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Race on the Agenda

MAKE THE INVISIBLE, VISIBLE

IN HOUSING, HEALTH & WELLBEING

RCRP 2025 REPORT

“I’VE STRUGGLED TO TRUST SERVICES… THERE’S NO POINT SEEKING SUPPORT, AS NOTHING SEEMS TO CHANGE.”

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FOREWORD

I am deeply proud of the peer researchers, participants and ROTA team in making this report possible.

It represents not only another research study but an authentic insight into the lived experiences of a broken housing and healthcare system for BGM groups. This is a system that has historically ignored, underfunded and dismissed pain.

For too long the voices and issues of BGM groups have been silenced and this report simply says: 'no more'.

The ROTA Community Research Programme (RCRP), places people who live in and among the issues that are talked about in this report, at the centre. It challenges the outsider perspective that collects data on BGM communities but then interprets it from a lens that is far removed from people's lives. This is what makes this report so powerful and so special, because it is deeply based on the principle of 'nothing about us, without us.'.

While research and reports are important, I also acknowledge they are not in and of themselves enough. They support the foundations for action, movement building, narrative and policy change. This requires a collective effort as no single person or organisation can address the significant challenge of our contemporary struggles.

Finally, I also want to acknowledge the important support of Propel London and the City Bridge Foundation for funding this program. It is the collective efforts of the ROTA staff (particularly programme leads Taranjit Chana and Kulvinder Nagre), peer researchers, our members, supporters, volunteers, board members and funders that make this partnership and work possible.

Matt Johnson, CEO

INTRODUCTION

This report marks the second year of the Race on the Agenda (ROTA) Community Research Partnership (RCRP), a flagship programme committed to transforming how research is conducted with and for Black and Global Majority (BGM) communities. Historically, research into the issues that our communities face has relied on an extractive model, where external academics co-opt lived experiences for professional capital without ceding power or ensuring meaningful benefit to the communities themselves. The RCRP exists to fundamentally challenge this dynamic.

Enabled by funding from the City Bridge Foundation via the Propel partnership, the RCRP operates on principles of co-production and capacity building. Each year, we partner with a cohort of Peer Researchers (PRs) from BGM communities, providing intensive training and support. These PRs then design and lead innovative, community-centred research projects that amplify their expertise and drive tangible change. Over its three-year lifespan, the programme aims to develop significant community research capacity, support 30 research projects, and co-produce four impactful campaigns for systemic reform.

Following the 2024 cohort's focus on the critical areas of education and employment, the 2025 cohort has turned its attention to housing and health and wellbeing. These themes reflect persistent, intersecting crises disproportionately affecting BGM communities in London, from the housing emergency and its mental health impacts to entrenched inequities in healthcare access and outcomes.

Our 2025 Peer Researchers are leading a diverse and vital portfolio of projects that exemplify our commitment to intersectionality and community-defined priorities. Their investigations include:

1. LGBTQ+ housing issues
2. The housing and wellbeing of Sudanese refugee communities
3. Wellbeing among migrant hotel residents
4. The housing and mental health impacts on families subject to No Recourse to Public Funds (NRPF)
5. Gentrification in Peckham
6. Wellbeing and mental health care for Sickle Cell patients
7. Mental health care provision at university
8. Maternal mental health care
9. Black women with chronic health conditions
10. Black women's wellbeing through art

This report presents the findings from these essential research initiatives. It underscores the power of placing research tools directly in the hands of those with lived experience, ensuring that the insights generated are not only authentic but are also owned and leveraged by the communities to advocate for a more just and equitable society

EXECUTIVE SUMMARY

ABOUT THE RCRP PROGRAMME

This report presents the findings of the 2025 cohort of the ROTA Community Research Partnership (RCRP), a programme committed to transforming research practices with Black and Global Majority (BGM) communities. Moving beyond extractive academic models, the RCRP empowers Peer Researchers (PRs) from these communities through training and support to design and lead their own research. Enabled by funding from the City Bridge Foundation, the programme's mission is to build community research capacity and drive tangible systemic change. The 2025 cohort focuses on the intersecting crises of **housing** and **health & wellbeing**, which disproportionately impact BGM communities in London.

The research demonstrates that for marginalised communities in London, housing is not merely about shelter, but about safety, dignity, belonging, and the ability to thrive. When housing is used as a tool of exclusion or control, it inflicts deep and lasting harm.

CROSS-CUTTING FINDINGS:

1. **Housing as a Weapon of Policy**: Immigration policies like **No Recourse to Public Funds (NRPF)** deliberately manufacture housing precarity for migrant families, leading to overcrowded, unsafe conditions and severe health impacts on children who are British citizens.
2. **Institutional Dehumanization**: Asylum seekers housed in Home Office 'contingency accommodation' (e.g., hotels) survive in conditions detrimental to health and dignity – inedible food, abusive staff, dangerous maintenance failures – revealing a culture of neglect.
3. **A Hierarchical Humanitarian Response**: The absence of a dedicated resettlement scheme for **Sudanese arrivals** (both citizens and refugees) after the 2023 war created a stark "limbo," marked by inconsistent support, discrimination, and avoidable hardship, contrasting sharply with responses to other groups.
4. **Displacement Through 'Investment'**: For **BGM communities** in gentrifying areas like Peckham and Brixton, redevelopment is a racialized and classed process. It displaces long-standing residents, fosters exclusion, and is perceived as local authorities prioritizing affluent newcomers over investing in existing community needs and social housing.
5. **The Mental Health Cascade**: Housing precarity directly fuels anxiety, depression, and isolation. This is acutely visible for **young Black LGBTQ+ Londoners**, where family rejection, discrimination, and unaffordability intersect with a near-total lack of culturally competent, affirming mental health services.
6. **Systemic Neglect in Healthcare**: Research into **Sickle Cell care** and the experiences of **Black women with 'hidden' disabilities** uncovers a system that frequently fails them, discounting pain through a lens of racism, sexism, and disbelief.
7. **Cultural Incompetence and Stigma**: Studies on **South Asian women's mental health** – both university-aged and mothers in the perinatal period – identify similar barriers: stigma within families, cultural incompetence in services, dismissal of concerns, and fragmented care. For mothers, this intersects with systemic racism in maternity services, creating dangerous gaps in support.
8. **Healing Through Community**: Conversely, the **Create in Mind** art and wellbeing programme for Black women demonstrated the transformative power of culturally safe, creative spaces for reducing stress, reclaiming identity, and building sisterhood – highlighting what is possible when community-led solutions are centred.

LIVED EXPERIENCE HIGHLIGHTS:

On LGBTQ+ Black Youth & Housing:
"I can't be open about an important part of who I am... I'm constantly monitoring my behaviour to avoid conflict."

On the UK's Response to Sudanese Arrivals:
"Sudanese evacuees received nothing close to what Ukrainians received. The system simply wasn't designed with them in mind."
"We all feel trapped here... What's the point of being British if we can't have our private life respected?"

On Life in Asylum Accommodation:
"They labelled me with a number." – An asylum seeker on being referred to by his room number.
"Meals nobody could eat... staff refused to eat it themselves."

On the Impacts of NRPF:
"I felt like we are not human beings actually... It really affected my mental condition and I was crying a lot, I felt hopeless for everything."
"The place had mould, dripping water, insects. I was working for the NHS during COVID and risking my life for others, but I couldn't even live in a safe house."

On Gentrification and Belonging:
"It feels really dehumanising... how detrimental it must be for our mental health to live in conditions that are not adequate and then be told that we kind of have to swallow it because we're poor essentially."
"Brixton was just Blacks on an estate... now the majority of Brixton is white... they've revamped it, moved all the Black people out."

On South Asian Mothers' Perinatal Care:
"It's institutional racism – when people look at you [pointing at skin colour], we're fobbed off as whining women." (Referencing "Mrs Begum Syndrome")
"The trauma of being dismissed, that your pain is invalidated because you are Brown."

On Healing in Community:
"I healed more in these sessions than in talking therapy... I feel much more peace." – A Black woman on the Create in Mind programme.
"We created our own little group. Our own Black women's space"

CHAPTER ONE: THE MENTAL HEALTH IMPACTS OF HOUSING INSECURITY AMONG LONDON'S LGBTQ+ BLACK AND GLOBAL MAJORITY COMMUNITY

EKHLAS KHADI

Young Black LGBTQ+ people in London face a unique set of intersecting challenges shaped by racism, homophobia, transphobia, and economic inequality. Housing insecurity is a critical issue in this community, as family rejection, discrimination in rental markets, and limited access to safe, affordable housing intersect with broader structural inequalities. At the same time, the UK's mental health system is under strain, with long waiting lists and limited culturally competent or LGBTQ+ affirming services. This makes it especially important to understand how housing precarity directly impacts mental health for this group.

The participants are young Black LGBTQ+ Londoners aged between the age range 18-30. They were recruited through community networks, social media, and peer referrals, with an emphasis on ensuring anonymity and confidentiality given the sensitivity of the topic.

My connection to participants comes from the fact that I have many close friends within the Black LGBTQ+ community in London. Through these friendships, I have been able to witness first-hand the challenges that housing insecurity and limited mental health support create in people's lives. This personal proximity gave me an informed perspective on the issues, while still allowing me to maintain critical distance as a researcher. Because of this, participants felt I could understand their realities, which helped build trust and encouraged openness. It also ensured that the project reflects lived experiences that are often overlooked in mainstream housing and health debates.

1. METHODS

Participants were recruited through a poster I designed and shared across different platforms. I posted it on LinkedIn, circulated it in group chats, and asked friends to share it within their networks. This approach helped me reach a wider pool of young Black LGBTQ+ Londoners, while still relying on community-based trust to encourage participation.

I used a mixed-methods approach. The poster directed people to take part in an online survey, which included both multiple-choice and open-ended questions. In addition, I carried out follow-up interviews with some participants who volunteered to share more detail about their experiences. The survey provided an overview of common issues, while the interviews gave space for in-depth, personal reflections.

I went through all the survey responses and interview transcripts to identify common ideas and experiences. This involved reading participants' own words and noting patterns that appeared across multiple responses. For example, many participants talked about being rejected or unsupported by their families, relying on friends or chosen family for help, and facing barriers to accessing mental health services. By grouping these experiences into categories, I was able to see broader trends in how housing insecurity affects mental health, while also highlighting individual stories that illustrated these patterns.

Initially, I had planned to do more in-person interviews, but participants expressed concerns about privacy and time commitments. To address this, I shifted towards using online surveys and virtual interviews, which felt safer and more convenient for many. I also simplified some of the survey questions after trialling them with a small group, making sure they were clear, sensitive, and not overwhelming for participants.

2. RESULTS

A thematic analysis of data from 17 young Black LGBTQ+ Londoners revealed five interconnected themes concerning housing precarity, mental health, and systemic barriers to support. The findings, supported by participant statistics and direct quotations, are presented below.

2.1 HOUSING PRECARITY IS WIDESPREAD AND MULTIFACETED

Housing insecurity was a near-universal experience, characterised by living in unsafe, unstable, or unsupportive home environments. Participants described family rejection, homophobia, transphobia, and intergenerational conflict as primary drivers. For 65% (11/17), the fear of losing housing led them to avoid expressing their identity at home.

One participant explained, *"I can't be open about an important part of who I am... I'm constantly monitoring my behaviour to avoid conflict."* This precarity extended beyond family homes; those in temporary accommodation faced severe physical and psychological neglect.

One participant recalled living in emergency council housing *"with bedbugs, mould everywhere, and boxes stacked up for years,"* adding, *"I started to feel discouraged because I thought I was going to be stuck in this housing forever which wasn't a place I wanted to call home."*

This instability caused profound stress, anxiety, and social isolation, directly hindering life progression. As one participant noted, *"it was difficult for me to study for school as I didn't have a dedicated area to focus,"* while another feared the future: *"I get more stressed thinking about what will happen after university rather than anything because being a student kind of gives you some sort of safety net."*

Furthermore, 59% (10/17) reported experiencing racism or discrimination when trying to access housing or support.

2.2 THE DIRECT IMPACT OF HOUSING ON MENTAL HEALTH

Participants consistently reported that unstable or unsafe housing directly worsened their mental health, with 71% (12/17) agreeing that housing insecurity negatively affected it. Feelings of anxiety, depression, and disconnection were frequently linked to housing conditions.

The psychological toll of an unaffirming home was severe, as captured in the quote: *"At home, I live with my parents, who hold religious, homophobic views... this definitely affects my mental/ emotional wellbeing."*

The experience of inadequate temporary housing also induced significant distress, with one participant describing a psychosomatic response: *"There was a time where I would think/feel myself being bit even though I wasn't."*

The core need for safety was paramount, with participants redefining "home" in constrained terms: "*Home to me has always been a place where I felt safe, so it's my room,*" while for others, the meaning had shifted entirely to chosen family.

2.3 SYSTEMIC BARRIERS TO MENTAL HEALTH SUPPORT

When seeking formal mental health care, participants faced insurmountable systemic barriers. These included prohibitively long NHS waiting lists—*"Have always been part of CAMHS growing up, it's harder once you're an adult since the waiting list is very long"*—and the high cost of private therapy: *"It's very hard to find mental health support in London without being on a month's long waiting list unless you go private which just costs so much money."* Most critically, there was a stark lack of culturally competent and LGBTQ+ affirming services.

A universal finding from the survey showed 100% (17/17) of participants disagreed that current services in London understand the needs of Black LGBTQ+ people. This was echoed in interviews: *"No, I don't feel housing and mental health services in London fully understand the experiences of people like me."*

Participants cited a lack of staff diversity and understanding of intersectionality as key failures, with one stating, "*the workforce of these sectors do not look like me or reflect the struggles that I go through."* These barriers eroded trust, leading to disengagement: *"Since then, I've struggled to trust services and often felt there's no point seeking support, as nothing seems to change."*

2.4 COPING STRATEGIES AND RELIANCE ON INFORMAL SUPPORT

In response to inaccessible formal systems, participants relied heavily on informal support networks and personal coping strategies, with 71% (12/17) identifying friends and chosen family as vital.

These networks provided essential emotional and practical support, often becoming a redefined concept of home: *"As home has changed meaning, from family to friends. Friends have always been there for me and welcomed me into their homes when my own home hasn't been welcoming."*

Participants also employed individual resilience strategies, such as journaling: *"Throughout the years journaling has helped me feel grounded. After writing I reflect on my feelings, and it makes me feel a lot better."* This theme underscores the critical role of community and self-care in navigating structural neglect.

2.5 PARTICIPANT-IDENTIFIED NEEDS AND POLICY RECOMMENDATIONS

Participants clearly articulated the changes necessary to support their wellbeing. Their key needs included:

- Safer, long-term housing options and LGBTQ+ specific emergency housing.
- Affordable, culturally competent therapy, a need expressed by 82% (14/17) of survey respondents.
- Accessible, community-based spaces for safety and support.

Their recommendations for services were specific and actionable. They called for better-trained, compassionate staff: *"Encourage more services to hire people with proper training and not just volunteers. Or even provide training to the volunteers that allows them to be more compassionate."* They emphasised the necessity of cultural competence: *"Therapy and housing services should be culturally adapted."*

Participants also advocated for proactive, community-focused models to bypass formal gatekeeping: *"I personally believe if there were more youth clubs in London a lot of young people would have more of a community where they can share their feelings and access services."*

Finally, they highlighted the fundamental issue of financial support, linking economic precarity to unsafe housing: *"I think financial support would help a lot, a lot of LGBTQ+ black youth resort living in places that aren't that safe because of how difficult and expensive it is to find housing in London."*

3. CONCLUSIONS AND RECOMMENDATIONS

My findings demonstrate that housing insecurity is a critical social determinant of mental health among young Black LGBTQ+ Londoners. Unstable or unsafe housing conditions - shaped by intersecting forces such as family conflict, financial precarity, racism, homophobia, and transphobia - were consistently associated with heightened anxiety, depression, and social isolation. This highlights how structural inequalities manifest within everyday living environments, producing cumulative stressors that undermine education, work, and personal development. Crucially, the findings show that housing is not reducible to physical shelter but is bound up with notions of safety, belonging, and the ability to express one's identity. Participants' experiences with mental health services further reveal systemic barriers: long NHS waiting lists, prohibitive private therapy costs, and the absence of culturally competent and LGBTQ+ affirming provision all limited meaningful access to care. In responding to the research question, the study underscores the inextricable link between housing precarity and mental health, mediated by both material deprivation and symbolic exclusion.

This research expands understandings of young Black LGBTQ+ communities by centring their intersectional lived experiences, which remain largely invisible within mainstream housing and health debates. Participants reframed "home" in non-traditional ways - sometimes confined to a single safe room, at other times located in chosen families and friendships - revealing how dominant policy framings fail to capture the complexity of belonging for marginalised groups. Their reliance on informal coping mechanisms such as journaling, fitness, and peer support reflects both resilience and the systemic inadequacy of formal provision. By situating these accounts within broader structures of inequality, the research illustrates how overlapping systems of race, class, sexuality, and immigration status shape access to stable housing and equitable healthcare. In doing so, it calls for a reconceptualisation of housing and mental health policy: one that recognises home as more than shelter, prioritises culturally responsive and affirming services, and invests in community-based spaces that foster safety, resilience, and self-determination for young Black LGBTQ+ people.

As such, this research makes the following recommendations:

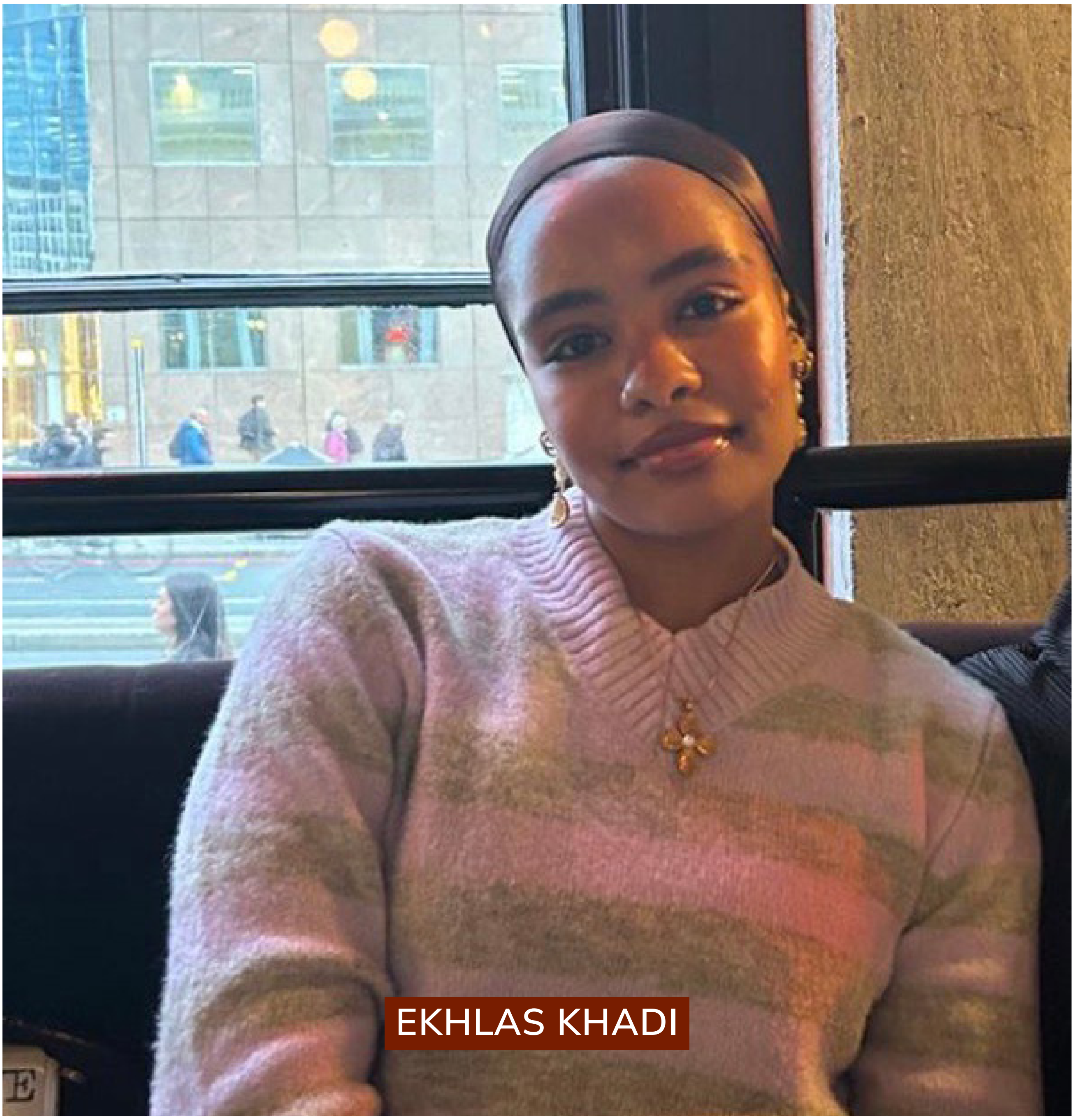
1. **Improve Awareness and Accessibility of Support Services Recommendation:** Create a simple, regularly updated online directory and printed guide listing local housing, mental health, and community services. Distribute these through schools, GP practices, and youth centres.
   Existing NHS and local authority information systems are fragmented and hard to navigate, especially for young people facing housing or mental health challenges. A unified, youth-friendly directory would strengthen the Mental Health Implementation Plan (2019) commitment to early access and clear signposting, ensuring no one is excluded due to lack of information or digital access.

2. **Ensure Consistent Equality, Diversity and Inclusion (EDI) Practice Recommendation**: Deliver annual refresher training on cultural competence and LGBTQ+ inclusion for all frontline staff, including housing officers, NHS administrative teams, and social workers. Co-produce training with community groups to ensure authenticity and accountability.
   While most services have EDI policies, implementation is inconsistent. This builds on the *Public Sector Equality Duty (2010)* by turning policy into practice - embedding reflection, empathy, and sustained inclusion across local authorities and healthcare teams.

3. **Expand Accessible and Culturally Competent Mental Health Support Recommendation:** Pilot free or low-cost counselling drop-ins in community hubs, run by trained counsellors or supervised trainees, with both in-person and online options.
   This complements the NHS Long Term Plan (2019) and Community Mental Health Framework (2021), which aim to bring services closer to communities. It addresses the gap in culturally safe, non-clinical environments where Black and LGBTQ+ youth can seek help without stigma or long waits.

4. **Fund and Empower Community-Led Initiatives Recommendation:** Provide small, flexible grants for grassroots mental health and housing projects. Repurpose underused public spaces, such as libraries and youth centres, into safe, peer-led wellbeing hubs.

Current funding favours large organisations, sidelining smaller community efforts that often reach marginalised youth most effectively. This supports the shift toward locally driven, preventative approaches in national mental health policy, recognising that trust and belonging are best built from within communities.


EKHLAS KHADI

CHAPTER TWO: IN LIMBO: THE EXPERIENCES OF SUDANESE BRITISH WHO ARRIVED IN THE UK AFTER THE WAR

FIDAA MAHMOUD

On 15 April 2023, Sudan descended into one of the worst humanitarian crises of the 21st century. Violent clashes between the Sudanese Armed Forces (SAF) and the Rapid Support Forces (RSF) devastated major cities, displacing more than 12 million people internally and forcing over three million to flee to neighbouring countries such as Chad, Egypt, Ethiopia and South Sudan. Despite this, the Sudan war received limited media and global attention, often overshadowed by simultaneous crises in Ukraine and Gaza.

Between 25 April and 3 May 2023, the UK government organised a restricted evacuation plan that lifted 2,450 people to the UK. Eligibility was limited to British citizens, their Sudanese partners and their children under 18, with a valid permission to enter or stay in the UK. Some other Sudanese family members without permissions were also lifted, and were given 6-month Out of the Rules visa, but no further extensions were offered.

Other Sudanese who hold British citizenship arrived in the UK via often dangerous and expensive routes through third countries. 800 have been compelled to seek support from mainstream services in the UK. On 12 May 2025, the UK Government issued guidance exempting people arriving from Sudan from residency rules in relation to benefits and housing.

This report draws on first-hand testimonies of people and some service providers to understand their immediate experiences of arrival, resettlement, and interaction with statutory systems in the UK. It highlights urgent challenges related to housing insecurity, mental health, discrimination, language barriers, and administrative obstacles linked to immigration and welfare benefits. While the needs of the population are broad and spanning immigration status, family separation, employment, education, and long-term integration, this study focuses primarily on two urgent and deeply interconnected areas: housing and health, particularly mental health.

The findings reveal a pattern of vulnerability and marginalisation, shaped not only by the trauma of war but also by systemic barriers within UK institutions. Importantly, the absence of a Sudan-specific resettlement pathway has left many people arriving from Sudan in a state of limbo—uncertain about their rights, unsupported in their needs, and caught between conflicting systems.

The findings reveal the absence of a Sudan-specific resettlement scheme, inconsistent and unequal application of government guidance, and systemic failures in housing, welfare, and health support. Comparisons with the structured support provided to other groups, such as Ukrainians, highlight inequities in the UK's service provision and humanitarian response. The report concludes with recommendations for a coordinated resettlement pathway, improved language access, and funding for community-led initiatives to ensure safety, dignity, and fairness for the Sudanese arrivals.

1. METHODS

According to the UK Office for National Statistics, in 2020, about 35,000 people of Sudanese origin live in the UK, mainly in Greater London and Brighton. Historically, Sudanese migration to the UK consisted of professionals, businesspeople, and academics until the late 1980s. The 1989 military coup marked a turning point, leading to increased asylum-seeking due to political instability and civil conflict, which reshaped the Sudanese diaspora. Over the past five years, more than 18,000 Sudanese nationals have sought asylum in the UK, reflecting the scale of Sudanese displacement.

This study adopts a qualitative research design, using semi-structured interviews to capture the lived experiences of the participants and those supporting them. Thematic analysis was used to identify patterns across testimonies, providing insights into both individual and systemic issues.

The group comprised 15 participants, who are Sudanese citizens (26.6%), British citizens (73.3%), singles and mixed families. All participants identify as Muslims, Arabic-speaking, originating mainly from riverain central Sudan. The participants' ages range from 18 to 90 years old. 80% were females, and 20% males. English proficiency varied widely, influencing participants' capacity to navigate UK services. The interviews were carried out in Sudanese Arabic, then translated into English. Interviews were conducted in London, Derby, Luton and Wales.

33% of the respondents came to the UK through the evacuation plan, while 67% came through a third country, mainly Saudi, Egypt or the United Arab Emirates. 14 interviews were held face to face, and one interview was conducted by telephone. These interviews were extremely emotional and at some point, challenging.

The interview process was divided into two parts:

1. Participants' past relationship with the UK, including events from 15 April 2023 and their subsequent arrival.
2. Their experiences accessing housing services and the impact on health and wellbeing.

The study benefitted from my experience in housing as well as in community work in the UK, and my engagement with the 15 participants since their arrival in the UK. I also deemed important gaining the perspectives of different stakeholders in designing, interpreting an implementing the Sudan arrivals experiences with services. To this end, a community advisor, an immigration advisor, two housing officers, a health manager and a government official were interviewed.

