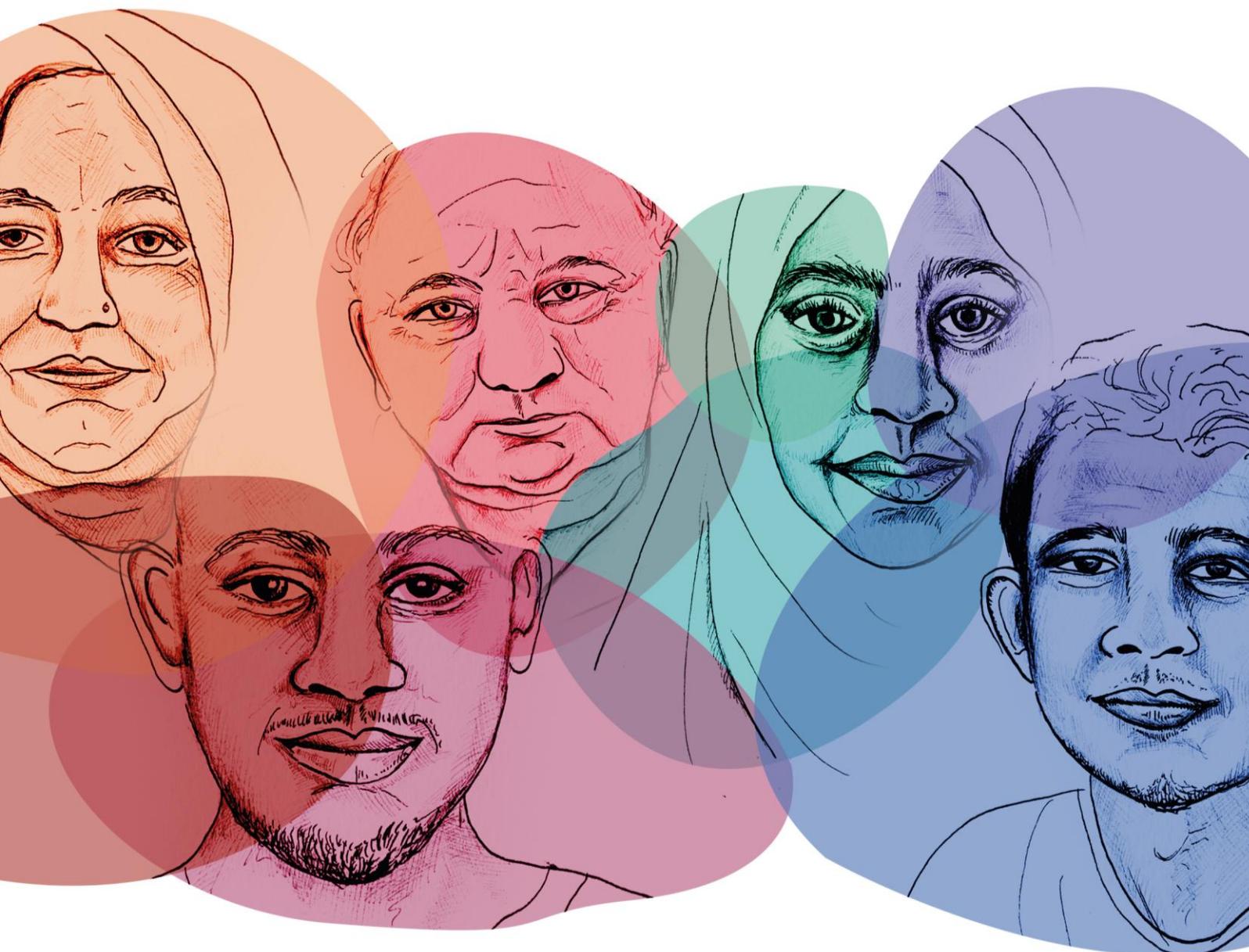


You only had to ask

What people with multiple conditions say about health equity

A report from the Taskforce on Multiple Conditions, July 2021



REVEALING REALITY

The
Richmond
Group
of Charities

In partnership with
Impact
on **Urban**
Health

Acknowledgements and thanks

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[The Taskforce on Multiple Conditions](#) was a cross-sector partnership between [The Richmond Group of Charities](#) and [Impact on Urban Health](#), supported by the [Royal College of General Practitioners](#).

First and foremost we would like to thank all the people who took the time to be interviewed and have generously shared their experiences within this report. Without you this research would not have been possible.

We would also like to thank the Taskforce on Multiple Conditions Expert Advisory Group members for their expert insight, challenge and support.

On behalf of The Richmond Group of Charities, we extend our thanks to our Taskforce partners Impact on Urban Health and our colleagues at the Royal College of General Practitioners.

Foreword

There are crucial decisions ahead for health and social care. Racial and economic inequity and their impact on health outcomes are in the spotlight as never before. And there is an increased profile for the multiple long-term conditions agenda, recognised in the Chief Medical Officer's annual report and in the Government's White Paper on integration and innovation.

So this has been the right time for the [Taskforce on Multiple Conditions](#) to focus not just on the two-way relationship between multiple conditions and inequity but on making sure decision-makers and frontline practitioners alike hear directly from the people most affected, who are so rarely asked – except at a superficial level – what they have experienced and what they really need.

This report marks the culmination of three years of the Taskforce's work and represent its final output. On behalf of The Richmond Group of Charities, I extend our thanks to our Taskforce partners Impact on Urban Health and our colleagues at the Royal College of General Practitioners. We are also grateful to everyone across a wide range of organisations who has engaged with our work and used it to make a real difference to people's lives, through research, policy and practice.

This is not the end of the story. Work on multiple conditions remains a central focus for The Richmond Group's strategy and we will continue to integrate it with our work on inequity, building on what we've all achieved through the Taskforce.

Very little is as deeply powerful as a clear, quiet human voice, when it's given the chance to be heard. This report provides that chance in depth for eight voices, together with the insights of a wide range of other people living with multiple conditions and the perspectives of the professionals trying to support them. We are grateful to the people whose openness about often very difficult subjects and experiences has provided this opportunity to improve the lives and outcomes of those who've rarely been asked.

We hope this report will challenge and support people working in a range of contexts, including in the voluntary sector, to use the opportunities presented by the development of Integrated Care Systems and Primary Care Networks to accelerate key themes in the NHS Long Term Plan, such as the personalised care agenda, shared decision-making, social prescribing and the role of NHS anchor institutions, in ways that will prove transformative in tackling the twin challenges of multiple conditions and health inequity.

We are open in the report about the impact of the constraints faced by the authors, Revealing Reality, in undertaking this kind of work under pandemic restrictions. There are experiences we would like to understand in more depth and breadth, and we will be keen to work with others in the future to do just that. But despite these challenges, we're proud of the way this report puts our participants' voices at the heart of discussions that are too often about people rather than with people.

The report points to several important areas of focus that will enable all concerned to make a difference to the inequity in people's experiences and outcomes. As The Richmond Group, we are publishing our own response and recommendations to sit alongside this Taskforce report and to inform our own future activity.

We want this report to be the start of a new phase in the conversations about multiple conditions and inequity. One that recognises that we can't eradicate this inequity without serious focus on and investment in the social determinants of health, but also that professionals, services and policy-makers can take action now, both within the health and social care sphere and through creative new relationships with, for example, the housing, employment and education sectors.

Please share this report widely and get the conversation going. But please also remember it's a conversation that needs to involve people like those featured in this report.

That's why the report's called 'You Only Had To Ask'. I know you'll be glad that you did.



Neil Tester
Director, The Richmond Group of Charities

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Executive summary

This report sets out the findings from ethnographic research to better understand life for people experiencing inequity and disadvantage and how this impacts the management of their multiple long-term conditions. The research was conducted by Revealing Reality for the Taskforce on Multiple Conditions, who work to ensure that people living with multiple conditions have their voices heard by policymakers and practitioners.

The COVID-19 pandemic has highlighted the real, everyday challenges associated with inequality of health outcomes across the country, and how deprivation and ethnicity play into this. This research acts as a follow up to our previous report, ["Just one thing after another": Living with Multiple Conditions](#), which explored the general experiences of people living with multiple long-term conditions (MLTCs). To follow on, this report looks at how multiple long-term conditions relate to health equity, to uncover opportunities for Integrated Care Systems (ICSs), Primary Care Networks (PCNs), frontline professionals and others to better support those facing these obstacles.

This work was conducted during early 2021, through changing lockdown restrictions while the COVID-19 pandemic was still very much shaping societal behaviours. As a result, a remote ethnographic approach was taken – focusing on four PCN areas, combining the insights of the professionals and services working in those places with those of the people living there. The areas were: Stockwell in South London, Manningham and Toller in Bradford, Balsall Heath East and Sparkbrook in Birmingham and North Ormesby in Middlesbrough.

These locations, and the people who were invited to be involved, were chosen because they brought to life the range of factors that are associated with health inequity – representing communities on low incomes, people from minority groups, and people living in urban and rural settings. There are some who have protected characteristics and others who are part of socially excluded groups.

At the heart of this work sit eight people who shared detailed insights into how they manage their own health, their own views and experiences of how well health and social care has worked for them, and how they would like to be supported. Their stories are captivating and powerful and bring to life some of the challenges they have faced throughout the COVID-19 pandemic and beyond.

Many of them, alongside the wider pool of 20 additional respondents within this work, were facing socially determined circumstances that were making it harder for them to prioritise their health and access the care and support they needed.

There were a range of factors in people's lives that make it more difficult to manage multiple conditions, which seemed to have a significant impact on their health approaches and how they engaged with professionals and services. These included the type of work they did, the area they lived in, financial troubles, the other people they interacted with and their beliefs about the world around them. As a result of pressure and challenges in their lives, many had developed unhealthy habits, such as a poor diet and lack of exercise, often out of necessity, which were hard to break. These habits had evolved through a lifetime and for many there was not clarity about how they related to their long-term experiences of health. Self-management of conditions – a key assumption of NHS care models – was also made more challenging by people's living situations, either in poor quality housing or being far from the provision of key services.

However, underlying many of these experiences was the fact that for many people, the health and social care system is often not taking steps to deliver any additional support to improve their health outcomes, despite evidence of the inverse case law being in effect. While significant investment in tackling the social determinants of health, in the NHS, in social care and in the voluntary and community sector may well be necessary, most of the people in this work would have benefited greatly from additional support, a lot of which would not have cost any additional money. Small but powerful adjustments, like simple, clear explanations of what had been diagnosed and what they need to do about their condition, professionals checking their understanding of what they had been told and asking their opinions on what they wanted to happen, would make a huge difference.

The current system of health and social care is set up to work best for confident people, who already feel they have agency over their health, for people who are driven to get the answers they need and with a good baseline understanding of what wider factors could be beneficial for their health. But this does not reflect the people spoken to for this work, who face the greatest health inequity and disadvantage. These people, who needed the greatest support to improve their health, were often unclear about what was wrong with them and didn't feel able to push for the help they needed. For those who didn't speak English, this was even more challenging.

Health and social care services need to do more to involve the people living in these communities, providing an extra helping hand and bridging the gap between people who can champion their own health needs and those who can't.

There are many ways this can be achieved, to help people prevent or manage a life with multiple long-term conditions. In particular, policymakers and professionals need to consider ways to:

- **Improve our understanding of communities experiencing inequity and disadvantage** → How can we ensure the experiences and voices of diverse communities and groups are recognised at all stages of service design and delivery? How clear are professionals on how the types of people who live locally compare to the types of people accessing services? How can we ensure services are designed around communities' particular needs and assets?
- **Address distance and distrust between communities and health and care** → Whose voices and experiences are missing from the evidence base? What more can be done to build trust with local residents and support community ownership and involvement?
- **Build the right relationships to tackle the social determinants of health** → How can ICSs, and other organisations they will support at a local level, build partnership relationships to address the impacts of wider social disadvantage on health? How well do services support people and the health and care system with non-medical issues?
- **Supporting people to take greater control of their health** → How can we ensure people can make a difference to their own health and get what they need from the health and social care system? How can we ensure people are able to make truly informed decisions?
- **Promoting good health across local groups** → What needs to be done to ensure information about healthy lifestyles and habits land with different audiences locally? What wider needs should be kept in mind in messaging around positive health behaviours?

Introduction

The Taskforce on Multiple Conditions at The Richmond Group of Charities has previously reported that around one in four people live with two or more long-term health conditions in England alone, and the number is growing rapidly relative to single conditions¹. In fact, some predict that by 2035, approximately 17% of the UK population will have four or more chronic conditions².

Life with multiple conditions can be challenging. It is difficult for the health and social care professionals treating patients and it is difficult for individuals and their families. The Taskforce has been exploring life with multiple conditions since it was established in 2018. Previous work³ has highlighted that people living with multiple long-term conditions (MLTCs) often describe it in terms of what they have ‘lost’ over time, including their mobility and social connectedness. Some people have developed self-management strategies, such as finding work, hobbies and daily routines that can adapt to their changing health situations. Others aim to develop and foster close relationships with the professionals involved in their care. But these strategies are time consuming, requiring effort and energy that not everyone can give.

The treatment of MLTCs can also be burdensome, as people attempt to deal with multiple professionals, appointments and medications for different conditions simultaneously. Some were more actively taking decisions about what types of care and support they wanted to use. Others felt so overwhelmed by the number of services and how they did or didn’t fit together that they struggled to engage. The volume and range of interactions they needed to have, with each condition being dealt with separately, caused significant and frustrating time and energy costs. National Voices’ recent report, *Ask How I Am*, has also highlighted that challenges like those outlined here with a single long-term condition can have consequences for people’s mental health and wellbeing – and the chances of having poor mental health with multiple long-term conditions can be greater still⁴.

Data shows that multiple long-term conditions are more common among populations living in deprived areas⁵, with some evidence that they also disproportionately impact Black, Asian and minority ethnic communities and other marginalised groups⁶. Social context seems to play a significant role as, rather starkly, multiple long-term conditions appear 10-15 years earlier in people living in the most deprived areas, compared to those living in the most affluent⁷. This has a significant impact on the healthy life expectancy for these populations.

What’s more, the recent COVID-19 pandemic has further exposed the impact of health inequity on the parts of our population that experience deprivation as well as MLTCs. One study showed that the presence of two or more long term health conditions linked to a 47% higher risk of a positive COVID-19 test⁸. Compared to white people, people of other ethnicities living with MLTCs had almost three times the risk of a positive COVID-19 test⁹. Ethnic minority populations also have higher rates of cardiovascular disease, obesity and diabetes and these have been shown to be common co-morbidities associated with COVID-19 mortality in a number of studies.

The Evidence Review¹⁰ that sits alongside this report provides more detail on the existing evidence around MLTCs and health equity, and what is already known about the demographic factors that impact MLTCs.

¹ https://richmondgroupofcharities.org.uk/sites/default/files/the_multiple_conditions_guidebook_-_one_year_on_december_2020_taskforce_2020_report_digital_a4_v2_1.pdf

² [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(19\)30222-1/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(19)30222-1/fulltext)

³ Richmond Group of Charities, *Just One Thing After Another*

⁴ <https://www.nationalvoices.org.uk/publications/our-publications/ask-how-i-am>

⁵ <https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity>

⁶ <https://urbanhealth.org.uk/insights/reports/easing-pressure-how-work-money-and-homes-can-make-our-cities-healthier-and-fairer>

⁷ https://richmondgroupofcharities.org.uk/sites/default/files/multimorbidity_-_understanding_the_challenge.pdf

⁸ McQueenie, R et al., *Multimorbidity, Polypharmacy, and COVID-19 infection within the UK Biobank Cohort*. 2020

⁹ [Independent-SAGE-BME-Report_02July_FINAL.pdf \(independentsage.org\)](https://independentsage.org/)

¹⁰ Richmond Group of Charities, *Health inequalities and multiple long-term conditions: Evidence review, 2021*
<https://richmondgroupofcharities.org.uk/taskforce-multiple-conditions>

About health inequalities

Health inequalities are defined as “unfair and unavoidable differences in health across the population and between different groups in society”¹¹. More specifically, they include differences in¹²:

- health status, for example, life expectancy and prevalence of health conditions
- access to care, for example, availability of treatments
- quality and experience of care, for example, levels of patient satisfaction
- behavioural risks to health, for example, smoking rates
- wider determinants of health, for example, quality of housing.

