing

## 2.5.3. Sample Demographics

In total seven SPLWs were recruited. All were working in the same London borough described above, employed by either a charity or the NHS. Participants were a mix of genders, ages and ethnicities. This has not been described further to protect their anonymity. Through the interviews, some of the participants chose to name and self-identify

their background or ethnicity, and this is evident in some of the quotations included in the Results section.

## 2.5.4. Sample Size

I anticipated recruiting between six and twelve participants in order to achieve data saturation as per Guest et al.'s (2006) criteria. In total, seven participants were recruited. This is discussed in more detail below.

## 2.5.5. Data Collection

Those who expressed interest in participating were sent an information sheet (Appendix E) via email if they had not been sent it already. They were also asked to complete and return a consent form (Appendix F). They were informed via the information sheet that they could choose to receive a £10 shopping voucher to thank and compensate them for their participation. A time and date for the interview was then agreed. Interviews took place remotely over Microsoft Teams and participants were supported to join if they were unfamiliar with this method. Before the start of each interview participants were reminded about confidentiality, consent and their right to withdraw from the study. They were also given an opportunity to ask questions. Interviews were recorded using the Microsoft Teams recording function and participants were asked for their consent before starting recording. Each of the interviews lasted between 45 minutes and one hour. Interviews were semistructured and therefore guided by an interview schedule (Appendix H) and by participant's responses. To ensure that the interviews covered topics that were meaningful and relevant for Black individuals with chronic pain, a draft interview schedule was discussed with my contact from the ICP, and with a member of the ICP's patient advisory group for chronic pain, who himself was a Black man with chronic pain. Following these discussions the interview schedule was amended accordingly. Each interview ended with a short debrief discussion and a debrief sheet was then emailed to participants (Appendix G).

## 2.5.6. Transcription

Microsoft Teams automatically generated a transcription of the recorded interviews, which I reviewed and checked for accuracy by listening back to each interview. Participant and

organisation identifiable information were then removed or pseudonymised from the transcripts.

## 2.6. Data Analysis

Reflexive thematic analysis (TA) was chosen as the analytic approach because it is epistemologically flexible, compatible with a critical realist approach, and acknowledges the subjectivity of the researcher in the analysis (Braun & Clarke, 2006, 2013, 2021a). TA is also a useful tool for addressing research questions which focus on subjective experiences and conceptualisations (Willig, 2021), such as those in the present study. Foucauldian discourse analysis was not chosen as it is not compatible with critical realism. It would not have allowed for claims of a reality within which social prescribing services and health systems are located, beyond how they are discursively constructed (Potter & Hepburn, 2005). Interpretative phenomenological analysis was not chosen because it is an idiographic approach which would have analysed the nature of the "lived experience" of working as an SPLW (Willig, 2021) therefore taking an epistemological position distinct from critical realism. Grounded theory was also discounted because it generates theories to understand the realities in question, whereas TA could produce data which made suggestions about the realities of the social prescribing role and social prescribing services (Tweed & Charmaz, 2011).

Below I have set out how Braun and Clarke's (Braun & Clarke, 2006, 2021a) six phases of thematic analysis were followed. These phases were followed in a flexible way that allowed for moving back and forth between stages until a coherent report was formed (Braun & Clarke, 2021a).

## 2.6.1. Data Familiarisation

During the data collection and transcription stages I re-read the transcripts multiple times to familiarise myself with the content. While doing this I typed notes and initial code ideas into the margin of each transcript (see transcript sample in Appendix I).

## 2.6.2. Data Coding

Codes are "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998). I used NVivo 20 to again review the transcripts and capture and organise initial codes for each transcript. When necessary to maintain the context and meaning of extracts I included the text either

side of the code segment (Bryman, 2001). Some data was coded more than once in order to capture multiple narratives within the text.

## 2.6.3. Generating Initial Themes

I took a flexible approach to generating initial themes, which allowed me to identify many possible relationships and patterns between codes. I used Nvivo and then Microsoft Word tables to group codes into a map of initial themes (Appendix J).

## 2.6.4. Developing and Reviewing Themes

Next, I checked the fit of the data to the initial themes by reviewing the selected coded extracts for each theme. I then reviewed and developed the themes by combining, discarding, separating, and creating new themes before re-reading the coded extract to again review their fit to the new themes. Next, I re-read the transcripts in full to check the themes against the full data set, followed by refining the themes as necessary. This is an iterative process which has no defined end point, so I chose to stop refining the themes when the changes at each iteration were no longer substantial. See Appendix K for the final thematic map.

## 2.6.5. Defining Themes

Themes were defined and summarised by considering their "essence" and the stories that they told about the data (Braun & Clarke, 2006). Themes were named accordingly, using relevant extracts from the data.

# 2.6.6. Producing the Report

The next chapter summarises the themes and sub-themes produced from the data analysis. Data extracts have been included throughout so that the reader can review how the themes reflect the data (Braun & Clarke, 2006). In the extracts, participant names have been removed, and the researcher is referred to as "Rupert".

# 2.6.7. Sample Size

Throughout the data collection and analysis process I held the concept of data saturation (Guest et al., 2006) in mind to determine sample size. I began coding transcripts and generating and reviewing themes after I had completed the fifth interview. Then as codes were added from the sixth and seventh interview transcripts, it became clear that my generation and organisation of themes would not be materially changed by the addition of data from further participants. I felt able to make this decision based on the fact that there was good depth of dialogue in all seven of the interviews, allowing for a rich interpretation of

possible relationships between codes. I therefore deemed that data saturation had been achieved after the seventh interview, and no further recruitment was done. I am aware of the critique that data saturation may not always be a useful concept for reflexive thematic analysis as new meanings are possible from additional data due to the researcher's interpretative practices (Braun & Clarke, 2021b). Nevertheless, I decided to employ the concept because it is widely used in the literature and it aligned with pragmatic considerations around the time and resources available to me throughout this project.

# 3. RESULTS

This chapter starts by setting out the context of the data analysis before providing an outline of the results. Each theme and subtheme is discussed in turn, with accompanying extracts from the data.

# 3.1. Contextualising the Analysis

In line with the aims of the study and the research questions, the interview questions focused primarily on social prescribing, chronic pain and racialised health inequalities. Understandably, participants spoke about issues beyond this narrow focus, for example, speaking about broader health inequalities and other health issues. Many of these participant reflections were still important and relevant to the present study, and so have been included in the analysis.

Throughout this chapter I have, at times, used the word "patients" to describe the people who access social prescribing services. This reflects the language that participants chose to use in their interviews. In using this language, I appreciate its medicalising implications, which are further discussed in this chapter.

# 3.2. Summary of Themes and Subthemes

The thematic analysis produced three themes and eight subthemes, as shown below in Table 1.

# Table 1

# Summary of Themes and Subthemes

Theme	Subtheme
Social prescribing: "it doesn't fix the	Contextualised understandings of inequalities
undercurrents of society"	
	"Black people are not taken seriously":
	Whiteness and racism in healthcare
Systemic factors affecting the SPLW role	"A very doctor-patient dynamic": Navigating
	the impact of a medicalised setting
	Hampered by deficiencies in healthcare,
	social care and civil society
Learning lessons and thinking differently	"Making it bottom up": Centring community
	assets
	Valuing SPLW strengths
	"We're here to mainly listen": Rebuilding trust
	Thinking critically about race and ethnicity

# 3.3. Theme 1: Social Prescribing: "It Doesn't Fix the Undercurrents of Society"

The first theme outlines the varied and complex ways in which participants made sense of the drivers of inequalities that impact Black people with chronic pain. It is important to note that participants were aware of the inequalities experienced by Black people with chronic pain, most notably that rates of chronic pain were highest amongst Black communities in the borough in which they work. However, the emphasis placed on different contextual drivers for these inequalities varied between participants.

# 3.3.1. Contextualised Understandings of Inequalities

Some participants held the view that social determinants of health, such as housing, employment, income, and racism are likely to be key drivers of why Black residents with chronic pain are affected by inequalities. Often these social challenges were witnessed by participants in the experiences of their patients in their day-to-day work. For example, Participant 1 spoke about how housing difficulties, poverty and working conditions might impact the pain experienced by their patients.

Participant 1: I guess, like, external factors that you can't control, like housing, for example. You know, if your house is making your health worse for whatever reason. Classic one is you live on the tenth floor of a flat and there's no lift. So, every day they have to walk up however many flights of stairs. And obviously you can't help them move house because there's a huge housing crisis in [this borough] ... well, everywhere, but [this borough] especially is really dire at the moment. I guess that's just one example. But understanding the other factors that are impacting their pain and not being able to do anything about that, that's very difficult (...) I think poverty is a big one, and also working long hours in bad job conditions. As I said, I know a lot of patients that have worked as cleaners. If you're doing long, hard hours doing manual labour and stuff like that, I'm sure that will mean that you're more likely to experience chronic pain.

The extract above also highlights a sentiment shared by some participants that social prescribing alone cannot reduce these health inequalities without there also being change at a broader systemic level which more directly targets the social determinants of health. For some participants this was accompanied by a sense of powerlessness or futility in the face of overwhelming social inequality. Participant 3 suggested policy change, in particular, as a necessary way of reducing health inequalities alongside social prescribing. For him, linking a patient in with a yoga group, one of the more commonly "prescribed" activities for people with chronic pain, seemed like a "surface-level" intervention when that person might be experiencing a range of complex social challenges.

Participant 3: I think social prescribing, it's not a fix. It doesn't fix the undercurrents of society, the structural inequalities, the racism that still operates within our institutions. And so I almost don't wanna say that I want social prescribing to be the answer. I don't want to say that it is going to fix everything because it's not. What we do can be very surface level, just linking someone into a group, when actually they have financial issues, they experience racism daily, they don't feel they can trust anyone. Linking them into a yoga group (...) as much as we find our group yoga group really

valuable, it's not significantly changing policy, right? So, I think it can complement, but it needs to go back up to the policy branch.

Some participants particularly focused on the contextual drivers of inequality that affect women with chronic pain, without specifically highlighting the intersectional experiences of Black women. For example, Participant 7 identified gender norms as a potential factor in why women are more affected by chronic pain. For her, the child-raising burden placed on women as a result of gender norms is associated with women's social opportunities and their experience of chronic pain.

Rupert: What do you think are the reasons for those inequalities in chronic pain? Participant 7: Well, it's always kind of financial. I've got to be careful what words I use, but the system, the modality, the capitalist system is going to oppress. It works on the premise of exploitation. So, who are going to be the most exploited people? The people who are most desperate for a job, the people who can't leave their children. Men can kind of leave their children, it doesn't matter what race they are. Women can't. They don't walk away from their children. It's very, very rare. They carry that burden.

Whilst some participants identified social determinants as potential drivers of inequalities in chronic pain, Participant 7 placed particular emphasis on the effect of trauma on the body as a way of conceptualising the causal link between social challenges and experiences of chronic pain.

Participant 7: The literature, although it's now 30 years old, we've only recently published books about the true effects of trauma. And this is not just about Black trauma, it's just trauma in general, because I think whether it's Black or White or religious or gender-based, the impact on the physical body is probably the same.

Alongside the conviction held by some participants in the links between the social determinants of health and the inequalities experienced by Black people with chronic pain, some participants also reported feeling uncertain about the drivers of inequalities. Participant 5 expressed uncertainty linked to unfamiliarity with research in this area.

Rupert: I'm wondering, what are your views on why those inequalities might exist? Participant 5: I mean, I'm not au fait enough with the details of the research to have a proper opinion as to whether I agree or disagree, or why I can agree or disagree with their conclusions. It's a really complex issue and I really don't think I've learned enough to have a proper stance.

Similarly, Participant 1, who held strong views about the role of social determinants in contributing to chronic pain inequalities, was also unsure about the role of genetics in this picture.

Participant 1: But then it may be that there is some kind of genetic makeup as well. I don't know, maybe Black women are more likely to suffer from chronic pain just because they are, I don't know.

This indicates that some participants were unsure if factors other than social determinants might play a role in driving chronic pain inequalities, perhaps pointing to a lack of access to the theoretical background in this area.

3.3.2. <u>"Black People are Not Taken Seriously": Whiteness and Racism in Healthcare</u> Current and historical racism in healthcare was identified by some participants as an important factor in the inequalities faced by Black people with chronic pain. This was conceptualised as a pattern in which Black people's pain is not believed or is minimised by healthcare professionals, leading to them receiving inadequate standards of care whilst also losing trust in health services and being reluctant to seek further help.