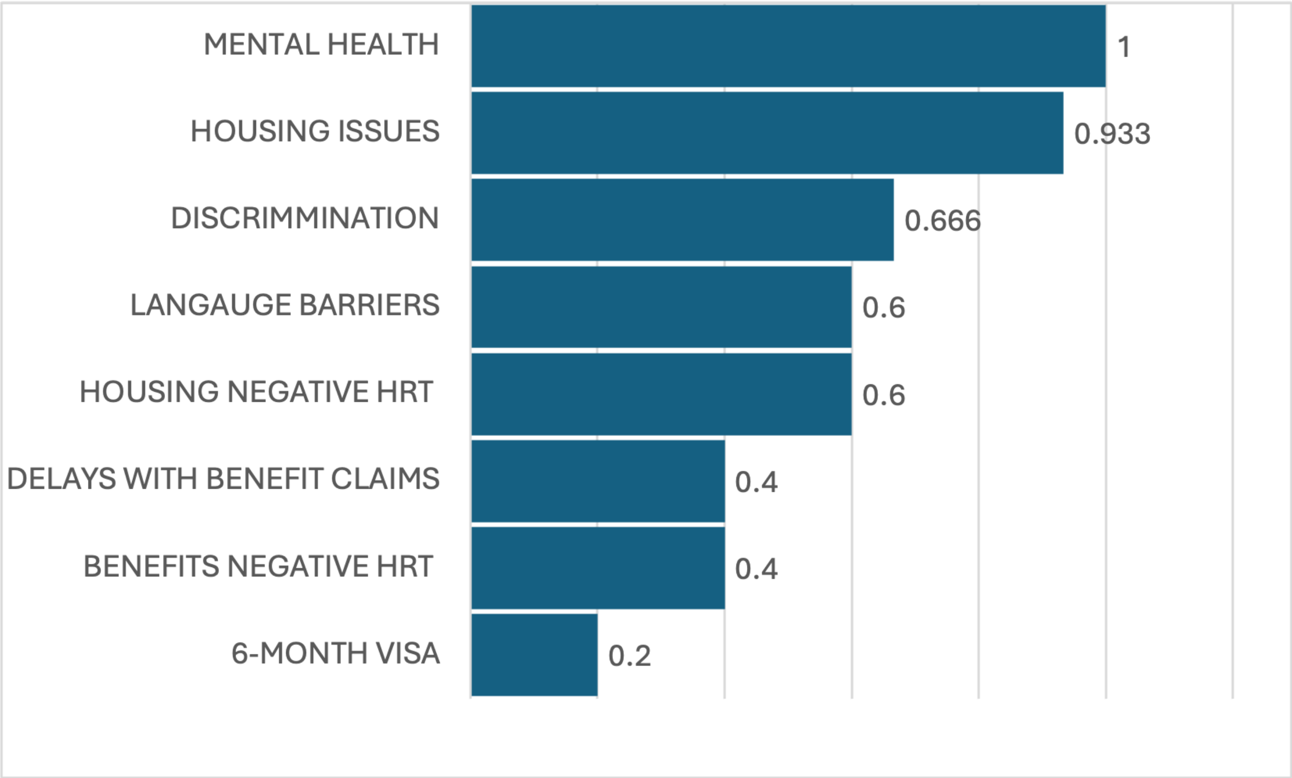
2. RESULTS

Sudanese and British Sudanese arrivals reported a wide range of challenges related to housing, mental health, discrimination, language barriers, and administrative systems. The data also reflects deep emotional trauma associated with war, loss, and prolonged uncertainty.

These experiences reveal a complex interplay of high needs, systemic gaps, and community-based coping strategies. Figures 1–3 provide a structured overview of these experiences, which the qualitative testimonies illuminate in depth.

WHAT ARE THE MAIN CHALLENGES YOU FACED SINCE YOU ARRIVED IN THE UK?

(Figure 1)



The experiences of Sudanese and British Sudanese evacuees reveal a complex interplay of high needs, systemic gaps, and structural inequities (Figure 1).

The experiences of Sudanese and British Sudanese evacuees reveal a complex interplay of high needs, systemic gaps, and structural inequities (Figure 1).

2.1 MENTAL HEALTH

All participants (100%) reported mental health challenges, including depression, anxiety, panic attacks, PTSD symptoms, insomnia, guilt and social isolation as illustrated by the following comments:

"I kissed my mother's hands and hugged my brothers. Leaving felt like tearing my life apart. I left my home, my work, and my identity."

"I am traumatised and until now I get shivers when I hear the noise of a plane."

"My daughter is unable to breast-feed. I think this is the result of the stress she's going through."

"Here, I was truly frightened because I was alone, didn't understand anything, had my little daughter in my arms, and we had nothing but the clothes we left home in."

Ongoing distress was compounded by inadequate support: few Arabic-speaking counsellors were available, and mental health provision relied heavily on medication rather than culturally sensitive therapy. Separation from family, loss of lively-hood and homes also intensified psychological strain:

"My GP diagnosed me with depression and prescribed Sertraline. He referred me to mental health support, but it was so difficult to get counselling in Arabic".

"I have suffered mental ill-health for a very long time, so, for a year after our arrival, I avoided going to the Council, I hated that time! I refused to deal with anything to do with it."

"I lost everything in Sudan, my house, family members, memories, the whole country. Since the war started, I lost two brothers and several cousins. It's heart-breaking It's very sad. The news kept coming about family members got killed, moved to other areas, the struggle to survive in war zones. Every day, I follow the news and feel so sorry for the devastation and misery our country is facing. For what reason? It is depressing and I often feel empty, though I am surrounded by my daughters in UK."

2.2 HOUSING INSECURITY

Housing insecurity affected 93% of participants, who were placed in temporary accommodation was often unsafe, overcrowded, tucked away from support networks and poorly maintained. Hotels often housed individuals with substance misuse issues, exposing evacuees to violence and further stress. Administrative failures—delays in bookings, inconsistent communication, and lack of interpreters—exacerbated vulnerability:

"The mould and damp became so bad, so I sent pictures to the housing. A woman came to visit and was shocked about the state of the property. I started to have severe headaches and insomnia."

"The hotel was for homeless people like us, but many had drug and alcohol related issues. There was so much violence too. It was very difficult to live there and be with people with such severe social issues. We felt that as British coming from war, we should be treated with respect."

"We stayed in a B&B for 6 months. It was far and the place was served by public transport every hour. I needed to travel to sort out our problems, so this was a big issue."

"The thing I find really distressing is that housing services book hotels for a certain number of days and would only renew it if needed on the same day. So, sometimes, the hotels kick people out of the hotel on the last day if the bookings do not get renewed in time. There is no consideration of disabilities or age or anything. I understand that there's a housing crisis but a bit more coordination and consideration is necessary."

"I feel that wasn't only discrimination. The system is broken, rotten! If we do things as we are being told, nothing will happen. If it wasn't for that security man, we wouldn't have been able to speak to the Housing."

2.3 DISCRIMINATION AND UNEQUAL TREATMENT

Two-thirds of participants experienced discrimination based on nationality, race, or language proficiency. Despite legal entitlements, some were treated as if their rights were irrelevant:

"We all feel trapped here, we are unable to bring our families here, we can't work in our field where we have experience, study what we want to study, this is hell. What's the point of being British if we can't have our private life respected and celebrated?"

"We had so many issues too, for example the bank refused to open a bank account for us without an address. We asked the council to issue a letter stating that they housed us in temporary housing, but they refused."

Stakeholders confirmed that policies were inconsistently applied, reflecting systemic inequities: *"Sudanese evacuees received nothing close to what Ukrainians received. The system simply wasn't designed with them in mind."*

A Housing Officer reflected: *"This dehumanisation doesn't differentiate between Black and Brown people either. Society doesn't care that the Sudanese approaching are British citizens. In this circumstance, their citizenship doesn't help them and you question what is even the point of having it? They can't claim asylum and receive the benefits (and I use the term benefits entirely loosely here) but they are also unable to reap the benefits that their citizenship entitles them to. Despite being British, they are pushed to the wayside and forced to fend for themselves."*

2.4 LANGUAGE BARRIERS

Language limitations affected 60% of participants, impeding access to housing, benefits, healthcare, and legal support. Children often acted as interpreters, raising ethical concerns:

"My son had to interpret for me when I spoke to social services. It was humiliating and confusing."

"A Sudanese advocate tried to help us and went to the Council with us, because we couldn't understand why they were refusing us but they told us that we were irresponsible people and that the children would be taken away from us."

"I realised that language is a big issue in trauma treatment, because a 3-way conversation is awkward, when people disclose their private life. I chose counselling because mental health is a taboo. I tried to find an Arabic-speaking counsellor but it's difficult."

2.5 ADMINISTRATIVE AND LEGAL CHALLENGES

Despite exemptions from the Habitual Residence Test (HRT) - which is the UK residency rule for benefits and housing support - 60% of participants faced negative homeless decisions compared to 40% who received negative decisions on for their applications for benefits. People arriving from Sudan continue to receive negative decisions on grounds of HRT, the last one known to the researcher was in August 2025. Delays with processing benefits claims and short-term visas and unclear guidance compounded stress and confusion by service providers; the following comments illustrate these issues:

"Two men interviewed me first; my son was interpreting for me. They then transferred the case to another team who called and asked me why we came from Sudan. It was so offensive. I thought that the government brought us to UK and now they want to make us homeless, it would have been more dignified to remain in Sudan with dignity in Sudan. You just want to humiliate us."

"Some individuals appeared unwilling to understand the problem in the first instance, this is why they could not sort it out. Some of them just wanted to do their 9 to 5 jobs and get their salary at the end of the month. They didn't react till they received a letter from the MP. The system has serious gaps. It seems to me that people are not happy with their jobs because anybody who likes what they do will do it well."

"I am not permitted to work to cover our rent and have money for food and bills, so we are at risk of becoming destitute and homeless."

"We were told to make a call to the Housing, but nobody answered the phone. There was a security man, I think he was Asian, he was the only one who helped us. He kept going inside to ask. We waited till 5pm, then finally they offered us a one room in a B&B."

"The thing I find really distressing is that housing services book hotels for a certain number of days and would only renew it if needed on the same day. So, sometimes, the hotels kick people out of the hotel on the last day if the bookings do not get renewed in time. There is no consideration of disabilities or age or anything. I understand that there's a housing crisis but a bit more coordination and consideration is necessary."

"They issued me with a negative decision for my Universal Credit because we did not live in the UK for 3 months. The funny thing is that my adult daughter who lives with me too, applied at the same time to Universal Credit but her claim got accepted. So, my housing benefit got cancelled."

"One of the constant issues was that the housing would not respond to my emails and they won't phone me. I didn't have knowledge of the system. The information they gave was often confusing and they contradicted each other."

"I kept calling the Pension Credit line for an update for over 3 months. Each time, I was told that the claim was still being processed."

A Sudanese advocate commented:
"I have been saying this since day one: having a scheme like the Ukrainian or Afghan scheme would have prevented a whole lot of issue, it would create a better understanding for everyone and made easier. Even talking about those schemes brings to mind the difference in treating refugees and Ukrainian was questionable as they've never recognised as refugees. Which caused lots of issues. So a uniform scheme for emergencies would make it easier to the rest of services."

Reflecting on the Sudan evacuation response, one government official stated: "It was not thought through."

WHO MOSTLY SUPPORTED YOU SINCE YOU ARRIVED TO THE UK?

(Figure 2)

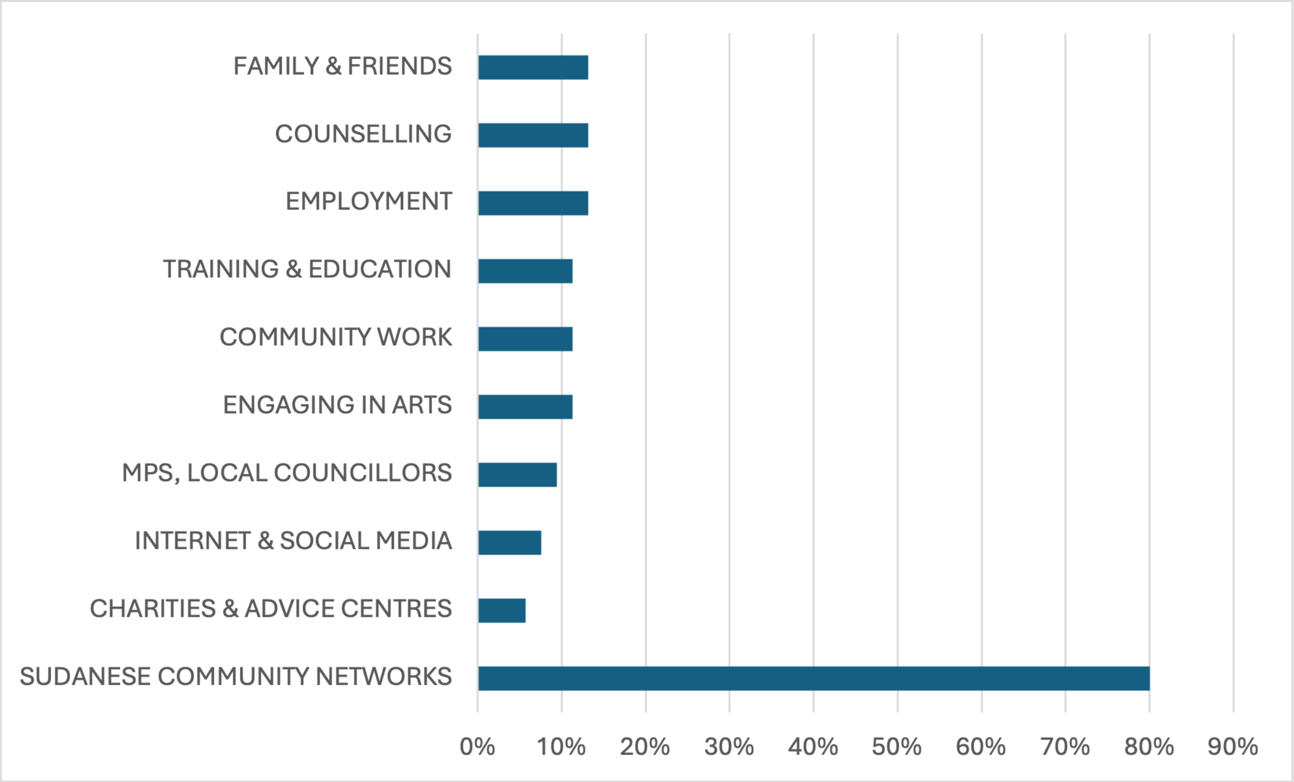


Figure 2 demonstrates that evacuees relied predominantly on informal networks, particularly community volunteers and Sudanese diaspora groups. These networks provided translation, navigation of services, emotional support, and sometimes emergency accommodation.

80% of participants reported that Sudanese networks, friends, relatives, and charities, served as secondary safety nets, offering both practical and emotional assistance. By contrast, support from councils and the NHS was limited, inconsistent, and often contingent on participants' persistence or advocacy, reflecting a gap between policy intentions and operational reality:

"The Red Cross staff who met us at the UK airport were very nice... but they also treated us as if we knew the system in the UK. I didn't even have a National Insurance Number or spoke English well enough to understand people."

Community groups and social media groups provided significant support:

"A Sudanese community WhatsApp group helped me write a letter to appeal the benefits decision and told them that I was exempt from residency rules. They finally agreed and backdated my claim when I applied 4 months ago. This was a stressful experience as the system is so complex, but I was lucky I found the right support."

"It was a difficult time, but music helped me to integrate quickly, and I featured in one of the city's posters. People from the church used to come to talk to us, and health workers were good with us, and I thank them for that."

"Helping other Sudanese who came helped me to regain confidence… this hotel manager used to harass this poor Sudanese family in front of their children. It was disgusting."

WHAT DO YOU THINK SHOULD HAPPEN TO MAKE SUPPORT PEOPLE ARRIVING FROM SUDAN?
(Figure 3)

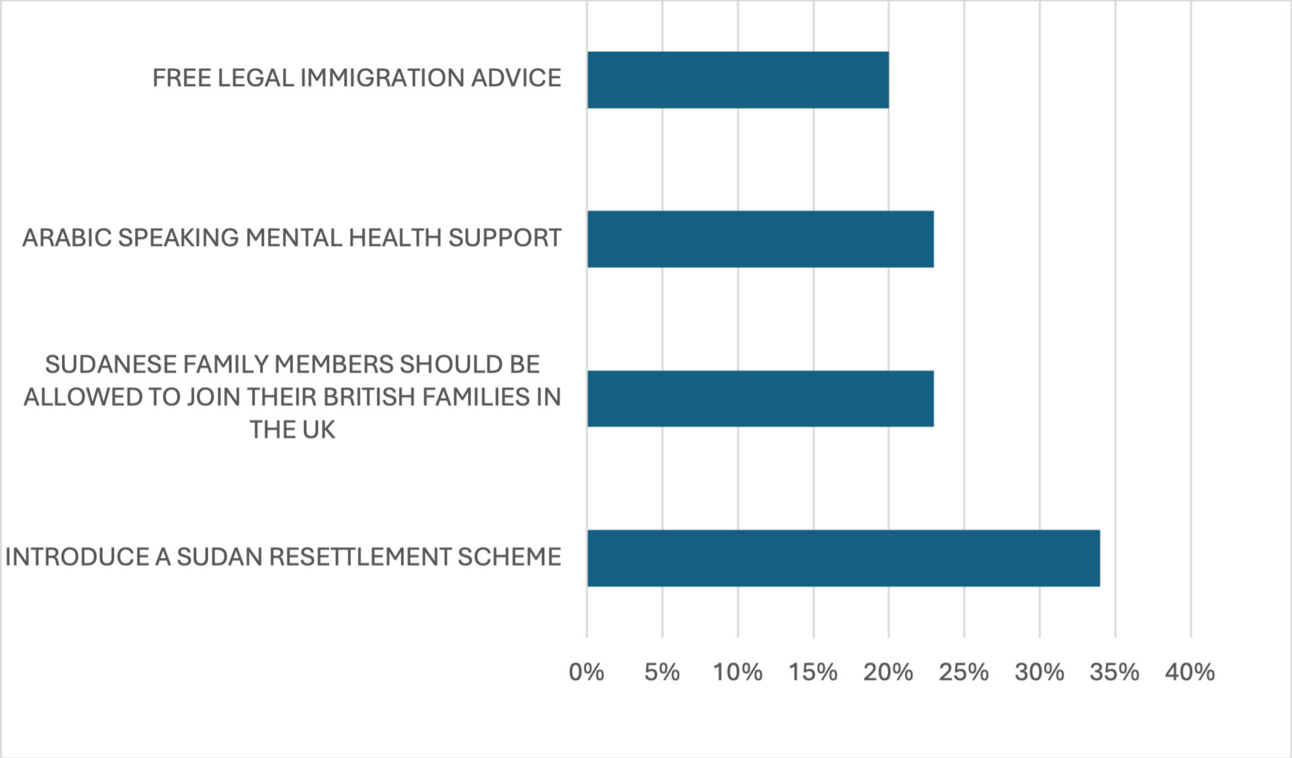


Figure 3 captures participants' proposed solutions, which largely reflect the barriers identified in Figures 1 and 2. Central among these is the call for a Sudan-specific resettlement scheme, ensuring that people arriving from Sudan receive coordinated housing, welfare, legal, and mental health support. Participants also emphasized:

- Faster access to safe, stable housing, and welfare benefits
- Arabic-speaking mental health services
- Trauma-informed and culturally sensitive practice by frontline staff
- Consistent application of HRT and benefits rules
- Access to legal assistance for immigration issues

As one participant put it:
"I don't understand why nothing was put in place to ensure that we get support with our immigration situation… After our horrific ordeal during the war in Sudan, we finally managed to get some stability in the UK."

These recommendations are not requests for exceptional treatment, but for clarity, consistency, and equity comparable to that provided to other groups such as Ukrainians or Afghans.

3. INTEGRATED INTERPRETATION ACROSS FIGURES

When considered together, the figures highlight several key patterns:

1. High need, low structured support: Sudanese arrivals experienced severe trauma, displacement, and housing insecurity, but support systems were inconsistent and largely reactive.

2. Fragmented system response: Participants frequently encountered contradictory guidance from the Home Office, local councils, DWP, and NHS. One policy officer acknowledged: *"There was no guidance, it was down to the individual officer's interpretation... not everything is black and white."*

3. Community resilience: In the absence of systematic support, evacuees relied on diaspora networks, volunteers, and faith institutions, highlighting the critical role of community-led organisations.

4. Inequity of humanitarian response: While the UK government has demonstrated its capacity to provide structured support for other groups (e.g., Ukrainians), Sudanese arrivals were left navigating complex systems with minimal guidance, exposing a hierarchy of humanitarian concern.

5. Compounded trauma: The stressors of inadequate housing, administrative delays, family separation, and language barriers intensified mental health challenges, sometimes producing crises.

4. STRUCTURAL INEQUITY AND SYSTEMIC BARRIERS

The experiences of the Sudanese arrivals reveal multiple, intersecting structural inequities:

- Humanitarian inequity: Unlike groups with dedicated visa schemes and support hubs, Sudanese arrivals received no comparable coordinated response.
- System fragmentation: Limited communication and coordination among government departments left evacuees exposed to contradictory decisions and repeated barriers.
- Cultural and linguistic exclusion: The scarcity of Arabic-speaking staff in housing, benefits, and health services reinforced feelings of invisibility and isolation.
- Resilience under pressure: Despite these challenges, evacuees demonstrated remarkable agency, leveraging informal networks to meet essential needs and advocate for themselves.

In sum, while the UK government has the capacity to respond effectively to humanitarian crises, in this instance the implementation gaps and absence of a Sudan-specific scheme created avoidable hardship, leaving evacuees dependent on community support and their own resourcefulness. Multiple examples illustrate the inefficiency within benefits and housing departments that largely contributed to mental ill-health.

5. RECOMMENDATIONS

1. Create a Sudan Resettlement Scheme providing structured support.

2. Exempt all immediate family members of British citizens from restrictive visa rules during humanitarian crises.

3. Issue and clear, standardised guidance to councils and the DWP on benefits exemptions.

4. Establish rapid-response housing teams for crisis arrivals and offer safe, stable temporary accommodation with appropriate facilities.

5. Ensure that accommodation placements consider disability, mental health needs, and proximity to community networks.

6. Ensure interpreters are available at all key service points and provide culturally sensitive mental health services.

7. Train frontline staff in trauma awareness and cultural sensitivity.

8. Fund community-based Sudanese-led community organisations.

9. Support peer mentoring and advocacy projects.

10. Promote anti-discrimination and awareness training for council staff.

6. CONCLUSION AND CALL TO ACTION

Sudanese and British/Sudanese arrivals in the UK have experienced a sense of being forgotten—“in limbo”—without a clear pathway to safety or stability. Yet, their resilience is evident. Community networks, volunteers, and diaspora organisations have played vital roles in filling systemic gaps. These strengths demonstrate that with the right investment, culturally rooted and community-led solutions can provide significant support.

The war in Sudan is still raging, and more people are expected to seek refuge in the UK. However, without urgent reform, British Sudanese arriving from Sudan risk prolonged hardship, deteriorating mental health, and long-term social exclusion. The UK must implement a coordinated, compassionate, and equitable resettlement approach—one that recognises the dignity and rights of Sudanese arrivals and ensures they are no longer forced to navigate crises alone.

FIDAA MAHMOUD

CHAPTER THREE: SURVIVING, NOT LIVING: THE SILENT STRUGGLES OF ASYLUM SEEKERS IN 'CONTINGENCY ACCOMMODATION'

HANNAH CHAABAN

This research aims to amplify the silenced voices of asylum seekers and refugees, shedding a much-needed light on the lived experiences of those housed in 'contingency accommodation'. My goal has been to create a safe, welcoming environment where people can share their stories and reflect on how their living conditions affected them. Volunteering at a local church hosting weekly community cafes for asylum seekers and refugees, I have become embedded within a beautiful, supportive community. Here we nurture a judgment-free zone where people, whose paths may not otherwise cross, come together to simply talk, eat, laugh, and enjoy their time together. This space facilitates conversation and care between local residents, carving out a space that seeks to bridge the seemingly growing divide between asylum seekers/refugees and British citizens. Through this, I have gained an extensive network within the community.

Drawing on my academic background as a master's student in Race, Ethnicity, and Postcolonial Studies, I employ a sociological and political lens to critically analyse the findings. Furthermore, being half Venezuelan and half Lebanese and having family, my own parents included, who are or have at some point in their lives been asylum seekers, I bring a personal awareness into the study. This combination of academic and lived experience drives my commitment to raising awareness and advocating for positive change in an increasingly hostile socio-political climate.

The findings reveal a significant lack of care on an institutional level towards asylum seekers, uncovering serious issues in 'contingency accommodation', particularly surrounding the food and building maintenance. Compounding this, it exposes abuses of power, systematic dehumanisation of asylum seekers, and the inextricable link between housing and both mental and physical health. All participants reported mental health struggles whilst living in hotels and half cited deteriorating physical health. The study also highlights inconsistency across hotels; while some offered useful resources such as information on local charities or English classes, others lacked this support. Its findings call for stronger institutional care, improved living standards, better staff training, proactive attention to health and safety, and greater access to community resources. Ultimately, this research offers actionable insights for policymakers and serves as a reminder that asylum seekers are people like anyone else—they laugh, cry, hope, dream, and aspire to build better lives.

TW: This chapter includes mentions of suicide and suicide attempts

1. BACKGROUND

There is a well-established link between housing and health, as the Marmot Review rightfully pointed out, housing is a 'social detriment of health.' Exploring this link with respect to asylum seekers housed in Home Office accommodation is crucial, especially given the fact that they are significantly more vulnerable to developing mental health issues. Compounding this with changing trends in asylum seeker housing in the UK underscores the importance of this research. Since 2020, there has been increased reliance on 'contingency accommodation.' This primarily refers to privately contracted hotels but also includes reception centres and ex-military facilities, like barges, where asylum seekers were housed up until January 2025. Compared with the rest of Europe, the UK is one of the countries that relies most heavily on hotels to house asylum seekers, and while hotel use has been on a downward trend nationally since 2023, London serves as an outlier. Accelerating this dependency is the backlog of asylum claims and the housing crisis, which is particularly acute in the capital.

As implied by the term 'contingency', such accommodation is supposed to be a temporary measure. However, this type of housing has become normalised, and people can end up living here for years. Consequently, despite terminology suggesting otherwise, the issues surrounding living conditions in hotels must be understood as long-term and having an enduring impact. This is exacerbated by the Home Office's prolonged and uncertain timeframe to process asylum claims. Work by independent non-profit organisations and charities illustrates that living conditions within hotels are largely inadequate. For instance, Women for Refugee Women published a report in 2024 uncovering that many women are subjected to coercion and control in hotel asylum accommodation. Other reports have focused on the negative impact hotels have on asylum seekers' mental health and the systematic dehumanisation they experience in hotels. Contributing to this growing area of research, this report helps shift the focus towards the community's perspective. It addresses the need for more qualitative studies that can accompany official statistics, which call for an end to the reliance on hotels for primarily monetary reasons. This is especially crucial given the current socio-political climate in which political parties across the spectrum harbour anti-migrant sentiment, working to demonise asylum seekers and inform policy-making. The far-right demonstrations held outside hotels are indicative of the need for more research spotlighting asylum seekers' perspectives. In recent months, the narrative has been dominated by the actions of those on the right and government officials, with minimal attention paid to asylum seekers themselves, making this research evermore critical.

2. METHODS

To enable participants to talk about their experience in their own words and lead this research, I draw upon the data gathered from 6 semi-structured interviews. The interviews were conducted on a one-to-one basis with individuals who currently live or have lived in an asylum hotel in the past 3 years. To protect participants' anonymity whilst ensuring they're given a voice, I have used randomly generated pseudonyms. This enables their stories to be conveyed cohesively and humanises them. All participants lived in West London, with some also having been housed in other areas of London and some outside of the capital, reflecting the policies of relocation which characterise the asylum-seeking process in the UK.

This qualitative approach involved me asking open-ended questions surrounding their lived experience within 'contingency accommodation' throughout the interview. These questions acted as a controlled variable, but outside this, I allowed the participant to lead the conversation and asked probing questions in response to their answers they provided. I found this form of interview created the most comfortable environment. It allowed for open and honest conversations, which centred on participants' experiences, yet also teased out key themes which enable a cohesive cross-interview analysis of their lived experience. Except for one interview, which took place over a phone call and a series of WhatsApp messages due to the participant's physical disability at the time, all interviews were conducted face-to-face. This proved to be the most effective in terms of building a rapport with participants and garnering personal insights into their experiences.