These inequalities are identified across four main dimensions: socio-economic status; geography; protected characteristics such as ethnicity, sex, disability; and socially excluded groups in society.

Applying a health equity lens to the conversation about MLTCs enables us to better understand some of the social factors that can impact people’s health. This in turn, can point towards solutions and innovations in how care is planned and delivered that would not be considered or uncovered without this focus.

To do this, there is a clear need to better understand life with MLTCs in the context of health inequity and disadvantage. Much of the existing literature focuses on the statistical relationship between socio-economic deprivation and multiple conditions, in particular the risk factors present and describing issues at a population level. However, there is little research that has explored, in depth, the experiences of individuals.

This piece of work aims to fill this gap in understanding, to incorporate the voices of everyday people into policy making through understanding life from their perspective. The objectives for this work centred on exploring the experiences of people living with, and caring for people living with, MLTCs from a range of backgrounds who are disproportionately impacted by MLTCs but underrepresented in research to date. More specifically, the aim has been to explore the intersections between MLTCs and different dimensions of health inequity.

This report starts with the communities who are trying to support people with MLTCs and are facing health inequalities; describing the four locations this work explored and the people that were met there. Within this, there is a focus on the people, illustrating their experiences of MLTCs, their approaches to management of conditions and interactions with health and social care.

It then looks thematically at the challenges people face in managing their own health followed by their experiences of interacting with professionals due to support them. The final section of this report highlights opportunities for the health and social care system to understand the impact of the relationship between health inequity and multiple conditions and provide the right kinds of support to improve these relative outcomes.

¹¹ England, N., 2020. NHS England » Definitions For Health Inequalities. [online] England.nhs.uk. Available at: <<https://www.england.nhs.uk/ltp/menu/definitions-for-health-inequalities/>>

¹² <https://www.kingsfund.org.uk/publications/what-are-health-inequalities>

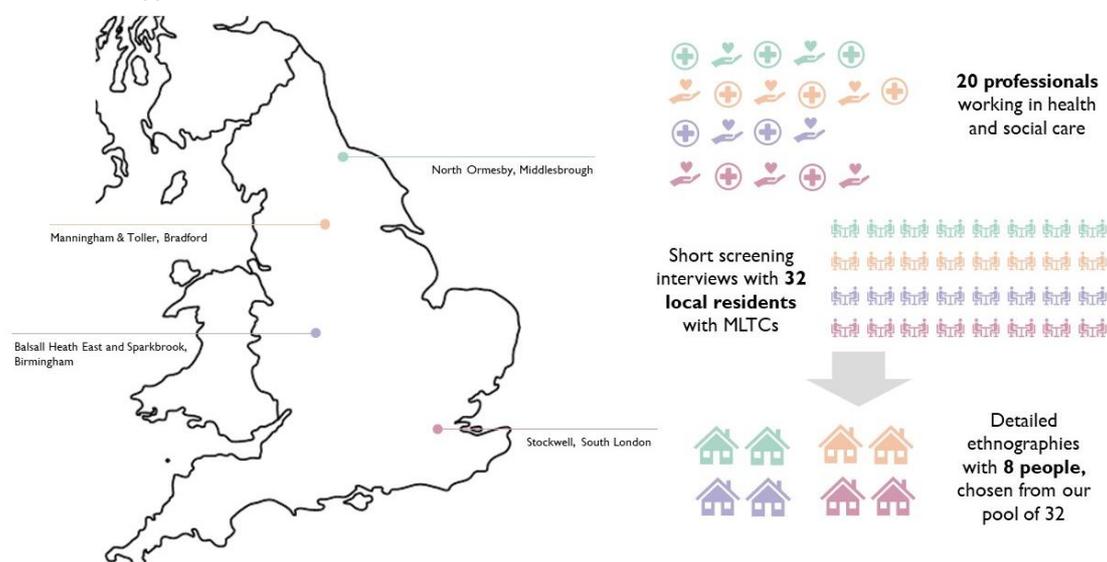
Method and sample

The purpose of this research was to hear from people living everyday life with MLTCs and experiencing health inequity and disadvantage. The research therefore utilised an ethnographic approach, aiming to understand four local health and care systems and the people who access that support.

The work focused on four, small areas within England in order to spotlight the challenges in a range of environments for people experiencing health inequity. The ambition was for these areas to align with PCN areas, but this proved challenging in terms of recruitment of professionals and people living locally with MLTCs. The areas we covered were:

- Stockwell in South London
- Manningham and Toller in Bradford
- Balsall Heath East and Sparkbrook in Birmingham
- North Ormesby in Middlesbrough

In each location, the research team conducted 'place-based ethnography', seeking to understand the systems and relationships in each place by triangulating the perspectives of different people. Across the four locations, there were three main types of fieldwork:



In total, the work included the views of 52 people living or working with MLTCs across these four areas. This was made up of 20 professionals and 32 people living with MLTCs, eight of whom were interviewed in more depth.

It should be noted that this work was conducted through the course of the COVID-19 pandemic and changing social restrictions. The primary fieldwork was supported by the secondary research, stemming from a detailed evidence review and input from three reference groups, made up of professionals and people with lived experience of MLTCs.

Sampling

The sampling frame for this project was relatively narrow, focusing on people living with MLTCs alongside interconnected characteristics that are shown, in the data, to have a role in their health outcomes.

The four locations, as listed above, were chosen because they have high levels of deprivation and diverse populations. This increased the opportunity for us to include people with the necessary characteristics to have experienced health inequity. These characteristics could be socioeconomic (e.g. low income), geographic (e.g.

rural), relate to specific characteristics (e.g. ethnicity, disability) or membership of socially excluded groups (e.g. refugees and those experiencing homelessness)¹³.

These characteristics were the focus for the short screening interviews, alongside experiences of MLTCs. Beyond the socioeconomic factors mentioned, the sample included a spread of ethnicities, disabled people, people of male and female gender, people living in urban and rural locations, and socially excluded groups such as refugees.

Recruitment for this work during changing COVID-19 restrictions was particularly challenging. The need to conduct the work remotely limited the research team's ability to build networks with support services in these local areas, as many were closed at various points. Without any face-to-face interactions, relationships are harder to build. We are clear that this has restricted our ability to secure as many participants and as fully diverse a sample as we had set out to achieve. In particular, we had hoped to capture more insight from Black African and Black Caribbean communities across the country.

Across all the people interviewed within this project, a wide spread of long-term conditions, including both physical and mental health, were covered. These included, but were not limited to: anxiety, arthritis, cancer, chronic pain, COPD, dementia, depression, diabetes (type 1 and type 2), epilepsy, high blood pressure, HIV and schizophrenia. These were often experienced alongside wider health challenges such as cholesterol, gastric pain, and muscle weakness.

The ambition throughout was to ensure a range of voices were included and therefore the research needed a spread of different types of experience, both in terms of long-term conditions and health inequity. From across the respondents screened and interviewed across the four locations, two were chosen within each area to provide the best spread of backgrounds and experiences for the detailed ethnographies.

Fieldwork approach

This research was conducted during spring 2021, when the COVID-19 pandemic meant social restrictions were still in place. This meant our fieldwork could not be conducted in person, within homes or within the local areas. Remote techniques were therefore used, such as video calls, video and photo diaries and triangulation of perspectives across a single area. There are limitations within this approach to the types of people the work can include, especially given that digital exclusion disproportionately impacts the communities focused on in this research¹⁴.

Across all the interviews, the goal was to ensure that the respondents were able to use their own words to describe and explain their health situation. Wider work has highlighted the challenges with language such as 'multimorbidity' and therefore this research sought to empower the respondents and echo their language. This approach also gave insight into how well people understood their health and conditions to provide additional data that was beneficial to the project.

Eight remote ethnographies

For the eight respondents interviewed in greater depth, discussions were centred around successive shorter interactions over the course of a week or two. This typically involved two phone or video interviews intercepted by remote activities and diary tasks. These activities documented the respondents' life histories and timelines showing how their conditions developed, as well as understanding the wider determinants to their health, such as employment, housing, social life, relationships and local communities. This contextual data sat alongside understanding their interactions with the health and social care system.

In the interviews specifically, data capture tools were used to capture more structured data and prompt recall. Timeline tools were used to help build a picture of how they developed MLTCs, and local area maps were used to understand their engagement with their community. These enabled researchers to reflect on gaps in knowledge and follow up with questions to further uncover the necessary details.

¹³ <https://www.kingsfund.org.uk/publications/what-are-health-inequalities>

¹⁴ <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>

The diary tasks and remote activities included a 3-day diary to understand how they spent their time each day, how they felt, what they did, anything related to diet and exercise and anything they needed to do to manage their health. This captured additional insight into daily life and provided clearer evidence of their understanding and approach to the management of their health.

Short screening interviews

Alongside the remote ethnographies, the team conducted short screening interviews with an additional 27 respondents across the four locations. These interviews typically lasted up to 30 minutes and were guided by a more structured guide to capture some introductory information about the health conditions people were living with, the main challenges in their lives around their health and their interactions with health and social care. These interviews were more structured than the main ethnographies, principally because of the time available with each respondent.

Please note that participants' names have been changed to protect privacy and anonymity.

Living with multiple long-term conditions

In this chapter we describe the four areas of England that this research focused on and the people living in these locations. We'll introduce the eight people with whom remote ethnographies were conducted, to portray the detail and nuance of their experiences. As mentioned previously, all four of these locations were chosen because they have some of the highest levels of deprivation.

Stockwell, South London



Lambeth is one of the 20% most deprived districts in England¹⁵ (in 2019) and one of the most deprived boroughs in London (8th most deprived in 2015¹⁶). Within it, the most deprived areas are mostly in Brixton and Stockwell¹⁷. There are estimated to be 15,000 people living within Stockwell¹⁸ specifically and many are international migrants.

There is a large Portuguese community, one of the largest in the UK, as well as a significant Brazilian community. Within this community, limited English is spoken, and many have low-income jobs, often leaving school at a young age back home¹⁹. The second largest ethnic group are Black, including people from the Caribbean, West Africa and Portuguese-speaking African countries.

Professionals and residents living in the area often talked about the lack of appropriate social housing locally. There was a clear narrative around the poor quality of housing and challenges in accessing social housing that could meet individual needs, such as ground floor flats or accessing aids and adaptations.

¹⁵ <https://fingertips.phe.org.uk/static-reports/health-profiles/2019/e09000022.html?area-name=lambeth#:~:text=Lambeth%20is%20one%20of%20the,live%20in%20low%20income%20families.>

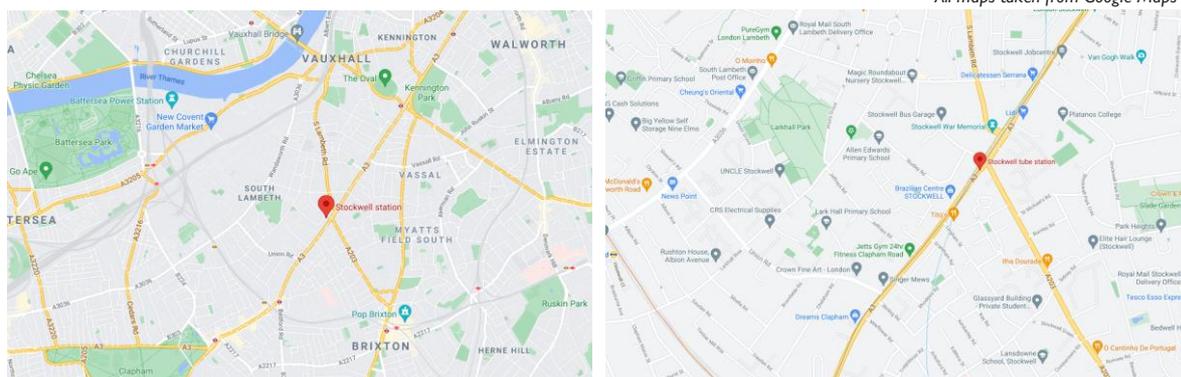
¹⁶ <https://www.lambeth.gov.uk/sites/default/files/State%20of%20Borough%202016%20-%20v3.pdf>

¹⁷ <https://www.lambeth.gov.uk/sites/default/files/State%20of%20Borough%202016%20-%20v3.pdf>

¹⁸ <https://www.lambeth.gov.uk/sites/default/files/ssh-lambeth-demography-2015.pdf>

¹⁹ http://irmo.org.uk/wp-content/uploads/2020/08/The-Portuguese-speaking-Community-in-Lambeth-A-Scoping-Study_dataprotectedversion.pdf

Local provision



All maps taken from Google Maps

Stockwell is a busy, well-connected area of South London, with easy to access transport links. Professionals working locally felt that there was an appropriate array of health, wellbeing, and social care services available. However, local professionals recognised that it remains a challenge to make it clear and easy for people to access the support on offer across the area.

The two hospitals that are closest to the area are St Thomas' and Kings College Hospital, and there are five GP practices. There are also some private practices in the area with Portuguese doctors.

Social prescribers and community workers play an important role in the area. They have a local project, Thriving Stockwell, aiming to create a holistic system of care and support. This project involves all five GP practices alongside a residents' association, schools, the council and charities.

There are a range of local charities and associations in the area that have community teams working closely with people living in the area and are well connected with wider services. Most are specifically focused on Portuguese speaking communities. They include organisations like [Stockwell Partnership](#), which connects locals with support with the aim of improving quality of life in the local neighbourhood. Similarly, [Lambeth Portuguese Wellbeing Partnership](#) is a network made up of over 40 local groups and community members, that states its aim as being to improve the health and wellbeing of the Portuguese-speaking community in Lambeth.

Alongside these charities, there are a wide range of other types of support, such as community leisure and sports centres, care homes, a GP access hub, and mental health charities like Mind.

Compared to other areas, Stockwell is a busier location, with a wider range of services on offer and better connections with the rest of the city. Within the locality, there also seems to be a better-connected network of health, social care and third sector professionals. Their connections to each other and the residents is stronger than was seen in other places – although it certainly didn't reach everyone locally.

The professionals interviewed as part of this research were all connected and working together, and included the local PCN leader, a local social prescriber, a charity worker from Stockwell Partnership and a worker at the Lambeth Portuguese Wellbeing Partnership, and an Osteopath.

Challenges:

From speaking to professionals working locally and residents, there was a general sense that a lot of the needs locally were 'non-medical', more often stress or mental health issues stemming from long working hours, poor housing or financial pressure. While there is a wealth of different types of support available locally, connecting residents with the right type of support and encouraging them to engage with non-medical help can be challenging.