Participant 4: I think it comes back to what we were talking about before, where people just aren't taken seriously, particularly with something like chronic pain where the physical side of it doesn't always match up with the mental. Someone might be in excruciating pain but an MRI shows up absolutely nothing or a very minor thing. I think there is a central issue of Black people not being taken seriously. They aren't listened to. They're accused of all these stereotypes, like being over the top or exaggerating. I do think if they're not listened to at the start, that can really spiral and that can develop mistrust, and that's not gonna make the relationship with GPs any better. It's not gonna help them manage their pain (...) And I think that happens with a lot of healthcare services. If they have a really poor experience, they feel that they're not being listened to, that can maybe not end it, but make them really

suspicious, make them not want to go to the doctor as much, which means their conditions might escalate even further.

This understanding was often expressed as knowledge acquired through working in the SPLW role and hearing the experiences of Black patients who have been treated unfairly by healthcare professionals and have lost trust in health services.

Participant 3: Just the marginalisation and distrust in the medical profession. I'm just trying to gather what I've picked up from patients along the line because, of course, I'm not Black, so I don't want to... I think a lot of Black patients I've spoken to who have ongoing persistent pain, they don't feel listened to, they feel marginalised from the medical community.

Other participants focused more on the intergenerational distrust of healthcare professionals and services passed down through families and communities as a result of historical racism and discrimination against Black people in the UK. Participant 6, a Black British woman herself, spoke about this in relation to the beliefs in her own family.

Participant 6: And I think that culturally there's still a lot of reluctance to engage with health services as well. Just the idea that you can't really trust doctors, and doctors don't really know, and "do you know that they still test medication on us?" and things like that. There is that kind of legacy, culturally, that goes back a few generations, because I know it came down through my family, through my dad.

Several participants expressed the view that Black women with chronic pain face marked inequalities due to the particular racism and discrimination which they experience in healthcare interactions, such as not being believed or assumed to be exaggerating their symptoms. Participant 1 thought that this was particularly pronounced for Black women who have migrated to the UK.

Participant 1: Black women [are] less likely to be paid attention to when they attend doctor's appointments historically, especially if they're migrants or have immigrated here.

Participant 7 held similar views around underdiagnosis for Black women across a range of health conditions, and particularly emphasised a White, male, medical paradigm as an important factor in this process.

Participant 7: So for women, you're going to see so many additional... chronic pain, COPD, mental health issues, hormonal issues, fibroids, which go so badly undiagnosed for Black women. They'll have had multiple children but their gynaecological care will be very, very poor because they're perceived in a different way, and historically they might have looked after their bodies in different ways, their bodies might have had different needs, which don't fit the traditional gynaecological paradigm. Because again, it's kind of White male, you know?

This idea of Whiteness in healthcare reported by Participant 7 highlights the belief that chronic pain healthcare is designed to best meets the needs of White people, and particularly White men, meaning that Black women may receive inadequate care and experience worse chronic pain outcomes as a result.

Similarly, Participant 6 felt that the lack of socioeconomic and ethnic diversity in the GP workforce made it more difficult for chronic pain inequalities to be addressed. She held a view shared by a number of participants that health professionals should do more to change how they engage with patients in order to directly target the Whiteness and racism that leads to chronic pain inequalities. In this case, Participant 6 particularly highlighted the lack of training that GPs receive on health inequalities.

Participant 6: And I often think that not enough health inequalities training is done with GPs and stuff like that, because it's not enough to employ receptionists from black and ethnic minorities and expect that to make our patients feel like, "these people are the right people for me," when the majority of our GPs are still middle class and from certain backgrounds. I was talking about this with somebody a couple of weeks ago and she sent me a link to some information about this. It essentially said that something like 65% of GPs surveyed said that they didn't feel they'd had enough, or any, health inequalities training. And obviously that, as a standalone comment, sounds absolutely staggering, but I straight away can imagine how that permeates into the way that clinicians are interacting with patients and understanding the way that patients communicate certain things.

#### 3.4. Theme 2: Systemic Factors Affecting the SPLW Role

The second theme sets out the systemic factors, or the factors associated with the environment in which SPLWs operate, which affect their role in addressing the health inequalities that affect Black people with chronic pain.

3.4.1. <u>"A Very Doctor-Patient Dynamic": Navigating the Impact of a Medicalised Setting</u> Some of the participants spoke about how the positioning of social prescribing within a medicalised setting impacted their work. Participant 1 noted how the location of SPLWs within GP surgeries and GP referral pathways may cause her patients to perceive her as more closely aligned with health professionals than with community workers. This is particularly relevant considering the subthemes above relating to Black people with chronic pain experiencing racism and discrimination at the hands of medical professionals, along with the related lack of trust in services.

Participant 1: I think my patients and my clients see me as being part of the health system, more than being a community worker, and because I'm attached to their GP surgery. So, I think that is an interesting aspect of it, which I wasn't as aware of because I'm technically employed by [a charity]. I think that does create quite a specific power dynamic, in a way, which maybe wouldn't be the case if I was just, like, a community worker or something.

The power dynamic reported by Participant 1 was also discussed in more detail by Participant 6, who described her journey towards understanding that the behaviour she was noticing in her SPLW relationships were influenced by the medicalised context of the work.

Participant 6: One of the things I noticed really early on is that patients were presenting to me in a very particular way that I wasn't used to, and it's because I've never worked in the NHS before, in a doctor's surgery. And for a while I pondered what was going on in this dynamic, and I realised it was a power dynamic, and I realised that patients were presenting to me in a very anxious way, and very quickly entering into a behaviour of, "let me convince you how needy I am, because you must be able to do something about this." And I thought about it, and I thought, well, that's a very doctor-patient dynamic. And I realised that it actually infantilises patients, that patients feel very disempowered. I also realised this because as link workers patients often tell us things, and I say, "well, if you mentioned that to..." and they say, "[gasp] I wouldn't." And unpicking some of the reasons that patients don't share certain things reinforced what I was observing. And so there was a real need, from my perspective, to disrupt that unconscious behavioural stuff between us and patients

Here Participant 6 emphasised the negative aspects of this power dynamic, that her patients may feel disempowered or unable to share important information about themselves, and how important it is for her to "disrupt" that process bearing in mind that a key goal of social prescribing is to empower people to be able to manage their own health. This highlights a clear challenge in which social prescribing patients are simultaneously disempowered by the medicalised context whilst also seeking to be empowered and gain a sense of agency through the social prescribing pathway.

Participant 4 added to the challenges expressed by Participant 6 above by noting the impact of medicalised language on the SPLW role. He described how the use of "prescribing" in the title contributes to the medicalisation of the role and creates confusion and unhelpful expectations for his patients.

Participant 4: We have to explain the role. It's not a title I'm really fond of. I feel like the prescribing bit is a bit patronising and confusing for people. They're like, "oh, you can prescribe medication." And it's like, "we can't do that."

This is linked to participants' use of the word "patient", as described at the start of this chapter. The implications of the use of this term were not explicitly noted by participants, but further point to the medicalisation of SPLW's relationships with the community members they support. It is important to note that there is a tension in participants wanting to challenge the medicalised nature of the SPLW role, whilst also using medicalising language, such as "patients".

Interestingly, a tension was identified within this subtheme as some participants identified more positive aspects of the medicalised context of social prescribing and SPLW's close association with GPs. Participant 7, in particular, held the belief that in spite of Black people with chronic pain often feeling unheard by medical professionals, they may still have more trust in GPs than in other institutions. For her, this made the positioning of social prescribing alongside GPs a valuable way to build trust with Black residents.

Participant 7: The thing about the work is that with the Black cohort, they've been fucked over by so many people, even though there's inequalities in the health service and Black people are twice as likely to suffer from chronic pain, very often it's the last

place of trust for black people. So, they put a lot of trust in their doctors, irrespective of how much they might complain about it and feel unheard. They don't put trust in the police, they don't put trust in education services, in their employers, and some of the churches, but by and large it will be the last port of call for them. And so there's something very precious in this potential relationship we've got, and we really need to build on it.

This suggests that SPLWs may have varying views about the degree to which Black serviceusers trust health professionals.

For Participant 5, who had been facilitating chronic pain workshops as part of her SPLW role, the medicalised context of the work brought up a feeling of discomfort around the policy objectives of social prescribing. She reported how the chronic pain groups seemed to be designed primarily to take pressure off GPs rather than to support people with chronic pain and reduce inequalities.

Participant 5: And the chronic pain project, it was not given to us in terms of assisting Black residents with chronic pain. It was given to us to assist chronic pain patients within the surgery, because cynically, they are generally taking up too many appointments with the GPs, and if we are able to assist them in other areas of their life, it will by default reduce the amount of appointments they have with the GPs (...) I think the real initial goal was actually to reduce the amount of appointments that people with chronic pain took in the surgery (...) I found the entire project very uncomfortable.

Participant 5 similarly reported how other decisions around chronic pain care were handed down to SPLWs with the primary aim of achieving key performance indicators (KPIs) for the GP surgery, and therefore more funding, rather than being aimed at more valuable outcomes for improving the wellbeing of patients. She gave the example of being told that to achieve a KPI she had to send a text message to a certain percentage of residents with a chronic pain diagnosis, inviting them to access social prescribing, without there being a discussion of whether this was helpful.

## 3.4.2. Hampered by Deficiencies in Healthcare, Social Care and Civil Society

Some participants spoke about the shortage of community groups and activities to link people with chronic pain into. For some participants, this was expressed as a frustration they felt at being unable to support people in the way they would like. Some participants also made sense of this community deficit as a result of COVID-19 and government austerity cuts in recent years.

Participant 1: I think that's the rubbish thing about it. Because a lot of them come and say, "Oh, I used to go to this really good place down the road for hydrotherapy," or "I used to do this, I used to do this, I used to do this, but since COVID it's not open anymore." And the reality is, almost all of the services that were available are not available anymore because of cuts or COVID and having to close down everything. So we haven't been able to offer much.

In particular, some participants expressed frustration at the lack of free community groups, and saw this as disproportionately affecting people out of work, on low incomes, or with additional care needs.

Participant 3: It's very difficult to try and get people into services that you have to pay for, usually with a care package (...) Specifically with chronic pain, often they're looking for free exercise classes, which are not available. That's another gap. There's no free gym memberships. That's what they're often looking for, is a free gym membership. Usually they're looking for a gentle exercise class or swimming classes, but they want them for free, and that's not always possible unfortunately.

On the community groups and spaces that do exist, Participant 3 spoke about them not always meeting the needs of Black patients. She gave the example of linking a Black Caribbean resident in with a local group, which they stopped attending as they did not feel comfortable attending a space in which all of the other attendees were White. Another participant shared that some of her Black patients have English as a second language, making it even harder to find suitable community groups. This area of discussion brought up interesting reflections from some participants around whether they would like to see more community spaces specifically for Black residents. Those who raised this issue generally held the view that in an ideal world groups would represent the diversity of the community, but because this is not happening they appreciated the arguments in favour of spaces designed by and for specific minoritised groups, where they can feel safe. Participants also felt that we should be doing more to ask people from minoritised groups what they would like their community assets to look like, and then supporting their development. This is discussed further in theme 3 below. On the topic of healthcare standards, some participants reported that the people they support with chronic pain often do not have a good understanding of their condition or how best to manage the pain. Participant 1 suggested that this was due to doctors not providing patients with sufficient information at the time of diagnosis, while other participants emphasised the lack of time that GPs have in each appointment to have a meaningful discussion with a patient about pain management.

Some participants highlighted that the social challenges faced by their patients were extensive and critical, yet health and social services were not able to meet their needs, leaving SPLWs feeling like they have to carry that burden. As a result, some expressed that being "in crisis mode" and "on our knees" made it difficult for them to provide meaningful, holistic support to people with chronic pain. Participant 6, in particular, went on to suggest that this model of social prescribing is flawed.

Participant 6: [There is] a lot of pressure on link workers to somehow take on the burden of all of these social issues and manage to juggle them in a way that is effective and meaningful to those patients. And if you think that a lot of our referrals are about crisis issues, or what feels like a crisis to the patients, then all we're doing is making social prescribing fit the model that healthcare already has and isn't working.

Again, some participants pointed to the fact that these issues tend to disproportionately impact Black residents in the borough.

Participant 4: We get so many housing issues, I think about 50% of the referrals we get. But because of the social housing conditions in the area we work in, that's something we have limited control over, but it does definitely disproportionately affect Black people.

Similarly to the first theme, the challenges that these structural deficits present for SPLWs were expressed by some participants by a sense of despondency and powerlessness.