3. RESULTS

Employing a thematic approach, I divide my findings into four broad themes: food, mental health, treatment by staff, and building maintenance. Upon coding the interview data, I selected the four tags with the highest counts, meaning they were the themes that were mentioned the most by participants. Holistic analysis of all four themes exposes an inconsistency of living conditions across hotels, a significant lack of care shown towards asylum seekers, and it reinforces the relationship between housing and health - the key focus of this wider research paper.

3.1 FOOD AND PHYSICAL HEALTH

Food was the main issue brought up by all participants and proved to be a major site of recommended improvement. Participants expressed varying concerns regarding taste and variety, but also more serious issues surrounding the preservation of food, lack of attention to allergies and dietary requirements, and the long-term health impacts of eating such food. All participants, at one point or another, lived in a catered hotel, meaning all meals were provided, and they didn't have access to a kitchen. Unable to cook for themselves and unable to afford to eat out, given the *"very limited budget"* the government provides (around £8 per week), people in these hotels are entirely reliant on this food. As Amina stated, *"we have no choice."*

"Prison-like conditions" —Omar

Omar explained how the food provided and the inability to cook made him feel as if he were in prison. This was compounded by other factors, like the monitoring of movement (as people have to provide their full name to security whenever they leave the hotel) and the fact that you could only see visitors in the communal lobby. The food was described as *"awful, especially in the long term"*, lacking nutritional value and being of poor quality. Leyla experienced low energy levels and explained that *"people would often get sick"* from the food. Frida developed a stomach ulcer and chronic health issues while living at the hotel, including gastroesophageal reflux disease (GERD). She had to undergo two endoscopies, and as a result of her GERD, she now has to stick to a strict diet and eat more organic food, which is very costly.

"Meals nobody could eat" —Adam

Adam shared that they were regularly given expired food, as once delivered, meals would not be refrigerated; rather, they were just left outside. He described the meals as "smelly", and when he asked staff to eat it, staff refused. The refusal of staff to even try the food was also brought up by Leyla, pointing to the sense of dehumanisation experienced by asylum seekers. Adam questioned why they were being forced to eat such awful food when the staff wouldn't even take a bite. He shared that his son had horrible reactions to the food, so bad that it got to the point that his son was constantly vomiting, unable to eat, and developed skin rashes all over his body. *"He wouldn't eat for days, we would have to force feed him",* his father painfully recounted. During their time at the hotel, Adam's son developed celiac disease, requiring him to eat a gluten-free diet. This was not consistently catered for, and thus, his father had to repeatedly raise these issues with the management, alongside the fact that the kids' meals that were supposed to be provided were suddenly no longer served.

3.2 MENTAL HEALTH

Asylum seekers are highly vulnerable to mental health issues, a reality reflected in this research as every participant mentioned struggling with their mental health whilst living in 'contingency accommodation.' Leyla and Frida both entered the UK with pre-existing mental health issues, which significantly worsened in hotel settings. Leyla recalled having daily panic attacks, which impacted her day-to-day life, particularly at college, as she was unable to concentrate: *"I saw that I had lost myself"*. Frida became severely depressed and suicidal, self-harming and attempting to take her own life. Adam also shared that whilst he was living in a hotel, he saw a woman attempting suicide, stating there were several such instances of suicide in that particular hotel.

"Everything I had was gone in a moment. I found myself crying and crying every day" — Amina

Amina and Sarah said they cried daily. Sarah shared she was battling depression, explaining how difficult it has been to leave her family and friends behind: *"I was lonely, deeply lonely"*. Leyla also spoke of isolation, often confined to her room due to lack of money. This sentiment was shared by all participants. Compounding this, rooms were described as *"very small"*, with no space to walk around, and some are forced to share with a stranger. The difficulty of shared rooms was repeatedly brought up; roommates would often argue, and there was a severe lack of privacy, worsening their quality of life. Hotel life is very stressful, Leyla described it as a 'comparative situation' where everyone compares themselves to one another. This is intensified by the uncertainty and limited institutional support, as everyone is confused and scared.

"Every time they move you, you have to start all over again" —Adam

Adam discussed the impact of relocation on his family, sharing that the 'instability' is hard for his kids as they have to change schools and make new friends everywhere they go. His children had to repeatedly change schools; one started lashing out, drawing police intervention. Adam shared that this was a *"really devastating time for the whole family".*

3.3 TREATMENT FROM HOTEL STAFF

The research exposed inconsistent staff treatment towards asylum seekers in hotels. While some were described as caring and understanding, others were said to have preferential treatment and exacerbated feelings of confusion, fear and isolation. Amina recalled when, during winter, her room was very cold and she needed to buy a heater. As an older woman, she struggled to use technology to purchase one, but a member of staff offered to order one online, and Amina would pay them cash. Another member of staff intervened to stop this, asking Amina what she was doing. This incident reflects not only the varying attitudes of staff but also the lack of humanity some hold towards asylum seekers. Additionally, it points to the ways asylum seekers are policed by staff in hotels.

Emphasising this, Sarah described the hotel managers as 'busybodies', a sentiment shared by other participants. Staff would ask invasive questions and intrude into private matters. For instance, one hotel manager often asks Sarah if her parents are in, where they are, and what they are doing - all matters that do not concern the manager, as they have designated security staff. Sarah also mentioned that staff sometimes enter her room without permission, and she returns to find her clothes messed up in a manner she did not leave them. Similarly, Adam brought this up during his interview, stating his hotel manager was accused of repeatedly entering women's rooms when they were in the shower. This abuse of power points to the severe lack of privacy and safeguarding afforded to asylum seekers in hotels.

Leyla spoke about how some staff had 'bad behaviour', particularly towards people who don't speak English. This was echoed by Omar, Frida, and Adam, who described some staff as holding 'racist' views. In fact, Leyla raised this concern to hotel staff, but it was brushed off and told that the staff's moods change depending on the day. Leyla was understanding of natural mood changes, yet rightfully stood firm for the need for staff who are 'patient.' Adam reported his concerns regarding the treatment of himself and his family by the hotel manager. An internal investigation was launched; however, the outcome found no wrongdoing, leaving Adam feeling helpless and a burning sense of injustice. *"I was so frustrated... It's about the survival of my family".*

"They labelled me with a number" —Omar

Omar recalled how staff would refer to him by his room number, making him feel no different to a prisoner being called by their cell number. This reinforces the sheer lack of care and respect shown to asylum seekers by some hotel staff. Taking this in conjunction with the policing of movement, the cramped rooms, the food and lack of access to a kitchen, as well as the sub-standard living conditions, exposes the systematic dehumanisation of asylum seekers within hotels. This finding builds on the report by Migrant Voice (2023), which discusses how hotels form part of an institutional system that dehumanises asylum seekers, denying them agency, privacy and independence.

3.4 BUILDING MAINTENANCE

Discussions across the interviews highlight serious health and safety issues associated with building maintenance. Hotels were described as outdated and in states of disrepair. Amina mentioned that the building had plumbing and drainage issues, causing frequent blockages in the bathroom sinks, toilets and showers. She also recalled the heating being broken and staff not taking her complaint seriously, leaving an elderly lady to suffer in a cold room: *"When I informed them that the heating was not working and that I needed a heater due to the severe cold, there was no quick response"*. Amina resorted to purchasing a portable heater, with which she faced obstacles discussed in the section above. However, she should never have had to resort to this, and this highlights the immense lack of care shown towards asylum seekers, some of the most vulnerable people in our society.

Adam informed me of the *"really dangerous"* living conditions of his hotel. The building was very old, and he told me that the insulation within the walls contained asbestos. *"If you touch it, your hand will be full of fibres like thorns",* he described. These fibres could also be found on the floor and were visible to everyone, including staff. Having a background in facility management, Adam was able to identify the asbestos and was aware of the serious health issues it causes, including asbestosis and lung cancer. He photographed this, reporting it to the staff, but nothing was actioned. 'They can see [the issues] but don't want to do anything about it', he frustratingly shared. Adam also mentioned that the panel on the lift button was broken, leaving the wires exposed, and this was not fixed. This is a hazardous health and safety risk, making those living in the hotel vulnerable to electric shocks and fires. In a building housing many people, including families with young children, this should have been addressed immediately.

This is a notable pattern, with reports exposing the Home Office 'cut corners' and house asylum seekers in 'high risk' buildings. The Northeye accommodation centre was found to be contaminated with asbestos and the migrants had to be moved off the Bibby Stockholm barge when it was discovered that its water systems contained Legionella bacteria. This reflects the institutional lack of care towards asylum seekers.

4. CONCLUSION AND RECOMMENDATIONS

This research reveals the lack of care and compassion afforded to those seeking asylum in the UK on a governmental level. Building on previous reports, it underlines the need for improved building maintenance, facilities, staff training, and overall, systematic change which humanises migrants rather than stripping them of their agency. Given that asylum seekers have fled life-threatening situations, with some forced to take long, dangerous journeys to the UK, care and patience need to be prioritised by hotel staff. Rather than this being a roulette, it must be standardised across hotels and incorporated into staff training.

Moreover, the fact that none of the health and safety violations brought up by participants were treated with any sense of urgency, and were often ignored by staff, underscores the systematic dehumanising and lack of care asylum seekers experience. Moreover, inadequate building maintenance and disregard of complaints concerning health and safety exemplifies their neglection on an institutional level. Being completely reliant on the Home Office to provide safe accommodation, people living in 'contingency accommodation' are at the mercy of the government. Additionally, participants emphasised the need for accessible resources to those in hotels on the asylum process; to help with learning English; and to direct them towards local organisations or charities.

As well as this, the research reiterates the fact that asylum seekers are just normal people. They have hobbies and want to help others. For example, Omar loves reading and spends his time exploring London's parks and volunteering at Oxfam. Leyla and Frida are aspiring to be lawyers in order to help people in their situations and while living in the hotel, Leyla would often write emails for others. Sarah is studying to improve her English at the local college. Amina values community and organised coffee meetings in the lobby, encouraging roommates to socialise. Adam works hard to be there for his family, constantly fighting for them to have a better life and standing up in the face of the asylum system even when the odds are stacked against him. Despite their immense struggles, all participants expressed gratitude and a sense of 'luck.' 'I'm not only the one suffering, everyone is, and some people [have it] even worse.' When asked about their future, participants remained hopeful and positive, a quality I found incredibly remarkable and inspiring.

CHAPTER FOUR: PATTERNS OF OPPRESSION: HOUSING INSECURITY AND ITS IMPACT ON THE HEALTH AND WELL-BEING OF COMMUNITIES LIVING UNDER NRPF

YASNA S. KHAN

The No Recourse to Public Funds (NRPF) policy prevents many migrants from accessing mainstream welfare support. Initially applied to non-European migrants, it now also affects some post-Brexit EU nationals with pre-settled status, leaving a growing number of households excluded from the public safety net. Migrants living under NRPF work, pay taxes, and raise children, many of whom are British, yet remain denied access to the very systems their contributions help sustain.

This exclusion produces sustained housing precarity, characterised by overcrowded, unsuitable, and unstable living conditions that undermine physical health, mental wellbeing, and family stability. NRPF operates within and reinforces a wider hostile environment, where attempts at integration become oppressive experiences, restricting the ability of migrant communities to build stability and flourish on equal terms.

This research centres the lived experience of families navigating life under NRPF, examining how housing insecurity, embedded with the policy's everyday operation impacts their health and wellbeing.

This research centres the lived experiences of families navigating life under NRPF to examine how housing insecurity, embedded within the policy's everyday operation, impacts their health and wellbeing. It reveals housing instability not as an unintended consequence, but as a predictable outcome of policy design and administrative practice. In doing so, the report points towards the broader policy transformation required to recognise housing not as a conditional privilege tied to immigration status, but as a foundational requirement for health, dignity, and justice.

As a community researcher and organiser, my work is shaped by years of shared learning with communities affected by NRPF, alongside my own experiences of navigating these systems. These encounters inform my understanding of the structural stakes involved. However, the political grounding of this research is rooted in its relationship with Together in Unity, a grassroots initiative led by and for people living under NRPF.

The leadership of Together in Unity has grounded the project from the outset, ensuring it remains accountable to lived realities and aligned with community-defined priorities rather than institutional agendas. People with lived experience form the analytical and ethical foundation of this report. Their insights shape both the direction of the research and the recommendations it advances into policy debate, where migrant families' experiences are too often marginalised or actively excluded.

1. BACKGROUND

No Recourse to Public Funds (NRPF) is a UK immigration policy that bars migrants with certain visa statuses from accessing most forms of welfare, housing assistance, and social support. Introduced under the Immigration and Asylum Act 1999, the policy has evolved into a structural mechanism of exclusion, disproportionately affecting racialised and migrant communities. Far from achieving its stated aim of reducing public expenditure, NRPF functions as a state apparatus of enforced precarity, determining who is permitted stability, security, and care.

Research from the University of Oxford's Migration Observatory and COMPAS demonstrates that NRPF produces widespread material deprivation, forcing individuals and families into insecure and unsafe living arrangements that undermine physical and mental health (COMPAS, 2023; Migration Observatory, 2022).

A qualitative evidence synthesis by A. Jolly (2022) drawing on multiple earlier studies, links the NRPF condition to increased psychological distress, chronic stress, and social isolation. During the COVID-19 pandemic, evidence from the Public Interest Law Centre (2021) revealed that local authorities frequently failed to meet even the most basic housing and welfare needs of people subject to NRPF, despite clear public-health risks.

The Unity Project's report Access Denied (2019) provides crucial insight into the policy's intersectional harms, showing that racialised women, particularly migrant mothers are disproportionately affected. Restricted from accessing benefits or safe housing, many are forced into exploitative labour, overcrowded accommodation, or remain in abusive relationships to avoid destitution. The report also documents the secondary impact on British-born children racialised through their parents' immigration status, who experience poverty, instability, and stigma despite holding citizenship rights. These findings expose NRPF as a policy that reproduces racialised and gendered inequalities, embedding intergenerational disadvantage and eroding the social foundations of well-being.

Economic analyses challenge the fiscal case for maintaining NRPF, with LSE (2022) demonstrating net economic gains from lifting the condition and WPI Economics (2023) showing that the current policy shifts substantial costs onto local authorities. Reports by the Joseph Rowntree Foundation (2024) and Trust for London (2023) similarly reveal that families affected by NRPF experience higher rates of food insecurity, rent arrears, and destitution, underscoring that the policy entrenches poverty rather than reducing costs.

Judicial findings have echoed these critiques. In R (W) v Secretary of State for the Home Department (2020), the High Court held that the Home office's policy of requiring individuals to fall into severe destitution before the NRPF condition could be lifted was unlawful, as it exposed people to inhuman or degrading treatment in breach of Article 3 of the European Convention hon Human Rights. In R (ST) v SSHD (2021) and R (AB & Ors) v SSHD (2022), the High Court held that the NRPF policy failed to comply with the statutory duty to safeguard and promote children's welfare, rendering the policy unlawful.

Collectively, this growing body of evidence shows that NRPF is not simply an administrative condition but a systemic driver of inequality and ill-health. By engineering housing insecurity, poverty, and psychological distress, particularly among racialised migrant women and their children, the policy reinforces the very patterns of structural discrimination and economic oppression that this research seeks to interrogate through a focus on housing, health, and human well-being.

2. RESULTS

2.1 NRPF AND THE INSTITUTIONAL PRODUCTION OF HOUSING INSECURITY

Across interviews, housing insecurity under NRPF emerged not as a series of isolated hardships, but as a structurally produced outcome of immigration policy that embeds instability into everyday life. Participants described consistent patterns through which immigration status shaped access to housing, welfare, and statutory support, narrowing options and funnelling families into overcrowded, unsafe, and exploitative environments. Denied access to public funds, families were pushed into temporary rooms, informal lets, and unsuitable shared accommodation, arrangements never intended to support family life.

A participant shared:
"Because I don't have space with him to play at home, I go with him to the park. But when you change places a lot, you don't know the area. I try to find a nursery for him, but when I do, we move again. Now I've found a place for him, but I already know we will move again."

Within this context, NRPF operates as more than a welfare restriction. It functions as an administrative filter that obstructs access to Section 17 support, even for British children legally entitled to it. Safeguards designed to protect children were repeatedly experienced as exclusionary mechanisms, where immigration control overshadowed statutory duties and recast families as undeserving of assistance.

As one participant explained:
"Even when you have children... you can't have access... your status depends on your immigration."

This manufactured precarity was further reinforced by discriminatory rental practices, unaffordable financial requirements, and practical barriers such as the inability to provide deposits, guarantors, or proof of stable income. What appears neutral in policy becomes, in practice, a system that embeds instability into everyday life.

This was echoed by another participant:
"The place had mould, dripping water, insects. I had to write to the council. I was working for the NHS during COVID and risking my life for others, but I couldn't even live in a safe house."

By positioning secure housing as a conditional privilege, NRPF threads long-term precarity through the lives it governs, deepening inequality across communities.

2.2 PHYSICAL HEALTH IMPACTS OF SUSTAINED HOUSING INSECURITY UNDER NRPF

Participants' accounts demonstrated that housing insecurity under NRPF had immediate and cumulative impacts on physical health. Poor-quality accommodation, frequent displacement, and prolonged instability combined to undermine bodily wellbeing, rendering ill-health a predictable outcome of structurally constrained living conditions.

Families described overcrowded rooms affected by damp, mould, inadequate heating, and poor sanitation. These conditions were linked to respiratory problems, skin conditions, recurring infections, and the worsening of pre-existing illnesses, particularly among children. Limited space and lack of privacy further restricted families' ability to rest, recover, or manage illness effectively.

One participant shared:
"The bathroom is like a cubicle, it's not enough space to wash properly."

Housing instability also disrupted access to healthcare. Frequent moves and insecure addresses made it difficult to remain registered with GP practices or attend follow-up appointments.

Participants reported delaying treatment due to uncertainty around eligibility, fear of costs, or concern that accessing services might expose their immigration status, often resulting in conditions becoming severe before care was sought.

A participant described:
"It gets you tired. I don't even report things anymore."

Participants linked ongoing instability to chronic fatigue, headaches, gastrointestinal issues, and stress-related conditions such as hypertension. Some reported developing diabetes or dangerously high blood pressure, which they attributed to prolonged stress and the physical strain of living in insecure housing.

As one participant described:
"I'm using sleeping tablets now. If I don't, I can't sleep till four in the morning. The stress, the moving from one place to another, it's made my blood pressure high. I'm on medication now."

Overall, physical ill-health emerged as a structurally produced and cumulative consequence of life under NRPF.

2.4 MENTAL DISTRESS, SOCIAL ISOLATION, AND LOSS OF CONTROL UNDER SUSTAINED PRECARITY

Participants described how the impacts of NRPF-related housing insecurity extended beyond material deprivation to shape mental and social wellbeing. Prolonged instability generated persistent psychological strain, eroded social connection, and diminished individuals' sense of control over their lives.

Mental distress was most commonly linked to ongoing uncertainty. Participants spoke of constant worry, hypervigilance, and an inability to relax, driven by unpredictable housing arrangements, landlord behaviour, and administrative decision-making. This continuous state of alertness disrupted sleep, concentration, and emotional regulation, producing cumulative exhaustion. Distress was framed not as individual vulnerability, but as a rational response to unstable conditions.

As one participant explained:
"I felt like we are not human beings actually. Wherever I was going, they were saying, 'Oh, we are helpless, sorry.' It really affected my mental condition and I was crying a lot , I felt hopeless for everything."

And another one shared:
"It makes you panic. There's uncertainty, anxiety about what's next, how long we will be here, what the next step is. A million and one things run through your mind."

Social isolation emerged alongside this strain. Frequent moves, overcrowded accommodation, and fear of eviction limited opportunities to form or sustain relationships. Many participants withdrew from social life due to embarrassment, lack of privacy, or practical constraints, undermining community belonging and discouraging long-term social investment.

These experiences contributed to a profound loss of control. Participants described feeling unable to plan, influence decisions, or secure stability for their families. For parents, the emotional labour of shielding children from instability intensified these pressures. Together, these dynamics produced mutually reinforcing mental and social harms that eroded wellbeing over time.

One of the participants explained:
"I'm feeling unheard, and I don't have the power to make changes. I feel very vulnerable in this situation."

2.5 HARM TO CHILDREN UNDER SUSTAINED HOUSING INSECURITY AND NRPF

Participants' accounts indicated that housing insecurity under NRPF shaped children's lives through ongoing instability rather than isolated crisis. Parents described how insecure and temporary housing structured children's everyday environments, routines, and sense of safety.

One of the participants explained:
"I don't have space for my children to play at home. Everything is in one room, sleeping, playing, everything."

Frequent moves and overcrowded accommodation disrupted children's ability to settle into daily life. Participants described repeated changes in living arrangements that limited opportunities for rest, study, and play. Housing conditions were often unsuitable for family life, constraining children's access to consistent routines, schooling continuity, and social relationships.

A participant shared:
"After we moved to another place, he (her 6 year old son) became more scared. He didn't feel safe."

Another participant described:
"My daughter is growing at this age, she needs privacy. But we are staying together in one small box room. When one is in the room, the other goes to the living room to get dressed."

Children were affected by housing uncertainty even when adults attempted to shield them from worry. Parents described children's awareness of instability and how this shaped their responses to changes in living arrangements.

One mother explained:
"I was scared the council might separate me and my daughter, put us in different places. I couldn't even speak honestly about what we needed."

These experiences were framed as reactions to sustained instability rather than individual or developmental issues. Despite children's legal entitlements to protection and support, participants described prolonged instability and delays in accessing appropriate assistance. Harm to children thus emerged not from parental failure, but from structural conditions that constrained families' capacity to provide stability. These accounts highlight the intergenerational consequences of NRPF-related housing precarity.

2.6 ADMINISTRATIVE NEGLECT AND GATEKEEPING UNDER NRPF

Participants' accounts demonstrated that housing insecurity under NRPF was intensified and sustained through administrative neglect and gatekeeping practices. Interactions with local authorities and statutory services were frequently described as prolonged, fragmented, and difficult to navigate, extending instability rather than resolving it.

A participant shared:
"They were just passing the ball. Nobody was taking responsibility."

Participants reported repeated requests for documentation, extended waiting periods, and unclear decision-making processes when seeking housing assistance or statutory support. These procedures required families to continually demonstrate eligibility while remaining in insecure accommodation. Administrative processes were experienced as exhausting and burdensome, often deepening uncertainty rather than providing resolution. As one participant explained,

access to support was frequently contingent on legal intervention that many could not afford:
"You have to get legal backing... you have to pay for it... if you don't have the funds... probably on the streets."

Gatekeeping was particularly evident in relation to statutory support, including Section 17. Rather than functioning as safeguards, administrative systems were experienced as barriers that prioritised procedural control over care. For some, the process itself compounded existing trauma:
"It's actually a depressing process... it stresses you out more than the DV you've been through."

Participants described impersonal modes of communication, limited opportunities for dialogue, and the absence of clear responsibility for decisions affecting their housing:
"You only communicate with some space on email... who will you hold responsible?"
"You don't really have somebody to talk to... they give you an email and a phone number... no result."

Overall, administrative neglect and gatekeeping functioned as structural mechanisms through which NRPF-related housing insecurity was reproduced and prolonged. Through delay, opacity, and conditional access, institutional systems sustained precarity and reinforced the harms identified across earlier themes.

3. CONCLUSION AND RECOMMENDATIONS

Taken together, the findings demonstrate that housing insecurity under NRPF is not accidental or episodic, but systematically produced through immigration policy, housing exclusion, and administrative practice. Structural constraints shape access to housing from the outset, while instability generates cumulative physical harm, mental distress, social isolation, and diminished control over everyday life. These conditions extend directly into children's lives, despite statutory protections, and are sustained through administrative neglect and gatekeeping. NRPF thus operates as a system that produces predictable and intergenerational harm, positioning housing insecurity as a structural driver of inequality rather than an administrative safeguard.

3.1 PARTICIPANT-INFORMED RECOMMENDATIONS

The following recommendations are derived directly from participants' accounts and are grounded in the lived realities documented throughout this report. They are presented to reflect the findings and to emphasise how housing insecurity under NRPF is produced and sustained through policy design and institutional practice.

1. **Ensure access to housing is not contingent on benefit eligibility in crisis contexts**
   Participants described how linking housing access to public funds rendered secure accommodation inaccessible, particularly during periods of acute need. Removing benefit-based barriers was identified as necessary to prevent housing insecurity that is structurally produced by NRPF restrictions.

2. **Ensure immediate access to safe housing for survivors of domestic abuse with NRPF**
   Participants highlighted how NRPF delayed or restricted access to safety, at times trapping women in abusive situations. Immediate access to stable and secure housing in crisis contexts was identified as essential to prevent further harm.

3. **Prioritise housing that is suitable for family life and physical wellbeing**
   Participants emphasised the physical harms associated with overcrowded, temporary, and poor-quality accommodation. Stable housing that enables rest, recovery, and the management of health needs was identified as a foundational requirement for family wellbeing.

4. **Recognise and support the emotional labour of mothers living under NRPF**
   Mothers described the sustained psychological toll of managing housing instability while attempting to protect their children, including experiences of shame and isolation. Participants identified the need for accessible emotional support and peer-led spaces that recognise this labour.

5. **Introduce trauma-aware administrative practice in housing decision-making**
   Participants described gatekeeping processes that intensified distress through suspicion, delay, and conditionality. Training frontline staff to reduce re-traumatisation and to respond more sensitively to intersecting forms of vulnerability was identified as necessary.

CHAPTER FIVE: ‘THEY ARE PASSING THROUGH’: RACIALISED AND CLASSED EXPERIENCES OF GENTRIFICATION AMONG BLACK AND GLOBAL MAJORITY SOUTH LONDONERS

VANESSA BOODHOO

1. BACKGROUND

Neoliberal policies of deregulation and privatisation materialise through the increasing loss of public land to private developers, reshaping London’s neighbourhoods and housing markets. Amid the cost-of-living crisis, declining housing stock and “affordable” housing priced at 80% of market rates, gentrification has increasingly facilitated the displacement of lower-income households from their communities.

However, this displacement does not occur evenly. The impacts of gentrification intersect with racial and socio-economic inequalities, with studies consistently highlighting that Black and Global Majority (BGM) residents face greater barriers in accessing affordable, decent and secure homes. These demographics are also disproportionately affected by the ‘renewal’ of council estates and council-led regeneration schemes, which displace residents under the guise of improvement.

Such redevelopments produce patterns of micro-segregation, in which luxury housing and high-cost businesses emerge, yet remain inaccessible to long-standing communities. These ‘stark income polarities’ heighten feelings of socio-economic exclusion and alienation among working-class Black and Global Majority residents living in historically diverse areas.

These dynamics make Lambeth and Southwark – two of the most ethnically diverse boroughs in England with rapidly gentrifying neighbourhoods – sites of interest to understand how Black and Global majority residents experience gentrification, and how it reshapes belonging and access to safe, affordable housing.

This chapter argues that issues within social and housing association (HA) housing, including delayed maintenance and institutional neglect, intensify housing insecurity. As social housing conditions deteriorate alongside growing investment in unaffordable developments, residents increasingly experience class- and race-based alienation, perceiving these changes as a manifestation of local authorities’ prioritisation of affluent newcomers.