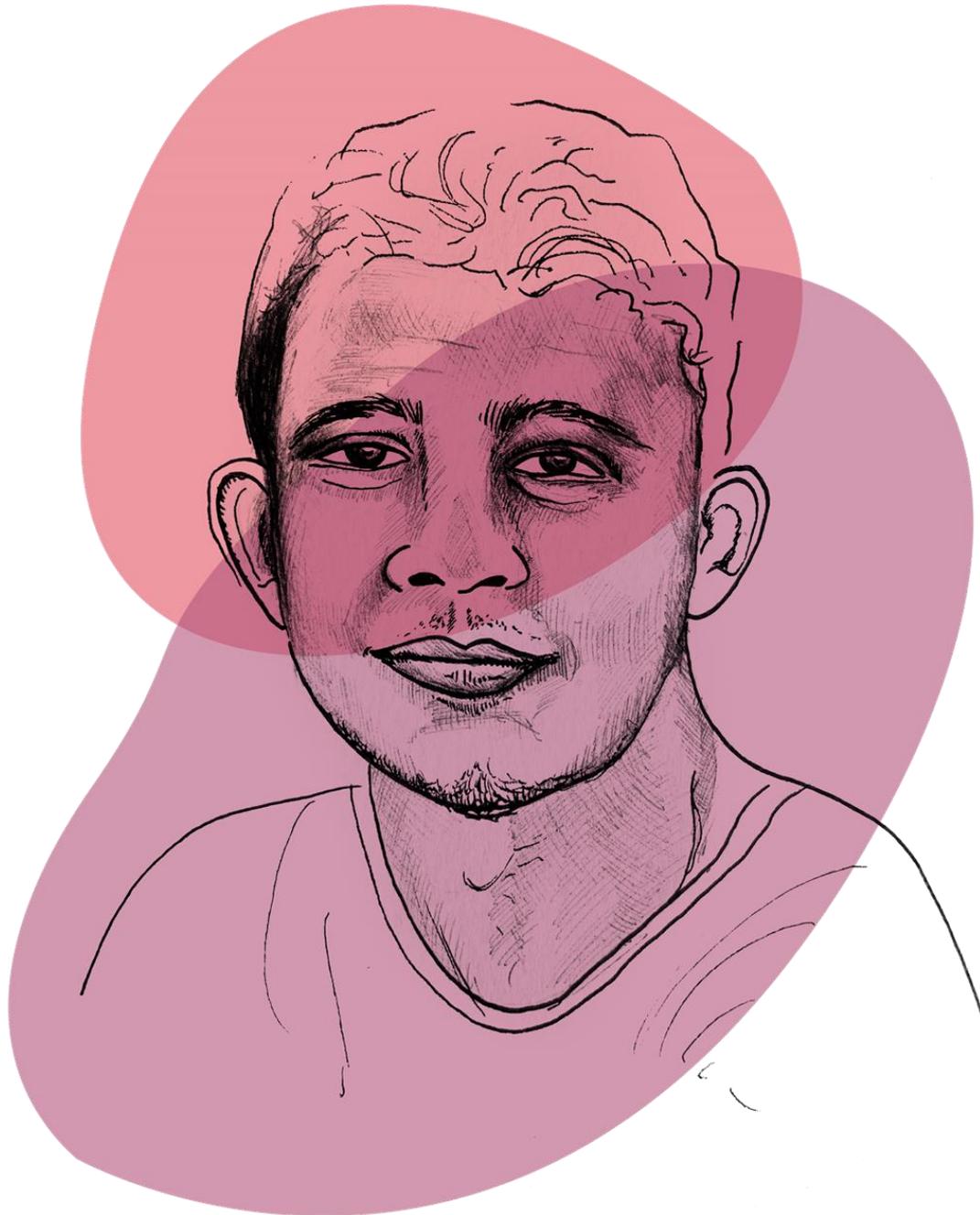
These issues are compounded by low educational levels and limited English language abilities among the residents. Support was in place, such as interpreters that can be accessed for appointments at the GP or local hospital. However, often people needed to bring their own interpreter, which could also be accessed through local charities.

Alongside language, the international community means they often bring a set of expectations and preconceptions about how the healthcare system works in the UK. Often these expectations have been built from experiences within their home nations, meaning there is limited trust in professionals and scepticism about their recommendations.

Kumar, 40, Indian, Stockwell

A loving dad, before the onset of his multiple conditions he worked at IKEA customer support and had a busy social life

Ulcerative colitis, type 1 diabetes



“I’ve come to realise that medicine alone isn’t going to help me.”

Kumar has lived in South London for his whole life. He recently moved back into his mother's home in Stockwell because he needed some extra support for his health. He was previously living with his girlfriend and youngest child, but his regular seizures, as a result of his diabetes, and trips to hospital became too distressing for them.

He was diagnosed with ulcerative colitis in 2009 and Type I Diabetes in 2013. Kumar struggles to understand how best to manage these conditions. He recently learned that his lifestyle, such as his diet and exercise, could have a big impact on managing these conditions and as such, he reflected that his doctor is potentially unable to solve everything with medication alone.

"I've always thought that medicine would just make things better. I thought oh I have a stomach issue; I'll take some stomach medicine. But now, even if I take the medicine, I'm never going to be better."

Kumar struggles to understand the advice from his doctor and other professionals, reporting that the language they use was difficult to understand and so he didn't always know what to do as a result. Kumar said he has asked doctors to repeat themselves several times per appointment and yet still feels unclear about what they are advising him to do. He also reflected that the time limits for his GP appointments meant he often felt pressure to quickly try to make sense of what he was being told, as his doctors were "always in a hurry." As a result, he hasn't always understood the severity of his conditions.

At the same time, his hectic daily life, spread between work, romantic relationships, friends and family, has made it hard to keep track of what he has to do. He has missed many appointments with specialists but he isn't sure how this would impact his future health.

"I went to see the dietician once, but I just felt so lost, so I stopped going. If the doctor explained to me back then that if I keep missing these appointments then it will have a bad effect on my health in the long run, I wouldn't have missed them."

Kumar relied heavily on the information he reads online and sees on television to help him make decisions about how to manage his health. He finds this more accessible than advice given by health and social care professionals. He was trying to eat a vegan diet where possible after watching a documentary that emphasised 'green is good'.

"They might be the wrong type of food. I'm not really sure."

When he was diagnosed with ulcerative colitis, he remembers being very unclear about what the doctors were telling him. It was not until he spoke to other people and looked at groups about the condition on sites like Facebook that he truly understood the condition he had and what it meant.

Regarding his diabetes, he was walking with a friend and passed by a mobile health unit and decided to have a check-up. He was then told that his blood sugar level was too high and that he should go to a hospital for further tests. He said the word diabetes wasn't brought up at that point, so he didn't follow the recommendation. He didn't follow up with the GP until a while later, when he was feeling faint at a friend's house. At that point, he was told 'if you're constantly feeling dizzy, that's something you have to see the doctor about'.

"When I took the test in the [mobile health unit] the word 'diabetes' was never mentioned. So I didn't know what was going on. They just said my sugar was up and down and to get a glucose test."

Vera, 74, Portuguese, Stockwell

A retired cleaner, she has always been the head of the family. Some of her children still rely on her to some extent for financial support

Angina, type II diabetes, cataracts, kidney cancer, dementia, undiagnosed depression, anxiety



“I would leave home for work at 5am and come back after 11pm, then do the house chores. So I’d just drink coke and eat cake throughout the day. It was quick to eat and gave me energy.”

Vera migrated to London from Madeira 30 years ago, hoping for a better life, more money and to be closer to her family. At the time, one of her daughters was in London and now her other seven children also live in the city. She was married for many years but her husband was abusive and an alcoholic. When Vera decided to leave him, he stabbed her in the chest.

She currently lives with one of her sons, who is her carer. He has no income, so her pension and benefits pay for them both. Prior to retirement, Vera worked as a cleaner for 22 years. She would wake-up before 5am, starting work early in the morning and getting home late at night, when she would do household chores. Rushing between different locations for work meant she often drank coke and ate cakes that were easy to grab on the go and gave her an energy burst. At around 50 years old, she developed type 2 diabetes.

After feeling ill for some time, when she was 61, she fainted in one of the houses where she worked. Her employer suggested she retired. When she did, it hugely reduced her physical activity, but she'd still walk around the area to the Portuguese coffee shops and church to meet local friends. COVID-19 had meant she'd stopped many of these trips out and was therefore walking less. Her legs are getting progressively weaker. Additionally, she's having memory loss episodes and once found herself unable to find her way home from the nearby supermarket. She now spends most of her days in bed watching Portuguese TV.

Vera speaks very little English. She has never prioritised learning the language since moving to the UK. In addition, as a child she wasn't able to access education and it seems that her reading and writing skills in Portuguese are also very limited. She has always lived either in Stockwell or nearby and is closely linked into the Portuguese community there.

"I have many friends and family around [Stockwell] ... all my [health care professionals] are around here ... I've been here for 30 years."

In the past her GP was Portuguese, but when he changed from NHS to private practice, she was given a new GP. Her current GP doesn't speak Portuguese, so she has always needed an interpreter (offered at the GP clinic, or someone from Stockwell Partnership, or her daughter) to come with her to her appointments. She felt guilty asking people to come with her as she knows they are busy.

However, Vera was very happy with her current GP and they had connected her to other support in the area. When she had kidney cancer, before a potential surgery, the GP clinic sent a nurse to her house for a check-up. The nurse saw the house was not suitable for her recovery – it was on the third floor and the lift was broken most of the time, and there was a high bathtub she couldn't get in easily. The nurse put Vera in touch with Stockwell Partnership, a local charity offering support and with many staff that speak Portuguese. They helped her liaise with the local council and move to a house better suited to her needs.

"I needed to move houses before I had the surgery [for kidney cancer]"

Her current house is on the ground floor. However, she hasn't been able to get adaptations for the bathroom yet. The bathtub is still too high for her to get in, so she currently sits on the toilet and uses a large bowl with water to wash.

Manningham & Toller wards, Bradford



Bradford is currently ranked 13th in terms of deprivation in England, and Manningham ward is the most deprived within the town^{20 21 22}. Across Manningham and the neighbouring Toller, there are estimated to be just over 40,000 people^{23 24}.

Bradford has the largest proportion of people of Pakistani ethnic origin in England. Within this, Toller and Manningham's data demonstrates that 70-80% of their population are people of Asian or Asian British ethnic origin²⁵. Toller ward has the highest percentage of people of Pakistani origin in the district (72.3%) and the highest percentage of Muslims in the District (76.1%)²⁶.

²⁰ <https://ubd.bradford.gov.uk/about-us/poverty-in-bradford-district/>

²¹ <https://ubd.bradford.gov.uk/media/1292/imd-2015-deprivation-at-ward-level.pdf>

²² <https://www.arcgis.com/apps/Cascade/index.html?appid=963ae350758341308404941cc3628f63>

²³ <https://en.wikipedia.org/wiki/Toller>

²⁴ https://en.wikipedia.org/wiki/Manningham,_Bradford

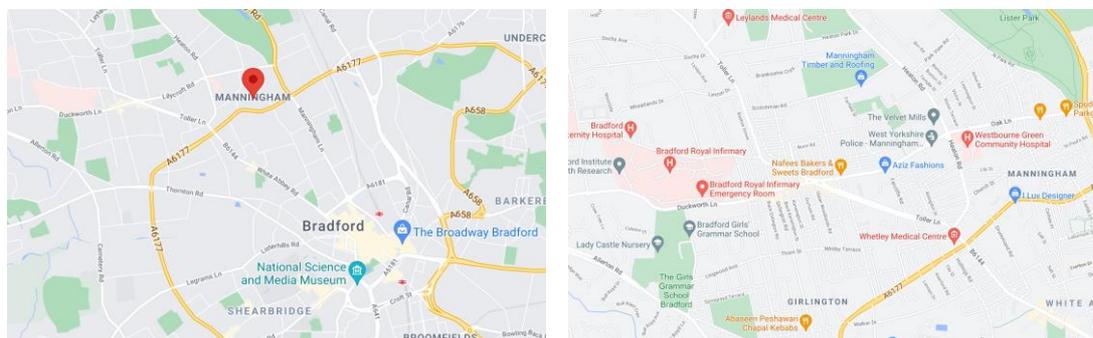
²⁵

<https://jsna.bradford.gov.uk/documents/The%20population%20of%20Bradford%20District/1.1%20Demographics%20of%20Bradford%20District/Demographics%20of%20Bradford%20District.pdf>

²⁶ https://bradfordforeveryone.co.uk/wp-content/uploads/2020/01/bradford_data_pack.pdf

Local provision

Manningham and Toller are in the northwest of Bradford, outside the city centre. It's approximately a 20-minute bus ride to the centre of Bradford, but there are also a lot of local amenities, such as Pakistani bakeries, supermarkets and clothes stores.



There are approximately 16 GPs within the ward area and at least two hospitals in the local vicinity (Bradford Royal Infirmary and Westbourne Green Community Hospital).

However, the professionals working locally feel that community organisations have to plug gaps in provision for local residents, particularly in terms of wellbeing, which wasn't being as well supported by local health services. There are several centres specifically focused on women's wellbeing, targeting South Asian women. There are other community groups scattered across the area who work to improve wellbeing in the area and focus principally on the South Asian community. There are also support groups for asylum seekers and refugees from the Middle East and Africa, that can offer healthcare support and interpreter services.

For this project, interviews were conducted with the patient engagement lead at a GP practice, a project worker at a women's community centre, a manager at a disability charity, the mental health co-ordinator at a community centre, project leads working with refugees, and an estate manager at a housing association.

Challenges:

From interviews with professionals and residents living with MLTCs, language and literacy were significant challenges for engagement with health and social care support. There are a growing number of GPs who speak the same language as the local population, so things are starting to improve. However, many people still require interpreters to help manage their interactions with the healthcare system, such as booking appointments and understanding referrals. The Project Lead at a community centre supporting refugees highlighted that while steps are being taken, such as information leaflets and posters in a range of languages, there is an ongoing challenge around literacy. Many of the refugees have come from small villages where they never went to school, so written documents in any language are challenging.

There are also cultural barriers around accessing help for certain conditions, most notably for mental health. Professionals reported high levels of resistance and concern around accepting diagnoses that relate to mental health and said it was common for people to disengage from support as a result.

Finally, many people described how the third sector often needs to clarify how the health and social care system functions and help people understand what type of support they can expect to receive from their GP. There are a number of myths and misunderstandings, such as not being aware that GPs can't treat all issues, and that they might be referred on to other clinicians or other types of help for further support.

Ibrahim, 70, Pakistani, Bradford

A practical man who can fix anything after a lifetime repairing machines in a textile factory

Osteoarthritis, osteoporosis, asthma, vitiligo, hearing impairment, visual impairment



“I’m doing ok. I like staying busy and helping others.”

Ibrahim moved to the UK from Pakistan in 1967 and has since been living in the same area in Bradford for over 50 years. Although he lives with just his wife now, their six grown-up children live close by, and he has a good family support network around him. He has eight grandchildren that would come round regularly, and he enjoys the busy house he has when this happens.

He didn't have the opportunity to go to school in Pakistan, so he has found it difficult to learn English. He has learnt a conversational amount, but the grammar has been harder for him to grasp.

In 1975, Ibrahim noticed his sight was deteriorating and was unsure why. He visited his GP who referred him to optical specialists. Initially, they were at a loss as to why this was happening to him. Ibrahim just assumed he would be prescribed glasses and then be done with it.

“I was very young, I was losing my sight, and the senior consultant was telling me that there is nothing wrong with me. They said that I was wasting their time.”

His visual impairment progressed, and Ibrahim's sight worsened over time. In 1976 he was registered as partially blind, but now he can only just about tell when it is day and night with the changing levels of light. He lost his job at the textile factory in 1980, which sparked a period of depression as his declining health and lack of education made his future feel insecure for him and his family.

Ibrahim's wife is also visually impaired, though not as severely as him, and is able to manage a few household tasks with her limited vision. In order to assist the couple with cooking, cleaning, and other ad hoc tasks such as ironing, Ibrahim has had a carer for the last 10 years that comes in for two hours every day.

Ibrahim has a several health conditions that affect his day-to-day life. A key one of these are his digestion issues. For years now, Ibrahim has been unable to stomach big meals, and finds that his dietary intake has to be really low as a result. For breakfast, he often will have a single egg, followed by a salad for lunch, and some soup for dinner. It upsets him that he has had to forgo many of his favourite foods over the years, such as chapatis, as they would trigger his digestion issues.

He was diagnosed with arthritis in his neck and shoulders in the 1990s, at a point when he wasn't working. Since then, he has been diagnosed with another form, he thinks osteoarthritis, in his knees, which has made it challenging to sit on the floor, in particular at the mosque. He's not particularly clear on what types of arthritis he has.