Participant 1: That's the most frustrating thing about working here. I'm sure you've found this as well. Doing social work, and doing this kind of work, is so frustrating because it's just so dependent on funding and cuts. The NHS and the charity sector and the social sector have been cut so much in the last few years by the Tories. It's just crazy (...) I think it's almost beyond community action at this point, because I

think everyone's doing their best, and I meet some really inspiring, wonderful people in this work. You know, we're all working really hard and we're all trying our best. But at the end of the day, if you don't have the money to fund something or you don't have the resources to support these people then you're at a standstill, aren't you? Because you can't ask people to be working for free all the time, or to be volunteering their time. Everyone's in the same boat at the moment, and it's a bigger issue than it should be.

Some participants reported that they navigate these challenges by setting up and facilitating or coordinating their own chronic pain events and workshops to compensate for the lack of free community groups and the shortcomings in health information provided by doctors.

Participant 2: To be honest, for chronic pain, there are very few services in [the borough]. I mean it's basically none at the moment, but we are working on it, to create something within the PCN and get something going. So that's what the [chronic pain] event was for. There was a physiotherapist, there was a doctor, to help people understand chronic pain, to get knowledge on what chronic pain is. Because when you're in the surgery, GPs don't have that much time to explain everything. So obviously this event was for them to understand the pain and how to manage it.

Some participants added that setting up their own groups was not strictly in the job description of an SPLW. However, they reported that the community development part of their role, through which they support the development of new and existing community-led groups, was proving extremely difficult with civil society so badly affected by COVID-19 and austerity policies.

# 3.5. Theme 3: Learning Lessons and Thinking Differently

This theme sets out participants' support for an approach to social prescribing that values both the strengths of Black communities as well as the knowledge that SPLWs acquire through their work. It also encapsulates the holistic and person-centred aspects of their direct work with patients which participants believed to be important in reducing inequalities for Black people with chronic pain.

## 3.5.1. <u>"Making it Bottom Up": Centring Community Assets</u>

Some participants spoke about the value of group spaces in which Black residents were able to discuss with each other their experiences of traditional or complementary treatments for

chronic pain, without fear of judgement from health professionals or SPLWs. Participants felt that this approach was not just culturally sensitive, but also increased people's confidence in managing their own health by centring their personal strengths and resources as well as those within their families and communities.

Participant 1: We had a really nice session last week in our chronic pain group where we had the pharmacists come in, but because they weren't seeing the patients in a clinical setting, because it wasn't in an appointment, they were able to, you know... Our pharmacist, his parents are Hindus, and he was talking about the benefits of turmeric, and stuff like that, and more traditional, herbal remedies, which are proven to be anti-inflammatory and stuff like that. And for a lot of the Black residents, that really spoke to them, because I think they use a lot of similar things, and they were talking about balms they've used and stuff. And I think our pharmacist isn't actually allowed to give that kind of advice in a clinical setting because he's restricted by, you know, he's a pharmacist and he's there to do that, and that's not really something he's allowed to do. But we just had a really, really good, nice discussion about natural remedies and it seemed to really, really appeal to the patients that were there. I think it spoke to them on a different level because there wasn't that clinical patient barrier, and it was a really nice discussion. Some of them were talking about ginger and ginger tea and stuff like that. And that was really nice because, in a way, that made them feel like they were doing something right. You know what I mean? Like the things that they've been doing to manage their pain are not wrong, and actually the stuff that they're doing is worthwhile, and they are managing it in a way that is approved by, I don't know. I think that was really nice. That was really good.

This ties in with the subtheme above on Black people not feeling heard by health professionals and a doctor-patient power dynamic which does not create space for patients' strengths to be identified and built upon. It also alludes to the constraints that health professionals might experience when working in a medicalised and professionalised context.

Participant 4 held a similar view and expressed how group interventions and peer support groups for people with chronic pain were a valuable way for people to share their experiences as well as explore their strengths and ways of coping.

Participant 4: I think even the best clinician, because they're busy, they probably will fall into a place of like, "I know what's best, I will tell you what's best, try this," which I think doesn't always work too well. That's my gut feeling. It's more like seeing other

people in the same boat, in the same place, being taken seriously, and knowing that if they say something about their pain, or if they say something that maybe isn't too medical, maybe they're not worried about looking stupid in front of other people because they don't know all the terminology or all the medical side of things.

Moving beyond SPLW-facilitated spaces, Participant 3 was in favour of supporting residents to run their own peer support groups for chronic pain, and learning from them how they would like SPLWs to help. Similarly, she was critical of top-down funding and decision-making in social prescribing, and advocated more involvement from residents throughout social prescribing service provision.

Participant 3: The money-moving is too top-down. The people at the top, making the decisions with the money, are not on the ground listening to the people. I've been told by managers that they sit in a meeting with all these different Step 3 organisations and voluntary charity groups, and people in the government, and they never actually talk about the patients. It's always about how the system works and where they can put the money in, but no one actually talks about the patients. So having more of a community-based approach, making it bottom up. If I was Prime Minister for a day, that's what I would do.

In line with this, Participant 5 highlighted that people with chronic pain, and particularly those with more complex health and social challenges, are less likely to be able to attend spaces to make their voices heard. She felt that the best way to centre the voices and assets of people with chronic pain is by going to them.

#### 3.5.2. Valuing SPLW Strengths

Some participants felt that SPLWs were underappreciated or not taken seriously by colleagues in their PCNs. They spoke about the knowledge, skills and experience that they have developed from working closely, over multiple sessions, with people with chronic pain as well as with people experiencing complex social challenges. In their view, their understanding of the community and people's needs could be harnessed by services to improve the holistic care provided to people with chronic pain. Participant 6, in particular, spoke about how her knowledge of the local chronic pain cohort could have been used to

make an externally facilitated chronic pain workshop more effective and accessible for Black residents.

Participant 6: In one of our meetings I kept saying "Tell me about how you deliver?" They said "Yeah, two hours, lecture style," and I was thinking there's just no way some of the people we work with are gonna sit still for two hours. Who wants to? I don't experience chronic pain and I don't want to! I was like, "Is it possible to break it up?". They said, "Yeah, we can have a break." I said "OK, blah, blah, blah", and then I was just talking about the demographics, I was saying, "Some of our patients have English as a second language, some of them speak English but may not be the most literate or educated, can we think about language? If you're introducing a new concept that isn't common language, we want people to be able to understand." And one of the people said, "Oh, well it's all delivered in English. We can't do it in other languages." They didn't even get the nuance or register it. And that's not to say that that programme doesn't work, it's about if you have a programme that works, how can you tailor it so it works for more people.

Other participants identified how their own backgrounds, and those of their SPLW colleagues, in areas like social work, local community work, the charity sector, teaching and counselling, gave them useful skills and knowledge which may be lacking in healthcare. Some expressed in more detail that these skills could help to bring about changes in chronic pain care that could lead to reductions in health inequalities for people with chronic pain.

#### 3.5.3. "We're Here to Mainly Listen": Rebuilding Trust

Some participants reported that they were acutely aware of the aspects of healthcare that historically and currently contribute to the lack of trust from Black communities towards health services.

Participant 6: So, in terms of a system level, and driving a bit of a culture change, it's about using what we've learned, what link workers have learned, what clinicians have noticed about changes in the way that patients are or aren't engaging in health services, or the feedback that they're giving, using that to come up with different models to engage patients around their health. And if we know that patients feel rushed, if we know that they don't feel confident, if we know they're distrustful, if we know that because of the whole way the system is set up now patients are more likely to present and feel anxious or overwhelmed or not be able to articulate

themselves well because they're worried they've only got ten minutes, and "Why is that doctor not looking me? Why is he typing? I've been waiting for this referral for..." You know, it's so angsty and it's angsty for both patients and doctors. So, it's about the way that healthcare is being administered.

Here, Participant 6 highlighted how Black individuals with chronic pain have lost trust in services through not being listened to or treated with respect and compassion. She outlined how this may have created barriers to accessing and engaging in health care that shape the inequalities that we see in this area. This extract goes further to suggest that SPLWs have the knowledge and experience to provide a different approach that acknowledges the lack of trust and tries to repair it.

Similarly, Participant 4 below spoke about SPLWs offering an alternative to clinician care.

Participant 4: We present ourselves as an alternative to clinician care. We try and be a bit more accessible. In our meetings we do try and be like, "We're not the experts. We're not gonna tell you what's right. We're here to mainly listen." And I think that is a way to get people in, give them space to be listened to, because I think they need a lot... I think everyone needs a lot more time than the 10 minute GP appointments we're having at the moment. But I think particularly for marginalised groups, you need more time, maybe you need more sessions, to overcome that distrust. That's not something a GP can do. That's probably not something a lot of clinicians can do, but maybe that's something we can have a bit of space for. And if they want to go back into seeing a clinician, they might feel a bit more confident, a bit less scared of the space.

This extract outlines an SPLW approach which aims to rebuild trust by addressing power dynamics in the professional-patient relationship. Specifically, Participant 4 spoke about acknowledging that patients are experts in their own care and experience of chronic pain, allocating more time for patient sessions, and gradually demonstrating that they as a social prescribing service were worthy of trust. He went on to suggest that this might have knock

on effects in which patients feel more able to access and engage with the more clinical side of their care.

A valuable and related reflection by some participants was that rebuilding trust is a very hard outcome to capture.

Participant 3: There's a lot of great work that we do with ethnically diverse groups that isn't captured by data. And a social prescribing success story is seen as maybe linking a Black person into a group or signposting them to this group. But actually there is just a lot of power in listening to people, hearing their stories, acknowledging that "actually, that sounds really shit. I'm so sorry that you experienced that in your workplace. I'm so sorry that you feel like you're alone, that there's no one in the community that you can relate to regarding your experience." That's very hard to capture in data.

Here, Participant 3 reported that even though SPLWs may be doing lots of important work to rebuild trust and directly address racialised health inequalities, this is not being captured or acknowledged by their services. She goes on to suggest that the outcomes that they do record do not show the full picture of the value of the SPLW role in this area – specifically listening to patients' stories in a more empathic and compassionate way, and in doing so provide a more trustworthy service for Black individuals with chronic pain.

# 3.5.4. Thinking Critically About Race and Ethnicity

Some participants reported that thinking critically about difference, racism and Whiteness in their work in this area was something that they reflected upon. This was particularly the case for White participants who acknowledged the different lived experiences between them and their racially minoritised patients.

Participant 4: I'm aware that I'm a White man. I'm not sure, consciously, how much it affects the work I do. I do try and be a bit more sensitive, a bit more empathetic, which sounds easy on paper. I don't know, I don't think I've got an easy answer to it. It's more an awareness that I'm coming from a different place than a lot of the clients

I speak to. I'm not going to understand all their experiences. I shouldn't assume I know all the answers. It's maybe something I should think about a bit more.

The extract above suggests that while SPLWs might consider it a difficult task to think critically about this issue in their work, some SPLWs felt that it was important, and something that they wanted to develop.

There was an interesting tension in this theme, highlighted by participant 2, who reported that their approach to social prescribing was much more 'colour blind' than other participants.

Researcher: How does your patient's racial identity impact your work as a link worker?

Participant 2: As a social prescriber, we provide support equally. I mean, there is no difference because we have limited resources to signpost to, and whoever comes for support, if someone is on low income we will try our best to find anything, or if they're eligible for any other benefits. If they need support with mental health, we'll try to signpost to any agency who provides help with mental health. So, all our patients, it depends what kind of help they need and then we try to signpost them. So there is no racial difference. And as I said earlier, we do it over the phone, so we don't have that information on the call. We just get the name, we get the telephone number and the problem on the form. So if we need to know the ethnicity, we have to find out ourselves because it's not relevant. That information is not relevant at our work because we don't ask that question.

It is not clear why there is this tension within the theme. Participant 2's views might be influenced by the scarcity of community resources to signpost to, leading to a sense that the limited time and resources that they have available should be evenly and fairly distributed to everyone. Their views might also be shaped by their own cultural background and beliefs, or norms in which a "colour blind" approach is the most fair and ethical way work in a multicultural context.

Some participants spoke more explicitly about navigating cultural difference in their work, highlighting the specific complexity of advocating for Black patients as a White SPLW.

Participant 7: But I often have to advocate for people who are not White. They're Black and I'm White and my patient's Black and I'm advocating for them. It's a very complex dynamic, but do I advocate more for my Black patients? I think no, I'm probably equal. Any human suffering I feel I take profoundly seriously.