2. METHODS

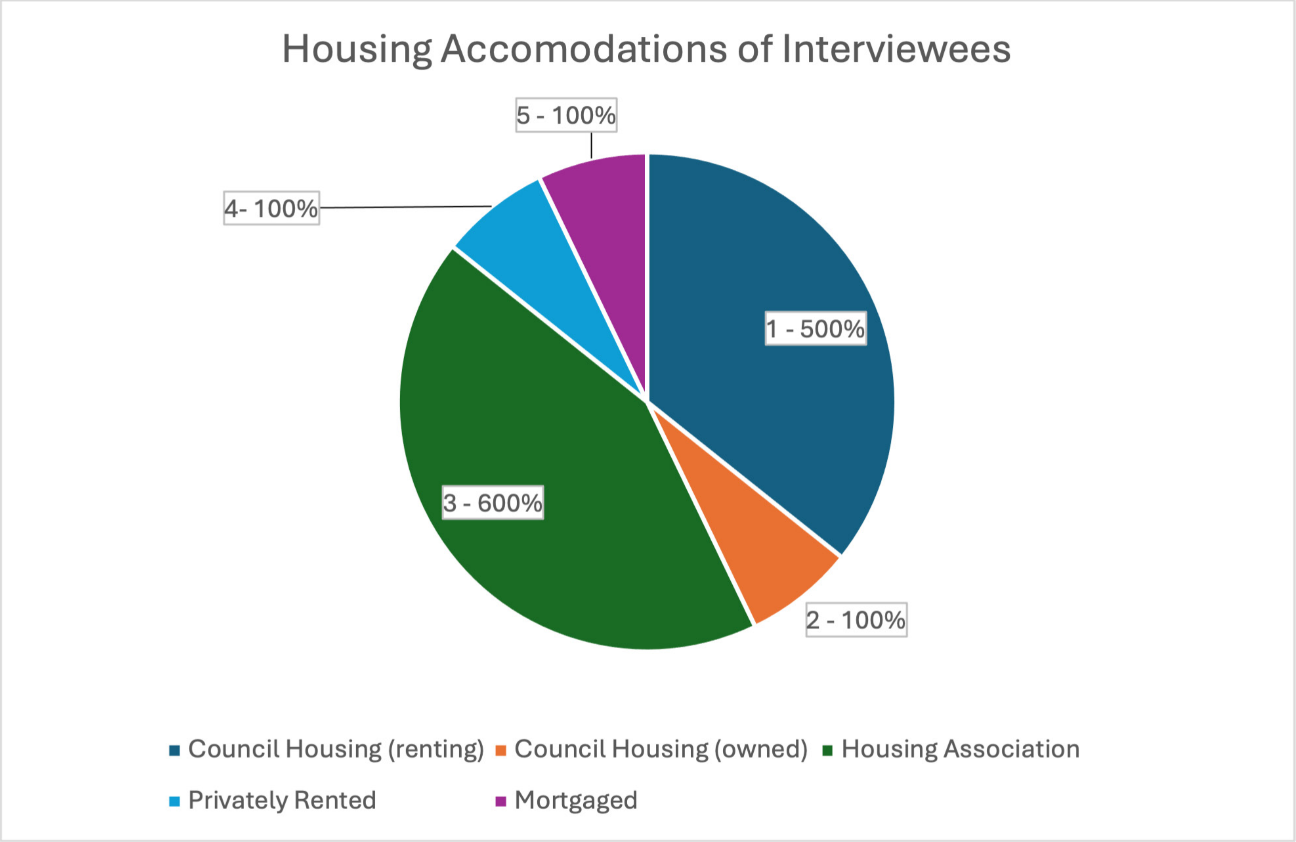
The research project adopted a qualitative method approach, using semi-structured interviews to prompt in-depth, detailed data while allowing participants flexibility in discussing relevant topics. A set list of questions ensured coverage of key themes relating to housing conditions and gentrification.

Eighteen interviews were conducted: fifteen with current Lambeth and Southwark residents and three with former residents who had relocated. All participants were Black and Global Majority individuals, recruited through existing networks, support from Stockwell Park Community Trust, and monetary incentives.

Interviews remained flexible but centred on housing conditions, neighbourhood changes and experiences of gentrification. Transcripts were coded inductively and thematically, with quantitative descriptors used to highlight recurring patterns.

3. RESULTS

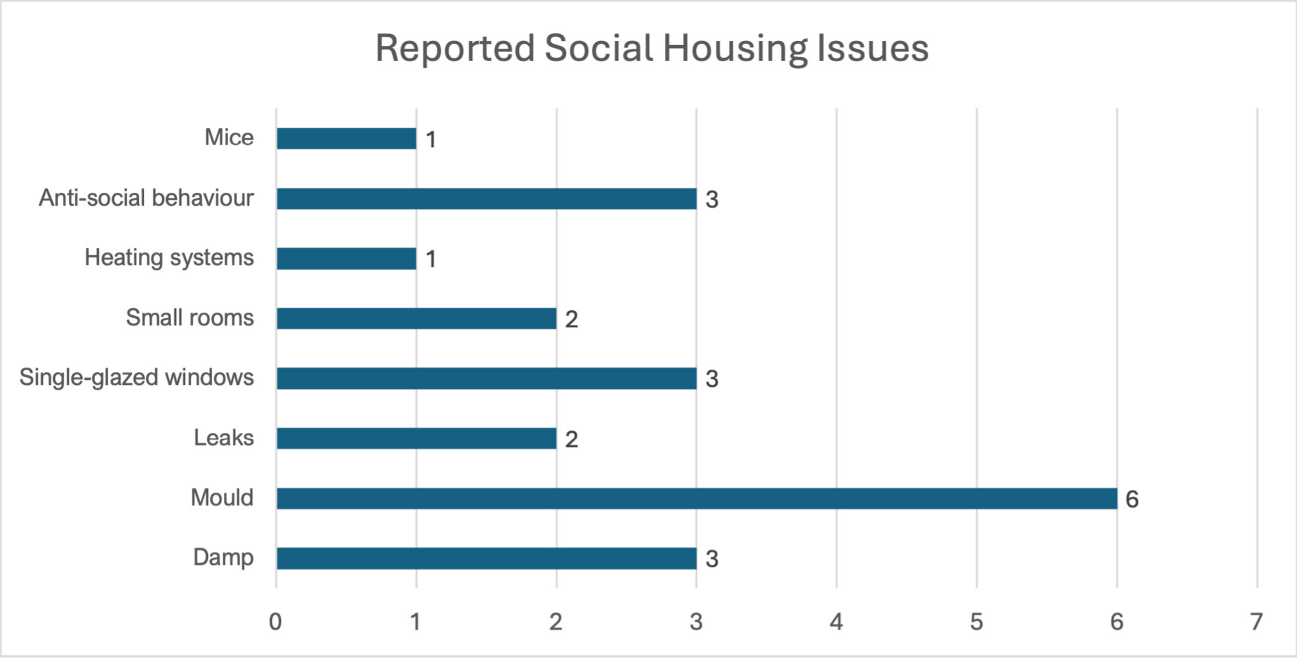
3.1 HOUSING CONDITIONS



This section examines participants' housing conditions across tenures, underscoring delayed maintenance and institutional neglect within social and HA housing.

Experiences of housing quality differed by tenure. Homeowners generally expressed satisfaction, likely reflecting the sense of agency and control associated with ownership. Private renters reported acceptable conditions, despite mentions of disputes over shared communal spaces and smoking policies.

Contrastingly, social housing tenants reported a wide range of concerns. 46% felt that their housing situation did not meet good or safe living standards, while 38% reported satisfaction. Nonetheless, even among those who considered their housing good and safe, 60% still reported issues such as water leakages, damp, mould, and single-glazed windows. Overall, regardless of their assessment, respondents renting social housing reported issues including:



Altogether, these results suggest that social housing residents experience both perceived and unperceived unsatisfactory conditions. The divergence between perceptions indicates that some tenants are more aware of the limitations of their housing, while others perceive their conditions as satisfactory despite significant problems. Such a belief may reflect a normalisation of poor quality of housing among Black and Global Majority or limited awareness of adequate housing standards.

3.2 RESPONSES TO MAINTENANCE CONCERNS

3.2.1 COUNCIL HOUSING

This subsection analyses how the council's delayed repairs are embedded within broader structures of institutional neglect, which marginalise tenants and undermine their sense of security and trust in the authorities.

Council residents appeared accustomed to long delays for repairs, yet still expressed confidence that the council would eventually respond. One tenant explained, *"It may not be immediately, but they definitely still call someone out, so it's all good",* while another echoed that *"they will handle it. They may take a while, but they will handle it."* These accounts suggest that despite the normalisation of delays, tenants trust the authorities to provide safe housing. Simultaneously, the tenants' acceptance of delays reflects a recurring sense of endurance and acceptance of limited institutional responsiveness.

Nonetheless, trust was not universal. A single mother with a young child, facing mould in her home, reported frustration that her health concerns were not treated with urgency, highlighting a misalignment between tenants' and the council's assessments of emergencies. Another tenant explained that delay in repairs encouraged self-reliance: *"unfortunately... a lot of the work has to be done by you"*, noting that this self-reliance depends on physical capacity. Such accounts highlight how slow repair systems shift the responsibility of upkeeping safe living conditions onto tenants, while also disproportionately affecting households with limited physical capacity, resources and time.

Systemic maintenance delays were specifically highlighted in the case of single-glazed windows. Tenants explained that single-glazed windows left homes *"really cold."* Residents expressed frustration at decades-long promises of upgrades to double-glazed windows that were never kept: *"it's 23 years later, and people in my block are still fighting Lambeth", "I've had a lot of correspondence at the council for almost 10 years now, but nothing's actually happened."* Since April 2002, building regulations have required replacement windows and rental properties to meet energy efficiency regulations of at least 'E', often ruling out single-glazed windows. The prolonged failure of the council to upgrade insulation in council property undermines institutional accountability and tenants' safety and well-being.

Together, these accounts illustrate how under-maintenance can contribute to feelings of marginalisation and erode trust in local authorities, by reinforcing residents' perceptions that the council does not prioritise their safety.

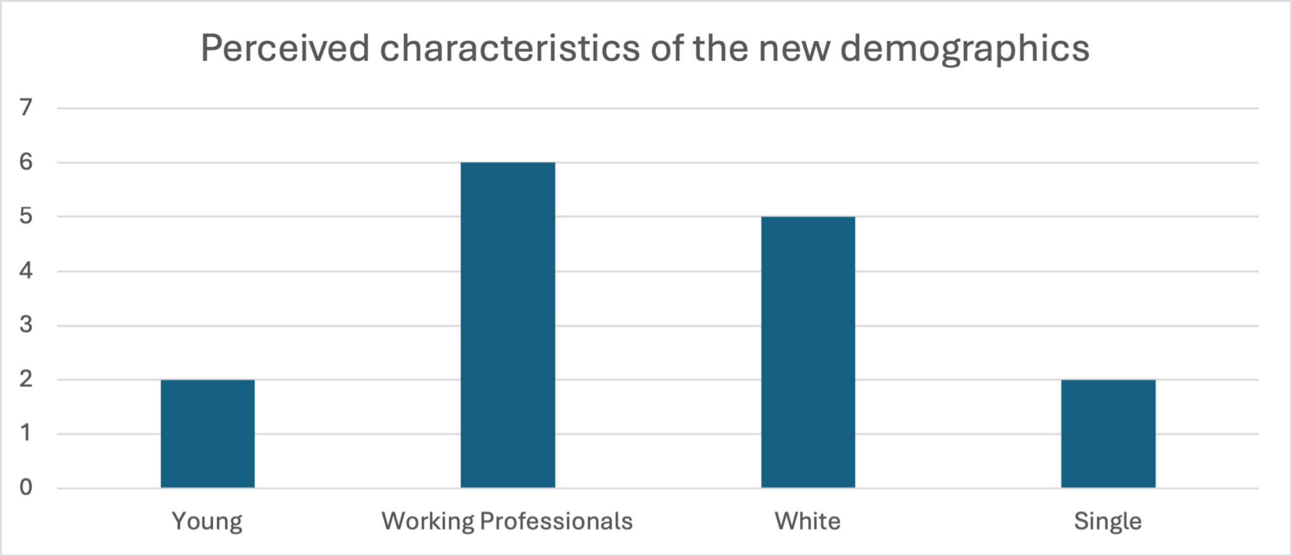
3.2.2 HOUSING ASSOCIATIONS

Similar patterns of neglect and delayed maintenance emerged within HAs, but with more severe consequences. One HA tenant facing extreme situations described the HA's repeated failure to provide a safe property. After a neighbouring flat's flooding left their bathroom light inoperative, no action was taken for four years, prompting legal proceedings. The tenant also reported repeated burglaries and blocked attempts to install a security gate, describing the HA as *"absolutely horrendous"* and causing *"ongoing suffering with how they deal with tenants."* The severity of the situations highlights significant concerns about HA inaction and negligence to provide a safe, well-maintained and secure property for its tenants, particularly within the wider context of council transfers to HAs.

3.3 NEIGHBOURHOOD CHANGES

This section explores residents' understanding of demographic shifts within their neighbourhoods and underscores how gentrification is interpreted through racial and class lenses.

Participants overwhelmingly reported a shift in the local population, with many noting an influx of young, white, single working professionals in their areas. Descriptors centring on whiteness and middle-class identity suggest that Black and Global Majority communities perceive gentrification as an intersecting racialised and classed process, with the often-unprompted nature of these observations underscoring how significant residents perceive this shift to be.



Black participants were more likely to interpret the demographic changes as forms of forced displacement and, consequently, as systemic racism. A participant reflected, *"Brixton was just Blacks on an estate... now the majority of Brixton is white... they've revamped it, moved all the Black people out."* Another participant shared that rising costs in Peckham are displacing Black residents in favour of affluent white newcomers, adding, *"I hope it doesn't happen to me."* These accounts highlight a sense of powerlessness from Black residents who experience gentrification as a racialised systemic process over which they feel reduced control.

This vulnerability is further contextualised by statements describing Southwark and Lambeth as places where participants feel *"culturally accepted"* and *"safe"* due higher proportions of Black residents. For these residents, gentrification threatens housing security, but also culturally familiar and safe environments that provide belonging.

Contrastingly, other residents focused more on the social behaviour of newcomers, describing them as transient and disengaged from community: *"they're passing through...it's not somewhere... that they care to engage community in",* and they are *"coming and going."* Michelle Killington, a participant and long-standing Brixton community member, resonated with these feelings: *"they don't really want to stay."* These accounts suggest a social divide between the long-standing communities and newer residents. The perceived lack of interactions and engagement of newcomers contributed to feelings of alienation for local communities, who see shared spaces being reshaped without community integration or involvement.

Further tension emerged from an older participant who expressed frustration with a perceived growth in the LGBTQ+ population and nightlife venues in Brixton. Notably, there are no specific LGBTQ+ clubs in Brixton, suggesting that the participant's concerns may stem from a perceived reduction in entertainment spaces catering to older residents. Whilst isolated in its nature, this perspective reveals how neighbourhood changes can grow generational and cultural tensions.

3.3 DEFINING GENTRIFICATION

During the interviews, participants were asked to define gentrification within the context of their neighbourhoods, with responses clustered around the themes of changes to local businesses and housing redevelopments. The following subsections explore how residents interpret gentrification as creating inaccessible and impractical environments that are misaligned with the needs of long-standing communities in both categories.

3.3.1 BUSINESS CHANGES

Participants described the replacement of familiar establishments with chains such as Whole Foods, Pret, Costa, Holland & Barrett and Gail's as *"an attempt to cater to that white community".* These shifts are understood both as a consequence of a growing white identity in the diverse boroughs of Southwark and Lambeth, and as a form of economic exclusion, with residents explaining that *"people can't really afford to buy stuff."*

Killington noted that the redeveloped Brixton Village supports her work in training and developing young people, but still observed a broader disconnect between the new businesses and the native Lambeth communities – particularly, older residents. Her account reinforces the view that despite some beneficial changes, gentrification often feels misaligned with the needs of long-standing residents.

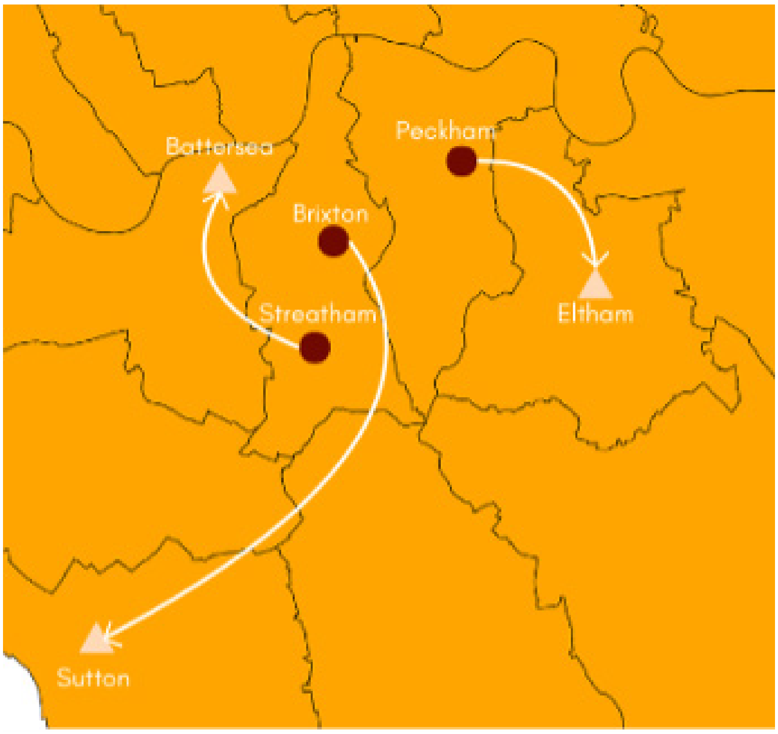
3.3.2 HOUSING AND REDEVELOPMENT

Some interviewees defined gentrification through reference to new *"shiny buildings"*and the closure of housing offices. Participants felt that these developments were not beneficial to existing residents - *"it's nice to have new things and all that, but it's not affordable to ordinary people like us."* These comments reflect the perception that redevelopment and investment

cater to incoming, affluent populations and consequently exclude existing communities from improvements.
Altogether, these findings suggest that residents experience gentrification as economic exclusion from housing developments and a diminished presence of local authority and support. Dichotomies between long-standing 'ordinary people' and incoming residents highlight a growing sense of while the closure of housing offices points to a perceived withdrawal of council support, which is often associated with gentrification.

3.4 DISPLACEMENT

For some participants, gentrification has already resulted in physical displacement. Three participants who were part of long-standing Southwark and Lambeth communities but had recently been displaced to outer parts of London described the direct consequences of rising living costs and gentrification. Two former Southwark and Lambeth residents described being *"priced out of our homes... it is where we've been all our lives, essentially. It was just too expensive to live there."* These accounts highlight how gentrification translates into a loss of belonging and economic exclusion, as those with fewer resources are pushed to outer London, while newcomers can take their place.



3.5 GENTRIFICATION AND THE COUNCIL

Participants explored their feelings toward local authorities by reflecting on funding decisions and investment within their boroughs, and how these relate to gentrification in the context of disinvestment from young and lower-income Black and Global Majority communities.

As participants discussed the impacts of gentrification, they described an emerging sense of social and economic exclusion. Residents perceive these changes as detrimental to their communities, highlighting the underfunding of local services amid growing unaffordable investments.

A recurring concern was the lack of investment in young people in Lambeth and Southwark. While older participants associated crime with youth, they simultaneously expressed empathy for young people and frustration at the limited available support. One participant worried that *"I just can't see it getting any better for the youngsters... The youngsters ain't really got nothing. There's no football pitch, there's no youth clubs."* Others voiced clear frustration over funding decisions.

One participant observed that *"money is moving in, but they are closing down youth centres and community centres"* while another lamented the underfunding of a Peckham youth club that *"was literally a saving grace when I was in secondary"*, adding that *"you look at some other things, and you'd expect it to be more funded."* Concerns extended to the future of housing for young people, as a mother explained: *"They need more social housing for the young people and not just for people that can afford it."*

These accounts suggest that residents perceive gentrification as entrenching class inequalities through selective investment perpetuated by the authorities. Lambeth and Southwark – home to child poverty rates of 39-40% - are expectedly places that participants identify as underinvesting in young people. Amidst incoming investments, residents feel that funding is not inclusive or redistributive, but rather, misaligned with community needs in favour of new affluent demographics.

Housing conditions were identified as another misaligned, underfunded area. A council house tenant expressed deep dissatisfaction with Lambeth Council's perceived lack of investment in providing a safe property for tenants, particularly when compared to the substantial funding allocated towards redevelopment projects. As the resident explained, *"it feels really dehumanising if I am honest... how detrimental it must be for like our mental health to live in conditions that are not adequate and then like on top of that be told that we kind of have to swallow it because we're poor essentially... you can't get basic amenities, like fixing the damp in the house but there's all these redevelopments."* The account reveals how interactions with Lambeth Council are contributing to feelings of devaluation and dismissal. The participant's observation that they are expected to *"swallow it because we are poor"* accentuates that these experiences are understood as rooted within socioeconomic status. For this participant, the authorities' neglect reinforces the belief that authorities are actively dismissing and divesting from long-standing communities that are *"viewed as a nuisance"* to prioritise redevelopment strategies to attract affluent communities.

Altogether, participants identified a broader pattern linking gentrification to class inequality in Lambeth and Southwark. Residents interpret new investments as misaligned with community needs, feeling that redevelopment operates through exclusive and selective investment. Experiences with delayed maintenance repairs mirror the participants' broader concerns about gentrification, reinforcing the perception that authorities prioritise attracting affluent residents over supporting their long-standing communities. Overall, residents perceive themselves, young people and other disadvantaged communities as being deprioritised and marginalised by the authorities through gentrification.

3.6 THE IMPACT OF GENTRIFICATION

This section analyses how gentrification shapes residents' housing concerns, particularly among younger communities who face housing insecurity.

Three participants stated that they had no concerns, two of whom were elderly male council tenants. Their lack of concern may reflect the perceived stability of council housing, but also a sense of resignation: *"that's beyond my control, so I do not worry about it...Whatever happens, happens."* These expressions of acceptance might reflect generational male socialisation towards control and resilience, as well as satisfaction with their current circumstances.

In contrast, the most common concern identified across participants was the affordability of housing. Out of the twelve participants who raised affordability as their main concern, ten were under 30. Younger adults described uncertainty about the future housing market: *"my fear is that just like I will live my life going from place to place, renting"* and *"I'm scared to see what the future holds, if it's going to get even worse."* These concerns point to the emotional consequences of young people being increasingly sidelined from the housing market.

Young adults made direct links between their housing insecurity and gentrification. A participant explained that "*Streatham.. is still one of like the few places where the rent is semi-affordable... but obviously with the threat of like gentrification I'm not really sure how long that is going to last', a sentiment echoed by other participants who 'hope prices don't go up."* The language used conveys a loss of control, as participants rely on 'hope', but predict that previously affordable areas will soon become inaccessible. This uncertainty is further contextualised by the fact that seven of these respondents would like to remain in their neighbourhoods, but do not believe they will be able to afford to do so. Overall, these responses reveal that young adults perceive gentrification as an immediate concern to their housing stability, but also belonging, exclusion and forced displacement within their areas.

Among the ten young people concerned about affordability, nine are living with their parents. This pattern reflects broader systemic inaccessibility for young adults attempting to enter the housing market, where high prices have forced continued dependency on families. Such dependency has been both a cause for anxiety *('I remember how anxious we were at the thought of like starting in our twenties and not being able to leave our family house')* and as a safety net (*'I would love to just have like a little flat to just me...but things are expensive... I might stick it out for a little bit longer at my mom's'; 'if I can stay with my parents as long as I can, I would because housing in general is very expensive')*. These findings illustrate wider generational inequality in housing, where stagnant wages and high rent prices have resulted in a normalised dependency among young adults.

4. COMMUNITY SOLUTIONS AND RECOMMENDATIONS

1. **Prioritise maintenance of existing social housing stock:** Allocate budgets to replace single-glazed windows and other critical repairs, ensuring residents live in safe conditions and feel valued.

2. **Funding for youth services:** Provide monetary support for existing youth clubs and sports facilities to assist underfunded younger generations, and offer residents guidance or free assistance with funding applications.

3. **Affordable Rent Schemes:** Government schemes should cap rents at 50% of local market rates to ensure housing remains accessible for lower-income households.

4. **Set minimum affordable housing quotas on new developments:** Require private developers to provide at least 50% affordable housing on new developments, reducing the exclusion and displacement of lower-income households.

5. **Improve communication within council housing services:** Lambeth and Southwark councils should provide clearer, faster and empathetic communication on maintenance issues, ensuring adherence to Awaab's Law (2025).

6. **Council-funded training for RMOs and TRAs:** Offer free training to RMOs and TRAs to support the transfer of management from the council to the residents, and co-create evaluation frameworks with residents.

7. **Strengthen community development:** Expand programmes that employ, train and involve residents within the council to foster local leadership and reduce alienation.

8. **Fund evaluation programmes for council housing services:** Allocate resources to evaluate council performance on transparency, accountability and community involvement.

9. **Open forums on planning and funding decisions:** Introduce open forums for residents to discuss development plans, funding allocations and priorities.

VANESSA BOODHOO

CHAPTER SIX: SICKLE CELL AND THE PSYCHOLOGICAL IMPACTS OF MEDICAL NEGLIGENCE AND IATROGENESIS

XAIRA OLAIFA-ADEBAYO

Sickle Cell Disease (SCD) is an inherited haemoglobinopathy characterised by acute, severe pain episodes caused by vaso-occlusion. The disease can lead to physical challenges such as progressive organ damage and psychosocial challenges (Franco, Gonzalez, McGirr-Crowley et al, 2024) (Ware, R. E., de Montalembert, M., Tshilolo, L., & Abboud, M. R. (2017). SCD primarily affects people with African or Caribbean heritage; thus, race as an intersectional frame of analysis is warranted when trying to understand the treatment of people with SCD in the NHS. Reports by Public Policy groups, such as the All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG), have responded to the recent rise of cases of medical negligence and substandard care towards sickle cell patients.

The report, largely filled with oral testimonies, documented the pervasive role of racism in substandard care for people with SCD. Likewise, themes such as inadequate knowledge of SCD by healthcare professionals, social stigma, lack of compassion and racialised biases towards pain management have been prevalent in research and reports completed over the past 30 years, which have recorded first-hand testimonies from SCD patients and carers. Longitudinal qualitative studies, such as those by Renedo et al., have highlighted the importance of producing research that emphasises the need to move beyond individual models of treatment for SCD to improve healthcare experiences, and instead integrates critical models of medical sociology that recognise the challenges people with SCD experience.

1. BACKGROUND

Evan Nathan Smith, 21, contracted sepsis after a gallbladder surgery, which triggered a sickle cell crisis. Evan died as a result of multiple organ dysfunction as a result of a sickle cell crisis caused by sepsis. The coroner, Dr Andrew Walker, concluded that the cause of Smith's death was a delay in treating him with a "timely exchange transfusion" and a "lack of understanding of sickle cell disease in the medical and nursing staff looking after Mr Smith (Guardian, 2019). Smith's case is not an isolated incident and has been ruled as a form of iatrogenic harm via medical negligence.

Iatrogenesis describes harm resulting from the actions of health care professionals, including but not limited to "side effects and risks associated with the medical intervention. (RF, Shabir N, 2018;7(2):309-314). Although iatrogenesis tends to describe the harm precipitated by particular health care practitioners, there are also structural forms of bias and inequity that contribute to medically induced harm. (Tao and Ksumi Clements, 2022, Vol 24. No. 8). The majority of observational and interventional studies on Sickle Cell and institutional neglect have been conducted in the United States, with funding still suboptimal in the UK. Between 2010 and 2023, a total of 387 projects were awarded by NIHR, UKRI and Wellcome for inherited genetic disorders; 19.4% went towards SCD. Contributing to this growing body of literature, this chapter focuses on the structural biases and practices that underpin iatrogenic harm and the long-term psychological effects of these events. Centring participatory action research, the report underscores the necessity of mental health screening as part of a multi-modal and multi-disciplinary approach to create and operationalise patient-centred care for people with Sickle Cell.