“I know I have two types, one in my back and one in my knees. I think one of them is osteoarthritis”

He takes painkillers regularly but also increasingly aims to take care of his body through movement. His doctor has spoken to him at length about the importance of exercise for his arthritis as the circulation will help with the pain. However, Ibrahim does not feel confident about walking outside due to his visual impairment. Despite having lived in his local area for over 5 decades, the constant new construction makes it difficult for him to navigate his way around – as there are always new diversions or road closures that interrupt the route he could walk intuitively. He has applied for a volunteer walker with a charity that supports those with sensory impairments, to better enable him to walk outdoors, but has been told there is currently no one available to assist him. To keep him moving, he walks 20-30 minutes around his lounge twice a day.

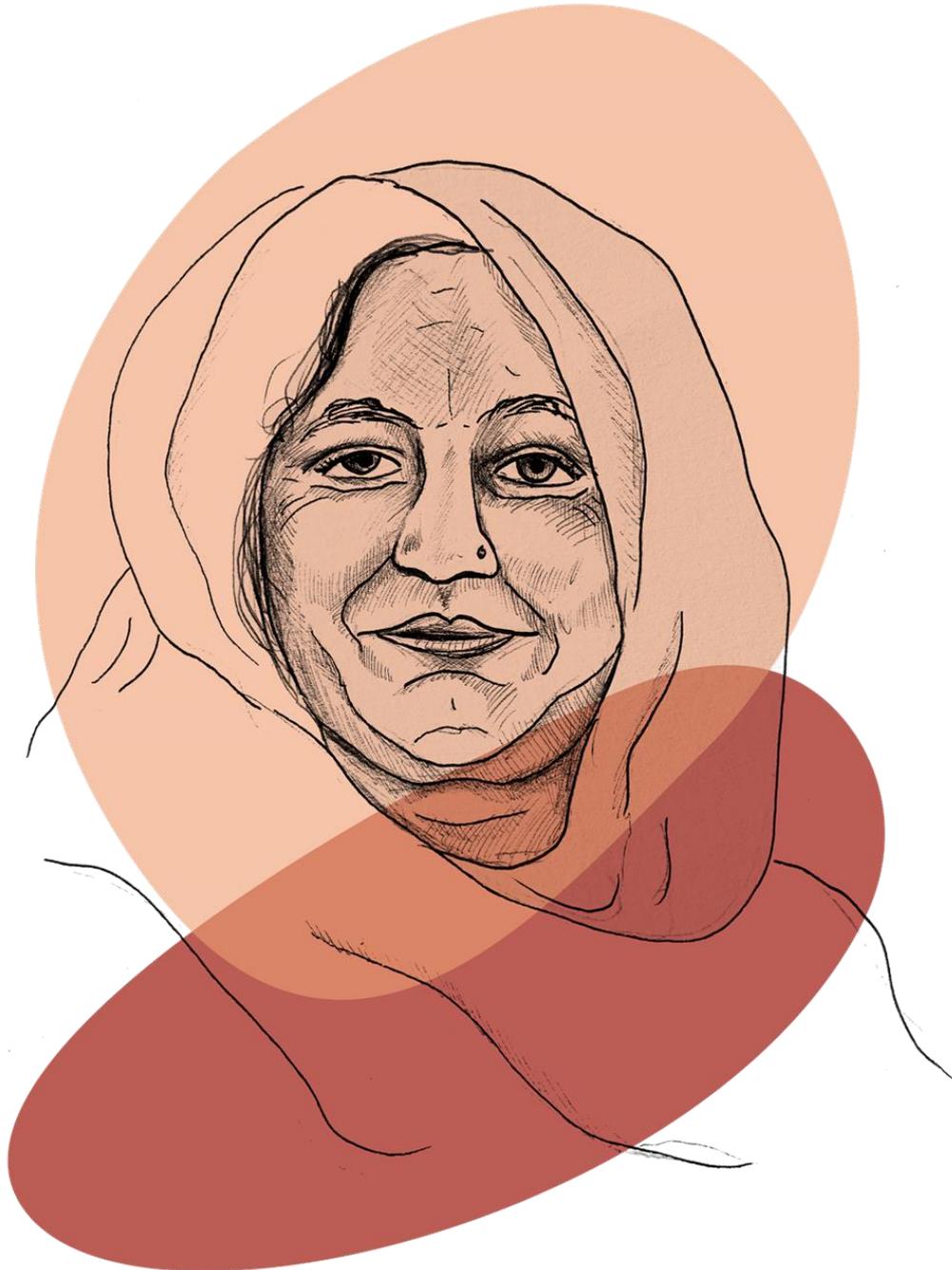
“I am pretty involved in the visually impaired community and probably know more than most about what's available, yet I still can't get a volunteer to go on walks with me”

A key frustration for Ibrahim in managing his health and wellbeing is being able to access information from his hospital. Despite knowing about his visual impairment, and his countless complaints, the hospitals continue to communicate with him mainly through written letters sent by post.

Sabba, 63, Pakistani, Bradford

Loves her daily visits from her next-door neighbour's cat and watching daytime TV

Anxiety, high blood pressure, arthritis, high cholesterol



“My mum takes a while to explain things and get to the point. I think this is why the GP doesn’t listen to her.” (Rahmiya, Sabba’s daughter)

Sabba has lived in Bradford for the past 50 years after moving over from Pakistan. She lives with her youngest son, who is 38, but sometimes also stays with her daughter, Rahmiya, who acted as an interpreter during the interview.

Sabba wakes up at 4am every day for the morning prayer and then goes back to sleep until 9am. She then makes herself some toast and waits for her food to go down before taking her medication. She takes a range of medications for high blood pressure, irregular heartbeat, weak bladder, digestion problems, antibiotics for gastric pain and paracetamol every other day for her arthritis.

Around 20 years ago, Sabba woke up with bad pain in her arm. It did not go away, instead moving into her neck and shoulders. She went to the doctors and was diagnosed with arthritis. Neither Sabba nor Rahmiya know the type of arthritis she has, 'it's just joint pain'. The GP referred her to a physio, where she had five solo sessions then a few female group sessions. She was then told she had to go to mixed-sex sessions. Sabba did not want to do this as she felt uncomfortable exercising in front of men and as a result stopped going.

"We haven't asked the GP again to refer her to the female-only physio classes. I think I could give it a try, but I don't feel confident they will do it"

Rahmiya and her mother don't feel positively about trying to access healthcare because they find it a struggle to get an appointment at the GP. Rahmiya takes responsibility for looking after her mum's health and care, and she struggles to balance this with responsibilities within her own home too. The appointment booking at Sabba's GP requires them to call at 8:30am to book, which is the time when Rahmiya is travelling to work. The lack of flexibility here means that trying to see a GP is often seen as the last option for them. They usually first attempt to treat issues by going to the pharmacy for over-the-counter medication or herbal remedies.

"It's really hard to just get through to the GP, and then it's even harder to get an appointment"

Sabba has bad anxiety after being in an abusive relationship. She won't sit in a car on her own, won't go to a café toilet on her own and calls multiple family members multiple times a day. During the lockdown, she could call some family more than 10 times a day. Sabba does not fully understand her anxiety, and Rahmiya wishes there was more support for her, or translators that could effectively explain what anxiety is and how to deal with it. She currently doesn't access any support for it. Rahmiya would really like her mum to have counselling but is aware that her mum feels there is a lot of stigma around it. She is struggling to find ways to encourage her mum to access it because she knows she will not attend if it's labelled as 'counselling'. Sabba would also like to be able to relate to someone before opening up to them, but this is difficult unless Sabba can speak in her own language. They have struggled to find counsellors that can facilitate this.

Rahmiya's expectations for her mother's healthcare changed five years ago when Sabba was getting a urine test due to discomfort and pain in her body. During this scan, they discovered that she had high levels of fat around her liver, and she was referred to see a nurse and make a diet plan, which surprised the pair as "they didn't put her on medication straight away". Having a clear plan in place and weekly check ins with the nurse made a world of difference to Sabba's engagement with the diet plan, and as a result she lost weight and saw her physical and mental health improve during that period.

"She sat with her and actually gave her that time every week... that was one of the best services I think my mum had"

Now that they have seen the positive impact a holistic approach can have on Sabba's health, and have seen how good healthcare can be, they wish that this same standard could be applied across Sabba's conditions.

North Ormesby, Middlesbrough



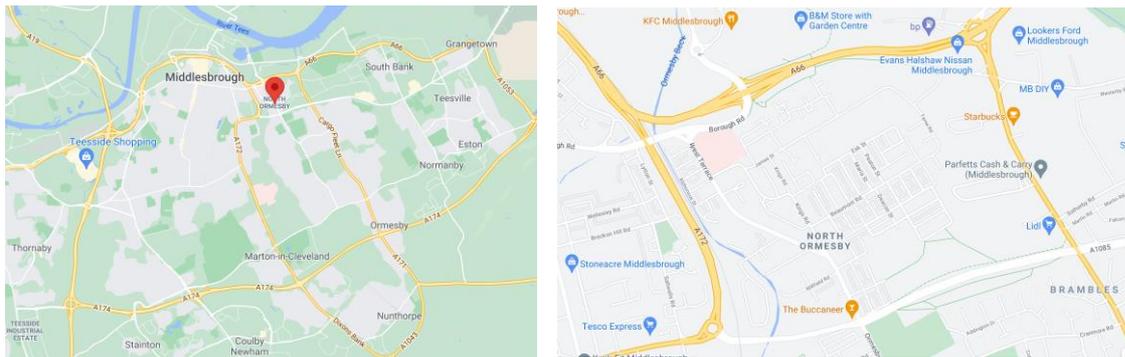
North Ormesby is a smaller area than the other locations within this research, as Middlesbrough is a smaller town. The district has a population of about 3,000 people.

It is the most deprived ward in Middlesbrough²⁷. Middlesbrough itself has some of the highest levels of poverty in the UK²⁸. The previous census reported that the rate of workless households in North Ormesby was 42%, compared to the 9.9% national average. It also has the second highest level of recorded alcohol and substance-related ambulance pick-ups²⁹.

The population of North Ormesby is not as diverse as the other areas. Most people living here are White British.

Local provision

North Ormesby is a small ward located in the north of Middlesbrough. It is surrounded by several A-roads and has a range of local amenities within its streets. It's approximately a 16-minute bus ride or 30-minute walk into the centre of Middlesbrough.



²⁷ <https://www.middlesbrough.gov.uk/open-data-foi-and-have-your-say/about-middlesbrough-and-local-statistics/index-multiple-deprivation-2015>

²⁸ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/835115/loD2019_Statistical_Release.pdf

²⁹ https://www.middlesbrough.gov.uk/sites/default/files/Census-2011_Poverty_Deprivation.pdf

There are 6 local GPs and the James Cook Hospital can be reached by bus in approximately 30 minutes from the centre of North Ormesby. There are three foodbanks and an array of community support services, in particular for older people.

The professionals and residents living locally don't think there is sufficient support available. They recognise that some of the challenges stem from attendance at support, but also generally the volume of provision is low. Some professionals compared the experiences in Middlesbrough with their experiences in other areas in the north and felt it was particularly poorly serviced in terms of support for residents.

There is a local community centre aimed at supporting adult education, but many said this was rarely used. Local churches also provide some community support, including cultural specific support for the Iranian, Chinese and Sudanese populations.

There are also very few, if any, options for physical wellbeing locally. There is a local park and two gyms in the surrounding area.

The professionals interviewed in the North Ormesby area include a manager of a living well team at the council who works on a programme to improve wellbeing, a Care Manager at a day centre that offers independence living skills for young people with learning disabilities, an Operations Director at a community centre that offers mental health support, and a volunteer at a community centre for refugees.

Challenges:

From these conversations, the main challenge locally centred on health literacy. Risk factors such as smoking, drinking and obesity are reportedly prevalent in the area, but professionals have a general sense that few people are confident and clear about the impact of these on their long-term health. Some professionals mentioned that many people have relatively low educational attainment, which meant they had to work harder to share information in an understandable way.

North Ormesby and Middlesbrough more widely, are also much smaller than the other locations within this work. There are rural parts to the town and villages within the area. This can mean accessing any services can be more difficult or require some travel, especially if they need to see a specialist. This can make it difficult for people to attend appointments, particularly when they have transport or mobility issues.

Roger, 70, White British, Middlesbrough

Loves folk music and regularly goes to folk night in the village town hall

Diabetes type 2, COPD, Ongoing ear problems, Osteoporosis, Spondylosis - previously had prostate and skin cancer



“I am quite forgetful and don’t really think about my medication much.”

Roger lives alone in an old council house in a rural part of Middlesbrough. He's lived in the area for over 50 years and is very well connected to the community and has a wide circle of friends. As a child, Roger had rheumatic fever, which led him to spend five months alone in hospital. While his mother was able to visit him for half an hour on weekdays, and two hours on the weekend, his father did not, nor did his siblings. After being discharged from hospital and returning home, Roger struggled to reconnect with his family and barely recognised his father and siblings. He believes this period of isolation triggered severe depression later in his life.

Following the circumstances around his illness and family dynamic, Roger heavily invested time in building strong relationships with friends. Most of Roger's friends live nearby and while his ability to travel is limited, his friends often make the effort and travel up to see him. Over his 70 years, Roger has had several jobs including working as a bus conductor for 14 years. While he enjoyed the job, Roger believes the car fumes had an impact on his asthma and could have contributed to the development of his bronchitis and COPD.

His current old council house is poorly insulated and gets very cold in the winter, which he knows is not good for his lungs.

"I've tried multiple times to get the house insulated, you can feel a draft all year round, but it's much colder in winter."

Roger has recently been allocated a social worker following the death of his wife. His social worker was concerned about his housing situation and was able to organise moving him into assisted living. Roger rejected the offer as it would mean having to give up his cats, a requirement that he was not willing to do. Instead, Roger is on the council waiting list for a bungalow with a garden. He doesn't know how long it will take to get one and is aware there is more demand than there is supply.

Having survived 3 heart attacks, Roger's GP is eager he builds up his heart strength and put him on a prescription of 'regular exercise'. This prescription allowed Roger to attend one exercise class a week in the local swimming baths. Despite being very committed and attending every session for six months, Roger did not enjoy the classes and was worried about 'over doing it'. He ended up having a heart attack 'out of the blue' and hasn't returned to his classes since.

"I had to walk to the swimming baths for my classes so was often tired by the time I got there"

In 2017, he discovered some exercises classes in the local church hall that were specifically designed for more senior people with health problems. Roger thoroughly enjoyed attending these sessions as they were less intense than the ones at the swimming baths and much closer. Unfortunately, the sessions stopped after the lady who organised them retired in 2019.

Roger takes 8 tablets in the morning and 4 at night. With his forgetfulness in his old age, and now living alone, he uses his Amazon Echo to remind him to take his tablets. He reflected that he doesn't fully understand what all of his medication does and for which conditions they relate to.