This extract illustrates that it is a specific area of her work that Participant 7 was critically reflecting on. In questioning whether she advocates more for her Black patients, she was perhaps examining her own biases or holding in mind the risk of causing harm by working with cultural difference in a particular way that might perpetuate racism or widen health inequalities.

A final aspect of this subtheme was the observation that some participants held the view that Black identity is not homogeneous and that different Black communities can have very different needs.

Participant 5: What is ideal in [this neighbourhood] is absolutely fantastic, but it's an ideal. It's not necessarily possible to mirror across. I know one of the other surgeries has a high population of asylum seekers, they don't speak English, they could have gone through very traumatic events. That is a very different need than what some of my patients need. They're very different demographics and you need to understand what the demographics are of your society before you're going to help them.

Here, Participant 5 highlighted that some of her Black patients were seeking asylum, or did not speak English, while others who also identify as Black varied drastically in terms of language, history, religion, nationality and multiple other intersecting factors. This demonstrates that SPLWs had the capacity and experiences to think critically about ethnicity in an intersectional way, allowing them to provide person-centred care to the residents that they support.

#### 4. **DISCUSSION**

#### 4.1. Overview

This chapter will summarise and explain the themes identified from the data, and the relevance of these findings in relation to the study's research questions. This will be followed by a critical review of the research, a discussion of its implications and recommendations, a reflexive account and a conclusion.

## 4.2. Summary of Findings

The aim of study was to make a novel contribution to the literature by hearing the views and experiences of SPLWs on the relationship between social prescribing and the health inequalities that affect Black people with chronic pain. The findings can hopefully inform policy and practice to ultimately reduce these and other health inequalities. These aims led to the research questions:

- 1. How do SPLWs conceptualise the health inequalities that affect Black people with chronic pain?
- 2. What do SPLWs see as their role in reducing these inequalities?

The data were organised into three superordinate themes. The first theme indicated how participants' understandings of these specific health inequalities were complex and informed by the social context in which they exist. This was divided into two subthemes. The first highlighted how participants understood these inequalities as being driven by social, political and economic factors. The second subtheme reflected participants' views on how current and historical racism and Whiteness in UK healthcare was a key driver of chronic pain inequalities. The second superordinate theme focused on systemic factors that affect the SPLW role. Subthemes included the impact of navigating the medicalised context of social prescribing, as well as how their work is hampered by perceived deficiencies in healthcare, social care and civil society. The third and final superordinate theme brought together participants' views on how social prescribing could more effectively reduce chronic pain inequalities through harnessing the lessons SPLWs have learned and taking different approaches. The subthemes identified were 1) a desire from participants to value and draw upon existing community strengths and resources; 2) for social prescribing programmes to learn from the knowledge and experience of SPLWs; 3) for SPLWs to rebuild trust with Black communities in order to improve engagement and chronic pain outcomes; and 4) for SPLWs to think critically about race and ethnicity in their work. In the next section I will discuss these

findings in the context of the two research questions, and in relation to existing literature and relevant theory.

# 4.3. How do SPLWs Conceptualise the Health Inequalities That Affect Black People With Chronic Pain?

## 4.3.1. Contextualised Understandings of Inequalities

Some participants held the view that the social determinants of health are key drivers of the health inequalities that affect Black individuals with chronic pain. Some participants went further to suggest that social prescribing should not be the primary solution to reducing these inequalities and should instead complement broader systemic changes, for example at government policy level. This diverges from Mackenzie et al.'s (2020) findings that many of the professionals involved in the delivery of a social prescribing programme in Glasgow saw individual factors like behaviour as the key drivers of health inequalities, or minimised the importance of the causal link between the social determinants and inequalities. This difference may reflect that Mackenzie et al.'s participants included GPs, nurses and other primary care staff (alongside SPLWs) who may hold more medicalised, and therefore individualised understandings of health problems than SPLWs due to their training and professional approach. An example of this is a study finding that physiotherapists had biomedical understandings of chronic pain (Daykin & Richardson, 2004) as opposed to the seemingly biopsychosocial approach of the SPLWs here. Similarly, it may be an indication of how the SPLW role both appeals to people with a more contextualised understanding of health inequalities and exposes SPLWs to their client's social worlds in a way that engenders a more contextualised understanding than their medical counterparts.

Importantly, this study explored SPLW's views on the specific health inequalities affecting Black adults with chronic pain, rather than health inequalities in general, like in Mackenzie et al.'s study. However, there is no reason to anticipate that the participants in this study would think about inequality differently if they were discussing health inequalities in other areas, such as diabetes or mental health. Overall, the contextualised understanding evidenced by SPLWs here may reflect the high visibility of influential literature on the contextual drivers of health inequalities faced by racially minoritised groups (for example, NHS England, n.d.; Raleigh, 2023), a topic that has formed a much greater part of public and academic discourse since the COVID-19 pandemic (Nagesh, 2023; Raleigh, 2023).

Where this study more closely aligns with Mackenzie et al.'s study is in the finding of a pessimistic view held by some participants on social prescribing's potential to reduce

inequalities. Again, this may be a reflection of the SPLW role, which by design exposes SPLWs to the social challenges that disproportionately affect their minoritised and socially excluded clients, and can make social prescribing interventions seem "surface-level", as described by some participants in the present study. Another similarity with Mackenzie et al.'s findings is the uncertainty expressed by some SPLWs around the drivers of health inequalities. This may reflect that SPLWs come from a variety of working backgrounds with varying levels of prior exposure to social issues. Equally, as there are no formal entry requirement for the role (NHS Health Careers, n.d.), SPLWs will have received varying levels of training and study to allow them to draw upon theories and model of health inequalities. Overall, the findings point to a context in which SPLWs are frontline professionals, directly observing and identifying inequalities, but some may find it more difficult to theorise the mechanisms driving these inequalities without having accessed training or education on relevant models or theories.

4.3.2. "Black People are Not Taken Seriously": Whiteness and Racism in Healthcare Some participants felt that current and historical racism in healthcare was a significant factor in explaining the inequalities experienced by Black individuals with chronic pain. This is consistent with the findings in the Ubele Initiative report (Durrant & Rolston, 2022) described in the scoping review above, with participants in both studies reporting that racism has resulted in Black communities lacking trust in health services. In the Ubele Initiative report, this position emerged from the views of varied social prescribing stakeholders including community groups and charities, whereas the present study identified this as a view held specifically by SPLWs. The findings of this study go further to identify SPLW views that Black people with chronic pain are often disbelieved, or their pain is minimised by health professionals. This illustrates that participants' views aligned with existing research showing that Black people with chronic pain are affected by racism and discrimination in healthcare (Hoffman et al., 2016; Meghani et al., 2012), and that the resulting lack of trust and fear of racist treatment can deter Black people from seeking help (Kapadia et al., 2022). Additionally, some participants held an explicitly intersectional understanding of the stark inequalities faced by Black women with chronic pain, pointing to higher diagnosis rates whilst also being even less likely to be believed by health professionals. In highlighting a gendered form of Whiteness in chronic pain care which particularly privileges White men, participants' views were consistent with studies demonstrating that Black women's pain is often not believed by health professionals (Denny et al., 2010; lacobucci, 2022a; Pryma, 2017). For some participants, they had developed these views from hearing their clients' stories, but it

was unclear to what extent their views were also influenced by academic literature or wider discourse.

Some participants felt that health professionals should do more to counter the Whiteness and racism that erodes trust and disadvantages Black people with chronic pain, for example by examining how they engage with Black patients and accessing training on health inequalities. This goes beyond previous research and perhaps illustrates the frustration that participants' felt that their role in reducing chronic pain inequalities was being undermined by continued structural racism and erosion of trust by health services.

## 4.4. What do SPLWs See as Their Role in Reducing These Inequalities?

4.4.1. <u>"A Very Doctor-Patient Dynamic": Navigating the Impact of a Medicalised Setting</u> Some participants highlighted how the positioning of social prescribing within GP surgeries and pathways unhelpfully aligned them with a medicalised approach which seemed to amplify the power imbalance between SPLWs and clients. The disempowering effect that this dynamic had on their clients is consistent with wider research demonstrating that people with chronic pain often feel disempowered in their interactions with healthcare professionals (McGowan et al., 2007), and that Black women can feel compelled to prove they are in pain and deserving of help (Pryma, 2017). GPs have also expressed that when they engage in social prescribing practices (for example, signposting to non-medical services) it can disempower their patients more than medical interventions because patients can perceive the GP as the gatekeepers of social resources (Cawston, 2011). The finding that the SPLW language of "prescribing" and "patients" may further medicalise the intervention has not previously been evidenced in existing literature. Overall, these findings are particularly troubling for social prescribing, as one of the main aims of the intervention is to support people to feel empowered to manage their own health effectively. attribute

There was a tension within this theme, in that two participants reported that the medicalised setting and association with GP surgeries helped them to support Black residents. Their perception was that Black communities generally do, in fact, trust in their GPs, and therefore trust SPLWs by association. This adds to research showing that Black service-users often report distrust of services (Kapadia et al., 2022), by suggesting that there is diversity within SPLW views on the levels of perceived trust of health services. This diversity may reflect differences between the many varied communities of Black service-users that SPLWs encounter, or it may be that within some Black communities there is more trust in GPs when

it comes to chronic pain, compared to mental health services which are the subject of the majority of research on distrust.

Some participants expressed concern and discomfort that the main policy objective of chronic pain groups and other chronic pain strategies was simply to reduce the burden on GPs and achieve regional KPIs, rather than improve chronic pain outcomes or reduce inequalities. This reflects the scepticism expressed by other academics and practitioners on social prescribing in general, that perhaps commissioners and managers are placing too much weight on the policy goal of reducing utilisation of NHS primary care services, and not enough on improving outcomes for those groups most affected by chronic pain inequalities (Brown et al., 2021).

#### 4.4.2. Hampered by Deficiencies in Healthcare, Social Care and Civil Society

Some participants reported that supporting people with chronic pain was hampered by a shortage of community groups and activities to link their clients into. Some participants felt frustrated that COVID-19 and government austerity policies had particularly impacted free community activities, like free yoga or exercise classes, which was disproportionately affecting their poorer clients. Similarly, many community facilities, such as libraries and recreation grounds, have been closed or are open for restricted hours due to finance problems. This is consistent with the Ubele Initiative report (Durrant & Rolston, 2022) in which social prescribing stakeholders agreed that this deficit was partly due to a lack of funding for community resources, and a particular lack of funding for organisations led by Black and racially minoritised people. The present findings also align with Gibson et al. (2021) who found that lack of economic capital (along with other forms of capital) negatively impacted their participants' capacity to engage in social prescribing interventions. While not explicitly reported by participants in the current study, their concerns about the disproportionate impact on more socioeconomically disadvantaged residents suggests an understanding that this could result in a widening of health inequalities, as similarly forecast by Brown et al. (2021) and McNally (2018).

Some participants felt that community resources were not meeting the needs of Black residents with chronic pain as they did not always feel welcoming or culturally relevant for Black residents. However, these participants were less sure whether this meant there should be more groups set up exclusively for Black residents. The Ubele Initiative report (Durrant & Rolston, 2022) produced related findings, with stakeholders advocating for more funding and

support for Black-led and culturally relevant organisations which should be better linked in with social prescribing services.

The reflection from some participants that doctors were often providing insufficient information to patients about chronic pain conditions and their management was linked to participants' views that NHS funding decisions have made GP appointments too short to provide an acceptable standard of care. This mirrors longstanding public and academic criticism (lacobucci, 2022b) that GPs' workloads and short appointment times can put patients at risk. Participants reported that this would sometimes result in them seeing clients with chronic pain who knew very little about their specific condition or how to manage the pain. It was unclear if participants felt that Black residents were experiencing this more than others, which might imply that there was racism and discrimination in doctor-patient interactions leading to Black people with chronic pain receiving a lower standard of care, as has been found in some areas of pain research (Denny et al., 2010; Hoffman et al., 2016; Meghani et al., 2012; Pryma, 2017).

Some participants felt that their clients' social needs (such as housing and benefits) were often not being met by overstretched social services. They reported that many of their clients were "in crisis", leaving SPLWs feeling despondent and powerless, and finding their work dominated by crisis-management, rather than supporting clients to access valued activities. Participants commented that this disproportionately affected their more socially disadvantaged clients, including many Black residents in the borough. This finding reflects the current context of this study, with social inequality being impacted by COVID-19, government austerity policies, and the rising cost of living (Office for National Statistics, 2023). The finding that participants sometimes felt powerless in the face of these structural challenges, and often found their work dominated by crisis-management, goes beyond the views of the "hopefully pessimistic" social prescribing professionals in Mackenzie et al.'s study (2020) to suggest that the current socioeconomic climate is having a significant impact on the SPLW role.