2. METHODOLOGY

The initial methodology for this study was a mixed-methods approach, with an initial survey circulated through personal networks; however, responses were sparse and fragmented. Thus, a qualitative study utilising semi-structured interviews was adopted later on. Participants were recruited via electronic flyers distributed through social media platforms and, later, in person at sickle cell conferences and sickle cell support groups. The sample included individuals ranging from the ages of 24 to 53 living with SCD and were ethnically mixed between Black Caribbean and Black African. There were six female participants and one male participant. Participants were compensated for their time. In order to promote anonymity, participants are not named in this report. Interview transcripts were thematically coded in NVivo.

3. RESULTS

3.1 GENERAL EXPERIENCE WITH PRIMARY AND SECONDARY HEALTHCARE

This section investigates the underlying structures and attitudes to adverse events (Iatrogenic harm). These events are not isolated but the result of compounding forms of negligence, dismissive attitudes, and racial bias that promote inequitable standards of care.

3.1.1 EMERGENCY SERVICES, GP PRACTICES AND LACK OR URGENCY

Participants were asked to describe their overall experience with the healthcare system as sickle cell patients. Prolonged waiting times, delayed intervention, failure to escalate and a pervasive sense of being deprioritised within primary and secondary care settings were prominent sub-themes of their responses. The average waiting time for participants to be admitted to A&E during an acute sickle cell crisis was 4 hours, whilst drug admission time was 3.5 hours after checking into A&E, despite NICE Guidelines recommending that analgesia should be administered within the first 30 minutes of admission. This often led some participants to use the A and E as a last resort when experiencing acute sickle cell crises. One participant noted that they *"avoid going to the A&E, they have us waiting for long periods in excruciating pain".* While another participant noted that *"waiting time for me takes more than 4 hours, in regards to getting medication, I usually need to ask about 5 times or more."*

Further, negligence and a dismissal of the urgency of care within GP practices were cited frequently by participants, with 57% reporting some negative experience with their GP. Participants described their experiences with their GPs as misinformed, lacking sympathy, and rushed. One participant recounted a particular experience where the GP refused to complete any basic checks required for sickle cell patients and told them *"to go to the A&E"* for any concerns, despite expressing discomfort and pain. Elaborating on how this encounter made them feel, the participant noted that *"it seemed like overall she didn't believe me, and it was quite cold... most of the issues I have had with accessing health care are with the GP practice."*

3.1.2 CROSS-DISCIPLINARY COMMUNICATION AND DOCUMENTATION HANDLING

Communication and documentation handling between primary care and other tiers of health care has been noted as a source of iatrogenic harm. Three participants highlighted that complicated surgeries were inappropriately handled due to insufficient communication between healthcare teams, including the GP and specialists, and the Haematology department. Participants mentioned poor co-ordination across multi-disciplinary teams, with one participant stating that *"sometimes you have to be the middle man, you have got to be pushing for it; my gastrologist prescribed me some medication and I didn't receive it until I went to the general ward 3 to 4 weeks later, the delay occurred as they had assumed that the haematologist would prescribe it, which wasn't the case."*

The failure to comply with ICP's (Individualised care plans), a healthcare plan often developed in collaboration with the patient and their haematologist that documents an individual's SCD history and tailored recommendations for management of APCs (acute pain crisis), was highlighted by participants as a recurring issue, leading to delays for appropriate treatment. Issues with adherence and implementation of ICPs have been documented in other reports, such as *"No one is listening"*, which highlighted the failure of compliance by medical staff. One participant highlighted that *"I would have to argue with doctors about how much blood I am supposed to receive, they would refuse to look at my notes... I have had to fight for them to read my charts."*

Another participant recounted a particularly traumatic experience where they were nearly administered for a Kidney transplant, due to poor procedural compliance by hospital staff. *"They said I had surgery, and I protested against this, even though I was very drowsy from the drugs... no one was listening to me. When they finally checked my notes, they realised they had gotten the wrong patient and I wasn't due for a kidney transplant."*

3.1.3 FAILURE TO ESCALATE

95% of participants commented that the general sentiment towards people with Sickle Cell by healthcare professionals was dismissive, avoidant, and reactive. This attitude often led to a failure to escalate regarding concerns with organ damage and chronic everyday pain caused long term irreversible damage. Three participants highlighted that they were told to *"wait and see a couple of weeks or months"* when they brought up unusual, prolonged pain and growing concerns for their health. *"At the age of 18, I was diagnosed with vascular necrosis in my right hip.. I feel like the NHS could have picked that up sooner...When I initially complained about my right hip, the professionals said to go away and come back six weeks later, but this kept extending until it was months... It was only after many attempts of complaining about the pain that they did a scan to discover that the bone was dying.... I think doctors and my GP could have done a lot more regarding offering preventative treatments, hydrotherapy, more physio... after my hip replacement, I didn't get any bi-yearly review or any physio at all... There isn't a lot of support or care for us in comparison to other people with long-term health conditions."*

The improvement of coordinated care is a necessary recommendation to diminish iatrogenic harm, especially in joint clinics with renal physicians, pain-management teams, obstetricians, and cardiologists. It is essential to emphasise the extension of this coordination to extend towards one that takes mental health screening in a proactive methodology.

3.2 STIGMA AND BIAS IN PAIN AS A RACIAL MECHANISM IN CLINICAL ENCOUNTERS

Clinicians' racial biases can act as pathways for the imposition of iatrogenic harm and inequitable health outcomes of black people (van Ryn M., 2002). Racial disparities in adequate pain management are examples of the kinds of harms and inequities that these biases cause. Various studies have highlighted how the racialised biases in pain perception impact overall treatment. For example, Hoffman and Trawalter et al investigated the prevalence of false beliefs about black people's tolerance by white medical students and how white medical students often rated black patients' pain as lower than white patients (Hoffman KM, Trawalter S et al, 2016).

3.2.1 SKEPTICISM ABOUT PAIN

Participants consistently commented on the stigma that Sickle Cell comes with as a racialised chronic illness, with many concluding that racism was a key factor in their mistreatment and the perception of their pain. One participant has highlighted that the bias from clinicians has sometimes led to them not intervening until the last possible moment, *"What traumatised me is that if I didn't say that I had fainted or fallen out of my bed as a result of being in so much pain. Nobody would have done anything. I feel like I always have to fight for basic treatment."* Staff scepticism about pain. Another participant describes being left unattended in the bathroom during a crisis by a nurse who refused to believe their pain *"My shoulders were in so much pain... I couldn't raise my arm* *to the lever... She didn't believe this, and she decided to leave me there."*

3.2.2 DRUG - SEEKING STEREOTYPES AND OPIOIDS

Opioids such as Morphine or Oxycodone are examples of analgesic treatment for APCs. Providing adequate pain control during severe episodes. However, stereotypes about black patients as 'drug seekers' and opioid dependent influences clinical practices in pain management. A study on the monitoring of patients on chronic opioid therapy highlighted how black patients were less likely to be referred to a pain specialist and more likely to be screened for substances and referred for substance use evaluation in comparison to their white counterparts. The study also commented on how some clinicians implicitly subscribed to the racially biased belief that black people exaggerated their pain and used deceitful practices to acquire opioids illicitly.

Participants highlighted how this perception of black patients impacted their treatment and often made crises unnecessarily painful due to a delay in further administration of drugs, due to scepticism. *"I have had to roll on the floor for extra pain medication... I remember having a chest of drawers crisis and getting out of bed and rolling, as I had been crying and screaming for extra medication for like an hour with the little breath that I had."* Another participant noted that *"I have had nurses say that I am addicted or drug-seeking, and I have had to fight for my pain relief. I have been in a particular situation where my pain relief is only understood by a particular nurse".*

3.2.3 INTRAVENOUS CANNULATIONS, LOSS OF AUTONOMY AND EMOTIONAL SUPPRESSION AS A FORM OF IATROGENIC HARM.

Intravenous cannulation, often a challenging procedure for those with SCD, due to recurring damage to the veins and irritation of the bloodstream for intravenous access, came up as a common site of iatrogenic harm. Four participants referred to Intravenous cannulations as an adverse event that generated long lasting psychological harm or immediate re-hospitalisation. One participant describes going in for a blood transfusion that ended badly due to issues with the cannula *"They couldn't find a vein and brought in loads of doctors jabbing my arms...I was supposed to be there for 2-3 hours. I ended up being at the hospital for a week after having a crisis due to blood clots formed during the procedure."*

Commenting on how they felt during this procedure, the participant recalled being *"very distressed and angry. I felt like my voice didn't matter, my sister tried to advocate for me, and no one was listening., The nurses were more compassionate than their colleagues. I felt like nothing. No matter how many times I told them to stop or get other professionals involved. It was excruciating."*

Participants noted that they were not listened to during these processes and not involved in the decisions about how to manage their emotions and their bodies. The violation of patient autonomy can generate copious amounts of distress but also forms of emotional suppression. *"When I was in hospital, I had a strong phobia of needles, you tend to develop a strong aversion to them, I remember being woken up in the middle of the night by the anaesthetists and nurses, they pressured me to go through procedure and forced me to* ***suppress*** *the panic attack I was having at the time, even till this day, that occurrence has given me PTSD, if I am in a particular situation or stressed that incidence comes up as a recurring flashback."*

3.3. LONG-TERM PSYCHOLOGICAL IMPACTS

Medical negligence can contribute and exacerbate pre-existing psychological conditions, but also generate new ones. When asked about their general mental health experience with SCD, many participants noted symptoms such as *"depressive episodes and lots of anxiety"* and general feelings of loneliness.

3.3.1 PTSD AND EMOTIONAL ALEXITHYMIA

Negligence in the form of inadequate monitoring of antibiotic treatments is even more concerning for patients with Sickle Cell, who become immunocompromised very easily. One participant received an insufficient duration of antibiotic treatment, which meant that the underlying infection progressed and developed into sepsis. This led to a near-death experience triggered by the sepsis-related sickle cell crisis and months of hospitalisation. After this adverse event, the participant noted that they had to get therapy due to experiencing bouts of PTSD, unwarranted flashbacks, and long depressive episodes associated with the adverse event. Thus, an example of how iatrogenic harm can lead to long-term psychological impacts.

Another popular sentiment was the inability to categorise how specific incidents made participants feel. Emotional alexithymia, a difficulty in expressing or identifying emotional distress as a result of compounding and ongoing trauma, was particularly evident among various participants. *"I don't know if I have processed it well... I am trying not to gaslight myself, like did this really happen or not?"* one participant said when recounting how they felt after they had been given a double dose of anaesthesia against their wishes.

An avoidance of certain health providers was noted as a short-term strategy to alleviate mental health symptoms such as anxiety. Further, participants reported delaying hospital admission when in acute sickle cell crises or avoiding care despite potential risk, thus demonstrating how iatrogenic harm can worsen health outcomes due to psychological effects. Other effects included hypervigilance and anticipatory anxiety when it came to complex procedures such as surgery, difficulty trusting healthcare staff and a reluctance to speak up when unsatisfied.

3.3.2 PROVISION OF MENTAL HEALTH SERVICES AND BARRIERS OF ACCESS

Sickle Cell, as a chronic illness, is complicated by mental health disorders such as depression and bereavement. Patients with chronic diseases are predisposed to psychiatric comorbidities. However, in the sickle cell disease (SCD) patient population, psychiatric comorbidities have been uniquely shown to exacerbate the disease through a psycho-somatic component. A co-existing diagnosis of depression is found in 1 of 3 patients with SCD, and they are more than 5 times more likely to suffer with a mood disorder than the general population (Phan, Dambala, Ilyas et al, 2023). Additionally, a study by Dirican et al (2025) highlights how pre-existing mental health conditions such as MDD (Depressive disorder) and anxiety elongated hospital stays for people with SCD. Thus, mental wellbeing is a crucial element of treatment for Sickle Cell patients.

One participant discussed in depth how other external life factors, such as the loss of a parent, impacted their physical health and how medical professionals often overlooked this. *"I would have a lot of crises after my mum died... I think a lot of it was caused by grief... but I was never given any psychological report or assistance to help cope, just hydroxyurea pushed onto me"*. The above testament provides an opportunity to invest more research and resources in understanding how mental health impacts the wellbeing of sickle cell patients and, more importantly, to screen sickle cell patients for pre-existing mental health conditions to develop a holistic, integrated care plan.

When it came to accessing mental health services in order to deal with the complexity of Sickle Cell as a chronic illness and post-iatrogenic harm treatment, many participants highlighted that this was not an option given as part of their health care plan. Mental health services were accessed mainly via other medical departments, highlighting the absence of an integrated psychological care within sickle cell treatment pathways. For example, the same participant commented on how they *"had therapy last year, but that was because of a car accident that I had.. and they recommended CBT. The CBT was about the accident, but I found that everything that had happened over the years was spilling out into the therapy session, i.e. I never had any bereavement when my mum died. I only had 10-12 sessions for the CBT."*

3.3.3 GENDERED INTERSECTIONS AND MODELS OF MENTAL WELLBEING FOR BLACK SICKLE CELL PATIENTS

Further, the experience of often being ignored, invisible, neglected and underprioritised seemed also to impact the level of action participants wanted to take in expressing further assistance with their mental wellbeing. This was particularly salient among black female participants. Feelings of helplessness were evident in some participants' responses.
"No one is going to be strong for me. So I have to do it for myself... it's not one battle... But it's continuous ... There's never any break. I have to be strong for my own sanity. I don't have time to break down and cry as such. The only time I cry is in a crisis. I just have to keep going."

The stereotype that black women were 'strong' and the expectation to 'deal with it' often meant that there was a lack of expectation that such women could experience mental distress and in turn, stopped them from seeking help. (Kalathil, J., 2011). Limited access to mental health support also deterred participants from seeking recovery from pre-existing psychological ailments or those generated through iatrogenic harm. *"I have never had mental health support. I have tried to get talk therapy, but because I am out of the catchment area, they said that there would be long waiting lists. Also many services have an age requirement of 18 and below. When I have tried to get different routes, I have always been turned down, and none of my healthcare professionals have helped me"*

The same participant describes the dismissive attitude from their GP concerning their mental wellbeing: *"Even trying to get tests done or anxiety or depression at my GP, they have been dismissive of me. They have said, 'oh, you're fine... you're bubbly."*

In an investigation into the implicit bias present in healthcare practitioners in decision making concerning depression, it was found that primary care doctors in this study across the US and the UK had difficulties diagnosing depression with black patients Further, it was proposed in the study that the pre-existing health conditions in black patients in both countries meant that doctors focused solely on physical conditions even though some diseases, for example cardiovascular diseases, are complicated and exacerbated by depression (Adams A., Vaila L., et al, 2014).

Overall the study highlighted how there was a greater uncertainty in the diagnosis of emotional problems and depression in black African and African Caribbean patients and the need for the development of a mental health model of a flexible mental health model of depression presentation in black patients. Similarly, with SCD, when patients attempt to receive mental health services to treat psychological effects of iatrogenic harm, this is dismissed by healthcare professionals or is structurally inaccessible. Thus, the perception of pain, whether it's physical or psychological, seems to be a precursor to the negligence of patients with SCD and simultaneously a probable cause of iatrogenic harm or the inability to treat the long-term psychological impacts appropriately.

3.4. BARRIERS TO REDRESS

When it came to taking action to report these experiences post-sickle cell crisis, many participants identified that they were too physically and emotionally depleted to pursue any form of formal complaint or negligence procedures. *"You tend just to shut down, and try to ignore that it's happening, because it's all too much to figure out."*

If participants did make formal complaints, they were more likely to be made by family members, such as mothers or partners. Further, when they did so in the past via the PALS system or switchboard structures, they found that no effort was made to correct the mistakes, or even an admission of negligence.

"I don't feel that the complaints are taken seriously, the Patient Advice and Liaison Service (PALS) will just write you a generic letter. I don't have faith in the NHS that they will ever accept accountability for any mistakes that have happened. They will always stick together because they don't want a costly lawsuit."

Other barriers included the fear of retaliation from certain medical staff, if the participant utilised their department frequently during acute pain crises and anticipatory stress. Iatrogenic harm is not only caused by the healthcare system, but it is also sustained by the existing structures meant to keep healthcare professionals accountable. Thus, the burden of accountability is implicitly placed onto patients struggling with chronic illness.

Participants' narratives highlight how institutional pressures, inadequate care pathways, and fragmented medical systems converge to produce and sustain preventable harm. This, in effect, shapes many sickle cell patients' responses within the healthcare system.

4. COPING MECHANISMS AND RECOMMENDATIONS

Participants expressed clear recommendations regarding the current treatment of sickle cell patients and ways to reduce medical negligence. Additional recommendations that have not been explicitly addressed in this article have also been included to acknowledge their importance in improving the care of SCD patients.

1. Implementation of routine psychological and neurocognitive assessments in a comprehensive Sickle Cell clinic.
2. Improvement of communication and documentation handling across multi-disciplinary teams.
3. General practitioners to be reviewed on their practice delivery for sickle cell patients.
4. Prioritising patient-centred care during procedures such as Intravenous cannulations.
5. Continued improvements to Sickle Cell specific training and education for staff and healthcare professionals.
6. Anti-racist education on opioid dependency and racial bias training towards pain.
7. Systems and structures of accountability for iatrogenic harm and adverse events should become more accessible for patients.
8. Further funding from NHS trusts to be allocated to sickle cell support groups.
9. Improvement in the procedures for escalation and medical treatment for organ damage, so that medical professionals address patient concerns within the shortest possible time.
10. Healthcare professionals should adopt a proactive approach to care planning for patients with Sickle Cell disease.
11. Developing flexible mental health models of depression, anxiety and grief presentation in black sickle cell patients.

XAIRA OLAIFA-ADEBAYO

CHAPTER SEVEN: EXPLORING THE MENTAL HEALTH EXPERIENCES OF UNIVERSITY-AGED SOUTH ASIAN WOMEN

ALIZA MATHEW

This chapter presents the findings of an exploratory study into the mental health experiences of university-aged South Asian women in London. Conducted by a Peer Researcher who is both a university student and a member of the South Asian community, this research employs a mixed-methods approach to understand the complex interplay of culture, stigma, and service accessibility. Through surveys and interviews with forty South Asian women, the study investigates key barriers to help-seeking, including long wait times, perceptions of dismissal, and significant cultural and familial influences.

The analysis reveals that while most participants faced mental health challenges, over half were unlikely to seek formal support, often turning instead to private coping mechanisms or confiding in friends. A critical finding is the powerful correlation between familial attitudes toward mental health and perceptions of service quality, underscoring the need for services that deeply understand these cultural dynamics. This chapter argues that effective support must cultivate trust, ensure cultural sensitivity, and value anonymity to resonate with this demographic and compete with preferred informal support networks.

1. METHODS

This study used a mixed-methods design with a 5–10 minute survey and optional semi-structured interviews. Forty South Asian women (18–24 years old) studying at London universities were recruited via convenience and snowball sampling. Three participants completed interviews.

The survey, hosted on Microsoft Forms, combined closed-ended, Likert-scale, and open-ended questions. It examined attitudes toward mental health, help-seeking, and the influence of culture, family, and stigma. To ensure anonymity and encourage disclosure, an anonymous text-based interview option was provided using Tawk.to live chat. Standard interviews were conducted via Google Meet.

Both instruments were structured around three themes from the literature: access, perception, and trust. Survey data were cleaned and analysed in Excel and Stata for descriptive statistics and correlations. Interview transcripts and qualitative survey responses were thematically coded in Taguette using sub-categories of the core themes.

The sample was primarily composed of Indian (45%), Pakistani (20%), and Bangladeshi (20%) students. Most (63%) attended King's College London, highlighting the network-based recruitment. All participants were 19–23 years old and predominantly (85%) undergraduates. While suitable for exploration, this limits representation outside Russell Group institutions.

Among 40 participants, 3 had a formal mental health diagnosis and 6 suspected they had one. The majority (75%) had no diagnosis. This demographic was intentionally sought to explore help-seeking behaviours in both service users and non-users.

2. RESULTS

2.1 NAVIGATING ACCESS

23 of the 30 non-diagnosed participants reported experiencing mental health challenges. 15 participants (38%) had accessed mental health services (MHS), with university counselling and NHS talking therapies the leading examples. When asked how well the MHS available met their needs, participants gave an average rating of 2.88 out of 5, indicating a consensus skewed towards the middle-to-low end of the scale (see fig. 1).

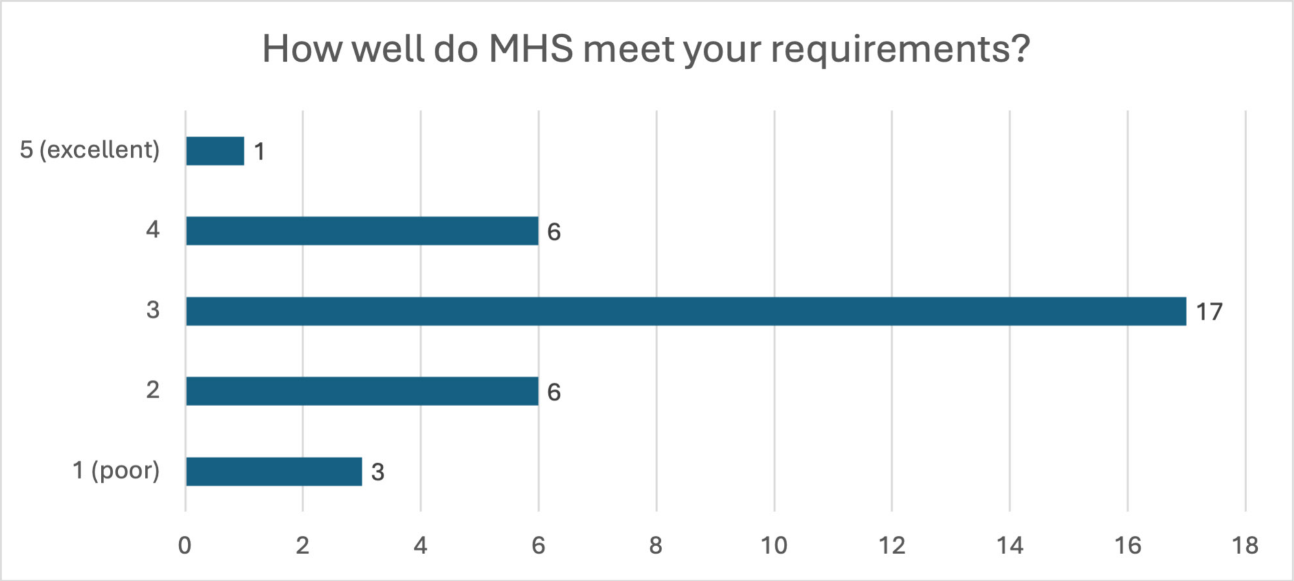


Figure 1 - participants' perspectives on MHS

Interview participants' perspectives on the quality of MHS varied between their individual experiences. Participants A and C reflected on positive experiences with services, describing talk therapies and university counselling as "very helpful". In contrast, Participant B, who discussed her experience with body image in relation to her MH, communicated several challenging experiences with services:
"I didn't feel comfortable telling them about my mental health, so I downplayed it and just asked about weight loss after COVID. The receptionist said, 'You need to tell me what's wrong, otherwise I can't book an appointment.' Later, when my blood test was normal, I called to speak to someone and was told, 'You don't need an appointment because everything is fine.' I said, 'But I want to talk to someone.' She said no. [...] How am I meant to talk to the GP if they're not letting me talk to the GP?" —Participant B

Incidents like this, where mental health concerns are minimised or dismissed, are not isolated. The survey found that over a quarter of the South Asian participants (28.2%) felt they had to advocate more than others to be heard or properly diagnosed in MH care, and 35.9% agreed that they had experienced dismissal or minimisation in these settings. The picture becomes more nuanced, with 33.3% agreeing that they felt their concerns were not taken seriously because of their racial/cultural background.

The limitations in services are exacerbated by NHS mental health backlogs, with individuals eight times more likely to wait over 18 months for mental health support than for physical healthcare. All the participants echoed the same concern that "long wait times deter people from going" and function as another distance to accessing formal services. Participant C noted that university services were more efficient in referrals and, as an international student, had been directed to the department early on for visa and immigration support, which introduced her to the counselling service. Participant A expressed stumbling upon the services by accident, while Participant B did not know about the service until the end of her second year. In the survey, 25.6% indicated that they did not feel confident that they could access suitable MH support if they needed it.

These issues compound to the point that over half of the survey participants (56.4%) were unlikely to seek service support when experiencing MH challenges.

This prompts critical questions about the barriers influencing South Asian women's help-seeking. Similar to a Canadian study on South Asian youth, which found a preference for informal well-being practices, participants here overwhelmingly turned to private outlets like journaling or music. For verbal support, nearly half (47.2%) confided in friends, far more than in family or formal services (both 8.3%). This suggests services may be more effective if they can cultivate the relatability and trust of a close friend and are perceived as supportive enough to compete with these preferred informal routes.

2.2 IMPORTANCE OF PERCEPTIONS

How those experiencing mental health challenges are perceived – by their communities, their families, and themselves – emerged as a key factor influencing support-seeking behaviour.

A significant majority (87.5%) acknowledged the presence of stigma surrounding MH within their cultural contexts. Additionally, 62.5% reported that their cultural background negatively influenced their attitudes toward seeking MH support, and 55% had felt ashamed or uncomfortable about doing so. The survey data indicated that even when distress is present, many SA women remain hesitant about presenting themselves to services. These ideas are reflected in qualitative findings in both the survey and interviews:
"I believe that my mental health problems aren't serious enough to seek support, and I may be 'wasting' resources" —Survey Participant

"Growing up with these cultural expectations has at times made it harder for me to recognise and express when I was struggling" — Survey Participant

"I was hesitant at first because I was like, 'Oh, my issues are not so severe, I feel like I don't need it then'" — Participant C

Many participants spoke about not wanting to feel like a 'burden', voicing concerns that their issues were not 'valid' enough and a preference to manage their challenges independently. This internalisation of problems was not fixed, as some interviewees described how contextual transitions shifted their attitudes:
"[Transitioning to university] meant that I can make my own decisions. I can have some sort of autonomy in doing what I feel like I need to do, because I know it's my decision and it's not based on what other people think or what my family feels about getting help and their thoughts about therapy. It's not based on them. It's based on what I need" —Participant C

Participants also expressed how the university experience helped them become more confident in pursuing support. They felt that these transitions toward greater independence allowed them to feel more comfortable in advocating for their own needs, rather than worrying about external judgement. These realities are also deeply connected to the experience of South Asian daughters, who are often shaped by cultural expectations placed upon them. Intergenerational norms can pressure these individuals to present as high-functioning and minimise their personal distress in front of others. These dynamics help explain why South Asian women struggle to legitimise their own needs and where their hesitation may originate.

"You know, the eldest daughter, I feel, has all those pressures that just shouldn't exist, but it's like tenfold of what a normal person would have" —Participant B

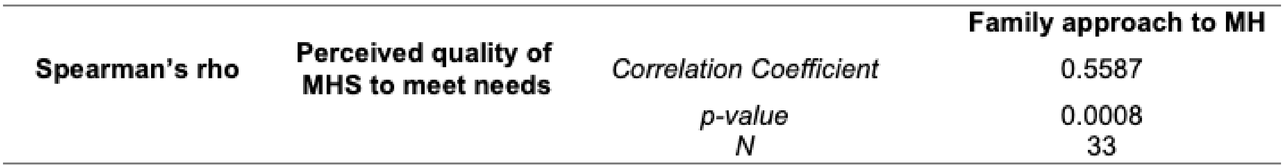
Across the participant group, the impact of family dynamics proved significant. 21 participants highlighted the relationship between their family's distance to accepting external help, with responses ranging from complete dismissal of MH to more neutral acknowledgements. Only nine expressed distinctly supportive family attitudes toward MH challenges; however, even within these accounts, support was conditional. For example, openness was limited to MH challenges stemming from "something that had physically happened", or support varied among different relatives.

These observations highlight how familial and cultural perceptions of mental health (MH) influence help-seeking behaviour. Two key themes emerged from participant responses.