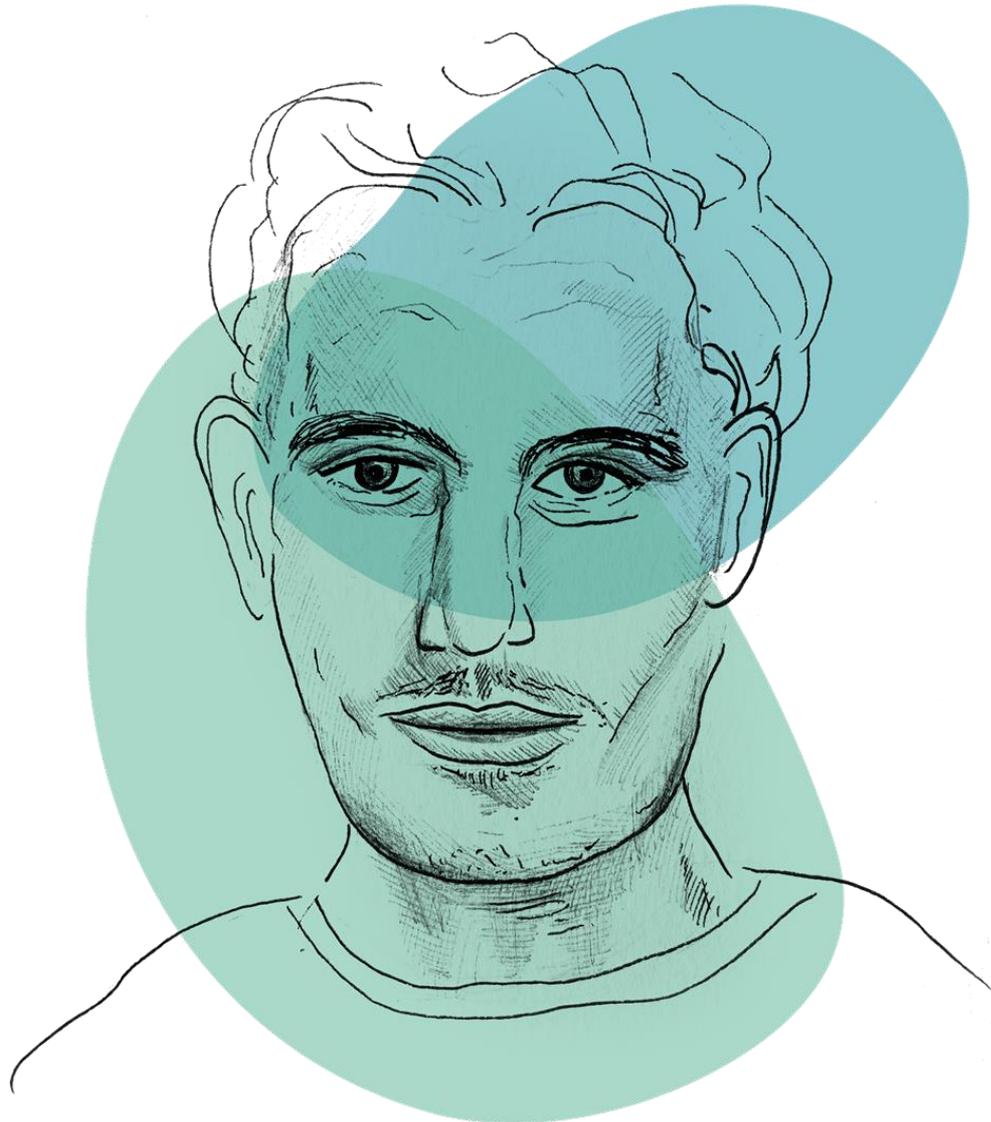
"When I get 'em, I understand them, then I forget"

Roger doesn't take any medication for his osteoarthritis and spondylosis aside from pain killers 'every now and then', instead he practices the exercises his physio gave him which are meant to help with the stiffness in his legs and his balance problems.

Nathan, 33, White British, Middlesbrough

Interested in fashion and antiques, he works in the family's tailoring business, but feels he can't contribute as much as he'd like because he is always very tired

Lymphoma, Narcolepsy, Fibromyalgia, Depression, Chronic IBS, Chronic back pain



“The story of my life is [HCPs] not taking me seriously.”

Nathan lives in a village near Middlesbrough, with his partner and dog. His GP is in his village but most of the other health care professionals he sees are in North Ormesby. He feels lucky his parents and his partner have always been able to drive him when he was unwell, or it would have been hard to get to his appointments.

“The doctors locally have got a really bad reputation. And my mum and dad didn't want to travel even further. So I stuck to mine, it was always the ‘better the devil you know’ type thing.”

Nathan experienced serious health challenges from a young age. As a child he lost his hearing in the left ear, and when he was 16 started to develop lumps in his groin, arm and neck. For two years he said these were dismissed by doctors, who insisted those were just a consequence of hormones when growing up. At 18 he was finally diagnosed with lymphoma, and by then it was in an aggressive stage. Doing chemotherapy, he spent months in hospital and in isolation as he had high risk of infection. He had to change his plans to attend the university he chose and went to a local one but was unable to participate in social events because of his treatment.

He has suffered depression since he was 15, which started after being sexually abused by an older man. His depression got worse with the cancer, and he reported how support groups made him worse. In the area he lives there weren't support groups with members who were younger people living with cancer, so he took part on groups with people who were much older. They constantly passed away, which gave him a bleak perspective of his potential future.

During the following years he developed a range of other conditions, including chronic IBS, chronic back pain, anxiety, had cancer a second time, fibromyalgia and narcolepsy.

“There was something seriously wrong with my back. [The doctor] kept going on about surgery and I said, I don't want surgery, I want to understand the cause of it. My dad came along to help and [the doctor] kept banging on about surgery, so we eventually just walked out. I saw a specialist, he was a lot more explanatory about the problems and did not recommend surgery.”

He reports that he has felt frustrated with health care professionals for his whole life, stemming from the experience of not getting cancer diagnosed because, he felt, doctors wouldn't listen or care. When new conditions emerged, he felt doctors would only look at his recent health history and not take into consideration a range of past conditions he experienced.

“My first [haematologist] consultant, you could tell he was coming towards the end of his career and was devoid of human touch in regard to connection and realising that you're actually human. When I got my new consultant, she was like an angel sent from heaven.”

Finally, a few years ago a haematologist he started seeing took matters into hand and is looking at all conditions together. Nathan feels she is the first professional that actually cares and is invested in him. Initially he was seeing her in Middlesbrough but she moved practice to a town further away. He drives over one hour each way to see her, as he feels no other doctors are really trying to help him.

His MLTCs have affected all areas of his life. He currently works at the family business, after many years of not being able to work because of poor health. Nathan reports having very supportive parents, who always tried to chase the best treatments possible for him and challenged doctors.

He has recently had issues with fertility that started when he had cancer. Before chemotherapy, he did cryopreservation of his sperm. Now, that he is thinking about starting a family, he reports having been told he is not allowed to use his semen for surrogacy because when he first froze it, he didn't state he was gay. Details were a bit unclear and discussing this in more depth would be very difficult for him. Luckily, he has now been tested and confirmed as fertile, so he no longer needs to go down a surrogacy route.

Sparkbrook & Balsall Heath East, Birmingham



Over the past two decades, Birmingham has seen a significant increase in its ethnic minority population³⁰. It is one of the most ethnically diverse cities in England – one in every three people identify as either Black, Asian or from an ethnic minority.

Birmingham is the seventh most deprived Local Authority in England³¹. Within this, Sparkbrook and Balsall Heath East is the most deprived ward³². It has a population 25,000 people³³. There is a large population of Asian people, with smaller groups of White, Black and Arab communities. As a result, there is a large Muslim community.

³⁰

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/390167/Birmingham_Evidence_Pack_for_publication_FINAL.pdf

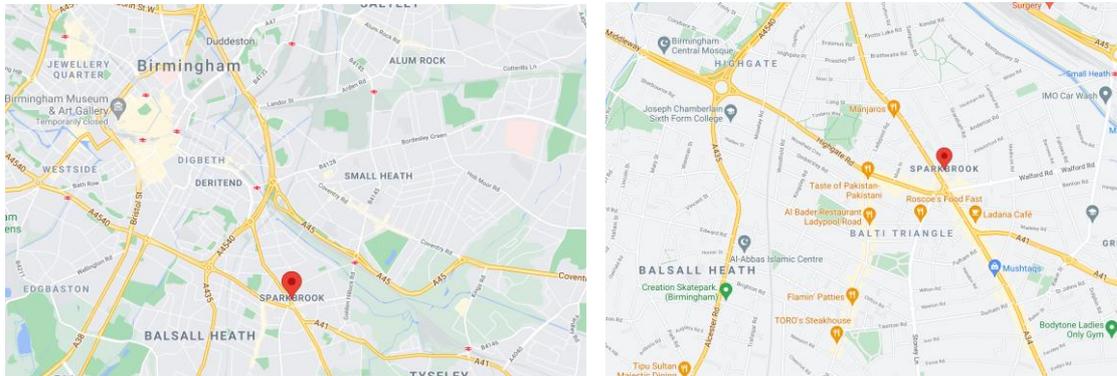
³¹ <https://www.sandwelltrends.info/deprivation-2019/#:~:text=Indices%20of%20Multiple%20Deprivation%202019%20%2D%20District%20Level&text=Sandwell's%20neighbour%20Birmingham%20is%20among,local%20authority%20in%20the%20conurbation.>

³² https://www.birmingham.gov.uk/downloads/file/2533/index_of_deprivation_2019

³³ https://www.birmingham.gov.uk/download/downloads/id/15502/sparkbrook_and_balsall_heath_east_profile.pdf

Local provision

Sparkbrook and Balsall Heath East ward is in the south of Birmingham. They are approximately 20 minutes by bus from the centre of Birmingham, or a 40-minute walk.



The closest hospital is the Moseley Hall Hospital, which is 20 minutes in the opposite direction. There are seven GPs locally and a range of health, social care and wellbeing services. Many of these support services focus on women's health, primarily targeting South Asian women. They can access fitness classes, physiotherapy and mental health support locally.

As this area is quite central to Birmingham, it is relatively well connected to the wider city, although it does not have a local train station. Most people however, felt that there was relatively good provision locally and that they didn't need to travel far to access the help they needed. They felt there was a good balance between formal support and charity support. The only gap they felt existed was in relation to mental health services, which were fewer than those supporting physical health.

To understand the overall picture of what health in Balsall Heath is like, we spoke to the co-ordinator at a south Asian women's sports centre, and a trustee at a day centre for the elderly in the community.

Challenges:

Professionals and local residents felt that the main challenges in terms of health and wellbeing in this part of Birmingham centred around language and culture. Similarly to Bradford, patients were more likely to engage with their healthcare service when it was being delivered by staff that spoke their language and understood what was culturally appropriate, such as interactions between women and men. However, this was not always possible given the provision locally.

The limited English language skills of many of the elderly members of the community also made engagement with healthcare difficult. Many were often resistant to getting help particularly in relation to mental health services and support.

Bekele, 26, British Somali, Birmingham

An ambitious data analyst who has taught himself to code

Severe asthma, type I diabetes



“[My conditions] have been a huge part of my life since I was very young. It’s the norm for me.”

Bekele lives with his parents and three younger siblings in Balsall Heath, Birmingham. His parents migrated to the UK from Somalia before he was born and speak only a little English. He was diagnosed with severe asthma when he was 9, and Type 1 Diabetes when he was 13. Bekele knew these ran in the family, but he found this quite difficult to deal with at times as it limited the things he would otherwise have done with his friends – like playing sports. His mum also has diabetes and helped him learn how to manage his condition. However, she found it difficult to communicate with doctors due to her limited English. Bekele remembers feeling like doctors were not taking her seriously and having to step in to help explain things from a young age.

“I remember having to tell them off... sometimes they would then take the issue more seriously. But it would always be a bit of an argument.”

He has several ways to manage his wellbeing but finds that it can still be socially isolating. Knowing that his asthma is worsened by congested air, Bekele avoids going outside between 11am-4pm every day when he knows the air pollution locally will be particularly bad for him. He also has an air purifier in his room.

“I had to save up to buy the purifier after my doctor suggested it. It cost £399. But, it’s definitely worth it. You feel the impact of it within minutes of switching it on. I instantly notice the difference in the air quality.”

His diet is heavily controlled by what is best for his diabetes. He keeps a food diary to help him identify which meals are best to avoid and cook his meals separately to his family to avoid fainting. Although it helps him with his physical health, Bekele finds it to be inconvenient and restrictive, taking the enjoyment away from food.

As much as he loves cardio-based sports, his asthma means he is unable to participate in these activities. Due to the severity of his condition, he monitors his asthma regularly in order to stay on top of changes that he might wish to speak to his specialist about. Every now and then, Bekele will experience a flare up, where it gets difficult to breathe, and he needs to get a referral for specialised support.

“I used to love playing sports – but I just can’t do it now”

His parents encouraged him to do well at school, and Bekele himself reflects that being the child of immigrants can make you feel more insecure about your future, so he always tried to do well at school. As a result, he spent a lot of time studying. He studied economics and development at university and later secured a job in data management. Through this process he also spent some time abroad in Korea and lived in London for a while when working.

When the pandemic started, Bekele moved back in with his family, which was difficult at first. He was always worried about his immune system and felt the pandemic had made him a lot more ‘claustrophobic’.

“I deal with something health related every day, whether that’s something small or big, or if it’s just having to speak to a doctor or having a look at my diary or what not”

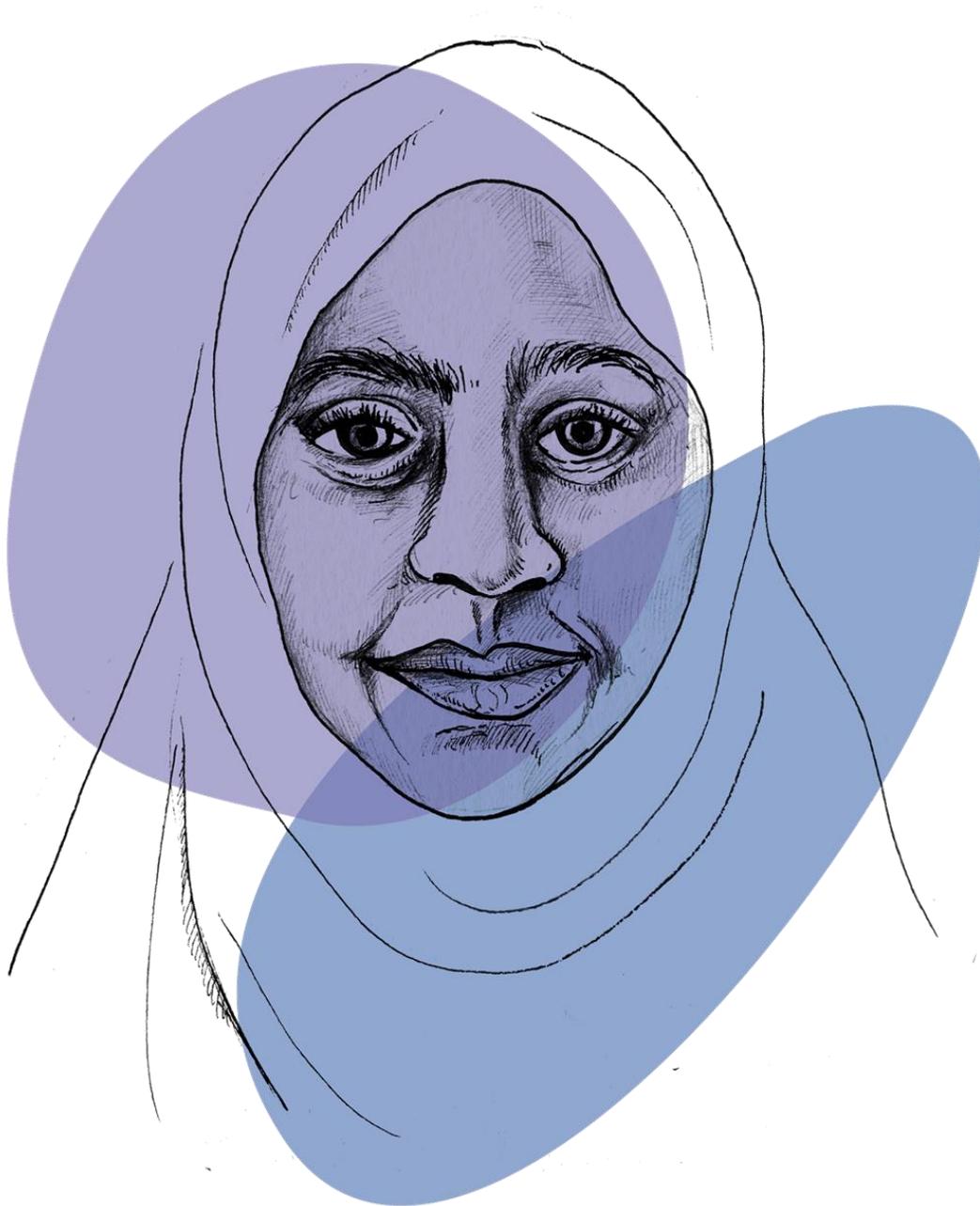
Bekele feels that the “oversubscribed” and “overpopulated” area he lives in is a key challenge for his healthcare. He thinks the professionals in his area are stretched which leads to longer waiting times and a low-quality, rushed service.