The related finding that participants were compensating for these specific deficits in healthcare, social care and community resources by setting up and facilitating their own chronic pain groups and workshops, suggests that the current model of social prescribing might not be fit for purpose. SPLWs may be less able to respond to residents' social needs, and hence mitigate health inequalities, if they are preoccupied by filling gaps in chronic pain health information. Similarly, they may be unable to support residents to access non-medical solutions or carry out the community development aspect of their role if the community is so

poorly resourced and funded. In spite of this, the fact that SPLWs have been able to change their approach in order to respond to the current needs of people with chronic pain in the borough is likely to have provided important health benefits to this population.

#### 4.4.3. <u>"Making it Bottom Up": Centring Community Assets</u>

Some participants praised the value of creating group spaces for people with chronic pain to share their individual experiences of pain-management, including their often-positive experiences of traditional or complementary treatments. They reported that spaces like these enable culturally sensitive discussions and increase people's confidence in managing their pain by centring people's personal strengths and resources. The participant view that this creates spaces for Black residents to feel heard, and not judged or disbelieved, is evidence of how SPLWs may be countering healthcare practice that often leaves Black individuals with chronic pain, and particularly Black women, feeling unheard and disbelieved (Denny et al., 2010; lacobucci, 2022a). It also indicates participants' views that these spaces may be countering Whiteness and racism in chronic pain care, by validating culturally relevant pain-management strategies, and helping to reduce inequalities as a result.

Some participants expressed a desire to reduce racialised chronic pain inequalities by further centring the service-user voice, through supporting racially minoritised residents with chronic pain to run their own peer-support groups and involving them more in the development and improvement of social prescribing services. This finding supports the recommendations from Tierney et al. (2022) and from the Ubele Initiative report (Durrant & Rolston, 2022), that stakeholders involved in social prescribing would like to see racially minoritised individuals and "BRM-led" organisations more closely involved with the development of social prescribing programmes. It also supports to be developed with racially minoritised individuals and relevant community organisations as the key stakeholders (Gupta, 2021). The present study adds depth to this by highlighting that this is a view held by some SPLWs as a way of specifically reducing health inequalities for Black individuals with chronic pain.

#### 4.4.4. Valuing SPLW Strengths

Some participants felt that the knowledge, skills and experience of SPLWs should be better valued and harnessed to reduce chronic pain inequalities. In particular, they shared how their knowledge of the lived experience and impact of chronic pain, along with their knowledge of the characteristics and needs of local chronic pain cohorts, could be used to improve chronic pain care not only through social prescribing but also by informing the wider

healthcare systems in which SPLWs are located. They also shared that SPLWs often have a background in social work, community work, the charity sector, counselling or teaching, giving them valuable insight into the social challenges faced by residents. These findings again suggest that participants had a biopsychosocial understanding of chronic pain (Turk et al., 2011) and felt that their strengths could be harnessed to make chronic care more holistic, culturally sensitive and inclusive. The findings also reflect Gibson et al.'s (2021) hypothesis, in that participants identified how the capital that an individual possesses can shape their capacity to engage in social prescribing interventions. One participant gave the example of how some residents might not have been able to engage in a planned chronic pain workshop due to their literacy levels or not having English as a first language.

#### 4.4.5. "We're Here to Mainly Listen": Rebuilding Trust

Some of the participants reported that they were trying to reduce health inequalities by rebuilding the trust that has been lost between Black individuals with chronic pain and the health services that are intended to support them. Participants were doing this by meeting with their clients for much more time than GP appointments allowed, listening to their clients' contexts and stories, and countering power imbalances by positioning themselves as partners alongside their clients rather than experts. This again shows that participants were aware of the distrust of health services within Black communities (Kalathil et al., 2011; Kapadia et al., 2022; Linney et al., 2020; Memon et al., 2016) and felt that their role allowed them to actively counter this. This also speaks to the importance of trustworthiness in relation to rebuilding trust between Black communities and services. In order to warrant trust, services and institutions have to be seen as worthy of trust (O'Neill, 2018). The work of the SPLWs goes some way to doing this by the way in which they are trying to engage with service-users.

As mentioned above, while some participants felt that social prescribing could not reduce health inequalities without concurrent structural changes (for example at government policy level), they expressed a level of optimism in their capacity to rebuild trust and therefore mitigate health inequalities that was closer to the "hopefulness" of some of the social prescribing stakeholders in Mackenzie et al.'s study (2020). As distrust is such a challenge for services working with Black people with chronic pain due to the justified fear of racist and dismissive treatment (Denny et al., 2010; lacobucci, 2022a; Pryma, 2017), participants may have identified this as a specific area of practice in which they feel they can make a difference in reducing health inequalities by working to rebuild that trust.

#### 4.4.6. Thinking Critically About Race and Ethnicity

Some participants spoke about the racialised differences and similarities between themselves and their Black clients with chronic pain. In particular, some were aware of the difficulties in understanding the lived experience of their clients' individual Black identity without having a Black or racially minoritised identity themselves. One participant was also thinking critically about racialised difference when advocating for her Black clients, and how that can be a complex dynamic to navigate. This perhaps hinted at a fear of denying agency to Black service-users and contributing to racism by reinforcing a paternalistic or dependant relationship between SPLW and client. In general, participants were keen to engage more in critical thinking about racialised difference, racism and Whiteness in healthcare. In tension with this, one participant was less keen to think critically about race and ethnicity. He advocated taking a "colourblind" approach in trying to treat all clients equally and maintained that a client's ethnicity was not normally relevant to the work. This demonstrates that there was significant variability in participants' ability and/or willingness to think critically around race and ethnicity. In general, research has found that healthcare professionals tend to construct healthcare as impartial or colourblind, and are often reluctant to discuss racism in their work (Hamed et al., 2022). This study demonstrates that colour blindness is a contentious concept, with SPLWs in this study coming down on either side of the debate. Accordingly, some participants were aware of the huge variation in history, language, culture, nationality, and religion captured within the label of "Black" identities and how the term (along with many other labels, like "Black African") can flatten and homogenise these identities.

#### 4.5. Critical Review

## 4.5.1. Ensuring Quality

I have used Yardley's (2000) principles as a model to evaluate the quality of this study. Below I have focused on each of the four key evaluative characteristics in turn. *Sensitivity to context:* At the heart of this research was a discussion of the social context of health inequalities affecting Black people with chronic pain. I made sure to address this in the narrative and scoping review, the design of the study, the interviews themselves, and in the data analysis and discussion. This included topics like individualised versus contextualised understandings of inequalities, and discussions around the social determinants of health and biopsychosocial theory. The study also considered the historical context of racism and discrimination in healthcare in the introduction and in the discussion of trust in services throughout the research.

# 4.5.1.1. Commitment and rigour:

I demonstrated commitment to the topic through my engagement with chronic pain in my previous clinical work, and through a thorough literature search. I also involved a serviceuser and another stakeholder at various stages of the project to ensure that the research was meaningful and relevant for Black people with chronic pain. At each step of the research I was committed to the quality and rigour of the process. In the data analysis phase, I acknowledged that my reflexive analysis of the data was necessarily subjective whilst also maintaining the integrity of participant voices using data extracts to illustrate this, and making sure to include the voices of every participant in the analysis.

# 4.5.1.2. Transparency and coherence:

I was open and transparent with the reader about the study in terms of the journey from epistemology to methodology and method. I also showed transparency in the data analysis phase by including an initial map of themes and describing how the final themes were produced. By sharing my personal perspective and reflections on the project at various stages in the study I demonstrated transparency in how my own beliefs and experiences may have impacted the research.

## 4.5.1.3. Impact and importance:

This study has contributed new evidence to an area which has produced very little research to date. Its impact and importance are demonstrated in the various practical and policy implications detailed below, for social prescribers, health services and policymakers. These implications can hopefully improve outcomes and experience of services for Black people with chronic pain and ultimately reduce health inequalities in this area.

## 4.5.2. Methodological Considerations

This section considers the strengths and limitations of the study.

This study used a purposive sampling method to recruit participants. Within the borough in which I recruited, participants self-selected their involvement. I was also introduced directly to some participants who my contact at the ICP thought would be interested in the study. This meant that the participant sample may be representative of a particular subgroup of SPLWs who were interested in the topic and perhaps felt more confident than others in speaking about racialised inequalities. Whilst not a specific theme to come out of the

analysis, some participants remarked that speaking about racism and racialised inequality, even in a confidential setting, was a difficult thing to do, and an area in which they often felt uncertain. As such, the findings may not represent the voices of SPLWs who were deterred from participating due to lack of confidence in this area. Those who did volunteer were perhaps more engaged with topic of health inequalities, and therefore may have been more aware of narratives around the contextualised nature of health inequalities. This in turn might have contributed to the finding that participants held contextualised understandings of chronic pain inequalities. It is worth noting that some participants may have volunteered more because of an interest in chronic pain than in health inequalities. So, it is difficult to gauge what the findings might be in a less self-selecting sample. In spite of this, the participant sample with its variation in gender, age and ethnicity, supports the finding's transferability to other social prescribing professionals and teams, in different parts of the UK (particularly in more multicultural areas), and in other areas of health and mental health in which there are health inequalities.

Being a White, middle-class, man carrying out research on racialised inequalities could have affected the willingness of racialised SPLWs to participate in this study. My background and cultural identity were not made explicit in the recruitment materials but the majority of potential participants in the borough had an opportunity to see and hear from me in the integrated care partnership meeting in which I first introduced the project. I aimed to mitigate this during recruitment by addressing the topic sensitively and stating my clear aim for the project to address racialised health inequalities.

The use of semi-structured interviews in this project meant that there was scope for me, as the researcher, to decide when and where to provide prompts and which areas to probe further. Whilst I tried to be led as much as possible by the participants, the decisions I made in the interviews are likely to have been influenced by my own personal interests and views. As such, this may have influenced the narratives of the participants. Similarly, the wording of information about the study, and the interview questions themselves, might also have indicated my own approach and views on the need to critically examine and challenge health policies, systems and structures. This might also have influenced the narratives of the participants of their role and their understandings of chronic pain inequalities. At the same time, it may have given some participants an opportunity to critically explore this area in a way that they might not usually

have had in their day-to-day work, and in this sense provide important new evidence in this field.

## 4.6. Implications and Recommendations

## 4.6.1. Implications for Practice

SPLWs' ability to contextualise chronic pain inequalities with a biopsychosocial lens, combined with their desire for their strengths to be valued and drawn-upon, suggests that SPLW voices could more centrally involved in decisions around service design and delivery. SPLWs could be given the opportunity to qualitatively feed back to policymakers on outcomes and observations in their work, and could be better involved in servicedevelopment and wider policy decision-making relating to health inequalities. This could include having a central role in working groups focused on tackling health inequalities. Similarly, the findings suggest that a key strength of SPLWs is their awareness of the capital (economic, social or cultural) possessed by individuals and communities in their borough. This knowledge could enable SPLWs to develop and tailor social prescribing programmes, as well as the health services with which they are linked, in order to reduce some of the barriers to access and engagement for Black individuals with chronic pain, and reduce the risk of widening existing inequalities. To support this, SPLWs could receive more training in areas that have been highlighted by participants as potentially effective in rebuilding trust with Black communities. This could include training on facilitating groups or on cultural understandings of health, that perhaps are outside the existing scope of SPLW training.

With their connection to, and understanding of, local communities, SPLWs are well placed to better involve local residents, and particularly racially minoritised individuals and those most socially excluded, as well as relevant community organisations, in social prescribing service development at every stage. This aligns with the value of centring community assets, and is an additional area in which SPLWs could receive more training and support.

There are related implications for clinical psychologists and other mental health professionals who work with Black people with chronic pain. Mental health professionals should seek to collaborate with SPLWs when possible. SPLWs' knowledge of the assets, strengths and needs of the local community can help inform the support that mental health professionals offer to racially minoritised individuals with chronic pain. It can also help mental health services to develop interventions for people with chronic pain that are more biopsychosocial and holistic in nature, and by doing so hopefully reduce racialised inequalities. Mental health professionals can also learn from the finding that SPLWs were

rebuilding trust with Black individuals with chronic pain by creating spaces in which cultural and traditional understandings of health were validated and individual and community strengths were recognised. In an area like direct mental health support, where trust with Black communities has been so severely eroded (Kapadia et al., 2022), this finding can hopefully help to inform practice and further reduce inequalities for Black individuals with chronic pain.