First, the perceived quality of available MH support was analysed alongside views on how culture influenced help-seeking attitudes. When these paired responses were plotted, a clear pattern emerged: all respondents who rated MH service quality at the lowest level also reported that culture had a negative influence on their help-seeking. Conversely, those who gave the highest quality ratings overwhelmingly reported that culture had a positive influence.

To further explore factors linked to perceived service quality, a Spearman's correlation was run between ratings of MH service quality and participants' perceptions of their family's approach to MH. The analysis revealed a statistically significant positive association (see Table 1). This indicates that participants from supportive family environments tended to rate services more positively, while less favourable family attitudes were consistently linked to lower perceptions of service quality.

In short, individuals from backgrounds with less open support for MH also struggle to feel supported by formal services. Therefore, services must understand these family and cultural dynamics to resonate effectively with this group.



			Family approach to MH
Spearman's rho	**Perceived quality of MHS to meet needs**	*Correlation Coefficient*	0.5587
		p-value	0.0008
		N	33

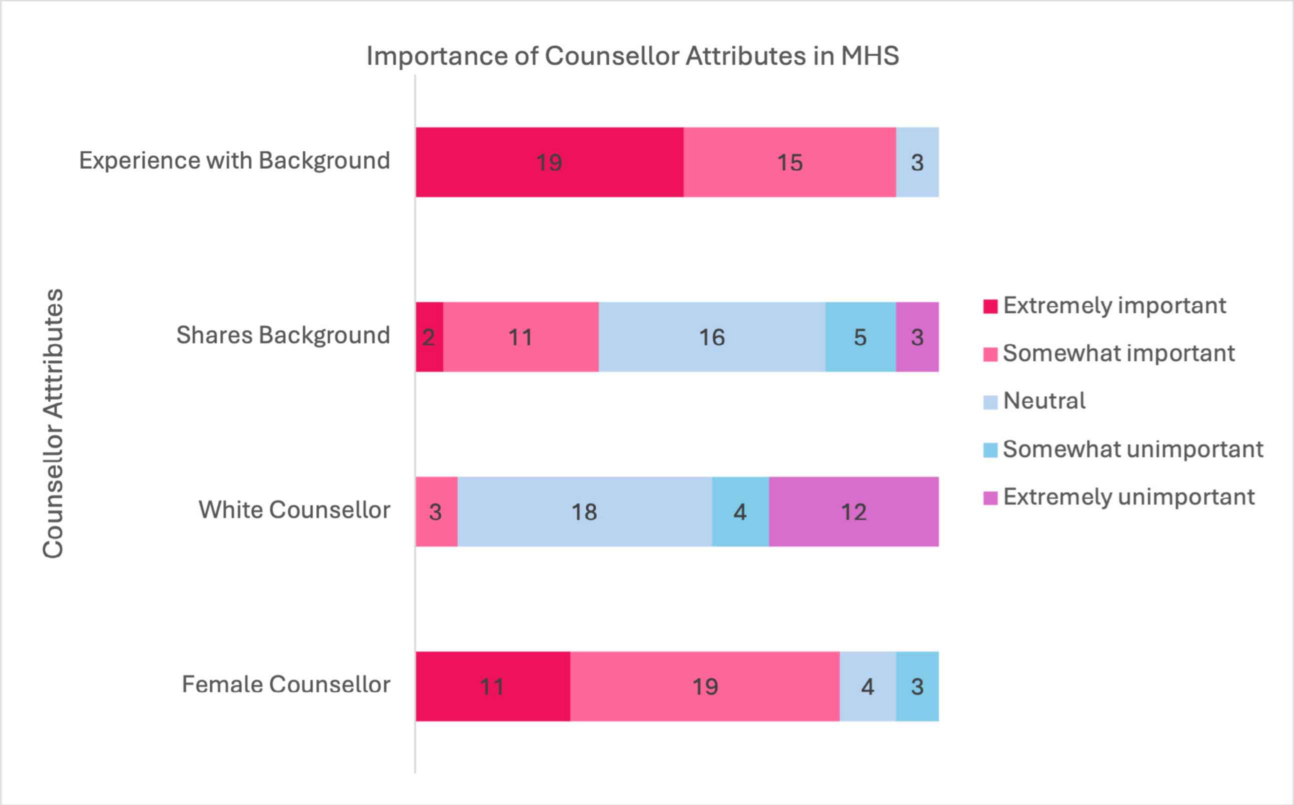
*p<0.05 (two-tailed), hence statistically significant

Table 1 Spearman's rank-order correlation between perceived quality of MHS and family approach to MH.

2.3 TRUST AND ANONYMITY

"I think accessing mental health is something that's like my last resort, almost. I don't want to say it, but it's something that I don't really consider because I feel like if I get judgement from one place, I might get judgement from the other. I built this whole thing of like, if my family aren't even receptive to it, then how are strangers going to be receptive to it?"—Participant B

For Participant B, family attitudes also influence the trust individuals place in services. As has been highlighted, a substantial proportion of individuals reported experiencing minimisation within mental health settings. Dismissal in their cases can foster mistrust and reinforce barriers to seeking support. Given the significance of these interpersonal dynamics, it was important to examine how individuals experienced MHS more broadly. 82.1% of participants reported that they could trust MH professionals with their experiences, indicating that a large proportion felt largely comfortable sharing with professionals. To explore what characterised a professional whom they could trust, the respondents were asked to rate the importance of various counsellor attributes within MHS (this question also encouraged responses from those without prior MHS experience). The findings are summarised in the graph below, with 81.1% rated it as important that their counsellor shared their gender. For many women, feeling safe within the therapeutic relationship appears closely linked to gender congruence, potentially due to the comfort and understanding that can be shared, which impacts the degree of self-disclosure. This correlation is especially significant when individuals face gender-specific issues.



"I like that it was a woman. I felt a bit more able to speak to her" —Participant A

"I think if [the counsellor] was female, I would have been much more comfortable because I would have been able to actually go into what I was feeling in terms of the pressures as a woman... I felt like he didn't ever experience that pressure" —Participant B

"Gender, for me, technically did matter at first, but now I've spoken to a trial counsellor, and she was like, honestly, gender may be something that's not as important compared to other things, unless you have certain gender issues" —Participant C

The survey data further underscored the importance of cultural sensitivity in MHS. Over half of the respondents (51.4%) considered it extremely important that their counsellor had experience working with people from their background, and an additional 40.5% rated this as somewhat important. The interviewees echoed this sentiment, with all three calling for better training of professionals to understand SA cultural norms and the complexities of their upbringing. In contrast, fewer participants prioritised the counsellor sharing their racial or ethnic background: 35.1% found this important, whereas a majority were neutral (43.2%). As a control, participants were asked whether it was important to them that the counsellor was white. This characteristic was predominantly rated as neutral (48.6%) or extremely unimportant (32.4%). The pattern suggests that, for many participants, the counsellor's race was not a primary consideration. For those who rated it as extremely unimportant, their rating may represent concerns about the cultural dissonance associated with White professionals:
"The advice that I got more from my CBT therapist, who was a white woman, was more helpful in the sense of bettering myself as a person, but the advice I got from the Asian counsellor on how to manage family dynamics and deal with cultural issues was much more helpful for me when it came to dealing with any cultural conflicts or anything like that. So I think I resonated more with my school counsellor,

who was Asian because she actually understood where I was coming from, and I feel like her advice really did help me more" —Participant C

"[My counsellor] being white and not like South Asian was a slight - not like an issue – 'cos she was really good, but sometimes she just didn't understand what it's like to be South Asian. I feel like Western therapy can be very individualistic" —Participant A

The small minority who rated this as somewhat important, conversely, could represent individuals who feel mistrust among Asian professionals:
"I realised that just because someone's of a South Asian background doesn't mean that they will be like you, and doesn't mean that they will not judge you, because I have received judgement from the same kind of people that I thought I was. So I think in that, in terms of that, you know, the politics teacher whom I used to confide in? She was a white British lady, you know, she was 40 plus years old. There was not much in common in terms of cultural background, but she understood me. She saw me, and I think that's what I valued most out of everything" —Participant B

Participants' perceptions of therapeutic safety and effectiveness are relational and contextual; it is not simply about ethnicity per se, but about whether the counsellor is perceived to be equipped to understand their experiences.

The final dimension of this research was the value of anonymity, which plays a critical role in enabling SA women to access mental health services. Participants emphasised the importance of speaking to someone who is not personally known to them in reducing the burden of disclosure:
"I prefer talking to someone who doesn't exactly know me because that just kind of makes it easier, as I feel like I'm burdening that person less" —Participant A

However, continuity with the same counsellor was also valued to avoid repeatedly explaining personal issues, highlighting the need to balance anonymity and trust. Concerns about breaches of confidentiality were raised, as one participant noted the erosion of trust when private information was shared without consent. When discussing her experience confiding in a teacher, Participant B explained that she *"told her not to tell anybody"*, but "*she went and told [her] head of year, who then contacted [her] parents*". Anonymity was also noted by participants in alleviating fears related to stigma impacting *"social, academic, and professional life"*, particularly within familial and cultural contexts. Survey comments mentioned *"being afraid of being found out by family"* and *"not being able to speak freely on the phone or video call, as everyone in the house would question"*. These findings reflect how many services become inaccessible, especially for those who wish to keep their identity and support-seeking private.

3. CONCLUSION AND RECOMMENDATIONS

University-age South Asian women tend to exhibit more internalised responses related to help-seeking. This research demonstrated the low likelihood of this group seeking mental health services and studied their behaviours under an intersectional lens to identify key determinants and patterns. The most prominent relationship drawn was the influence of family perspectives on participants' perceptions of mental health services. Individuals from less mental health–positive environments perceived these services as less able to meet their needs, calling for greater cultural understanding within mental health care. This study highlights that services should be made more approachable, leading to the following recommendations:

1. Integrated Care Boards should commission and mandate enhanced cultural competency training for primary care and psychological therapy providers. This should use co-designed training modules with South Asian community organisations and meet the aims of the

Patient and Carer Race Equality Framework.

2. Local authorities and employers should roll out anti-stigma campaigns in South Asian-dense areas and workplaces. These campaigns can be delivered through multi-language posters, social media campaigns and community- or employer-based workshops which signpost clinically verified NHS and charity resources.

3. Universities should expand mental health outreach through a formalised termly communication plan for mental health resources. This could include:
   - Mental health resources and information emails at the start and end of each term
   - Visible posters in high-traffic areas like libraries and SU common areas
   - Mental Health Support stalls at induction and fresher's fair

4. Government and local authorities should allocate funding within a 5-year framework to expand access to alternative therapies such as art therapies and designated wellbeing practices. These can be integrated into school and workplace wellbeing programmes, using culturally trained counsellors.

5. Charities/NGOs/academic institutes should commission the development of a secure digital platform that can be utilised in research for conducting anonymous interviews. This would enable participants to engage in interviews and remain contactable through encrypted messaging, with the protection of their identity from all parties.

6. NHS Talking Therapies should expand text-based therapy options, supporting patients who prefer anonymity.

7. The Department of Education should extend mandatory mental health first-aid training and cultural sensitivity modules for teachers and pastoral staff so early-support touchpoints are accessible to students of all background.


ALIZA MATHEW

CHAPTER EIGHT: THE PERINATAL MENTAL HEALTH EXPERIENCES OF SOUTH ASIAN MOTHERS

ANITA KAMBO

Maternity care in the UK has come under intense scrutiny in recent years as systemic racism continues to underpin stark inequalities in access, care and safety. As compared to their White peers, South Asian mothers experience delayed diagnoses and greater maternal mortality.

Perinatal mental illness (PMI) – the most common complication of the perinatal period (encompassing pregnancy, birth and two years post-birth) – is the leading cause of maternal death. South Asian mothers are not only at higher risk of PMI, but they also face greater barriers in accessing support, poorer experiences of care and worse outcomes. This has a significant and enduring impact on the wellbeing of mothers, children, families, and society as a whole and carries major cost implications. As such, preventing PMI is a public health priority.

These marked disparities are a result of systemic failures, with mothers often experiencing racial and cultural discrimination, stereotyping and insensitivity. Furthermore, conversations around PMI are often silenced within South Asian communities because of cultural expectations, stigma, and feelings of shame. The complex interplay of these structural and sociocultural barriers can prevent or delay mothers from getting the support they need and deserve, putting their safety and lives at risk.

There is a critical absence of evidence to understand and tackle these failings. This research seeks to provide a holistic understanding of the PMI experiences of South Asian mothers and make policy and practice recommendations for urgently needed tangible change.

METHODS

A choice of a creative focus group (in-person) or in-depth semi-structured interview (in-person or online) was provided to enable most comfortable preference. The focus group was conducted first, and emerging themes informed a flexible topic guide for interviews. Questions were open-ended, allowing participants to guide conversations. Questions about racism were intentionally omitted to avoid any steering or presumptions and instead enable this topic to arise organically, if at all.

As a South Asian mother with lived experience of PMI, the researcher's positionality supported a culturally responsive approach – facilitating authenticity, rapport, trust and openness. Given deep complexity surrounding PMI in South Asian communities, protecting emotional wellbeing took precedence. Mothers were encouraged to prioritise their wellbeing in ways that worked for them, including stepping away or withdrawing at any point.

The informal and low-pressure focus group took place in a trusted community centre. Relaxed creative activities were interspersed throughout to ensure it did not feel reductive, draining or exposing. Photovoice adaptations, guided I-poetry and eco-mapping facilitated accessible, open-ended and safe discussions. Participants could share via voice recording, drawing, or notes if preferred to speaking aloud. Sharing food together was an intentional element, reflecting cultural practices for connection and storytelling. Children were welcome so as to remove any childcare barriers. Mothers were given a wellbeing bag to support continued creative practice. These strengths-based approaches enabled meaningful knowledge-production whilst prioritising wellbeing. They facilitated collective healing, collaborative reflection, reimagination and solution building. This was important for countering historical trauma, dismissal and misrepresentation by institutions. This approach disrupted the power dynamics and extractive nature of conventional research – creating a validating space for joy, laughter, "good" tears, and sharing without fearing judgement.

Eligibility included identifying as South Asian, having lived experience of PMI, being over 18, and living in London. Recruitment was via flyers (electronic and paper) distributed across mental health, women's, South Asian and faith organisations; and advisory, lived experience and WhatsApp groups.

Discussions were recorded and transcribed. Identifying details were removed to ensure anonymity. Transcript were read multiple times for familiarisation, coded inductively and subjected to thematic analysis.

RESULTS

PARTICIPANTS

Fourteen South Asian mothers with experiences of PMI participated. Backgrounds included Indian, Pakistani, and Bangladeshi. Most were UK-born or arrived in early childhood, with three having migrated as adults. Twelve resided in London. Two mothers outside London participated due to limited local opportunities to *"have a voice."* Not all mothers had received formal diagnosis, but for those who had, this included postnatal depression, reactive depression, anxiety, obsessive compulsive disorder, posttraumatic stress disorder, and loneliness.

Three mothers took part in the focus group, and eleven in interviews. Despite variation in age, family context and background, their candid narratives revealed significant commonalities around systemic, cultural, social, and relational dimensions of PMI. The following interwoven themes reflect the complexity of these experiences.

1. "SYSTEMS THAT MISS US": RACISM, CULTURAL INCOMPETENCE & FRAGMENTED CARE

Conversations revealed a complex, painful and sometimes harrowing set of interactions with perinatal healthcare systems. Mothers reflected how *"a racist system,"* cultural invisibility, fragmented care, and missed opportunities shaped their sense of mental wellbeing, safety, agency, and trust.

1.1 SYSTEMIC RACISM & "NAVIGATING SYSTEMS NOT MADE FOR US"

Mothers faced structural, overt, and subtle manifestations of racism including assumptions about pain tolerance, family structures, supposed *"complaining,"* and willingness to endure poor care.

One mother described *"Mrs Begum Syndrome"* as a racist tendency in healthcare to dismiss South Asian women's concerns, which reflected her own experiences: *"it's institutional racism – when people look at you [pointing at skin colour], we're fobbed off as whining women."*

Structural racism in perinatal service design, *"based on White metrics",* left mothers feeling *"out of place"* or misunderstood: *"Services aren't fit for different cultures and communities."* One mother recounted her third labour experience: *"All my babies are on the same percentile, but suddenly you want to induce me – I'm under 5 foot, my baby's not going to be big!"*

These experiences created acute distrust, prompting self-protection and workaround strategies: *"You make choices because you don't trust the system to serve you well."*

"The system isn't fit for your needs, so you work around it with limited choices."

"I requested a caesarean – not out of preference – but out of fear of worse outcomes for Brown mothers."

Along with a broader legacy of distrust rooted in historic racial injustice, their experiences led mothers to remain silent about mental health struggles for fear of having their child removed: *"The fact that the trust and rapport to be open isn't there is a massive thing – this fear of having your kid taken away so not speaking to professionals."*

1.2 FEELING INVISIBLE, UNHEARD & DISMISSED

A dominant thread was a profound sense of not being listened to, believed, or taken seriously. Concerns about pain, labour progression, physical trauma, and mental wellbeing were routinely minimised or normalised. This created an enduring impression of being *"invisible," "silenced"* and *"less deserving."*

Mothers recalled traumatic experiences of dismissal of pain, often attributed to stereotypes of resilience or emotional excess. This led to delayed treatment, major complications, and emergency interventions:
"The trauma of being dismissed, that your pain is invalidated because you are Brown."

"I felt invisible – like we're supposed to be stronger than White mothers, expected to put on a brave face."

"Women go through horrific experiences to the point it puts them off having another child."

"They didn't stitch me up – they left me in stirrups bleeding. If my mum hadn't walked in and shouted, I don't know what would have happened to me."

One mother described dismissal of agonising pain over a prolonged period, resulting in a severely bruised cervix: *"she was brutal to the point where her checking me hurt more than my contractions. I was screaming in pain, I said it was hurting, but she wasn't listening. She had no intention of even easing up a bit, she said 'oh, it's just normal.'"*

Being denied mobility during labour despite no contraindications and knowing that was what their *"body needed"* often led to unravelling complications:
"My body was telling me I need to walk around but I was emotionally blackmailed to stay still, otherwise I'd put my baby at risk"

"My needs and instincts [to move around] were overridden by staff."

"I tore in labour – that wouldn't have happened had she allowed me to be mobile"

Mothers were silenced into *"being grateful for what we get"* and avoided being seen as *"another Brown person complaining."* They *"felt guilty taking up NHS resources."* Shame and confusion around seeking help contributed to mental health decline, some believing their postnatal depression and anxiety were directly linked to these experiences.

1.3 CULTURAL INCOMPETENCE & EMOTIONAL TOLL OF EXPLAINING

Repeatedly explaining cultural context to clinicians who lacked basic understanding left mothers feeling *"exhausted"*, judged and misunderstood. This emotional labour led to withdrawal from services, limited disclosure or seeking private therapy despite financial struggles:
"Mainstream therapists aren't equipped to understand the nuances of Asian communities."

"If somebody doesn't have understanding of your background, they mislabel it and mislabel you."

Culturally illiterate infant-feeding support also impacted mental wellbeing – inducing guilt,

shame, anxiety, reduced confidence, and confinement to home:
"Breastfeeding guidance doesn't take into account South Asian family dynamics of preserving modesty."

"Some professionals assume Asian women just know how to breastfeed."

"There's no guidance for weaning on a South Asian diet... how do we make daal for a six-month-old?"

Existing support for racialised communities was considered scarce, outdated and based on narrow assumptions: *"The professional South Asian first generation are overlooked – we don't need translation, we're not refugees. But we're not white. So, the racism we experience – it's just different."*

1.4 FRAGMENTED CARE & MISSED NEEDS

Absence of joined-up care across maternity and mental health services was a repeated concern. With focus on physical health, PMI symptoms routinely went unnoticed.

Two mothers with preexisting mental health diagnoses were not once asked about their mental wellbeing during the entire perinatal period: *"Even though I have a history of OCD, this has been completely ignored both times I've been pregnant."*

Others discussed histories of fertility struggles, baby loss or complicated pregnancies, where warning signs of PMI were missed, especially when mothers themselves were *"not in a place to draw the connections"*:
"It's taken seeing a private therapist for me to only just recognise how trying to conceive and pregnancy itself was massively related to my maternal mental health struggles"

Many saw a different midwife at every appointment, preventing trust and requiring repeated retelling:
"I was exhausted repeating everything to every different midwife... don't they talk to each other?"

"Continuity of human relationships and care is so important and that's massively missing."

Recently migrated mothers expressed unfamiliarity with navigating healthcare and administrative systems. One was not seen by any practitioner at all until she experienced an emergency at 36 weeks of pregnancy: *"Unless someone reaches out or notices you, you don't know what's out there."* Additional barriers – including housing, finances, language, migration status, and everyday tasks like navigating supermarkets – compounded PMI.

2. "A CULTURE OF HIERARCHIES" & GENDER ROLES: NORMS OF SILENCE & SACRIFICE

Mothers noted deep-rooted cultural norms around emotional endurance and suppression of distress. Conflicting with their lived realities, these idealised expectations left many feeling their struggles were not *"valid"* or *"legitimate,"* denying them *"permission"* to seek help or invoking severe self-criticism: *"I look back and feel so sorry for myself and how harsh I was – the level of expectation and pressure I put on myself."*

2.1 "GETTING ON WITH IT": STOICISM, STIGMA & MAINTAINING APPEARANCES

Mothers were shaped by older generations who modelled stoicism and silence. These inherited norms led them to internalise mental health struggles, and intensified self-critique, shame and pressure to *"just get on with it"*:
"You never saw your mum ill, even if she was, she'd get up and cook."

"There's this sense I should be able to deal with this because my mum got through it and it was much harder for her. So, it's an indulgence to have mental health issues."

Some described mental health as an alien concept within South Asian cultures – with PMI dismissed as *"just being hormonal."* For older generations, *"there's no such thing as mental health and being down."*

Others described stigma that framed PMI as *"weakness, failure or madness".* This created fear of judgement and pressure to conform to *"the good mother"* ideal, despite their better judgement: *"There's that need to show you have it together, that I'm a good mum, whatever that means. I know intellectually that's not right, and it just serves to be more isolating to have that attitude."*

Feeling compelled to *"keep the mask on"* was emotionally laborious:
"I felt I needed to present this appearance of competency."

"You put on that face that you're this superwoman, you've got it all together."

This *"culture of secrecy"* contributed to feeling *"gaslit"*: *"There's pressure to put on an appearance that everything is okay, better than okay. People don't openly talk about difficulties. That makes it even worse because it looks like everyone else is doing so well, and you feel why is it that something that should be so natural feel so hard?"*

Even when mothers disclosed mental health challenges to parents, openness remained limited:
"We just kept it between us, we didn't tell others."

2.2 "GOOD DAUGHTER-IN-LAW" IDEAL & MARTYRDOM NARRATIVE

The expectation to prioritise in-law and family needs above their own carried a heavy emotional toll. Mothers felt *"very over stretched",* having to *"muddle through."* Existing challenges of being a mother became *"further compounded by in-laws"*:
"Expectations are heightened in Asian families – in-law pressures to be looking or behaving a certain way or doing certain things"

"I was sick during pregnancy, and I still had to look after my sister-in-law"

"My in-laws expect that you just don't ask for help and you get on with it and you're a martyr"

"Everyone around you expects you to always be there, do everything"

Some described a sense of *"being watched."* Even choice over what she ate during pregnancy was eroded for one mother: *"you've always got your mother-in-law or sister-in-law watching and judging you – there's no privacy"*

Others experienced blame when it came to fertility: *"It was 'what's wrong with you?' It never occurred to them [in-laws] that it could be male infertility."*

Mothers longed for autonomy *"to just do things on your own terms and look after yourself and your child, rather than in-laws."* However *"speaking up"* felt impossible *"without being seen as the enemy".*

2.3 "A SECRET CLUB": SILENT SOLIDARITY & GENERATIONAL SHIFTS

Despite silence and taboo, mothers felt a sense of quiet solidarity from elder women: *"I suddenly came into a secret club when I had a baby. My mum, sister, aunts would ask 'how are you?' as if there was a recognition that this is a time when you're vulnerable, your mental health might be an issue, and maybe they've experienced that too."* This sense of support, however, was *"very hush-hush"*:
"It's not discussed with fanfare. But they were trying to let me know and asking me how I was"

"It would be within a very closed circle, acknowledged subtly, but not openly discussed."

Mothers noted generational shifts, with peers more open to discussing PMI: *"I found it easier speaking to my generation – there's more openness, there isn't the same stigma".* However, stigma was so ingrained for some, they struggled to share feelings even with receptive friends: *"I know I would be able to talk about it with my friends, but there's just something about motherhood that makes that feel harder."*

3. IDENTITY UPHEAVAL: LOSS, RENEWAL & RECONFIGURATION

Early motherhood was a period of stalled personal, professional and existential mobility, and profound identity upheaval and reconfiguration.

Mothers experienced a painful sense of suspended and unreachable ambitions or erasure of pre-motherhood roles, feeling *"moulded"* into being *"just a mother"*:
"I completely lost my sense of identity becoming a mum and that's all I can really identify with now. I'm really struggling to remember what life was like before the children."

"In South Asian cultures, it's expected your child should become your all...and you lose yourself."

"I've been trapped for so long, stopped doing things that I've wanted to do for so long."

In response to a Photovoice adaptation one mother wrote:

Dreams frozen in time
Past
Beauty, beautiful life, youth
Seems far away now
Observing from the sidelines the activity of the world

These words, she said, represented her experience of motherhood: *"I have all these ideas but no time to do anything with them. The combination of overwhelm, so much going on, so much change and stress – that makes all those things feel frozen."*

Newly formed *"lack of focus"* made it not only difficult to hold onto goals but also caused *"blurry lines"* between what was *"normal"* post-birth adjustment and what was mental ill health.

Some experienced an erosion of adult identity: *"I feel like a trapped child myself – that base thing that I wanted to do was not established."*

Others expected motherhood to bring clarity but instead felt lost or uncertain. They discussed *"messy and confusing"* journeys of identity reconfiguration:
"I feel so lost at times... trying to figure out who I am now."

"I hear other mums say it becomes clarifying... but I feel indecisive and unsure."

One mother felt *"lucky in finally clawing back"* pockets of time to *"reprioritise"* her sense of self, though competing priorities and roles still weighed heavily.

3.2 LOSS OF PROFESSIONAL IDENTITY & FINANCIAL INDEPENDENCE

Mothers expressed loss of professional identity, feeling pressured to pause or relinquish careers. Some feared being viewed as *"irrelevant"* on return to work. Loss of financial independence and being *"financially insecure and reliant"* on others felt significant: *"[It's expected] your child should become your all, but what about my work and financial independence?"*

Working mothers experienced stress of balancing employment with other roles expected of them:

"I'm finding myself very overstretched trying to be a mother, a diligent employee and all the other roles that you assume – a daughter, daughter-in-law, a partner."

"There's high work responsibilities and navigating that alongside everything else that comes with having a young child – it has been overwhelming and definitely felt unmanageable at times."

3.3 RENEWAL OF CULTURAL IDENTITY FOR FUTURE GENERATIONS

Motherhood prompted renewed commitment to cultural identity to ensure continuity for children. There was a fear that without this, children would be detached from their heritage, especially for those living away from wider family or whose children were of mixed heritage: *"We live where there aren't Indian families and I'm married to someone White, so having cultural awareness for me and my son was important."*

"I was desperately trying to connect with something so that it wouldn't feel that this was a White baby."