He also believes that a late diagnosis of his asthma was caused by doctors undermining his mother’s concerns over his health and recalls them being very dismissive. This was exacerbated by the fact that his parents’ limited English at the time meant they were struggling to communicate his symptoms accurately, leading to frustrating interactions with GPs.

Shaima, 32, British Pakistani, Birmingham

A keen cook who enjoys experimenting in the kitchen with new recipes, and baking with her children

Blood cancer, Depression



“In the past I have neglected my health to look after the children.”

Shaima has lived in Birmingham her entire life. She currently lives with her two children, aged five and seven. She was previously married, but divorced her husband five years ago after he was abusive.

She was diagnosed at birth with a rare blood cancer. The condition is genetic, which her mother also has, along with Shaima's five-year-old daughter and her brother, who passed away at only 18 years old.

Due to the cancer, Shaima had her thyroid removed at three years old, and has been taking medication for this ever since. She recalls that until the age of 29, she found her condition to be 'fine' and manageable, even though she did end up in hospital a number of times before then. For her, periods of time where you only have a few hospital trips felt like a positive thing.

"I saw my mother go in and out of hospital my whole life and I've had the condition since birth so I don't really know any different."

Shaima's mental health took a hit in 2015 when only days after the birth of her daughter, her brother passed away. It was only months after this when she also decided to leave her abusive husband, who retaliated by filing for custody, claiming Shaima's condition made her unfit to be a mother. The battle was particularly draining for her as, being unable to afford a lawyer, she did all the admin for her case on her own as no support was available to her.

Further cancerous cells were discovered in her adrenal glands when she was 29, and she attributes the tumours to the stress of the courts, raising a new-born and mourning her brother.

"It got very unpleasant during the divorce. Even now I'm still battling him as he doesn't pay any child maintenance despite working and living alone."

Shaima finds it quite difficult to engage with HCPs about her illness, as the challenges of a rare condition mean that there is very little understanding of it. She has found that her GP often won't take her symptoms seriously as she is young and looks healthy. She has recently experienced severe knee pains and finds it hard to walk around. When she enquired about being referred to a physiotherapy service for this, her doctor was dismissive and instead suggested she watch exercise videos online and do them herself.

Despite having had the same doctor her whole life, it is frustrating for her that he is still so unaware of her condition, and her main use of the GP is to get referrals to the specialists that she believes will be more helpful to her.

"I was on hold for about four hours the other day trying to get an appointment. They are rubbish, but if I move to a different GP they will know even less about my condition."

Although she feels her GP has not been supportive about her physical health concerns, she found that he was very supportive when she was seeking support for her mental health. She was referred to a counsellor during the pandemic when the stress of shielding and pressures from her ex-husband led to increased feelings of stress and isolation. However, when she completed her sessions and asked if there was further support available to her, she was frustrated to hear that the only realistic options offered to her were with a private therapist, which she could not afford.

Shaima's experience with her health and her marriage have inspired her to try and help others. She is currently completing a counselling course to be able to support others, after finding the counselling she had following situations with her ex-husband helpful. The interest in helping others stems from a lifelong passion, as she had also graduated from university in 2010 with a degree in Social Work but was unable to pursue this at the time due to a shortage of job vacancies.

Managing health inequity and multiple long-term conditions

Many of the individuals you have just met were in situations which made it harder for them to manage their conditions – often these situations were out of their control, and other times impacted by relationships, social pressures or competing priorities.

This echoes findings in our previous report, ["Just one thing after another": Living with multiple conditions](#); there were some respondents who had the time, confidence and support to more successfully manage their conditions – they felt a sense of agency over the treatment and support they received – however, others, in particular those facing inequity and disadvantage, were often struggling to manage their conditions and felt they had less control over their own health outcomes.

In the next two sections, we'll explore in more detail what **factors in people's lives** make it more difficult to manage their multiple conditions, and how the **health system** is, in some cases, failing to support individuals to overcome these.

What factors in people's lives make it more difficult to manage multiple conditions?

The stories of the people at the heart of this work bring to life the wide range of issues that people can face when it comes to managing multiple conditions. Only by exploring people's experiences through a health equity lens is it possible to see how factors in people's lives, such as money troubles, living in unsuitable housing or experiencing family or work-related pressures, many out of people's control, inhibit their ability to manage.

Because of this, individuals were less likely to prioritise their health. In some cases, health management behaviours were conflicting with their day-to-day lives, and in others, they hadn't always been supported to acknowledge or understand the importance of healthy behaviours for their conditions.

"The GPs in this area see a lot of patients, but around 40% of the appointments are not even biomedical. It's usually other things that they need support with such as stress, sick certificates, letters for better housing... we try our best to signpost them to social prescribers and other support because they need help. But we aren't the ones that can do it." Local PCN leader, Stockwell

Working in manual jobs meant exercise was deprioritised

The low-income backgrounds of many of our respondents meant that they had often worked in manual jobs that were sometimes physically exhausting, and often required long hours. Rest was seen as a luxury, and something they were keen to do in their downtime or in retirement. In contrast, physical activity was not often considered something that could be done for pleasure.

Vera's habits around diet and exercise developed while she was working as a cleaner. She'd have energy drinks to keep her going from 6am to 10pm, and after a long day of physical work she would wind down at home. Since retirement, her habits around relaxation and sugary drinks have continued, which, combined with no longer carrying out physical tasks, are having an increasingly negative impact on her health. However, Vera struggled to see why she should change her longstanding habits, especially as they brought her enjoyment.

Many respondents were more focussed on their work, and sometimes other people's wellbeing, rather than their own health.

A health worker we spoke to struggled to make time for her own health needs, despite managing a wellbeing team in Middlesbrough. She has diabetes and admitted that she wasn't always on top of her own health. She spends her time finding ways to help people manage their conditions and stay active in the local area, however, because she spends a lot of time travelling and is on her feet all day, she reflected that she neglects her own health and prioritises others.

"My diabetes nurse keeps telling me I'll be no good to anyone if I don't start looking after myself" Healthcare worker, Middlesbrough

A project lead at a community centre for women in Bradford explained that this was a common theme among the homemakers in the area, who focused heavily on their role and ensuring everyone else was taken care of.

“A lot of our service users are women who haven’t been in a position to prioritise their healthcare as they have large demanding families. They put everyone else’s needs above their own” Project lead, Birmingham

Inadequate living situations often made health management more difficult

Some faced problems with their homes, particularly those in social housing, making it even harder to take action to improve their own health and manage multiple conditions.

The geographical location of housing was often cited as causing problems with access to necessary services. In some cases, management of conditions and attending appointments was made more time consuming because of significant distances to services, affecting how frequently they engaged with necessary support. This was particularly true for respondents living in rural areas.

Roger lives in Loftus, rural Middlesbrough. To get to the hospital he either has to take two buses and walk for 20 minutes, which he finds extremely tiring, or book a spot on the hospital transport service, which takes about two hours there and back as it picks up multiple patients from all over the valley. This has put him off going to some of his hospital appointments, particularly when the appointment itself might only be a ten-minute check-up, as he doesn’t feel it is worth all the time and effort.

“If it’s just a check-up and is at 9am I would have to consider whether it is worth it [making the journey]” Roger, 70, Middlesbrough

In addition to geography, suitability of the accommodation itself was also a common issue. In Bradford, a staff member at a local housing association mentioned that multigenerational homes are common in the local area, particularly among the Pakistani community. This often equates to larger than average family sizes living in the same property and leaving little space within the home. They perceived that this could be a barrier to exercise, as there is limited, if any, space to exercise at home in an appropriate manner.

In some cases, respondents had to make difficult trade-offs between living in suitable housing, having access to the support they needed, and maintaining important aspects of their current lifestyle. Social housing services, reflecting a trend in support provision in general, were often unable to flex to the more human and personal needs of the people they were supporting, whether that be a much-loved pet or ties to a particular area.

Multiple respondents were living in housing that was unsuitable for their needs, however, would not accept other options provided because they required sacrifices which would impact their wellbeing.

In addition to living in an area far away from health care services, Roger lives in an old council house which is poorly insulated. Roger believes living in this cold house is bad for his health, particularly his COPD. Recently his social worker offered him the opportunity to move into assisted living housing, but he declined the offer as he was told he would not be able to take his cats with him – an important source of company and comfort after the death of his wife. Instead, he has been put on the waiting list for a council bungalow but isn’t sure how long this will take.

“I want to keep my cats y’know, they need a garden” Roger, 70, Middlesbrough

Josie lives in a tall estate building with a broken elevator. Due to her living with HIV, Josie experiences frequent fatigue and finds that having to take multiple flights of stairs makes her exhausted. However, housing options are limited, and she is keen to stay in the Bradford area to be close to her sister, meaning she is yet to find somewhere suitable to move to.

Another respondent, Charlie, was forced to decide between suitable housing, keeping his dog and staying in his hometown in Kent. Charlie suffers from physical ailments such as prolapsed disc and nerve damage, as well as mental health conditions like depression. He has become very reliant on an emotional support dog to maintain his mental health. Kent County Council were unable to find him suitable housing that would also allow animals. His decision to keep his dog meant he was rehoused over 200 miles away in Bradford, hours away from his family, which he said has been an incredibly lonely experience.

Not speaking English can make navigating healthcare particularly challenging

There were a smaller group of people included within this work for whom English was not their first language.

For these individuals, many aspects of managing MLTCs were made more difficult. They faced additional challenges around understanding their diagnoses, conditions and treatment – as well as the options for how to manage their conditions. This means that making *informed* decisions about their health and care is almost impossible. There were often some options for access to interpreters, whether they were family or formally available within healthcare settings, but most were worried about being a burden on others. This meant they sometimes went without language support or avoided accessing care when they needed it, due to concerns around the language barrier.

This was particularly true for Vera. When going to her appointments for her diabetes or other conditions, she needed her daughter to come along to act as an interpreter. She knows that she can access one through the GP practice, but this additional request makes her feel uncomfortable about attending or booking an appointment.

“I just don’t want to cause any problems for other people. It’s annoying for my daughter to have to come with me.” Vera, 74, Stockwell

It can also mean people feel unconfident expressing themselves or articulating their symptoms or issues, even when using an interpreter. For some this can have real or perceived challenges in receiving the right diagnosis. Bekele, 26, felt that his diagnosis of asthma as a child was problematic because his parents struggled to communicate his symptoms and experiences, and as a result, the healthcare professionals didn’t take his mother’s concerns seriously.

“I remember on a few occasions when I was younger, my mum was trying to describe my symptoms and what I had been going through to the doctor and he kept dismissing her which would frustrate me... my mum would have to calm me down. She was so used to it and told me not to take it seriously because it was normal for her to be treated this way” Bekele, 26, Birmingham

Angelica, 69, and her husband had lived in Stockwell for a long time, but had recently moved to Canada Water. In Stockwell she had a good relationship with the local healthcare professionals and could easily get translation support. However, in Canada Water, she found it hard to access similar networks needed to help her navigate the healthcare system.

As she had not yet had her second COVID-19 vaccine she was concerned about going to hospital, which meant she was struggling to access support for a hernia which was bleeding during the course of the pandemic. Booking her second vaccine proved problematic as she hadn’t found anyone locally to help by acting as an interpreter. She didn’t know how to communicate with the health system that she wanted support to get her vaccine and also deal with her hernia. Instead, she was just waiting until someone contacted her about her vaccine.

For people who don’t speak English, accessing and interacting with services was particularly challenging, however there are also issues with communication and understanding faced by individuals without language barriers.

Many people did not have a clear understanding of what conditions they have or how to manage them

Across the board, there were many people who were unclear about what conditions they were living with, how these conditions impacted their body and how to manage their symptoms. There were many instances where people couldn’t tell the research team the name of their condition, or their carer might disagree with them about their diagnosis.

These challenges point to issues in how important information related to conditions and treatment is being communicated, at the point of diagnosis and on an ongoing basis. In order to improve health literacy, improvements need to be made in how information is shared to enable people to make more informed decisions about their own care.

When Kumar was diagnosed with ulcerative colitis in 2009, he reflected that he didn't really understand the details of his condition or how it would impact his life. He refused a colostomy bag because he didn't know why he needed it or how serious his condition was. He felt the services he interacted with did not make much of an effort to help him understand his condition and treatment options, instead accepting his decision without making sure he was fully informed and confident in his choice.

"I couldn't really comprehend what it was, what was going to happen, what will happen. I told the doctors I wasn't ready for it at the time, and then they just left it"

"[The doctors] can only get so much time with one patient... but they still could have given me other routes, or advise me on some things more... I would have liked more support. I was young and suffering." Kumar, 40, Birmingham

Kumar also spoke in detail about the many times he had ended up in hospital due to low blood sugar, caused by his diabetes. He has had diabetes for almost a decade but admitted that he still feels very unsure about how to prevent it getting to a point where he is hospitalised.

Kumar was by no means a solitary case. Ibrahim, 70, could tell the research team that he had "two types of arthritis" but was unable to provide any information on what these two conditions were, how they differed from each other or what they meant in terms of managing his health into the future. Ibrahim faced additional challenges around communication due to his visual impairment, as he was often sent letters about his health and treatments that he was unable to read.

Jade, 44, was living in Birmingham with anxiety, sickle cell and asthma. She did not feel confident that she understood what her anxiety is, what has caused it or why she has to take medication every day. She also doesn't feel clear how the pill she takes can help her with her condition, which led to her trying to stop taking them. However, when asked, her doctor just told her to keep taking them, again with no explanation as to why.

A similar situation occurred for Sabba when she was prescribed medication for her high blood pressure and was not told at the time that she had to take them for the rest of her life. She had assumed the pills were a temporary measure to relieve symptoms, unaware that her condition is one that needs continuous management.

"The doctor told me to take them and that was it. I didn't know how long I was meant to take them for or what the pills were doing" Sabba, 63, Bradford

Due to the factors outlined above, it was often much harder for people to adopt healthy behaviours

Unhealthy behaviours were ingrained for many of the respondents, often as an outcome of the challenging living situations they were in, and sometimes because they provided enjoyment within the context of otherwise quite turbulent or difficult lives. Healthcare professionals found it difficult to encourage people to change behaviours or provide the support that would enable them to do so in the context of their work, housing, culture and wider family needs.

In particular, professionals trying to support people to change lifelong poor diets struggled to find ways to help. The manager at a community centre in Middlesbrough reflected on how common it was to see middle-aged people that are overweight and have diabetes. She has spent time trying to educate people on healthy eating but has found it hard to make a difference when people's eating habits have been cultivated over many years.

"It's hard to educate a 30-year-old about healthy eating when they've been eating microwaveable food their whole life" Community centre manager, Middlesbrough

It was, understandably, hard for people to break longstanding patterns, born of challenging circumstances, that might be at odds with maintaining a healthy lifestyle. Often this impacted how well they engaged with medical professionals or took the advice given around managing their conditions.

Alice works at a foodbank in Bradford. She said a large number – around a third – of adults that come to the foodbank have diabetes. The foodbank is able to adjust food packages to meet their dietary requirements, however a large proportion of individuals, often single men, say they do not want the healthier, diabetes friendly package, and would rather have the normal package that contains some unhealthy treats.

"I know that a lot more of people have diabetes too but don't want to tell me. Most people care more about having the 'tasty' food than their health" Foodbank manager, Bradford

Vera's story may go some way to explain why this might be the case. As described previously, Vera had developed a pattern of eating cakes and drinking a lot of Coca Cola while working extremely long hours during her work as a cleaner. She struggled to follow advice around changing her diet as she had been doing this for so many years, and it was something which brought her happiness.