The erosion of trust, and fear of dismissive and racist treatment highlighted by SPLWs in this study, could be addressed by health professionals being better trained in health inequalities and racism and Whiteness in healthcare. Service-users with chronic pain could be given longer appointments, and the quality of information given to service users about their pain diagnosis and how to manage it, could be monitored and improved. It is a great strength that SPLWs in this study felt that they were effectively rebuilding trust with this population, but this work should be complemented with a more preventative approach which addresses the continued erosion of trust from Black people's experiences of chronic pain healthcare. Finally, the problematic nature of the medicalised context of social prescribing could be addressed by increasing physical and ideological separation of social prescribing "and its medicalising effect. De-medicalisation of social prescribing might allow for more supportive, validating and culturally relevant spaces, such as more freedom to have peer-led discussions around traditional pain management approaches.

## 4.6.2. <u>Wider Implications</u>

This subsection details some of the larger, more structural changes that the findings of this might study point to. I am aware that many of these implications are long-term and difficult to connect to practical action in the here-and-now. However, there is still value in highlighting these wider implications as they can help guide thinking on this topic.

The SPLW perspective that social prescribing alone cannot reduce racialised chronic pain inequalities without concurrent structural change, complements literature summarised in the discussed suggesting that we should be focusing more on long-term structural change. This might include government policies directly targeting unequal distribution of the social determinants of health, such as housing and education. In the long run this would also result

in fewer people experiencing the 'social crises' that SPLWs report seeing in lots of their dayto-day work.

It is also positive that SPLWs reported being able to be responsive and flexible in their approach to addressing chronic pain inequalities, for example by creating and facilitating chronic pain information and management workshops. However, with more government funding for health and social care, there would be fewer 'gaps' (e.g., in health information) for SPLWs to fill, allowing them to focus more on the primary aim of their role, linking people in with community resources.

Similarly, the government could do more to resource and financially support local communities, charities and community organisations that provide free activities and groups to local residents. This will allow SPLWs to better support those residents who are most socioeconomically disadvantaged, and would provide a much better foundation for the "community development" aspect of the SPLW role.

#### 4.6.3. Research

Leading on from this study, a valuable area to research would be to directly hear the voices and narratives of Black individuals with chronic pain on similar issues. It is always vital that service-user perspectives are researched as it is their health and wellbeing that is at stake. Here, it would be useful to explore if Black individuals with chronic pain think about social prescribing and inequalities in a similar way to the SPLWs in this study. It would also be useful to understand more about their experiences of social prescribing and what changes they would like to see. There might also be merit in exploring the perspectives of a combination of SPLWs and service-users, perhaps in a focus group setting, to see what narratives arise when these topics are jointly discussed.

An important area of further research might be to investigate novel ways of capturing valuable SPLW outcomes that are not currently being captured. For example, if SPLWs in this study felt that rebuilding trust was a vital part of their work in this area, how can this trustworthiness be captured? While it might not be an easily measurable outcome, it could perhaps be estimated by markers such as length of time spent in sessions with Black individuals with chronic pain, or through measuring factors like openness and transparency.

Further research in this area might allow services to better rebuild trust with Black (and other minoritised) communities and therefore hopefully reduce health inequalities.

Finally, an interesting finding from this study was that SPLWs often encountered Black residents with chronic pain who had been given insufficient information about their pain condition and how to manage it. It would be a valuable area of further research to explore this potential driver of health inequalities in more depth. This could be from the perspective of Black service-users, qualitatively examining their experiences of their diagnostic appointments. It could also involve a more quantitative exploration, attempting to assess whether this is something experienced by large numbers of Black service-users.

#### 4.7. Reflexive Account

My prior working experience in clinical settings, and particularly in a chronic pain service, helped me to feel fairly confident engaging with SPLWs and discussing sensitive topics in interviews. I was curious if my experience of qualitative research at doctoral level would be different to my research experiences prior to clinical psychology training. I was very pleased to reflect that my experiences of qualitative interviewing in this project felt better in a number of ways. From reviewing the transcripts I noticed that I was much improved at listening to participants' accounts, asking relevant follow-up questions, probing areas that seemed pertinent, and also listening for things that were unsaid. This allowed me to carry out interviews that were truly 'semi-structured' and, to varying degrees, guided by the participants, as opposed to research prior to clinical training in which my semi-structured interviews tended to be much more structured. I reflected that this was a direct result of my level of confidence in direct clinical work, in which I have developed skills and experience in active listening and holding models and theories in mind whist talking to people.

In designing this study I was also curious as to how much SPLWs would open up to me as an outsider with different professional background. I reflected that most participants seemed to greatly appreciate the opportunity to share their views, and the majority of participants had lots to say, particularly about the challenges they face in their work. As mentioned above, this might have been a reflection that SPLWs feel unheard or underappreciated in their work. If so, I was pleased that this project will hopefully provide more of a platform for SPLW voices.

One of the more challenging reflections throughout this project was around my identity as a White, middle-class, British man, carrying out research on the health and wellbeing of Black

individuals. This gave me a drive to critically examine the design of the study, and the language I used, as I was aware of my many blind spots in this area, and the potential that I could be perpetuating Whiteness and racism within both research and healthcare. I aimed to navigate these challenges by involving Black service-users and stakeholders at various stages of the project and I tried to ensure that their participation was closer to partnership than simply consultation. I hope to reinforce this by staying in touch with the stakeholders and service-users who were involved in the project, meeting privately with them to discuss the results of the study, and discussing future research ideas and further opportunities for collaboration.

Having completed this project, I have become even more aware of how pain is a function of social and environmental conditions, and how people's experience of pain depends on how well the community is resourced. This project has also clarified for me how political and budgetary choices and restraints can have varying consequences for people living with chronic pain. As a clinical psychologist working in the field of physical health, I intend to hold this in mind throughout my practice and consider how factors at multiple systemic levels interact to influence the individual experience. I also intend to draw upon the implications from this study in my own practice by working closely with SPLWs when possible, to learn from their knowledge of community strengths and needs, as well as learning from and valuing cultural understandings of health.

#### 4.8. Conclusions

I hope that the dissemination of these findings will positively impact the health and wellbeing of Black individuals with chronic pain, reduce the health inequalities that they face, and have a positive impact on the professionals and services that are involved in social prescribing. This study has shown that whilst harmful health inequalities exist for Black individuals with chronic pain, there are SPLWs, communities and service-users with the skills, knowledge and desire to make meaningful changes in this area.

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#### 6. APPENDICES

#### 6.1. Appendix A: Glossary

I am aware that each of these terms is contested in its definition and usage, however, I have chosen to use these definitions as they best meet the needs of the present study.

**Socially excluded**: A person is socially excluded through a "complex and multi-dimensional process" where they lack or are denied "resources, rights, goods and services", leaving them unable "to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas" (Levitas et al., 2007).

**Systemic racism**: Systemic racism, and the closely related concept of structural racism establish the idea of racialised discrimination being embedded into laws, policies, political and economic systems and societal practices (Z. D. Bailey et al., 2021; D. R. Williams et al., 2019). This is different to discriminatory attitudes and prejudices at the individual level.

**Racially minoritised**: 'Racially minoritised' acknowledges the social processes, shaped by power, that actively minoritise people, as opposed to accepting minority categorisation as fact. In the UK this language has been proposed as a shift away from the acronym BAME (Black, Asian and minority ethnic), which is critiqued for its lack of specificity and focus on skin colour (Milner & Jumbe, 2020).

**Whiteness**: Whiteness is a racialised structure and form of domination established through historical economic and political colonial hierarchies. White supremacy privileges 'Whiteness' and disadvantages 'non-Whiteness' (Mills, 2019). Recognising and confronting the normative value placed on Whiteness is a foundation for addressing systemic racism (hooks, 2013)

#### 6.2. Appendix B: Scoping Review Search Terms

("black" OR "afro-caribbean\*" OR "afro caribbean\*" OR "african\*" OR "caribbean" OR "ethnic\*" OR "race" OR "racial\*" OR "racis\*" OR "BME" OR "BAME" OR "minorit\*" OR "health inequalit\*") AND ("social prescrib\*" OR "socially prescrib\*" OR "community refer\*")

## UNIVERSITY OF EAST LONDON School of Psychology

## APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS (Updated October 2021)

FOR BSc RESEARCH; MSc/MA RESEARCH;

PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

	tion 1 – Guidance on Completing the Application Form ase read carefully)
1.1	<ul> <li>Before completing this application, please familiarise yourself with:</li> <li>British Psychological Society's Code of Ethics and Conduct</li> <li>UEL's Code of Practice for Research Ethics</li> <li>UEL's Research Data Management Policy</li> <li>UEL's Data Backup Policy</li> </ul>
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must <b>NOT</b> commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).
1.5	<ul> <li>Research in the NHS:</li> <li>If your research involves patients or service users of the NHS, their relatives or carers, as well as those in receipt of services provided under contract to the NHS, you will need to apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance.</li> <li>Useful websites: <u>https://www.myresearchproject.org.uk/Signin.aspx</u> <u>https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-inneed/hra-approval/</u></li> <li>If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&amp;D approval. This is in addition to separate approval via the R&amp;D department of the NHS Trust involved in the research. UEL ethical approval will also be required.</li> </ul>

	<ul> <li>HRA/R&amp;D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example.</li> <li>The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.</li> </ul>
1.6	If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: <u>https://fadv.onlinedisclosures.co.uk/Authentication/Login</u> You may also find the following website to be a useful resource: <u>https://www.gov.uk/government/organisations/disclosure-and-barring-service</u>
1.7	<ul> <li>Checklist, the following attachments should be included if appropriate:</li> <li>Study advertisement</li> <li>Participant Information Sheet (PIS)</li> <li>Participant Consent Form</li> <li>Participant Debrief Sheet</li> <li>Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5)</li> <li>Permission from an external organisation (see section 7)</li> <li>Original and/or pre-existing questionnaire(s) and test(s) you intend to use</li> <li>Interview guide for qualitative studies</li> </ul>

- Interview guide for qualitative studies
- Visual material(s) you intend showing participants

Section 2 – Your Details		
2.1	Your name:	Mark Rupert Goodman
2.2	Your supervisor's name:	Kenneth Gannon
2.3	Name(s) of additional UEL	Nimisha Patel
	supervisors:	3rd supervisor (if applicable)
2.4	Title of your programme:	Professional Doctorate in Clinical Psychology:
		2020-2023
2.5	UEL assignment submission date:	May 2023
		Re-sit date (if applicable)

#### **Section 3 – Project Details**

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.