Mothers sought opportunities to connect children with their heritage: *"when my older sister visits from Pakistan, she gives my son access to our culture."* Everyday practices became symbolic: *"I made chapatis obsessively to give my child a smell of home."*

4. LONELINESS & "ISOLATION IN MIDST OF OTHERS"

Isolation was a recurring theme – not just being alone, but feeling cut off from places, people, routines, and identities – with motherhood intensifying feelings of *"disconnection."*

4.1 EMOTIONAL LONELINESS

Mothers described emotional loneliness amid constant responsibility, uncertainty, overwhelm, and fear of *"getting things wrong"*: *"I had no clue what I was doing, it led to feeling so insecure and anxious and lonely."*

Younger mothers, particularly, lacked confidence and felt unprepared or *"trapped"*: *"I was a mother too early. It would have been nice to wait until I knew myself first, felt maturer and able to cope and speak up for myself."* Whereas older mothers felt excluded among younger peers: *"My age made it feel isolating, I felt so much older than everyone else... this feeling of otherness."*

Isolation was apparent even whilst surrounded by others, particularly when cultural expectations prevented openness. One person perceived *"isolation in the midst of others."* For another, sleep deprivation exacerbated emotional detachment: *"I just felt sad. I showed no emotion, no connection – I was a robot."*

4.2 ABSENCE OF "A VILLAGE"

Mothers reflected on extended family systems that raised them: *"There was this mentality of 'a village to raise a child' when I was young. I was looked after by my grandma, my aunts – there was an immense support network".*

Absence of similar instrumental support – where *"now you just get left in your little units to get on with it"* and *"have no one to take the baby just for ten minutes"* or *"ease the practical burden"* – heightened emotional burden. Mothers felt *"exhausted"* and unable take care of their mental wellbeing: *"All your energy and focus is on caring for this tiny newborn but there's also this sense that you really need looking after as well. I had this really strong sense I just wanted my mum or my sister; I wanted to be kind of held and that didn't happen much."*

Recently migrated mothers described bureaucratic systems when seeking temporary stay for family: *"We applied for my mum's visa so she could help me with the baby, but they said it was stuck in the embassy for 1 1/2 years".*

4.3 PRACTICAL ISOLATION

Structural barriers – housing, transport, finance, and language – amplified isolation and confinement, inhibiting access to support: *"If you're stuck in your house, you don't have the capacity to find services."*

Living in multi storey flats, with no outdoor space and no lift or level-access for buggies, was incredibly isolating for some:
"I was on the third floor with no lift and a baby, so it was just difficult – leaving the property was really difficult."

"I was living in a one-bedroom flat and found myself pregnant with no garden and trying to take a pram up and down three flights of stairs – just so much isolation."

Local infrastructure failures further shrank mothers' worlds: *"The week he was born, my local tube station lift went out of service, it was out for the whole year. That really shrunk where I could go."* Some relied on just one or two locations they could access safely with a buggy: *"We ended up going to just one place. We'd walk there every day. It was convenient but it made my world very small."*

5. "HOLDING ON & HOLDING EACH OTHER": PATHWAYS TO COPING

Given widespread systemic neglect, mothers came to rely heavily on individual resilience, selfcare strategies and informal support networks to protect their mental wellbeing.

5.1 PARENTAL AND SIBLING SUPPORT

Despite the emotional weight of cultural expectations, mothers received invaluable support from their parents and siblings for which they felt immensely grateful. Temporarily moving in with parents, for some, was *"lifesaving"*: *"My mum, dad, brother, sister – their support really made a huge difference. I'm very very lucky."* One mother described the impact of her family after particularly neglectful care during labour resulted in major complications: *"If it weren't for my mum and dad, I don't think I would have got through it, I really don't. I don't think I would have come out the other end."*

Mothers and sisters, in particular, provided intuitive and nurturing restorative support during early motherhood:
"Other women just know what you need without you asking for it, and that was massive – you just feel nurtured and cared for. My sister and my mum – when they were there, I felt held by them."

"When my sister comes around, I can just relax, have a nap or do something for myself."

Cultural practices of extended family – traditional meals, faith, and generational storytelling – also provided comfort, connection, and belonging during a period of identity transition.

However, even in the midst of family support, mental health remained undiscussed: *"Even though we didn't openly talk about my postnatal depression, practically and emotionally all that love and support was there from my parents, and really that's all I needed."*

5.2 SUPPORT FROM STRANGERS & UNEXPECTED SOLIDARITY

Small acts of relational care from unexpected sources – neighbours, community members, and strangers – were deeply impactful. One mother returned home post-birth to an unknown neighbour offering support: *"I'll never forget that encounter. She said, 'I know what it's like, you're not alone.' It touched me so much."*

For some, being amongst people outside their circle made it safer to open up and *"say what you* *want*": *"Trying to talk to people you have an attachment with, they're personally invested. As hard as they try, they'll never be neutral."* One mother received support in a journalling class: *"I was able to feel safe and I broke down. It was so nice to have them come up and hug me – you need those spaces where you don't actually know anyone".*

5.3 SELF-HELP & STRENGTH FROM ADVERSITY

Mothers were keen to use resilience that emerged from their experiences of PMI to support others by *"turning negative situations into something positive and sharing stories"*: *"I tell ladies to focus on the good things, because services don't hold your hand. So, we have to build ourselves up again."*

Self-help strategies for mental wellbeing included spirituality, faith, creativity, journaling, and gratitude: *"Sometimes you have to see the little light – that's what keeps me going."*

6. REIMAGINED VISIONS OF SUPPORT

Drawing from their experiences of being repeatedly failed by existing systems, mothers articulated clear visions for creating, redesigning and improving PMI support at relational, educational, community and service levels.

6.1 CULTURE-WIDE, FAITH-BASED & PUBLIC EDUCATION

Training in self-advocacy was deemed urgent *"to speak up"* within structurally racist maternity systems. Education on female health, for South Asian communities, was felt necessary to challenge gender stereotypes and destigmatise PMI. Mothers emphasised the need to target boys, not just girls, and span generations. Understanding how PMI *"shows up"* was considered essential, given that mothers often struggle *"to join the dots".*

Faith institutes – *"mosques, gurdwaras, temples"* – and religious texts – *"hadith or prayers"* – were considered key to normalise PMI: *"If faith leaders spoke about it, my mum would take it seriously."*

Mothers also felt optics from prominent South Asian public figures would be powerful: *"Someone very visible – some Bollywood star who's been through it. Or if postnatal depression was a storyline, there'd be widespread visibility."*

6.2 COMMUNITY & PEER SUPPORT

There was a strong desire for peer networks in trusted community hubs *"where cultural norms are just understood"* without explanation: *"Somewhere where we all resonate, you want banter with people who understand your background".*

Peer networks would span pregnancy through postpartum, with *"cohorts of women that have tools, knowledge and are equipped to support each other".* Online and in-person, groups would address practical and holistic needs – exercise, healthy eating, housing, and finance – because *"mental health doesn't exist on its own"*: *"We could share practical tips like recipes for weaning on a South Asian diet".*

6.3 SYSTEMIC & SERVICE-LEVEL CHANGES

Whilst it was felt *"resisting a racist maternity system is not an option,"* need for culturally literate or matched clinicians who *"see you as you"* and *"meet you where you are"* was emphasised. Mothers called for continuity with the same practitioner, longer appointments, relational time, clear follow-up, and proactive signposting at existing contact points.

7. CONCLUSION & RECOMMENDATIONS

This research reveals that siloed maternity and perinatal mental health (PMH) systems – marked by systemic racism and cultural incompetence, widespread fragmentation, and lack of accountability – are failing South Asian mothers throughout pregnancy, birth and the postnatal period. This is both causing and exacerbating PMI, eroding trust and accessibility, and suppressing disclosure. These institutional harms are compounded by social, cultural, and relational forces that intersect to shape PMI in profoundly unequal ways for South Asian mothers. Urgent action is required to address these entrenched inequities.

The findings of this research call for the reconceptualisation of policy and practice. The following recommendations are made in line with the NHS 10 Year Health Plan, the NHS England Core20PLUS5 and PCREF – specifically in relation to the domains of prevention; reducing inequalities in maternity and severe mental illness healthcare; person, community and culturally centred care; improving experience and trust; equitable access; accountability and outcomes monitoring; coproduction; and wider determinants of community and racial inequity. It is recommended that the upcoming National Maternity and Neonatal Taskforce, which is being established to develop and oversee the implementation of a new national action plan, takes into consideration the findings and recommendations of this research.

ANTI-RACISM TRAINING, PRACTICE & LEADERSHIP

Commencing with the next commissioning and revalidation cycles – NHS England, Integrated Care Boards (ICBs), NHS Trusts, and professional bodies (RCM, RCOG, RCPsych, RCGP, NMC) must introduce mandatory annual training for staff and students on anti-racism and cultural responsiveness and safety. Training and practice standards must be embedded across PMH and maternity services, and co-designed with experts-by-experience to include:

a. PMI presentations within cultural contexts
a. Recognition and avoidance of racialised assumptions
a. Skills in active listening, critical self-awareness, cultural humility, curiosity, respect, compassion, empathy and flexibility
a. Specialist training for PMH practitioners on culturally congruent assessment and intervention, faith-integrated conversations, and collaborative safety planning
a. Increased representation of South Asian mothers in leadership roles

CONTINUITY OF CARER

Within 12–24 months – NHS England, ICBs and NHS Trusts must implement practice that prioritises South Asian mothers for Continuity of Carer maternity models, ensuring the same midwife or clinical team throughout pregnancy, labour, and postnatal period.

PMI SCREENING

NHS Trusts and Local Authorities (LAs) must immediately embed proactive and enhanced PMI screening and signposting at every existing perinatal touchpoint. This includes routine appointments, scans, and screenings taking place within GP, maternity, midwifery and health visiting services. Screening must adopt narrative-based questions and culturally literate tools and language about how PMI symptoms may present– all of which must be co-designed with experts-by-experience.

EXTENDED CONSULTATIONS

ICBs and NHS Trusts must ensure that GP, Maternity and PMH services offer extended consultations for mothers with complex needs or family dynamics, prior trauma, or migration-related barriers.

CULTURALLY-MATCHED THERAPISTS

NHS Perinatal Mental Health and Talking Therapies services must partner with organisations specialising in racialised PMI to develop a workforce of culturally matched or skilled therapists.

INFANT-FEEDING SUPPORT

Midwifery and Health Visiting services must partner with experts-by-experience, the Breastfeeding Network and other key infant-feeding support organisations to co-design and deliver culturally responsive infant-feeding support.

NATIONAL ACCOUNTABILITY & ANTI-DISCRIMINATION SAFEGUARDS

Within 12 months – NHS England and DHSC must integrate the following into the Maternity Disparities Taskforce:

a. PMH equity indicators for South Asian mothers, including routine monitoring of PMI prevalence, screening rates, referral timelines, Continuity of Carer access, and outcomes.
a. National guidance protecting mental health disclosure, ensuring it does not trigger disproportionate safeguarding interventions.

ANTI-STIGMA EDUCATION & PUBLIC AWARENESS CAMPAIGNS

LA Public Health teams must partner with VCSEs, Faith Organisations and prominent South Asian public figures to deliver community education programmes and public awareness campaigns, co-designed with experts-by-experience. These must raise awareness about and normalise female health issues across the lifespan (menstruation, fertility, pregnancy, perinatal period, menopause) including how PMI might present. These should be inclusive of children, young people and gender and incorporate faith-informed messaging. This should be piloted within 6–12 months, with evaluation after one year.

STRUCTURAL BARRIERS

The Home Office must prioritise fast-tracking visitor visas for family providing postnatal support.

LAs and transport operators (e.g. TfL) must improve step-free access in existing housing blocks, ensure new housing meets accessibility standards, prioritise lift maintenance, and improve accessible routes at stations.

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ANITA KAMBO

CHAPTER NINE: 'CHRONICALLY SEEN' NAVIGATING THE INTERSECTION OF 'RACE', GENDER, AND CHRONIC ILLNESS FOR BLACK WOMEN IN THE UK

ABIGAIL ARLENA GREEN

This research study is a critical exploration of the often overlooked and underrepresented experiences of Black women living with chronic, hidden disabilities in the UK. The findings from this research aims to shed light on their unique challenges and provide recommendations that are deeply shaped by their voices, lived experiences, and the resilience they demonstrate in navigating both healthcare systems and societal expectations.

At 24, I was diagnosed with Stage 5 Chronic Kidney Disease (CKD), a condition that has profoundly reshaped my life. As a Black woman navigating chronic illness, I share many of the experiences and challenges faced by the community I chose to work with. Drawing from my lived experience as a Black woman with a hidden disability, I bring a unique and informed perspective on the intersection of 'race', gender, and disability, and how these factors collectively shape experiences within healthcare systems and broader society. I conducted this research from the position of an 'insider,' as described by Seale (1999), meaning that my personal experiences informed my approach to the study. However, the findings I present are derived solely from the interviews I held with the Black women I engaged with. While my own experience as a Black woman with a chronic illness motivated me to explore this topic, my research was driven by a broader desire to amplify the voices of Black women who often remain unheard in discussions surrounding health and disability. I believe it is both important and empowering to centre their stories, not only to uplift and validate their experiences but also to contribute to a larger conversation that can spark positive change. Too often, the unique intersection of 'race', gender, and disability is overlooked in mainstream health discourse, and this research aims to shift that narrative by placing Black women at the forefront of the discussion.

The key findings from this research highlight the compounded challenges Black women with chronic, hidden disabilities face, including systemic dismissal and disbelief in healthcare settings, the intersectional impact of racism and sexism and the importance of age and visibility in navigating their health experiences. This research also emphasises and speaks to the empowering role of community spaces in amplifying their voices and advocating for change.

Trigger Warning: The themes explored in this research include experiences of dismissal, discrimination, racism, sexism, ageism, and health-related trauma. It's important to practice self-care when engaging with the findings from this research due to the sensitive nature of these themes.

Acknowledgements: I extend my deepest appreciation to the participants involved for their time, transparency, strength, and vulnerability in sharing their experiences. A heartfelt thank you to colleagues at ROTA for creating space for this research, and to all those involved in their wonderful Research Partnership Programme for their continued support.

1. BACKGROUND

Existing literature consistently demonstrates that chronic illness and disability are not experienced uniformly, but are shaped by intersecting social identities such as 'race', gender, age, and class. Crenshaw's (1989) foundational theory of intersectionality has been widely applied within health research to show how overlapping systems of oppression produce distinct and often compounded health inequities. Within the UK context, scholars have increasingly highlighted that Black women experience disproportionate barriers to diagnosis, treatment, and validation within healthcare systems. Research on racialised health disparities in the UK indicates that Black women are more likely to report negative healthcare encounters, including being dismissed, disbelieved, or having symptoms minimised by healthcare professionals. These experiences are particularly pronounced for individuals living with chronic or 'hidden' illnesses, conditions that lack 'visible' markers and therefore rely heavily on patient testimony. The marginalisation experienced in healthcare settings often mirrors and informs similar patterns of exclusion in other institutional spaces. Consequently, the systemic biases shaping the healthcare experiences of Black women living with chronic, yet hidden, conditions frequently extend beyond clinical settings and into professional environments such as the workplace.

A significant historical factor that continues to shape these disparities is the colonial legacy embedded in the healthcare system. Historically, the healthcare system has been shaped by colonial legacies that continue to influence how women of colour, particularly Black women, are perceived and treated in medical settings. Colonial practices of racial hierarchies, medical racism, and the marginalisation of non-Western health practices have had lasting effects on the trust and accessibility of healthcare for Black women. These colonial frameworks, which often position Black bodies as 'other', persist in contemporary healthcare systems, leading to continued stereotyping and invalidation of Black women's health experiences. This legacy informs not only how Black women's conditions are diagnosed but also the care they receive and their ability to navigate healthcare systems effectively. By acknowledging the colonial roots that still shape healthcare today, this research aims to further dismantle the systemic barriers that hinder the health and wellbeing of Black women and work towards creating spaces where their experiences, needs, and identities are both validated and respected.

Despite a growing body of research, significant gaps remain. Much of the existing UK literature examines 'race', gender, or disability in isolation, failing to centre the specific, intersectional experiences of Black women living with chronic and often invisible conditions. Additionally, patient advocacy and inclusion-focused policy interventions are underexplored within empirical research. This study directly addresses these gaps by foregrounding Black women's narratives and examining how intersecting identities shape experiences of healthcare, self-advocacy, and workplace inclusion. My research seeks to speak directly to how Black women navigate the 'invisibility' of the conditions they live with, the invisibility these women face as a product of their 'race' and gender and how these women create spaces for their voice and advocacy. In doing so, my research contributes critical evidence to inform more equitable healthcare practices, advocacy roles, and inclusive workplace policies within the UK context.

2. METHODS

To explore the experiences of Black women living with chronic conditions, I conducted semi-structured one-on-one interviews, with a small pool of participants, as a Peer Researcher. This approach allowed for in-depth conversations, providing participants with the opportunity to share their personal stories while also ensuring flexibility to explore emerging themes. The semi-structured format of the interviews provided a balance between guided questioning and the freedom for participants to express their experiences in their own words. Creating space for their voices was essential, as it empowered participants to shape the narrative and allowed their lived experiences to directly inform the research, ensuring that their perspectives were at the forefront of this study.

To engage and recruit participants, I designed a poster that was circulated through community groups, contacts and networks that I'm actively part of. This approach facilitated access to participants whose lived experiences closely aligned with the focus of the research. The quotes included in this body of work are directly from interviews conducted with participants. To maintain their anonymity and respect their privacy, all names have been withheld, and participants remain unnamed. These voices are shared with the utmost care and integrity to preserve their confidentiality.

Given the sensitive nature of the themes explored, thorough ethical considerations were imperative. All participants were fully informed of their right to withdraw from the study at any stage, the measures in place to ensure anonymity and confidentiality, and the support and self-care resources available to them should participation evoke emotional distress. Informed consent was obtained from all participants before their full involvement in the research.

3. KEY FINDINGS: NAVIGATING INTERSECTIONAL INVISIBILITY AMONG BLACK WOMEN LIVING WITH CHRONIC HIDDEN ILLNESS

3.1 LACK OF REPRESENTATION AND THE ERASURE OF BLACK WOMEN'S ILLNESS NARRATIVES

A central finding of this research is the pervasive lack of representation experienced by Black women living with chronic illness within UK healthcare narratives, clinical materials, and provider expectations. Participants consistently reported that dominant depictions of illness and disability did not reflect their bodies, experiences, or cultural realities. This absence extended beyond visual representation to include language, case studies, and clinical assumptions that implicitly centre White, male, or visibly disabled bodies as the 'normative patient experience'. This finding aligns with existing UK research that critiques the racialised construction of the "default patient" within medical frameworks (Nazroo et al., 2020). Participants described feeling as though their experiences existed outside what medicine was designed to recognise or respond to, particularly when their conditions were invisible, fluctuating, or poorly understood. The lack of representation also shaped clinical encounters. Participants noted that healthcare providers often appeared surprised or sceptical when Black women presented with conditions commonly associated with other demographic groups. This reflects broader patterns in which racialised assumptions influence diagnostic reasoning, leading to delayed or missed diagnoses. For Black women with chronic hidden conditions, my findings revealed that invisibility operates on multiple levels, such as their illness remaining 'unseen' and their identity being further marginalised.

"We need more spaces where we can see people who look like us, who truly understand and share our experiences as Black women. Not just to cry together, but to empower each other, celebrate our resilience, and find joy in living despite it all, supporting one another in ways that society often fails to because we don't matter enough."

Participants described significant barriers to self-advocacy, rooted in the disconnect between their lived experiences and narrow, stereotypical ideas of what disability or chronic illness 'looks like'. Many felt compelled to repeatedly justify their symptoms, limitations, and needs, often encountering disbelief or minimisation from healthcare professionals, employers, and even family members. This finding resonates with literature on injustice in healthcare, where patients from marginalised groups are less likely to be viewed as credible knowers of their own bodies. For Black women, self-advocacy was further complicated by racialised and gendered stereotypes, including expectations of strength, resilience, and emotional containment. Participants reported that assertiveness was frequently misinterpreted as exaggeration or aggression, while passivity risked being ignored altogether. The emotional and cognitive labour required to self-advocate emerged as a hidden burden of chronic illness. Participants described having to research their conditions extensively, prepare for appointments, and strategically frame symptoms to be taken seriously. This labour was particularly pronounced in cases involving hidden conditions, where the absence of visible markers heightened scepticism. Rather than empowering patients, self-advocacy often became a survival strategy within systems not designed to listen to Black women.

Despite the lack of representation and barriers to self-advocacy, some participants reported using this absence as a catalyst for their advocacy work, creating and sharing personal narratives through their own lens as Black women. Although not all participants, a number shared how they have personally used social media platforms or organised events to raise awareness about their healthcare challenges and lived experiences. This act of self-advocacy revealed how Black women, who often remain 'unseen' in broader discussions surrounding disability, have taken the initiative to create their own spaces where their voices can be heard, ensuring they are actively shaping the conversation about chronic illness from their unique perspective.

3.2 WORKPLACE INCLUSION AS EITHER A SITE OF HARM OR A POSSIBILITY

Workplaces emerged as critical sites where inclusion could either be actively fostered or systematically undermined. Participants' experiences varied widely, with some describing supportive environments that offered flexibility, understanding, and accommodations, while others encountered rigid policies, stigma, and punitive responses to disclosure. Consistent with UK disability employment research, participants noted that chronic illness accommodations were often framed as exceptional rather than standard. For Black women, requesting adjustments carried additional risks, including racialised perceptions of incompetence or unreliability. Several participants expressed concern that disclosure would negatively impact career progression, job security, or professional credibility.

"It feels like I'm always under a microscope at work."

The intersection of 'race', gender, and illness shaped how participants were perceived in the workplace. Black women described being scrutinised more closely than colleagues, with absences or reduced capacity viewed as personal failings rather than legitimate health needs. These findings echo studies showing that Black women are less likely to receive workplace adjustments despite comparable or greater levels of disability-related need. However, participants also identified inclusive workplaces as transformative spaces. Where managers demonstrated trust, flexibility, and cultural awareness, participants reported improved wellbeing, productivity, and a stronger sense of belonging. This highlights the potential for workplaces to function not merely as sites of exclusion, but as environments where intersectional equity can be meaningfully enacted.

3.3 THE INTERSECTION OF RACISM, SEXISM, AND AGE IN HEALTHCARE ENCOUNTERS

Participants overwhelmingly described their experiences of chronic illness as inseparable from the intersecting forces of racism and sexism. Healthcare encounters were frequently shaped by implicit biases that positioned Black women as either exaggerating symptoms or possessing higher thresholds for pain, assumptions that have been widely documented in UK and international health research. These intersecting biases influenced diagnostic pathways, treatment decisions, and communication styles. Black women frequently expressed feeling spoken over, dismissed, or infantilised during consultations, particularly when presenting with non-specific or fluctuating symptoms. Such experiences reflect what scholars describe as 'intersectional invisibility', where individuals who don't fit 'dominant prototypes' are overlooked within institutional settings. The impact of racism and sexism was not limited to individual interactions but was embedded within structural processes, according to the experiences shared by participants. Their experiences demonstrated how healthcare systems often fail to address the intersectional nature of discrimination, resulting in diminished trust and poor health outcomes for Black women.

“Intersectionality isn’t just a buzzword for me - it’s the reality of how my race, gender, class, and disability intersect and shape every part of my life. It’s why I face challenges no one else does, and why my lived experience as a Black woman with a disability is uniquely mine.”

While racism and sexism were consistently identified as critical factors shaping the healthcare experiences of Black women, age also emerged as a significant factor in shaping how these women navigated their chronic conditions and asserted their visibility. Although not initially considered a key variable, age was identified as crucial in how enabled Black women felt to advocate for their health and create visibility for themselves. Out of the women I spoke to, younger Black women (aged 18 - 34) reported heightened scepticism from healthcare providers, with their symptoms often attributed to stress, anxiety, or lifestyle factors rather than being thoroughly investigated clinically. This age-related invisibility meant that their health concerns were often minimised, and they were perceived as “too young” to be seriously ill. On the other hand, older participants, while sometimes afforded greater legitimacy in their healthcare interactions, still encountered ageist assumptions that framed their illness as inevitable or unremarkable. These assumptions reinforced the notion that chronic illness is a natural part of ageing, further diminishing the urgency of their symptoms and leading to delays in care.

“I’m always the youngest patient at the clinic I go to. I see Black women, but they’re much older. Then I see women my age, but they’re not Black. I often wonder if the fact that I’m a young Black woman has influenced how people treat me and my disability.”

The intersection of age, ‘race’, and gender created a compounded layer of invisibility for Black women, particularly in healthcare settings. These compounded forms of invisibility were not limited to healthcare interactions but also extended to their workplace experiences. Younger Black women, in particular, faced pressure to maintain uninterrupted productivity despite their chronic conditions. Older Black women encountered assumptions about their decreasing ability to contribute effectively, contributing to ongoing discrimination in the workplace. These findings underscore the need to understand age not as an isolated factor but as an intersecting axis of marginalisation, shaped by ‘race’ and gender, which significantly impacts how Black women navigate chronic illness. My findings revealed that age plays a crucial role in how Black women are able to create visibility for their experiences, whether through healthcare systems, in the workplace, or within broader social contexts.

3.4 AFFIRMING VERSUS EXCLUSIONARY SPACES OF BELONGING

Participants identified clear distinctions between affirming and exclusionary spaces in their lives. Online communities, peer networks, and select professional environments were frequently described as validating spaces where participants felt seen, believed, and supported. These spaces played a critical role in mitigating isolation and fostering collective understanding of chronic illness experiences. In contrast, healthcare settings, workplaces, and family environments were often described as exclusionary. Participants reported feeling misunderstood or judged by family members who struggled to reconcile invisible illness with cultural expectations of strength and endurance. Within healthcare and employment contexts, exclusion was often subtle but persistent, manifesting through microaggressions, disbelief, or procedural barriers. The importance of affirming spaces aligns with research on peer support and community-based health resources, which emphasises the value of shared lived experience in countering institutional marginalisation. For Black women, affirming spaces were not merely supportive but essential to survival, offering counter-narratives to dominant discourses that rendered them invisible.

"As Black women, some of us, not all but some of us, don't fit into the disability mould. We're not the definition of disabled that society wants to cater for. Society has branded us as strong, as resilient, as immune to struggles and hardship and tears. I'm not surprised workplaces can't support us when society constantly tells a story about us which says we don't need support, or kindness, or care."

3.5 IDENTITY AS BLACK WOMEN AND THE MEDICAL GAZE: NAVIGATING HYPERVISIBILITY AND INVISIBILITY

A significant number of the women reported waiting for years to receive an accurate diagnosis, enduring multiple referrals, misdiagnoses, and sometimes inappropriate treatments before the correct diagnosis was made. These delays were frequently attributed to healthcare providers who either minimised their symptoms or wrongly attributed them to non-medical causes. However, participants were adamant that these delays were not due to disengagement from healthcare services. Instead, they were symptomatic of deeper systemic failures, including failures to listen to their concerns, recognise their pain, and provide timely, appropriate care.

"When I enter any space, my Blackness is undeniable. My gender may be assumed, but my Blackness is always visible. I don't want to hide it, but it means I often face challenges related to my race before my disability, even though both are equally important to me. In medical spaces, I feel both seen and unseen at once. It's hard to explain, but even harder to navigate."

Throughout my interviews, the theme of 'being disbelieved' stood out as a consistent and powerful narrative. Many of the women expressed feeling dismissed or misunderstood, even after receiving a diagnosis. This sense of disbelief extended to how their conditions were perceived by healthcare providers, who often questioned the severity or legitimacy of their symptoms. The women spoke about how, in response, they felt forced to overexplain their symptoms, advocate tirelessly for themselves, and sometimes even adopt strategies to 'prove' their disability. This phenomenon was not just about feeling 'disbelieved' in a medical context, but extended to the very essence of how their bodies were understood, or rather misunderstood, by healthcare professionals and society at large. The emotional toll of this invalidation was clear; participants described a sense of isolation and frustration when their lived experiences did not align with the conventional expectations of what an illness or disability should 'look like'. This feeling of being 'dismissed' or 'disbelieved' was not only emotionally taxing, but it also added a layer of complexity to their healthcare journey. Many reported feeling as though they were being "too emotional" or "overreacting," even when their symptoms were clearly impacting their lives.