For some, there were culture-related customs and cuisines which made it harder for people to make dietary changes. A team member at Bradford African Community reflected that many service users suffered from diabetes due to a diet that was high in sugar. She found service users were often reluctant to give up the foods they have been eating their whole lives as they had not been supported to understand the link between their diet and their condition. A social prescriber in Stockwell similarly emphasised that diabetes from was more common among the Spanish and Portuguese community that she supports who suffer from MLTCs.

Other studies have further investigated the structural factors underpinning poor diet. For example, *Bite Size: Breaking down the challenge of inner-city childhood obesity*³⁴, explores how deprivation, urban environments, and diversity all impact food behaviours to differing extents. The study, which took place in Lambeth and Southwark (encompassing Stockwell), found that the urban environment – for example, cramped and uninviting kitchens and the high density of fast-food outlets – alongside often stressful and chaotic living situations, relating to work and financial difficulties, had a significant impact on the diets of parents and children.

Sometimes unhealthy habits were developed because they were socially expected by the people around them. Many of the people we spoke to would drink, eat or smoke while socialising with family and friends. Roger described being heavily reliant on his friends for support when he was younger, and that a significant part of their friendship culture was attending the pub. After years of pub culture, Roger had gained significant weight and had suffered three heart attacks. His friendships and their behaviours around the pub were more important to him at that point in his life than his physical health.

Unemployment and minimal access to leisure facilities were also thought to play a big factor in the prevalence of smoking and excessive drinking in some areas. The community centre manager in Middlesbrough felt that because of the high levels of unemployment locally, people were far more likely to drink and smoke to pass the time.

Health and social care professionals may need to think beyond providing information around healthy diets and exercise – to investing more in understanding how diet and exercise can fit within people's lives, and what wider changes may need to be made to support people to change their behaviours.

³⁴ Guy's & St Thomas' Charity, *Bite Size: Breaking down the challenge of inner-city childhood obesity*
<https://urbanhealth.org.uk/insights/reports/bite-size>

Some did not feel able to make a difference to their own health

Some respondents had not been supported to understand the impact of their diet and habits on their health and were not aware of how they could manage their conditions beyond taking prescribed medications.

Gloria (43) and her husband Edgar (47), who came to Bradford from Congo three years ago as refugees, did not understand why she had been referred to a dietician for her leg pain, and they did not see the connection between obesity and lower limb pains. As her leg pains started when she was at a lower weight, they believed her diet and weight had little to do with it and wanted a quick fix from the GP, rather than advice around her lifestyle.

“They sent her to a dietician. How is a dietician supposed to help leg pain?” Gloria’s husband Edgar, Bradford

A community centre for the Muslim South Asian community in Bradford described that many of the people they speak to often feel resigned to the fact that they are ill. She explained that this sometimes stems from the belief that “if this is what I’ve been dealt with then it is God’s will”.

Overall, individuals often showed a lack of confidence in their own ability to manage their condition, whether due to a lack of knowledge around the impact of diet and exercise, or a lack of perceived agency over their own outcomes.

Others were taking steps to manage their conditions in the face of adversity

Some individuals were taking steps, despite challenges or lack of support, to manage their own health, and in some cases were supporting others to do so too.

Ibrahim needed assistance to exercise outside of his home due to his visual impairment and applied for a volunteer to help him do so. He has, however, been told that there is no one currently available to take him for walks. Instead of resigning himself to this and as a result not doing exercise, he has taken it upon himself to walk 20-30 minutes around his lounge twice a day. And Roger, who lives alone and has to take multiple medications a day, has set up an Amazon Echo to give him reminders to take his tablets and overcome his forgetfulness.

Shaima has taken a lack of service provision into her own hands. She benefitted greatly from counselling to help her with the stress of shielding and pressures from her ex-husband, however, was only able to get a few sessions free on the NHS, and could not afford private care. Shaima is now pursuing counselling training to help others who have been through similar experiences.

Section summary

Within the research we did not see individuals attributing their experiences of health and wellbeing to particular protected characteristics. However, as a result of people’s living situations, financial positions and upbringing, their choices were limited around health management – they weren’t always able to make the necessary changes to manage their health. They also might not be able to access the same support or services as people who have been better supported to manage their health.

The healthcare system needs to be doing more to both ensure all people have access to an equal level of care, and that individuals, or the services they require, are supported to overcome situational barriers in order for people to successfully manage their condition. We explore the role of the healthcare system in detail within the next section, uncovering structural barriers to tackling health inequality.

What elements of the health system make it more difficult to manage multiple conditions?

All of the barriers that people face in looking after their health and managing multiple conditions present opportunities for the health and social care system to improve.

While there are examples of good practice and high-quality support on offer, it is clear through the structural problems outlined in this section, that the current system is not working for everyone equally. The support is rarely adequate for people in challenging situations, causing them to face inequity and disadvantage. More needs to be done to bridge the gap between these communities and the support on offer. The system needs to take some steps to meet them where they are in relation to their health and priorities.

This chapter describes some of the challenges in more detail, demonstrating the ways in which the current system is not working as well as it could for these audiences.

Some services were struggling to work together effectively to deliver a joined-up service

The quality and provision of support varied considerably across the different locations. In some instances, an increased number of services existed that were also working together far more effectively to meet the needs of local people with multiple conditions.

Stockwell provided the best example of where services were working together effectively. Social prescribers and community workers played an important role in supporting the health and social care needs of residents, and many had adapted to meet the needs of the large Portuguese community in the area. A local project ‘Thriving Stockwell’, aimed to create a holistic system of care and support, involving all five GP practices alongside a residents’ association, schools, the council and charities.

However, this example of holistic care was not universal, and not observed to anywhere near the same extent within the other areas explored for this work. As mentioned in previous work, *“Just One Thing After Another”*: *Living with multiple conditions*, often formal and informal support is focused on single, specific conditions, rather than the combination of conditions that any one person could face³⁵.

A community centre manager in Middlesbrough said that, amongst other things, the centre offers local support for people with mental health problems. One of the challenges the manager was trying to tackle was building connections with local GPs, to enable GPs to refer patients to their support groups and other activities. She knew that a lot of people locally have issues with their mental health and there is a high prevalence of people taking medication for it. And yet, despite many attempts, she has struggled to get engagement from local healthcare professionals, while the Local Authority, schools and social prescribers have all been receptive to collaboration.

There were a few other instances of services working together effectively to support residents with their multiple conditions – showing the benefit of collaboration between medical and non-medical services. For example, a women’s sports centre in Birmingham was being utilised by the hospital as their site for physiotherapy – enabling the healthcare professionals to access and engage the local community more easily.

Some locations had minimal services available

However, for many of the people in this research, accessing the support they needed in the first place came with additional challenges. The most notable challenge was that there was often minimal local provision for

³⁵ Richmond Group, *“Just One Thing After Another”*: Living with multiple conditions

their health, either meaning they struggled to engage with support at all or were required to travel significant distances in order to access it.

Nathan had experienced an excellent level of care from his haematologist; however, she had recently moved to a new area. He was so appreciative of the support he had received from her, that he was now driving an hour each way to see her. Nathan had previously found local support to be lacking, and had historically poor experiences with services, so he didn't want to risk being referred to a new haematologist who he thought probably wouldn't be as good.

Nathan also recalled that living in a rural Middlesbrough, it was hard to find the emotional support he required when he was going through his cancer treatment as a teen. He reflected:

“I had to join a support group where everyone was much older than me, and they constantly passed away. It just made my future feel really bleak” Nathan, 33, Middlesbrough

Also in Middlesbrough, Roger, 70, had struggled to access exercise classes locally since the sessions he attended had stopped. After his first heart attack he was advised to exercise more and had found some local classes that he really enjoyed. However, the instructor retired and then the classes stopped. At that point it wasn't easy to find an alternative option to travel to as the other classes were too far and he would often be tired by the time he got there, so he stopped going.

For Roger and Nathan, while they could access some of the formal and informal support they need, it was a significant distance from home. This meant some people are facing long journeys and sometimes expensive travel costs in order to access healthcare. This was particularly prevalent for people living in more rural areas but was certainly not exclusively an issue for these groups.

People in challenging situations weren't always receiving adequate support

Existing services weren't always able to give the additional level of support required for individuals with more complex needs – these needs ranged from impairments or disabilities to cultural or religious sensitivities.

Ibrahim was living with visual impairment alongside osteoarthritis, osteoporosis, and heart conditions. He knew that exercise was important for his heart and his arthritis but struggled to navigate the local area due to his sight. As we have outlined in the previous chapter, he had applied for a volunteer to walk with him but was told that there were none available in his local area at that time. As an alternative, Ibrahim was walking around his lounge for 20 minutes, twice a day, to try and keep moving.

“I have an app on my phone. I walk around the room for 20, 30 minutes. I walk 2km in my lounge” Ibrahim, 70, Bradford

A volunteer at a local refugee community centre in Middlesbrough explained that one of their Muslim service users had waited weeks to get screened by a female doctor for breast cancer after developing a lump, as she did not feel comfortable being seen by a male doctor for this issue.

Similarly, the lead at a women's health centre in Birmingham described that a major barrier in the area is not just the availability of services, but also the availability of culturally sensitive services. She found that women in the area were travelling long distances to attend hospital appointments for physiotherapy, only to find they would be seen by a male practitioner, which made many of the women feel extremely uncomfortable. More recently however, the physiotherapy service has moved to the centre of town, which was not only closer to where the patients' lived, but also has more staff who are female and from the same cultural background as many of the patients, which has led to appointment retention rates increasing noticeably.

We heard in the previous chapter that often emotional needs weren't always being taken into account by housing services, such as ties to family or pets. Similar, human needs also weren't always being taken into account by healthcare services. For example, Sabba's daughter Rahmiya explained that due to the past trauma in her mum's life, she found it difficult to open up to just anyone in counselling service for her anxiety, particularly if the options provided by the GP were helplines or online chat functions. Rahmiya felt that Sabba's

need to “relate to someone and emotionally connect with them” before she can effectively open up in a counselling session was not being taken into consideration when they were referred these services.

Services should support patients to take control

Throughout this work, many, if not all, of the respondents demonstrated some degree of deference to the healthcare professionals supporting them to manage their multiple conditions. They often had a great deal of respect for their doctors and other professionals and, when they did engage with them, trusted wholeheartedly their recommendations. However, in some cases, this meant they would wait for a healthcare professional to tell them what to do around their health and would rarely proactively seek further information or consider other options for looking after themselves, such as exercise or diet changes.

Some also accepted experiences of care that might be unacceptable to others – such as significant delays or a halt to treatment – rather than pushing for better support. Jessie, 30, living in Birmingham, completed a series of eight physiotherapy sessions prescribed by her doctor for her plantar fasciitis. After these sessions, she did not feel that her condition had really improved, however, Jessie never went back to her GP to ask about other options, or to request additional physiotherapy. Jessie is now in chronic pain, unable to walk and has been unemployed ever since her treatment stopped – despite plantar fasciitis being a treatable condition.

“If I could have had more physiotherapy then the GP would have sent it to me. They knew I still had pain.” Jessie, 30, Birmingham

Similarly, Shaima, 32 from Birmingham, had pain in her knees and therefore asked her GP if she could have access to a physiotherapist. Her GP was reluctant to refer her for support, telling her there was a long waiting list and he didn’t think it would help. His advice instead was to search for exercises on YouTube or online. Shaima still feels unclear as to why physiotherapy wouldn’t be appropriate. She did search for videos online, but found the volume and range of them overwhelming; there were too many things to choose from and she wasn’t clear which would help her the most. Therefore, Shaima decided not to do any exercises for her knees because she worried about doing more harm than good.

Jessie and Shaima both felt unable to ask questions about decisions made about their treatment or make healthcare professionals aware that aspects of their treatment were not working well for them.

It is important to recognise the role of the individual in managing their own health

This deference to healthcare professionals often seems to stem, at least in part, from how the healthcare system works and what is expected of patients.

As detailed in the previous chapter, health literacy was low among many of the people living with multiple long-term health conditions and facing inequity and disadvantage. And yet, there was evidence from many of the people interviewed, including professionals, that more could be done within each interaction with a patient, to ensure understanding and support people to take greater control of their health. Instead, at present, the power imbalance between the doctor and the patient is maintained, pushing some people included within this work further from being able to manage their health. This is not easy to do, especially in a landscape of high pressure on professionals working within health and social care. But the gains could also be felt by the system further down the road, as more people are better able to manage their own health and rely less on professionals to dictate next steps.

Many people reflected principally on the lack of time they are able to have with healthcare professionals, most notably their GP, and how that time was used. They felt that professionals talked quickly and used a significant amount of jargon, making it challenging to fully understand their diagnosis, treatment, medication or expectations of them in terms of looking after their health.

For example, Kumar was particularly unclear about why the doctors treating his diabetes were making the decisions they were, which he often attributed to the language they used in their explanations. When he went to hospital for low blood sugar, he was often given Lucozade. He felt the doctors never clearly explained why this was the case, so he came away assuming that Lucozade was one of the best things for his diabetes.

“I only recently learned that it’s not good for me. I wish someone had properly explained it to me. In normal English.” Kumar, 40, Stockwell

There were also some indications that healthcare professionals were unlikely to talk to patients about self-management of their health, instead prescribing medication with little support to make active changes to their lifestyles. In Birmingham, a centre for women with long term conditions, including many who have multiple long-term conditions, felt that local doctors were prescribing medications without any wider support to educate people in the steps they can take alongside this medication to improve their health and wellbeing.

“Many of the GPs in this area have a very old-fashioned attitude towards illness and they are quick to prescribe pills to mask the problem, instead of helping people understand their conditions...

... They give medication at first diagnosis as the main form of treatment, and don’t understand that people need full knowledge on conditions in order to make lifestyle changes. The messaging just isn’t there.” Project lead, Birmingham

In Middlesbrough, the manager of a local community centre saw similar outcomes in their local area. They felt that the result of this behaviour was that many local people were struggling with poor mental health with limited support to make genuine change to their lifestyles and health.

“About 80% of the people that come to the centre are on anti-depressants, but the doctors need to do more than just give people pills. Most of them have mental health problems because they’re isolated and lonely and have nothing to do. The doctor can give them a pill and think they are helping them, but they will only go back, take it, and then continue to sit in their living room feeling depressed all day.” Community centre manager, Middlesbrough

Sabba’s story of a positive interaction with a healthcare professional demonstrates how well patients can be supported when HCPs treat conditions holistically and take the time to consider the patient’s needs. When a scan presented high levels of fat around her liver, Sabba was referred over to a nurse who took the time to understand Sabba’s lifestyle and overall wellbeing needs, before putting together a diet plan to follow. By approaching her healthcare in a holistic way, and scheduling weekly appointments to check Sabba’s progress, the treatment worked effectively and Sabba felt well supported throughout. Not only did they solve the issue with the fat around her liver, but Sabba also found that her mental health and arthritis had also gotten better through this plan.

There are lots of opportunities for healthcare professionals to rebalance the dynamics they have when seeing patients. The benefit of any behaviour of this kind is to better support people to understand their health conditions, to feel able to ask questions, engage and ultimately to take better control of their health more widely. This, combined with access to multi professional teams and holistic support plans that use a shared decision-making approach with patients, could make a big difference.

People need to be supported to fully understand their own conditions and treatments

The fact that many of the respondents were left unclear on their conditions, as detailed in the previous chapter, demonstrates that professionals are not actively checking that people understand the information that is being presented to them. For people facing inequity and disadvantage, this lack of clarity can be incredibly disempowering, when in fact *more* needs to be done to ensure they are able to manage their conditions.

Some of the people specifically said that professionals hadn’t explained their condition/s, the relationships between different conditions or what to do to manage them in a clear or accessible way. There were particular challenges around medication and treatment, where many people felt that their doctors hadn’t properly explained why they were taking certain medication, how long they should take it for or what part of their multiple conditions it was actually helping.

For Ibrahim, he felt particularly unclear about his cholesterol and his heart:

“They don’t explain. They just tell you.” Ibrahim, 70, Bradford

Jade, who lives with anxiety (alongside sickle cell and asthma) in Birmingham, wanted to come off her medication. When she spoke to her doctor, they told her to keep taking it, but she felt they were very unclear as to why, not explaining it in a way that she could understand.