3.1	Study title:	How social prescribers conceptualise their role in
	<u>Please note -</u> If your study	reducing the health inequalities that affect Black
	requires registration, the title	adults with chronic pain
	inserted here must be <u>the</u>	

	<u>same</u> as that on PhD Manager	
3.2	Summary of study background and aims (using lay language):	Black adults in the UK report significantly higher rates of chronic pain than other racial or ethnic groups, yet their needs are often not met by statutory services. Social prescribing is intended to be a way of connecting people to a wider range of holistic support options, such as community groups and peer support. As such, health and care organisations often see social prescribing as one way of reducing the health inequalities that affect Black adults with chronic pain. However, there is little research on how social prescribers (such as social prescribing link workers) conceptualise their role in this process. The proposed study aims to explore how social prescribers understand their role in reducing the health inequalities that affect Black adults with chronic pain in the UK. Individual interviews with social prescribers will be analysed using a reflexive thematic analysis approach. The findings will help to improve the care and support provided to Black adults with chronic pain and to highlight the structural barriers that they face.
3.3	Research question(s):	<ul> <li>How do social prescribers (SPs) understand the needs of Black adults with chronic pain?</li> <li>How do SPs conceptualise the role of social prescribing in general, and more specifically for those with chronic pain and racialised groups?</li> <li>How to SPs understand the challenges and opportunities in this area?</li> </ul>
3.4	Research design:	The research will adopt a qualitative methodology, using semi-structured individual interviews.
3.5	<b>Participants:</b> Include all relevant information including inclusion and exclusion criteria	I will aim to recruit eight to twelve participants. Participants will be people engaged in social prescribing for those with long-term health conditions, for example, social prescribing link workers. Participants will most likely be employed by, or volunteer with, civil society organisations. They will not be employed by the NHS. Participants will be aged 18 or over living in the UK.
3.6	<b>Recruitment strategy:</b> Provide as much detail as possible and include a backup plan if relevant	Participants will be recruited through engaging with civil society organisations and local/integrated care partnerships that work with Black communities and people with chronic pain.
3.7	Measures, materials or equipment:	For the semi-structured interviews I intend to co- produce the interview schedule with stakeholders. Below I have included some broad areas that might

	Duravida datailad information		
	Provide detailed information, e.g., for measures, include	be covered in the interviews	
	scoring instructions,	1. Why do SPs think race is a	particular issue in this
	psychometric properties, if	area?	
	freely available, permissions	2. What are SPs' views on w	
	required, etc.	chronic pain care, and on the with chronic pain?	e needs of Black adults
		3. How do SPs conceptualise in chronic pain?	/talk about inequalities
		4. How do SPs conceptualise	their role in social
		prescribing in general, and s	
		health inequalities that affect chronic pain?	
		5. What are SPs experiences	of trying to address
		these inequalities? Challenge	
		6. How do other factors mak	
		gender or type of pain diagn	-
3.8	Data collection:	Semi-structured interviews	
0.0	Provide information on how	participants on an individual	
	data will be collected from	qualitative data and demogr	-
	the point of consent to	interviews will last approxim	•
	debrief	be conducted remotely, via	-
		software (MS Teams) ideally	
		to face if this is not possible,	
		device like a Dictaphone.	using an audio-recording
		device like a Dictaphone.	
		Interviews will be recorded a	and transcribed via MS
		Teams or in the case of telep	phone interviews/face to
		face interviews, the interview	w would be recorded
		through the use of an audio	recording device and
		then transcribed manually.	VIS Teams will be the
		default; telephone or face to	o face interviews will only
		take place if the participant	has no access to a
		PC/laptop or prefers to use t	he phone or be face to
		face.	
		All transcripts generated wo	
		(names would be changed, a	
		information would be remove	• •
		saved on the encrypted UEL	
0.0		recordings would then be de	-
3.9		YES	NO
	Will you be engaging in		
	deception?		
	deception? If yes, what will	If you selected yes, please pr	
	deception? If yes, what will participants be told about	If you selected yes, please pr here	
	deception? If yes, what will		

	inform them about its real nature?		
3.10	Will participants be reimbursed?	YES	NO
	If yes, please detail why it is necessary.		
	How much will you offer? <u>Please note</u> - This must be in the form of vouchers, <u>not</u> <u>cash.</u>	£10 voucher per participant	
3.11	Data analysis:	Interview transcripts (saved will be analysed using a refle approach. This will be done, software, licensed by UEL.	exive thematic analysis

#### Section 4 – Confidentiality, Security and Data Retention

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.

4.1	Will the participants be anonymised at source?	YES	NO ⊠	
	If yes, please provide details of how the data will be anonymised.			
4.2	Are participants' responses anonymised or are an anonymised sample?	YES	NO □	
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed during transcription, pseudonyms used, etc.).	Interview recordings will be collected in either .mp4 or .mp3 format. The recordings will immediately be made into transcripts in.docx format. All personally identifiable information will be removed/altered in the transcripts (names would be changed, and identifiable information would be removed or replaced),		

		and the recordings will subsequently be deleted. Transcripts will be saved on the encrypted UEL OneDrive. Demographic information will be removed from the transcripts and combined into a single file in .docx format, saved on the UEL OneDrive. No direct identifiable information will be collated, for example pseudonyms would be used as names, and for demographic information age will be obtained as opposed to DOB, and participants will not be asked to provide their address/location etc.
4.3	How will you ensure participant details will be kept confidential?	All data, which are stored on the UEL One Drive, are encrypted. Any identifiable data will be stored in separate folders from the pseudonymised and anonymised data to protect participant anonymity (e.g. consent forms, demographic information and the transcripts will all be stored in separate folders). Consent forms will be sent and received via a secure UEL email address in password protected files, and stored on the encrypted UEL One Drive.
4.4	How will data be securely stored and backed up during the research? Please include details of how you will manage access, sharing and security	The anonymised transcripts will be stored on the UEL OneDrive, which is a secure and encrypted university data cloud. The files will be accessed on a personal, secure and password protected laptop. The recordings of the interviews will be deleted once anonymised transcripts have been saved. Only the researcher and supervisor will have access to the files (and examiners during examination). Recordings will be transferred from the audio recorder (if applicable) to the UEL OneDrive and then deleted from the audio recorder. Once transcribed, the recordings will be deleted, and transcripts will be stored on the UEL OneDrive. Recordings made using Microsoft Teams are stored by default on the Microsoft Stream Library. Once transcribed, they will be deleted, and transcripts will be stored on the UEL OneDrive. The consent forms will be sent and returned via a secure email address, password protected,

		and stored on the UEL Or folder to the transcripts t anonymity.	·
		The demographic informative the interview will also be protected files in a separation OneDrive, to ensure anor	stored in password ate folder on the UEL
4.5	Who will have access to the data and in what form? (e.g., raw data, anonymised data)	Only the researcher, super will have access to the Or one else will have access Any data shared with the examiners will be done so the OneDrive for Busines shared with anyone else.	ne Drive Data files. No to the research data. research supervisor or o through the faculty of s. The Data will not be
4.6	Which data are of long-term value and will be retained? (e.g., anonymised interview transcripts, anonymised databases)	The anonymised transcrip 3 years, post examination the research to be writte for publication. During th transferred to the superv safely and securely stored shared with any other res	n. This is to allow for n up, with the potential is time, the data will be isor's OneDrive, to be d. The data will not be
4.7	What is the long-term retention plan for this data?	The anonymised transcrip 3 years post examination data will be transferred to OneDrive, to be safely an the supervisor and resear to the password protected	. During this time, the o the supervisor's d securely stored. Only rcher will have access
4.8	Will anonymised data be made available for use in future research by other researchers?	YES	NO ⊠
	If yes, have participants been informed of this?	YES	NO
4.9	Will personal contact details be retained to contact participants in the future for other research studies?	YES	NO ⊠
	If yes, have participants been informed of this?	YES	NO

#### Section 5 – Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

5.1	Are there any potential physical or psychological risks to participants related to taking part? (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	YES ⊠	NO □
	If yes, what are these, and how will they be minimised?	social prescribers, and inequalities that affect chronic pain, may be demanding or distress be given an information form to sign before bo forms will be written participants will be given ask questions. Particion that they can take bro or reschedule or with interview. Participant	et Black adults with emotionally sing. Participants will on sheet and consent eing interviewed. The in plain English and ven opportunities to pants will be informed eaks whenever needed, draw from their ts will be given to access psychological
5.2	Are there any potential physical or psychological risks to you as a researcher?	YES ⊠	NO
	If yes, what are these, and how will they be minimised?	General health and sa working or conductin offices of charities or organisations. Health of the venue will be f	g interviews at the community and safety protocols
5.3	If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that you have attached a GRA form as an appendix:		/ES ⊠
5.4	If necessary, have appropriate support services been identified in material provided to participants?	YES N	NO N/A
5.5	Does the research take place outside the UEL campus?	YES	NO
	If yes, where?	Interviews may need offices of charities or organisations	•
5.6	Does the research take place outside the UK?	YES	NO ⊠

	If yes, where?	Please state the country and other relevant details
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard). Please confirm a Country-Specific Risk Assessment form has been attached as an appendix. <u>Please note</u> - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics survey), regardless of the location of the researcher or the participants.	YES
5.7	researcher or the participants.	

Sec	Section 6 – Disclosure and Barring Service (DBS) Clearance				
6.1	Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?	YES	NO		
	If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project				
* You are required to have DBS or equivalent clearance if your participant grou involves:					

(1) Children and young people who are 16 years of age or under, or
(2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak with your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible.

	be used whenever possible.		
6.2	Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?	YES	NO □
6.3	Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?	YES	NO □
6.4	If you have current DBS clearance, please provide your DBS certificate number:	0017 0344 5535	
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	Please provide details of the type of clearance, including any identification information such as a certificate number	
6.5	Additional guidance:	1	

- If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian).
  - For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.

Sec	tion 7 – Other Permissions		
7.1	Does the research involve other organisations (e.g., a school, charity, workplace, local authority, care home, etc.)?	YES	NO
	If yes, please provide their details.		
	If yes, written permission is needed from such organisations (i.e., if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material <b>YES</b>		E <b>S</b> दा
	owned by the institution/organisation). Please confirm that you have attached written permission as an appendix.		7
7.2			

	adapt it by replacing words such as 'my' or 'l' with 'our organisation' or with
	the title of the organisation. This organisational consent form must be signed
	before the research can commence.
•	If the organisation has their own ethics committee and review process, a
	SREC application and approval is still required. Ethics approval from SREC can
	be gained before approval from another research ethics committee is
	obtained. However, recruitment and data collection are NOT to commence
	until your research has been approved by the School and other ethics
	committee/s.

Section 8 – Declarations			
8.1	Declaration by student. I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor:	YES	
8.2	<b>Student's name:</b> (Typed name acts as a signature)	Mark Rupert Goodman	
8.3	Student's number:	2075204	
8.4	Date:	02/12/2022	
Supervisor's declaration of support is given upon their electronic submission of the application			

#### 6.4. Appendix D: Evidence of Ethics Approval

## School of Psychology Ethics Committee

### NOTICE OF ETHICS REVIEW DECISION LETTER

#### For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in blue | Student: Please complete/read sections in orange

Details		
Reviewer:	Luis Jimenez	
Supervisor:	Kenneth Gannon	
Student:	Mark Rupert Goodman	
Course:	Prof Doc Clinical Psychology	
Title of proposed	How social prescribers conceptualise their role in reducing the health	
study:	inequalities that affect Black adults with chronic pain	

Checklist (Optional)			
	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)			
Detailed account of participants, including inclusion and exclusion criteria			
Concerns regarding participants/target sample			
Detailed account of recruitment strategy			
Concerns regarding recruitment strategy			
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)			
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample			
Clear and detailed outline of data collection			
Data collection appropriate for target sample			
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point			
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation			

Concerns regarding data storage (e.g., location, type of data, etc.)		
Concerns regarding data sharing (e.g., who will have access and how)		
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)		
If required, General Risk Assessment form attached		
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise		
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise		
If required, Country-Specific Risk Assessment form attached		
If required, a DBS or equivalent certificate number/information provided		
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)		
All relevant information included in the participant information sheet (PIS)		
Information in the PIS is study specific		
Language used in the PIS is appropriate for the target audience		
All issues specific to the study are covered in the consent form		
Language used in the consent form is appropriate for the target audience		
All necessary information included in the participant debrief sheet		
Language used in the debrief sheet is appropriate for the target audience		
Study advertisement included		
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)		

	Decision options
APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. <b>Minor amendments guidance:</b> typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE- SUBMISSION REQUIRED	In this circumstance, a revised ethics application <u>must</u> be submitted and approved <u>before</u> any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

Major amendments guidance: typically insufficient information
has been provided, insufficient consideration given to several key
aspects, there are serious concerns regarding any aspect of the
project, and/or serious concerns in the candidate's ability to
ethically, safely and sensitively execute the study.

## Decision on the above-named proposed research study

Please indicate the decision:

**APPROVED** 

## **Minor amendments**

Please clearly detail the amendments the student is required to make

# **Major amendments**

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher				
Has an adequate risk	• YES	NO		
assessment been offered	• 🗆			
in the application form?	If no, please request resubmission with an <u>adequate risk</u> <u>assessment.</u>			
If the proposed research could expose the <u>researcher</u> to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:				
		sical		
	<ul> <li>, please rate the degree of risk:</li> <li>Please do not approve a high-risk application. Travel to</li> </ul>	sical		
or health and safety hazard	<ul> <li>please rate the degree of risk:</li> <li>Please do not approve a high-risk application. Travel to countries/provinces/areas deemed to be high risk should</li> </ul>	sical		
	<ul> <li>, please rate the degree of risk:</li> <li>Please do not approve a high-risk application. Travel to</li> </ul>	sical		

MEDIUM	Approve but include appropriate recommendations in the below box.	
LOW	Approve and if necessary, include any recommendations in the below box.	$\boxtimes$
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature	
Reviewer:	DR LUIS JIMENEZ
Date:	16/12/2022

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee

#### **RESEARCHER PLEASE NOTE**

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments		
(Student to complete)		
I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data		
<b>Student name:</b> (Typed name to act as signature)	Please type your full name	
Student number:	Please type your student number	
Date:	Click or tap to enter a date	

Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required

#### 6.5. Participant Information Sheet

Version: 1 Date: 02/12/2022



#### PARTICIPANT INFORMATION SHEET

# How social prescribers conceptualise their role in reducing the health inequalities that affect Black adults with chronic pain

#### Contact: Rupert Goodman Email: u2075204@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

#### Who am I?

My name is Rupert Goodman. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Professional Doctorate in Clinical Psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

#### What is the purpose of the research?

I am conducting research into the role of social prescribing in reducing the health inequalities that affect Black adults with chronic pain. Black adults in the UK have significantly higher rates of chronic pain than other racial or ethnic groups, yet their needs are often not met by statutory services like the NHS. Social prescribers (such as link workers) are uniquely positioned at the interface of communities, community organisations, and statutory services. Therefore, this study aims to draw upon the experience and expertise of social prescribers to explore the role of social prescribing in reducing the health inequalities that affect Black adults with chronic pain. The long-term goal of the study is to improve care and support for Black adults with chronic pain by highlighting and removing structural barriers. The findings of this study may also be useful for improving care and support for other racialised minorities and for people with other long-term conditions.