"As a Black woman, navigating racism, sexism, and ableism every day is exhausting. I've had moments on public transport where I've needed a seat, and people either ignore me or question why I'm sitting down, not seeing the pain I'm in. Or when I try to use the disabled toilets, even with my Access Card, and I'm challenged, like I have to prove I deserve that space. It's like the world constantly questions my right to exist, to take up space, to be seen and heard. It's hard, and it's tiring, but you keep pushing through because you have no choice."

In navigating the disbelief, many participants found that one way to assert their visibility and reclaim a sense of self-worth was through the creation of online communities. These spaces became essential for Black women to share their experiences, support each other, and validate their struggles in a world that often made them feel invisible. For example, several participants spoke about joining or establishing online forums specifically for Black women with chronic illness, where they could engage with others who understood and shared their unique challenges. These platforms not only allowed for shared stories but also provided emotional and psychological support, enabling participants to find solidarity in their collective experiences. One participant described how being able to "finally be believed" within these online communities was an act of empowerment, where she could openly discuss her symptoms without fear of being doubted or dismissed. Another noted how such spaces also allowed for mutual advocacy, where women could exchange tips on navigating healthcare settings, share resources, and even discuss strategies for how to assert their rights within workplace environments. These online communities became and continue to act as vital affirming spaces that provide participants with a sense of visibility, representation, and belonging that was often denied in physical healthcare and workplace settings. Through these networks, Black women could experience the validation of their lived reality, creating a visible space for themselves and others often rendered invisible by dominant systems of care and societal perceptions. The creation of these digital spaces also allowed for a collective effort to challenge and resist the broader systemic forces of invisibility that often surround Black women's health, particularly with chronic and invisible illnesses.

Furthermore, participants consistently articulated that their identity as Black women fundamentally shaped how their chronic illness was perceived, treated, and understood. Rather than being incidental, 'race' and gender were central to clinical encounters, influencing tone, assumptions, and outcomes. This finding supports intersectional health scholarship that critiques the neutrality of the medical gaze, arguing that it is shaped by social hierarchies and power relations. Participants described feeling 'hypervisible' in some respects, including feeling both scrutinised and stereotyped, but invisible in others, particularly when expressing pain or vulnerability. This paradox of being 'hypervisible' and 'invisible' at the same time is a critical issue that impacts Black women living with chronic conditions. Participants expressed that when they felt most 'visible', it was often in the form of harmful stereotypes that influence how their pain is perceived, such as the stereotype of Black women as "strong" or "resilient," which can lead to their suffering being downplayed or ignored.

Despite the above challenges experienced by the participants I interviewed, there was also a significant shift in the narratives of some participants who expressed that they had begun to experience more positive care outcomes, especially when their healthcare providers were more informed about the intersectionality of 'race', gender, and chronic illness. Overall, participants proclaimed that this shift in care could be attributed to the growing work of charities, increased commitment to EDI efforts and advocacy groups dedicated to diversifying patient stories and advocating for the inclusion of more diverse voices within medical narratives. Several participants described how these charities had helped amplify their struggles, making their invisible illnesses more visible. Through the efforts of these organisations, Black women with chronic illness were able to see themselves reflected in health campaigns and patient resources, which made them feel seen and validated. As this research shows, despite the overwhelming challenges, there are signs of positive change. With ongoing advocacy, the work of charities, and the growing visibility of Black women's health experiences, there is hope for a future where Black women with chronic conditions are no longer dismissed, overlooked, or misunderstood but are instead supported and empowered in both healthcare and social environments.

4. CONCLUSION AND RECOMMENDATIONS

This research highlights the profound challenges faced by Black women living with chronic, hidden disabilities, who navigate the intersection of 'race', gender, and disability in healthcare systems and workplaces. Through the stories and lived experiences of the community engaged in this study, it becomes evident that systemic barriers, ranging from healthcare providers' implicit biases to delayed diagnoses and workplace discrimination, continue to marginalise this group, exacerbating both their physical and emotional suffering. Despite these obstacles, the research also reveals that Black women's resilience, advocacy, and the creation of empowering community spaces are critical in challenging these systemic failures.

The findings underscore the need for a more inclusive, culturally competent approach in healthcare settings, as well as the importance of centring the voices of Black women in policy development. Based on these key insights, I propose five key recommendations that aim to address the ongoing challenges faced by Black women living with chronic conditions:

1. **Cultural Competency and Implicit Bias Training for Healthcare Professionals**
   One of the most pressing issues identified in this study is the recurring dismissal and disbelief of Black women's symptoms within healthcare settings. To combat this, I recommend the implementation of ongoing training on cultural competency, implicit bias, and intersectionality for all healthcare staff. By partnering with experts in racial and gender health disparities, training modules should be developed that specifically address the unique needs of Black women with chronic illness. These modules should include real patient narratives to humanise the experiences being discussed and help healthcare providers understand the compounded challenges of navigating both chronic illness and societal discrimination. This training could also support the decolonisation of healthcare and workplace environments by challenging long-standing racialised perceptions of illness and reimagining these spaces as inclusive and equitable. The integration of this training into Continuing Professional Development (CPD) requirements will ensure that healthcare professionals are continually evolving in their understanding of the intersectional nature of patient care. Monitoring the impact of this training through patient feedback will allow for the tracking of improvements in care and equity.

2. **Creation of Intersectional Patient Advocacy Roles in Healthcare Settings**
   To ensure that Black women are heard and adequately supported in healthcare settings, it is essential to introduce dedicated patient advocates who are equipped with cultural competency training and/or lived experience of chronic illness. These advocates would act as intermediaries during consultations, helping patients articulate their concerns and ensuring that their needs are taken seriously. By positioning these advocates as trusted figures within healthcare teams, patients would have a direct line of support that respects their individual needs and experiences. This role would be particularly beneficial in reducing the impact of systemic neglect by assisting in the interpretation of medical advice, explaining healthcare options, and providing patients with the information needed to make informed decisions. Similar roles already exist in some healthcare settings, such as Patient and Public Involvement Leads (PPIs), focused on marginalised groups, who have proven successful in improving communication, patient engagement and patient outcomes. Drawing from this model, dedicated patient advocates for Black women could enhance trust between patients and healthcare providers, increase the visibility of Black women's health issues, and offer tailored support that recognises the unique intersectional challenges they face. Integrating such roles into healthcare teams would not only empower Black women to be active participants in their care but also contribute to a more inclusive and compassionate healthcare environment.

3. **Inclusive Workplace Health and Disability Policies**
   In the workplace, Black women with chronic illnesses face additional layers of stigma and discrimination, as their health needs are often not properly recognised or accommodated. To address this, I recommend the development of inclusive workplace policies that take into account the intersectional experiences of employees with chronic illness, particularly Black women. These policies should update existing Human Resources (HR) and occupational health guidelines to reflect diverse experiences of disability and chronic illness, ensuring that employees feel supported in disclosing their health needs without fear of stigma or job insecurity.
   As my research highlighted, the workplace can also be a site of inclusion and belonging,

offering a space to reconsider how employers can better support Black women living with hidden disabilities. To address this, I recommend that workplaces proactively create more inclusive environments by implementing intersectional health and disability policies, ensuring that accommodations are standard practice rather than exceptions. For example, offering flexible working hours or the option to work from home when needed and without challenge, as well as providing disability awareness training for managers, could significantly improve support for Black women in the workplace, fostering a more inclusive and equitable environment. Regular equity audits and anonymous staff surveys will help ensure that workplace inclusion efforts are effective and responsive to the needs of Black women living with chronic illness.

4. **Redefining Disability Models to be More Inclusive of Hidden Disabilities**
   To address the dual marginalisation of Black women with chronic, hidden disabilities, it is essential to redefine existing disability models to better reflect the diverse experiences of this group. Traditional disability models often focus on visible impairments, which can overlook those with hidden conditions. I recommend that disability frameworks be revised to adopt a more inclusive, flexible definition of disability, one that recognises both visible and invisible health conditions and the intersectional barriers faced by Black women. This could involve updating the Social Model of Disability to explicitly address the compounded effects of race, gender, and disability, ensuring that all aspects of a person's identity are considered in healthcare, workplace, and societal contexts. In practice, this could include the inclusion of hidden disabilities in disability legislation and a focus on training for disability organisations to recognise and support the needs of those with invisible conditions. In line with the need for a more inclusive definition of disability, I also recommend the implementation of intersectional health assessments within disability services. These assessments would consider not just the medical aspects of disability, but also the social, cultural, and systemic factors that uniquely affect Black women. This would enable more nuanced, tailored care that addresses the unique barriers faced by Black women with chronic illnesses. Intersectional health assessments could include questions about experiences of racialisation, gender, and disability, alongside traditional medical histories, ensuring a holistic approach to care. This recommendation aims to transform the disability landscape by ensuring that both visible and invisible conditions are recognised within policy and practice, fostering a more inclusive and equitable environment for Black women living with chronic disabilities.

5. **Support for the Creation of Affirming Online Communities**
   Finally, my research revealed the importance of online spaces where Black women could find solidarity, share their experiences, and provide mutual support. I recommend that efforts be made to support and amplify the creation of these online communities, which offer a sense of belonging and visibility that may not be found in healthcare settings or workplaces. These platforms could serve as vital spaces for Black women to connect with others who understand their unique challenges, exchange resources, and advocate collectively for change. By supporting these communities through partnerships with advocacy organisations and healthcare providers, more Black women will have access to the emotional and informational support they need to navigate their health journeys. Additionally, fostering these communities will contribute to broader advocacy efforts that challenge medical and societal norms, ultimately contributing to positive changes in healthcare policy and workplace practices.

In conclusion, the dual invisibility of being both Black and chronically ill creates a unique form of marginalisation that cannot be fully understood through single-axis analyses. This research foregrounds the necessity of centring Black women's voices in health research, policy development, and clinical practice. By making space for Black women's stories and experiences, we begin to challenge the dominant medical narratives that often erase or distort their

lived realities.
This work also calls for a more inclusive and comprehensive understanding of chronic illness, one that accounts for the ways in which race, gender, and disability intersect to shape health outcomes and experiences. The challenge lies in dismantling structures that render Black women's pain 'invisible,' while also challenging harmful narratives that make them 'hypervisible' but disregard their unique needs.

This requires a decolonial approach that challenges colonial narratives of Black women, combined with an intersectional framework that not only acknowledges the overlaps of racism, sexism, and ableism but understands how these intersecting oppressions uniquely shape Black women's experiences as they navigate and overcome systemic barriers. These recommendations aim to address the key findings of this research and create a more inclusive, supportive environment for Black women living with chronic, hidden disabilities. By implementing these changes, we can begin to break down the systemic barriers that have long silenced and overlooked the health and wellbeing of Black women. This research highlights the importance and necessity of ensuring their voices are not only heard but fully validated and respected within both healthcare and workplace environments.

Through continued advocacy, meaningful policy reform, further research, and the amplification of their stories, we can create a future where Black women living with chronic conditions are not just acknowledged but truly seen and heard in every space they occupy.

ABIGAIL ARLENA GREEN

CHAPTER TEN: CREATE IN MIND: EIGHT WEEKS OF MINDFUL ART & LIBERATION WORK WITH BLACK WOMEN

BIRUNGI KAWOOYA

1. BACKGROUND

As a disabled Black woman, my own healing is woven into my research. Experiences of racism, gender based violence, workplace harm, trauma and chronic stress has necessitated my wellbeing and liberation work. I create space for Black women's to practice mindful art as a form of research because this creates safety for imagination, wellbeing and hope. I create art because imagination has saved me and I want all Black women to express what thriving feels like.

The Combahee River Collective, a Black feminist lesbian organisation, is credited with the statement: *"if Black women were free, it would mean that everyone else would have to be free, since our freedom would necessitate the destruction of all systems of oppression"*.

The *Create in Mind* programme was introduced as an eight-week creative wellbeing journey for Black women. When I entered the space as a participant facilitator and peer researcher, I looked closely at how mindful art, embodied sensory work, and community connection support Black women's healing. Our experiences are not abstract; they are shaped by racism, class inequality, gendered violence, migration, caring responsibilities, and disabled life. These patterns live in our bodies, shaping our everyday lives and have long lasting impacts. It is my belief most women, especially Black women live with undiagnosed trauma.

The cohort I surveyed, interviewed, and reflected with consisted entirely of 8 Black women aged 46–66, including African, Caribbean and Black British heritages. Many were retired, self-employed, carers, neurodivergent, unwell, or juggling complex life demands. Black women with decades of survival and thriving experience. Black women who have held families, communities, faith spaces, workplaces, and themselves often alone with their fears.

Although the programme was advertised as a Black-women-only space, it was unfortunately not held as such. The organisers elected to admit Asian women into the space, which served to fundamentally alter the landscape of cultural safety. Black women repeatedly told me they felt disappointed, misled, and emotionally unsettled. This is not because they reject others, in fact the organising body Black Women's Kindness Initiative welcomes global majority women, but because Black women have so few spaces that are truly ours. When a promised boundary is not upheld, it reinforces patterns we have been trained to accept: our wellbeing is not a priority and Black people gathering is not supported. As one woman said, the broken promise *"tainted the experience".* However, Black women still built something beautiful and bloomed.

Despite structural shortcomings, the programme created moments of softness, grounding, joy, and self-recognition. Women walked in with anxiety, shame, PTSD responses, creative doubt, and exhaustion and still made art they were proud to share. Still found breath. Still found pieces of themselves they had forgotten. One woman told me she healed more in eight weeks here than she had in therapy. Another called the programme *"a retreat,"* saying she didn't know she could feel that level of peace.

This report documents what I witnessed: when Black women are given spaciousness, creativity, and cultural belonging, we transform into our true selves. Our transformation is justice. Mindful art has the power to reduce stress, promote self-advocacy and enhance the quality of our lives.

2. RESULTS

A thematic analysis drawn from my surveys, interviews, observations, and the words of Black women themselves.

2.1 EMOTIONAL WELLBEING

Throughout the eight weeks and during the reflection in week 10, I witnessed a profound shift in emotional grounding. Black women who arrived masking overwhelm, shame, anger and anxiety spoke openly about finding calm, rest, and emotional release through creative work.
One participant described arriving late and flustered, burdened with shame from years of ADHD-related misunderstandings, yet:
"I was committed. I healed more in these sessions than in talking therapy... I feel much more peace"

Another shared:
"I learned how to relax, not take everything so seriously, and just let go of bad things"

Through sensory practices, gentle arts-based tasks, and group reflection, women noticed:

- reduced stress
- more inner spaciousness
- improved emotional regulation
- increased self-soothing ability
- renewed hope

As a peer researcher and wellbeing facilitator, I observed how quickly Black women enter a state of hypervigilance in mixed or unsafe environments and how creative practice returns them back to their natural state. The rhythm of painting, the slowness of flower observation and arranging, the focus of writing, and the grounding of scent and texture became counter-practices to stress and survival mode.

One woman shared that her husband admired her painting every day, wanting to frame it. That detail stayed with me this woman is on the quiet humble side and was proud to share his praise with the group.

2.2 EMBODIMENT

Many of us live in bodies that have had to shut down sensation for a form of survival: trauma, racism, overwork, chronic pain, caring duties. In the programme, I watched women slowly reinhabit themselves.
The floral workshops were particularly powerful:
"I can create displays I used to think only professional florists could make... it calms me and fills me with passion"

Women described smelling herbs differently, noticing colour in parks, slowing their pace in nature, and creating rituals at home. From my lived experience these are not small shifts they are the beginnings of reconnections to the senses that colonial, capitalist, patriarchal systems repeatedly assault us out of engaging with.
One woman said:
"I am more mindful about everything around me. I pause now"

As a researcher, I observed how sensory grounding offered a bridge between Black ancestral traditions and contemporary wellbeing practices. A return to intuitive knowledge our grandmothers held when working with their hands.

2.3 CREATIVE IDENTITY

This programme unlocked creative identity in ways that astonished participants.

Many began by saying:

- *"I'm not good at art."*
- *"I haven't painted since school."*
- *"I don't know if I have any talent."*

Eight weeks later, they were saying:

- *"I am an artist."*
- *"I want my home full of Black art — including my own"*
- *"I produced a miraculous creation"*

Women signed up for new art classes, bought sketchbooks, invested in materials, and began painting outside the sessions.
Creative writing also opened inner worlds:
"Writing unlocked a new world. I didn't know I could express myself like this."

From my vantage point, these were not just artistic outcomes this is justice. When Black women reclaim creativity, we reclaim imagination, possibility, and authorship over our lives. Creative confidence is a liberation tool and may be why the arts funding is becoming more competitive.

2.4 CONFIDENCE

Over and over, I witnessed participants transform and express increased confidence rooted in self-belief, clarity and self-worth.
Women shared:

- *"I'm choosing myself more"*
- *"I speak up now"*
- *"I know what I deserve"*
- *"I'm less tolerant of negative environments"*

One woman explained how harmful facilitation triggered a spiritual and emotional response in her. Yet she also recognised her growth:
"This is the first time in 60 years I've been triggered like that. But now, I remove myself. You won't catch me twice"

Recognising harm swiftly, refusing to stay in it, and choosing self-preservation without apology. This is counter to how Black women are raised which is to anticipate and sustain attack.

Another participant said she planned to keep Tuesdays as her wellbeing day forever:
"I will tell work this is my day. I will be creative, answer no phone, walk in the park"

Create in Mind had Black women designing lives around our needs, a declaration and act of resistance.

2.5 SISTERHOOD

Creative skills grew, however sisterhood may have been the programme's greatest achievement.

Women described:

- deep emotional trust
- shared humour
- cultural understanding without explanation
- holding space for each other
- forming friendships outside the programme

One woman said:
"We created our own little group. Our own Black women's space"

I observed how quickly Black women create kinship when given the chance — creating space at a table for a latecomer or new face. Kindness to each other is vital especially when the outside world is hostile. The Black Women's Kindness Initiative has created a community that is a healing force.

2.6 NEURODIVERGENCE

One Black woman with ADHD shared a story that illustrates the urgency of culturally safe wellbeing:
"Despite shame, despite embarrassment, I kept coming. These sessions healed me more than therapy"

Her testimony reveals the failures of diagnostic and therapeutic systems that misunderstand Black women's neurodivergence. In this programme, she was not pathologised or picked apart, instead she was seen as whole and welcomed. I saw how kindness softened her and it will stay with me.

2.7 STRUCTURAL BARRIERS

As a researcher committed to honesty, I must note the structural failures that impacted the programme:

1. **The space was not held as Black-women-only.**
   This created:
- reduced safety
- feelings of being misled
- racialised power dynamics
- unequal resource access
- cultural dissonance

Black women repeatedly emphasised the emotional significance of this breach and their observations highlighted the structural roots.

2. **The timing excluded most working Black women.**
   Tuesday mornings reinforce inequalities:
- Black women are more likely to work
- Asian women in the borough more likely to be full-time homemakers
- This shaped who could attend

3. **Facilitation inconsistencies impacted wellbeing.**
   One facilitator's approach caused distress, triggering spiritual and emotional alarm.
   Participants described her content as:
- unprepared
- culturally misaligned
- harmful
- detached
- unsettling

These factors underscore the necessity of culturally competent, trauma-informed facilitation when working with Black women.

3. RECOMMENDATIONS & CONCLUSION

3.1 WHAT BLACK WOMEN NEED FOR LIBERATION-FOCUSED WELLBEING

1. **Hold Black-women-only spaces with integrity.**
   Boundaries must be honoured consistently and unapologetically as they are essential for our safety, softness, and healing.

2. **Fund Black women to lead, design, and facilitate.**
   Creative wellbeing spaces must be shaped by Black women: artists, therapists, facilitators, sensory practitioners, healers.

3. **Choose accessible timing.**
   Evenings and weekends open the door for working Black women who were structurally excluded from weekday daytime sessions.

4. **Build trauma-informed, culturally aligned practice.**
   Every facilitator must understand the emotional, spiritual, and political realities of Black women's lives.

5. **Embed sensory, creative, and embodied work.**
   Drawing on Black women's healing lineages sensory creative art practices are central to wellbeing.

6. **Provide long-term, stable funding.**
   Black women cannot thrive on short-term projects. Liberation requires sustained investment.

3.2 CONCLUSION

What I witnessed in *Create in Mind* was not simply "improved wellbeing". It was:

- reclamation
- remembrance
- rest
- artistic awakening
- trauma release
- boundary setting
- joy
- community
- cultural rootedness

I witnessed Black women transform their posture, their voice and volume, their artwork, their laughter, their confidence.

We deserve and can create structural conditions that allow us to live full, creative, liberated lives.

This programme showed what becomes possible when Black women are given spacious, culturally grounded, creatively rich environments designed with our needs at the centre. And if disabled Black women are free — everyone is free.

BIRUNGI KAWOOYA

POLICY AND PRACTICE RECOMMENDATIONS

The following integrated recommendations address the cross-cutting themes of institutional neglect, racialised inequity, and the critical need for community-led, trauma-informed solutions. They are directed at key stakeholders with the power to enact systemic change.

FOR UK GOVERNMENT & NATIONAL POLICYMAKERS

1. END HOSTILE ENVIRONMENT POLICIES AND REDESIGN IMMIGRATION SUPPORT.

- **Abolish No Recourse to Public Funds (NRPF):** Recognising its role as a primary driver of destitution, housing insecurity, and severe health harms for families (including British children). Replace with a fair support system decoupled from immigration enforcement.
- **Establish Equitable Humanitarian Response Pathways:** Create a dedicated, structured resettlement scheme for Sudanese arrivals, with rights and support parity to schemes like those for Ukrainians. Mandate clear, consistent guidance to all local authorities and the DWP to prevent unlawful application of residency tests.
- **End the Use of Contingency Accommodation for Asylum Seekers:** Phase out the use of hotels and barges. Invest in dignified, safe, and stable housing with proper facilities, enforceable standards, and independent oversight.

2. MANDATE ANTI-RACISM AND CULTURAL COMPETENCE ACROSS PUBLIC SERVICES.

- **Introduce Legislative & Funding Levers:** Require mandatory, co-produced annual training for all frontline staff in the NHS, housing, social care, and benefits agencies on anti-racism, cultural safety, and trauma-informed practice. Link service funding to demonstrated competency and improved equity outcomes for BGM communities.
- **Enforce Accountability for Racial Disparities:** Strengthen the Public Sector Equality Duty. Require all NHS Trusts, ICBs, and local authorities to publicly report on and action plans to eliminate disparities in housing outcomes, maternal health, mental health access, and pain management (e.g., for Sickle Cell).

3. REORIENT HOUSING POLICY FROM MARKET INVESTMENT TO COMMUNITY WELLBEING.

- **Prioritise Security and Condition of Social Housing:** Introduce a legally enforceable ‘Right to a Safe Home’ (building on Awaab’s Law) with swift remediation timelines for damp, mould, and disrepair. Launch a national fund to retrofit social housing, starting with energy-inefficient properties in gentrifying areas.
- **Halt Displacement through Planning Reform:** Reform planning policy to give communities democratic control over development. Mandate a minimum of 50% genuinely affordable housing (linked to local incomes) on all new developments, with robust community benefit agreements.

FOR LOCAL AUTHORITIES & INTEGRATED CARE SYSTEMS (ICSS) IN LONDON

4. IMPLEMENT PROACTIVE, INTEGRATED HEALTH & HOUSING HUBS.

- **Co-locate Services:** Establish one-stop community hubs in areas of high need, integrating housing advice, mental health drop-in services (with culturally matched therapists), welfare rights, and immigration support. These must be co-designed with BGM community organisations.
- **Adopt a 'Housing as Healthcare' Model:** Train and deploy specialist housing officers within NHS mental health and perinatal teams to prevent health crises exacerbated by poor housing. Fast-track safe housing for survivors of abuse and those with chronic health conditions, regardless of immigration status.

5. INVEST IN AND DEVOLVE POWER TO COMMUNITY-LED SOLUTIONS.

- **Create Sustainable Funding Streams:** Allocate long-term, core funding to BGM-led community organisations (e.g., Sudanese diaspora groups, Sickle Cell peer networks, Black women's wellness initiatives) to provide culturally specific support, advocacy, and peer mentoring.
- **Commission by and for the Community:** Change commissioning practices to favour participatory grant-making and community-owned research. Repurpose underused public assets into community wellbeing hubs run by and for BGM residents.

FOR THE NHS, HEALTHCARE PROVIDERS & PROFESSIONAL REGULATORS

6. ERADICATE RACIAL BIAS IN CLINICAL PRACTICE AND PAIN MANAGEMENT.

- **Implement Mandatory Sickle Cell & Pain Management Protocols:** Enforce NICE guidelines on prompt analgesia. Introduce mandatory, specialist training for all A&E and primary care staff on Sickle Cell disease, focusing on anti-racist pain management and challenging "drug-seeking" stereotypes.
- **Embed Culturally Competent Perinatal & Mental Health Care:** Guarantee continuity of carer for Black and South Asian mothers. Integrate routine, culturally-attuned perinatal mental health screening. Develop and fund a national network of culturally matched therapists within IAPT and specialist perinatal services.

7. INTEGRATE HOLISTIC WELLBEING INTO CHRONIC ILLNESS CARE.

- **Introduce Routine Psychosocial Screening:** Make routine psychological and neurocognitive assessments standard in chronic illness clinics (e.g., for Sickle Cell, CKD). Develop flexible models of mental health support that recognise the presentation of depression and anxiety in BGM patients.
- **Fund and Validate Community Healing Modalities:** NHS ICBs should commission and fund evidence-based, community-led wellness programmes (like Create in Mind) as complementary health interventions for BGM communities experiencing racial trauma and stress.

FOR EMPLOYERS, UNIVERSITIES & EDUCATIONAL INSTITUTIONS

8. CREATE INTERSECTIONALLY INCLUSIVE ENVIRONMENTS.

- **Develop Inclusive Disability & Wellbeing Policies:** Reform workplace policies to recognise and support hidden disabilities and chronic illnesses. Mandate flexible working, proactive reasonable adjustments, and manager training on intersectional inclusion to prevent discrimination against Black women and disabled BGM staff.
- **Guarantee Culturally Safe Student Support:** Universities must provide mental health services with dedicated BGM and LGBTQ+ counsellors. Run proactive, anti-stigma campaigns co-created with BGM student unions and embed cultural competence training for all pastoral and academic staff.

FOR FUNDERS & COMMISSIONERS (CHARITABLE, PUBLIC & CORPORATE)

9. TRANSFORM FUNDING PRACTICES TO EMPOWER, NOT EXTRACT.

- **Adopt Trust-Based, Long-Term Funding:** Provide multi-year, unrestricted core grants to BGM-led organisations. Simplify application and reporting processes, valuing lived experience as expertise.
- **Fund Advocacy and Systemic Change:** Direct significant resource towards community organising, policy advocacy, and strategic litigation led by those with lived experience (e.g., challenging NRPF, poor housing conditions). Support the infrastructure for community research and peer-led accountability.

CORE PRINCIPLES FOR ALL STAKEHOLDERS

- **Nothing About Us Without Us:** All policy design, service reform, and research must be co-produced with the affected BGM communities, ceding power and decision-making.
- **Intersectionality is Non-Negotiable:** Solutions must address the compounded discrimination faced by people who are Black, migrant, LGBTQ+, disabled, women, or living in poverty.
- **Housing is a Healthcare Intervention:** Stable, safe, and affordable housing must be recognised as a foundational determinant of physical and mental health.
- **Accountability Through Data & Story:** Combine quantitative disparity data with the qualitative lived experience evidence in this report to measure progress and hold institutions to account.

This report is a testament to the power of community-led research. The recommendations above provide a roadmap for translating that evidence into justice, equity, and wellbeing for all.

“I FELT LIKE MY VOICE DIDN’T MATTER... IT WAS EXCRUCIATING.”

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Nothing about us without us.