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

To address the study aims, I am inviting social prescribers, such as social prescribing link workers, to take part in my research. If you are aged 18 or over, you work or volunteer as a social prescriber, and you live in the UK, you are eligible to take part in the study. It is NOT essential that your clients have had chronic pain, nor is it essential that you have worked with Black adults. Your views and experiences in social prescribing will still be extremely valuable in thinking broadly about this area of research.

It is entirely up to you whether you take part or not, participation is voluntary.

#### What will I be asked to do if I agree to take part?

If you agree to take part, you will be asked to participate in an individual interview with me. The interview will be an informal chat, covering topics relating to your experience of social prescribing. For example, we may chat about the challenges you face in social prescribing for people with chronic pain.

The interview will last no longer than one hour and will take place either on a video call (using Microsoft Teams) or over the telephone. If neither of these methods are convenient, we may be able to arrange for the interview to take place face-to-face in the offices of a local charity or community organisation.

The interview will be recorded using either Microsoft Teams (video and audio recorded) or an audio recording device. All information you provide will be kept secure and confidential (see more details below).

You will be given a £10 gift voucher in payment for your time and participation. The voucher can be spent at many high-street and online retailers.

#### Can I change my mind?

Yes, you can change your mind at any time and withdraw without explanation, disadvantage or consequence. If you would like to withdraw from the interview, you can do so by asking to stop the interview at any point. If you withdraw, your data will not be used as part of the research.

Separately, you can also request to withdraw your data from being used even after you have taken part in the study, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

#### Are there any disadvantages to taking part?

You may find it emotionally demanding or distressing talking about race and chronic pain in relation to your work. During the interview you will be able to take breaks whenever needed and you can reschedule the interview at any point if you would like. You will also be provided with information on how you can access psychological support.

#### How will the information I provide be kept secure and confidential?

After the interview, the recording will immediately be typed up and saved as a text document on a secure, encrypted, university drive. The recording will then immediately be

deleted. All personally identifiable information (such as your name or other identifying details) will be removed or altered in the typed version of the interview. Demographic information will be kept in a separate text document, also stored on a secure, encrypted drive.

You will be asked to sign a consent form before participating in the study. This consent form will be sent and received via a secure university email address, in password protected files, and stored on the encrypted university drive in a separate folder.

During your participation in the research, in the unlikely event that there are concerns for your safety or the safety of others then I may be required to share your identity with other people or services. If this were to happen I would always try to speak with you first and discuss how best to share this information with others.

For the purpose of completing and examining my postgraduate studies, my university supervisor and examiners will have access to the anonymised data that result from your interview. No one else will have access to the research data. Any data shared with the research supervisor or examiners will be done so through the encrypted university drive. The data will not be shared with anyone else.

The typed up, anonymised version of the interview will be kept for three years after the research has been written up, to allow time for it to be published (if you choose to consent to this by ticking the correct box on the consent form). If you do not consent to this then your data will be deleted. With your consent, your personal contact details will also be stored for three years after the study has completed (on a secure and encrypted drive) in order to keep you updated on the outcome and impact of the research and any related matters.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/dataprotection

#### What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository (Registry of Open Access Repositories, ROAR). Findings will also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, or blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally as all personally identifying information will either be removed or replaced.

The same is true for any quotes or extracts of the conversation we have used in the report as evidence of study findings.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data (such as interview transcripts) will be securely stored by Dr Kenneth Gannon (University of East London) for a maximum of 3 years, following which all data will be deleted.

#### Who has reviewed the research?

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

#### Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

#### Rupert Goodman Email: u2075204@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Kenneth Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: k.n.gannon@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

#### Thank you for taking the time to read this information sheet

#### 6.6. Appendix F: Consent Form



#### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

# How social prescribers conceptualise their role in reducing the health inequalities that affect Black adults with chronic pain

#### Contact: Rupert Goodman Email: u2075204@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet dated 02/12/2022	iniciai
(version 1) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may	
withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using Microsoft Teams or if	
necessary, an audio recording device.	
I understand that my personal information and data, including video or audio	
recordings from the research will be securely stored and remain confidential.	
Only the research team will have access to this information, to which I give my	
permission.	
It has been explained to me what will happen to the data once the research has	
been completed.	
I understand that short, anonymised quotes from my interview may be used in	
material such as conference presentations, reports, articles in academic	
journals resulting from the study and that these will not personally identify	
me.	
I would like to receive a summary of the research findings once the study has	
been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

Date

.....

#### 6.7. Appendix G: Debrief Form



#### PARTICIPANT DEBRIEF SHEET

# How social prescribers conceptualise their role in reducing the health inequalities that affect Black adults with chronic pain

Thank you for participating in my research study on the role of social prescribing in reducing the health inequalities that affect Black adults with chronic pain. This document offers information that may be relevant in light of you having now taken part.

#### How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

#### What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository (Registry of Open Access Repositories, ROAR). Findings will also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) This might be through journal articles, conference presentations, talks or blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally as personally identifying information will either be removed or replaced. This includes quotes or extracts of the conversation we have used in the report as evidence of study findings. Please let me know if there is any part of our conversation that you do not want to be included in quotes in the final write up.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by Dr Kenneth Gannon for a maximum of 3 years, following which all data will be deleted.

As a reminder, you have <u>3 weeks from today</u> to request all or part of your interview from today to be removed from analysis. You can also <u>request to review your transcript</u> for accuracy or to provide elaboration, please let me know if you would like to do so.

#### What if I have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

#### Mind Infoline: 0300 123 3393

Their Infoline provides an information and signposting service. They're open 9am to 6pm, Monday to Friday (except for bank holidays).

#### Aashna

https://www.aashna.uk

Provides a list of therapists working to recognise the ways in which culture, faith, religion, colour, social background, sexuality, gender and neurodiversity affect people's experiences.

#### BAATN (The Black, African and Asian Therapy Network)

www.baatn.org.uk

Provides a list of therapists from Black, African and Asian backgrounds, and signposts to local mental health and advocacy services.

Resources for professional practice:

Healthy London Partnership

https://www.eventbrite.co.uk/o/hlp-31905452669

Organises peer support sessions for Social Prescribing Link Workers. Check the Eventbrite website above for dates.

#### Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me: Rupert Goodman, email: u2075204@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Kenneth Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: k.n.gannon@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

#### Thank you for taking part in my study

#### 6.8. Appendix H: Interview Schedule

#### Semi-Structured Interview Schedule

- 1. What does your day-to-day look like as a social prescribing link worker?
- 2. As a social prescribing link worker, what are the main objectives that you are working towards?
  - a. (Prompt) What do you see as your role as a social prescribing link worker?
- 3. How much of your social prescribing work is with Black residents with chronic pain?
  - a. What do think went well / didn't go so well (challenges)
  - b. What resources are in place for Black residents with chronic pain in [Borough]?
    - i. Where would you find out about these resources?
    - ii. What role do support groups play in managing pain for Black residents?
  - c. How does your patient's racialised identity impact the support you provide?
  - In general, how do you think social prescribing could be improved for Black residents with chronic pain? (Prompt for intersectional experiences)

Interviewer note: Link to next section, e.g. "We've been talking a lot about race and chronic pain care and you've said... and talked about your experiences of..."

- 4. From my own experience working in a chronic pain service, and from my understanding of the literature, there seem to be certain inequalities that affect Black residents with chronic pain. For example...
  - I'm interested to hear your views on <u>why</u> you think inequalities like this might exist? a. What do you think could be done to improve things?
- 5. We've talked a fair bit about racialised inequalities, what do you think the role of social prescribing is in reducing the health inequalities that affect Black residents with chronic pain?
  - a. Do you have any example of where social prescribing has worked well in reducing health inequalities for Black residents with chronic pain?
    - i. What are the challenges / barriers?
  - b. How much do you personally feel <u>able</u> to address these racialised health inequalities in your work?
    - i. What would help you to do this more effectively?
  - c. <u>Why</u> do you think this is your role?
  - d. How else do you think we should be addressing the inequalities that affect Black adults with chronic pain?
- 6. Is there anything that we haven't covered that you would like to add?

#### 6.9. Appendix I: Example of Annotated Transcript

#### Researcher

And I'm interested to hear what your views are on why these inequalities exist?

#### Participant 4

All this is subjective, I'm definitely not an expert, I can only speak from experience, but I think it comes back to what we were talking about before, where people just aren't taken seriously, particularly with something like chronic pain where the physical side of it doesn't always match up with the mental. Someone might be in excruciating pain but an MRI shows up absolutely nothing or a very minor thing. I think there is a central issue of Black people not being taken seriously. They aren't listened to They're accused of all these stereotypes, like being over the top or exaggerating. do think if they're not listened to at the start, that can really spiral and that can develop mistrust, and that's not gonna make the relationship with GPs any better. It's not gonna help them manage their pain. We hear this a lot with people who've had really bad experiences with counselling or something like that. If the first time it goes really badly, that's kind of it for a lot of them. It can be really hard to repair that relationship. With the local talking therapy session we have, for a lot of people it really works, it's a really good one. But I've had a few patients personally who've had a really bad counselling experience, maybe 10 years ago or 15 years ago, and that's just put them off for good. We can gently talk about it, we can suggest they try again, but they're not having it. And I think that happens with a lot of healthcare services. If they have a really poor experience, they feel that they're not being listened to, that can maybe not end it, but make them really suspicious, make them not want to go to the doctor as much, which means their conditions might escalate even further. I think for me, the common thing is, "We're not being listened to. We're not being

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### 6.10. Appendix J: Map of Initial Themes

Theme	Possible subthemes
Problems with healthcare	Barriers to accessing health services
	Racism in healthcare
	Feeling unheard
	Inadequate medical information provided
Medicalisation of chronic pain care	Patient desire for medical answers
	Impact of medical setting of social prescribing
Systemic challenges for SPLWs	Lack of community resources
	COVID and austerity have impacted community resources
	COVID impacted group interventions
	Government cuts to health services and social care
SPLW knowledge and awareness of inequalities and their causes	High rates of Black clients with CP
	SPLWs see more Black women with CP
	SPLWs are aware of inequalities
	Social causes of CP inequalities
	Trauma as a cause of CP
	Intersection of gender and CP
	No training on racial inequalities
SPLW perspectives on what works for what they "prescribe"	Culturally diverse practices are validated not judged
	Inclusion of complementary and alternative medicine
	Peer support is helpful
	Support for psychological interventions

SPLW perspectives on what works in their practice	SPLWs listen
	SPLWs fill gaps in health education
	SPLWs listen and provide health advocacy
	SPLWs create and facilitate CP interventions
	SPLWs build connections with the community
Effects of health inequalities on the SPLW role	SPLWs are doing crisis management
	Some have fewer resources for self- advocacy

### 6.11. Appendix K: Final Thematic Map

Theme	Subtheme
Social prescribing: "it doesn't fix the	Contextualised understandings of inequalities
undercurrents of society"	
	"Black people are not taken seriously":
	Whiteness and racism in healthcare
Systemic factors affecting the SPLW role	"A very doctor-patient dynamic": Navigating
	the impact of a medicalised setting
	Hampered by deficiencies in healthcare,
	social care and civil society
Learning lessons and thinking differently	"Making it bottom up": Centring community
	assets
	Valuing SPLW strengths
	"We're here to mainly listen": Rebuilding trust
	Thinking critically about race and ethnicity