Sabba, 63, in Bradford, had similar experiences around medication. She was given medication for her high blood pressure, but felt the doctors never explained to her that this would become a medication she took for life. She left her early appointments eight years ago believing that she would need to take it for the short term but has continued to take it ever since. She also felt the GP didn’t explain why she was taking it at all.

“They never explained it to her at the time and what it would mean having to take medication for the rest of her life” Rahmiya, Sabba’s daughter, Bradford

The result of this wide-ranging lack of understanding is that people didn’t feel they had ownership of their conditions or were able to feel in control of the medications they are taking. They didn’t feel confident making decisions about what type of care and support they needed and they weren’t as able to make informed decisions about their health and care.

People need support and better information before they are ready to self-manage, particularly in populations who are already facing health inequity. There are opportunities for the health and social care system to consider how information is communicated to ensure all people are able to understand and engage.

Many healthcare services didn’t have strong links with local communities

While previously we have outlined access problems relating to geography or availability of services within any local community, not all barriers stem from these issues. There were also barriers that centred on different people’s perceived connection to and understanding of the health and social care support available in their area. Many of the people across the four areas had experienced at least one of these types of issue in accessing care.

This was often because of weak links between the professionals and services delivering support and the people living in the communities themselves. While in some places there was evidence of engagement activities by some organisations and individuals to try and clarify the roles of different organisations and professionals for residents, as well as to build trust, this was fairly uncommon across the four localities.

One of the mental health charities in Bradford was finding it challenging to encourage the South Asian residents to engage with their support, even though they felt there was a need for it locally. They outlined a number of challenges they were attempting to overcome, including issues around language spoken and need for interpreters, and the need for female therapists for female clients. They felt more work was needed to build closer relationships with their local South Asian community so that they could better understand what more they could do to encourage engagement.

In contrast, Stockwell PCN did have activities focused on connection and engagement with the local residents, in particular with the local Portuguese community. Healthcare professionals and other support workers were actively looking for ways to build links with people, to understand their needs in terms of engagement and overcome the barriers to accessing professional support.

For the residents who were connected into this network and these engagement activities, there were numerous benefits to them and their health, as was the case for Vera. She was able to get support for her housing, translation services for her appointments, and support with health admin through the local services available to her and the other members of the Portuguese community in Stockwell.

However, this level of community engagement wasn’t consistent. Others like Angelica (69) and Ernesto (73) had recently moved from Stockwell to Canada Water. They quickly found it was harder for them to access

healthcare and wider support. They explained that they have found it difficult no longer being close to the Portuguese community, as they had been in Stockwell. Having fewer people to rely on for translation, they often felt about bad asking them for help, and so were engaging with their health needs a lot less.

Weak links with local communities can lead to a distrust of service providers

Across the areas explored, people regularly reported feeling disconnected from the services and professionals that are delivered in their area. Even within Stockwell, Kumar didn't have the same connections with the professionals working in the area, as he wasn't part of the Portuguese community. He was quite distrusting of the professionals he had spoken to, often because he hadn't fully understood the information or instructions they had provided him. As a result, he felt somewhat misled, and that health and social care professionals weren't the best people to give him advice and information. Instead, he turned to websites, social media and the television for information.

Similarly, Bekele, 26, felt that the local healthcare professionals and other support in Birmingham were quite socially disconnected from communities like his. He felt that the professionals and the residents were living very different lives, which could create a lack of empathy for each other and an "air of hostility".

"Doctors are on a good salary and would tend to be in a different income class than some of the patients they're seeing, so there might be a bit of a disconnect socially between them. Sometimes, there might even be an air of resentment." Bekele, 26, Birmingham

Throughout the four areas there were examples of local residents feeling distrust for and disconnected from the professionals working to help them, and professionals who were frustrated at the lack of engagement with the support they could offer. Bradford African Community, a local support organisation, felt that one of the biggest barriers for the refugee community to access healthcare was the rumours and misinformation that travels around the community about services in the UK. A lot of this misinformation focused on the idea that professionals do not have the patients' best interests at heart, meaning people are averse to seeking support or listening to the information that has been provided.

Health and social care support needs to work harder to overcome these issues of trust in, and understanding of, the system, by building closer connections with the local communities they work in. Without these relationships, bridges can't be built to help those people facing health inequity and disadvantage from accessing the support they need.

Section summary

Many of the challenges people face in maintaining their health seemed to stem from how the system was treating them.

Some were living in areas where the provision of healthcare and wider social support was fragmented or simply minimal. This meant they would have to travel long distances or were unable to access the help they needed.

Further to this, when they did engage with healthcare professionals, it felt as though the system was set up for confident, capable individuals who have agency when it comes to their health. But many of the more vulnerable people, who were facing health inequity and disadvantage, were not in this situation. They were deferent to professionals. They awaited instructions. They were often unclear about what was wrong with them. And they didn't feel able to push for the help they needed. For people who didn't speak English, this was even more challenging.

Some professionals and services were trying to build better connections with the communities they served, however this is a challenging task and many services had not yet made strong links with people living locally. This meant there was often a lack of trust and people weren't always being given the right kind of support that was sensitive to their needs.

As a result, the most vulnerable are not having their needs met by the healthcare system we have in place.

Conclusion and opportunities

Many of the challenges in managing MLTCs for the people in this work reflected issues raised in the previous report, *“Just One Thing After Another”: Living with multiple conditions*. However, exploring this topic through a health equity lens has surfaced new insights into the social, structural and more human factors that can impact people’s experiences of health and their interactions with the health and social care system.

For many people the situations they were in, with regard to housing, work and relationships, made it difficult to take proactive steps to look after their health, to engage appropriately with treatment and support, and manage the array of information associated with their different conditions. Competing priorities often, not unexpectedly, took precedent. For some, the burden of health management was too great to balance with other challenging needs, such as caring responsibilities.

Most of the people interviewed for this project didn’t cite a specific characteristic as having an impact on their experiences and management of MLTCs. But there were factors which united many of our respondents and did seem to impact on their experiences and needs. These factors were largely centred around ingrained behaviours and attitudes towards health, often the result of wider social disadvantage, and how these are managed by the healthcare system. In many cases, disentangling some of the personal factors from structural challenges in our society and the system of care we have is incredibly difficult.

People also didn’t always have access to necessary local support to overcome this set of hurdles or to help shift longstanding behaviours developed over a lifetime.

There are also wider aspects to health inequity, that have been mentioned within this report, but not explored as thoroughly. People who are part of the LGBTQIA community, disabled people and other marginalised groups can face additional challenges in their relationships with health and social care services.

The current healthcare system is not set up to be sensitive to these barriers. It doesn’t seek to overcome the additional hurdles these people face as a result of their situations. And so, we see evidence of the people who most need health and social care support, being the least likely to access it.

There were too many people who weren’t being supported to fully understand their conditions, let alone being able to play an active role in managing their own health and preventing further decline. This can have problematic consequences, as people stop seeking additional help, disengage entirely or allow problems to escalate because they feel unclear about what to do next.

For some, language barriers exacerbated these issues. With many struggling to understand their diagnoses and any instructions for management. However, even for individuals for whom English is their first language, there were communication challenges; medical language can be inaccessible or intimidating, in some cases no one had taken the time to explain their conditions and treatment to them and often information around self-management was not being talked through.

A lack of community engagement can also increase the difficulties people face in seeking adequate support and adopting the behaviours required for managing their conditions. In areas such as Stockwell, where services had made efforts to reach out to specific communities, and address their needs, engagement rates were reported to be far better. However, in other areas services remained disconnected from the communities and as a result struggled with attendance rates among particular groups of local residents.

The current service landscape can be a problem for everyone, no matter their situation. But for people experiencing disadvantage, these issues have a much bigger impact. It’s important to zoom out from these people’s individual experiences of multi-morbidity, to look at the structures in place that might cause or exacerbate the health outcomes of certain groups. Currently the system isn’t trying to bridge the gap they experience in accessing healthcare.

So, how can the system better support all people with multiple conditions, particularly those facing the greatest disadvantage, and close the gap in healthy life expectancy?

Opportunities moving forward

There are many ways in which the system could enhance the support for people facing health inequity and disadvantage to prevent and to manage a life with multiple long-term health conditions. ICSs and PCNs are well placed to provide support, alongside wider health and social care professionals, policy makers, charities and support groups – as well as carers and people themselves.

In particular, policymakers and professionals need to consider ways to do the following:

Improve our understanding of communities experiencing inequity and disadvantage

All of the people in this research share stories with much individual variation and nuance in terms of personal experiences. However, what unites these accounts is the sense that the communities that they are part of have been systematically underrepresented in the health and care system.

It is crucial that the communities impacted by the range of challenges described in this report are part of conversations about change. They need to sit at the centre of decision-making to ensure solutions are based on understanding about what is needed and will work locally.

For policy / service design: How can we ensure the experiences and voices of diverse communities and social groups are recognised at all stages of research, service design and delivery? How do we ensure that this incorporates the voices of those traditionally excluded? How can we critically reflect on the themes from this work and how they relate to existing knowledge on groups who have not been represented as fully in this research?

For health and social care professionals: How can any outreach work with communities be reinforced and supported by the connections they have with frontline professionals? How clear are frontline professionals on how the types of people who live locally compare to the types of people accessing services? What tailored support might need to be delivered for particular groups or sub-groups of the community? How can you support residents who don't speak English to feel confident interacting with health and social care professionals?

For charities / support groups: Where can you help local residents feel clearer about the different health and social care organisations operating locally? How clear are you on how the types of people who live locally compare to the types of people accessing services? How can you support residents who don't speak English to feel confident interacting with health and social care professionals?

For carers: How well do you understand the professionals working locally and what they do? What support do you need to help your loved one engage with health and/or social care? To what degree have you provided feedback on the barriers your loved ones face to engaging with support?

For individuals: How well do you understand the professionals working locally and what they do? What could be done to help you place greater trust in the services being delivered locally?

Address distance and distrust between communities and health and care

Throughout this work, we've seen that dynamic, proactive and determined networks of people can enable some individuals who are currently facing health inequity and disadvantage to overcome some of the additional challenges they face in accessing care. They can enable trust-building which can have great consequences for engagement and attendance rates. They can enable people to improve their health literacy through closer relationships with others. They can help people engage with support at the right point in their journey.

But these networks are not easy or simple to build or maintain. And they certainly don't yet exist everywhere. They take time and energy to find ways to connect with the right people, to build trust and to continue to bring residents into the support on offer.

PCNs in particular, and ICSs more widely, are well placed to implement community-centred approaches to tackle inequity. They are based on expert local knowledge and promote collaboration across teams and across areas.

For policy / service design: How can we champion service design approaches which encourage *genuine* listening and co-production? How can we ensure services are designed around these communities' particular needs and assets? Whose voices and experiences are missing from the evidence base?

For health and social care professionals: How well do you understand the needs of different groups within your community? How well do your interactions with local community residents reinforce and support any outreach activities happening locally? What more can be done to build trust with local residents and support community ownership and involvement?

For charities / support groups: How can charities and support groups develop ownership and involvement from the communities impacted? Can peer-led approaches and upskilling local community members help to build capacity and ownership?

For carers: How well do you understand the professionals working locally and what they do? What support do you need to help your loved one engage with health and/or social care services? To what degree have you provided feedback on the barriers your loved one faces to engaging with support?

For individuals: How well do you understand the professionals working locally and what they do? What could be done so you are able to place greater trust in the services being delivered locally? What would support more people with multiple conditions to speak out, and become champions for improvement?

Build the right relationships to tackle the social determinants of health

The evidence shows that the point at which each person goes from one to many conditions varies hugely, but we know it does not vary randomly. Rather, multiple long-term conditions track issues of deprivation, culture, lifestyle and place.

As this research illustrates, many of the challenges described are not biomedical, and yet the system does not currently recognise the reality of how these conditions affect people. People need support with stressful working environments, housing insecurity, finance and other factors that add further complexity to ill health, and the accumulation of further illnesses.

For policy / service design: How can ICSs and the other organisations they will support at place level, including local government and the voluntary sector, build partnership relationships to address the impact of housing, financial and employment circumstances? In what ways can policy innovations strengthen the social safety net?

For health and social care professionals: How can health and care professionals work in partnership with others to tackle these wider issues? How can you better consider the impacts of multiple conditions across the whole household?

For charities / support groups: How well do services support people and the health and care system with non-medical issues? What more can be done to increase public awareness of the issue and impact of multiple conditions?

For carers: How might a greater understanding of the needs and experiences of carers for people with multiple health problems help inform partnership initiatives?

For individuals: Do you feel able to talk to your health and care professionals about your wider circumstances and what matters most to you?

Supporting people to take greater control of their health

Many of the people experiencing life with MLTCs displayed behaviours of deference towards healthcare professionals. They were waiting for instructions and following them diligently. They rarely pushed back or requested the care they thought they needed. If something didn't work, they would just wait for the next thing the doctor suggested. They understandably assumed healthcare professionals were always acting *proactively* on their behalf.

And many of these beliefs were shaped by their interactions with the system. By professionals who speak to them in a manner that portrays authority and control. By information that is communicated poorly, leaving them unclear about what it means.

A significant shift could be made in supporting people to access the care they need and deserve by improving the degree to which the system supports people to truly make informed decisions about their care. Widespread work is being conducted on health literacy, which could be a fantastic first step. But more needs to be done to address the challenge.

For policy / service design: How can jargon be eradicated from how health and social care professionals engage with everyday people? What can be done to reduce the power imbalance in health interactions? How can ensuring people have agency become the central goal of all healthcare interactions?

For health and social care professionals: How can you talk to patients and their families in a way that increases their control? How can you ensure all patients and families understand what is wrong with them? How can you ensure all patients and their families understand the treatment they are being provided? How can you better understand their concerns or misunderstandings about what you have said to them?

For charities / support groups: How can you help interpret information that comes from health and social care professionals? How can you help people to prepare for their interactions with health and social care?

For carers: What support can you provide to help people push for better care? What information do you need in order to support someone to make informed health decisions?

For individuals: How can you better understand what you should expect in terms of quality of care? How can you feel more confident asking questions and exploring what else could be done?

Promoting good health across local groups

Across the people included in this work, there were a wide range of people who didn't have the habits to proactively look after their health. They didn't necessarily understand the benefits of a healthy diet and exercise. Or they misunderstood how much they were moving and burning calories during a given day.

A wide range of factors were seen to impact on people's attitudes and behaviours around their health and managing their conditions. For some it was their experience with work, for others their family life and habits around food, their beliefs or the 'culture' of their social groups.

However, often respondents did not feel they had been supported to understand the steps they could take themselves to manage their conditions, beyond medical intervention. Following the principles described in 'Making Every Contact Count'³⁶ could go a long way in instilling messaging around healthy behaviours for individuals. Wider evidence shows that the right kinds of reassuring, encouraging and behaviour change-focussed conversations can make all the difference³⁷.

A lot of work is underway to improve health literacy among more disadvantaged groups, but it is by no means an easy thing to fix.

For policy / service design: How can we make healthy lifestyles possible for a wider range of groups within society? What beliefs about health and wellbeing does any guidance need to bear in mind?

For health and social care professionals: What myths can be tackled about healthy behaviours in interactions with patients? How clearly are you communicating the types of behaviour that are good for managing specific conditions or combinations of conditions³⁸? How can we ensure advice is mindful of the cultural context that someone is living within? What particular barriers to healthy behaviours exist locally that should be prioritised? How clear is the language used to talk about healthy habits?

For charities / support groups: How can you bridge the gaps between formal professional advice and everyday life and pressures? How can you clarify the language used to talk about healthy habits? How can you help healthcare professionals better understand the local barriers and issues around healthy living?

For carers: Where could you look for information about health habits and your loved one's health conditions? What types or formats of information would work best for you? (e.g. videos vs. text vs. leaflets).

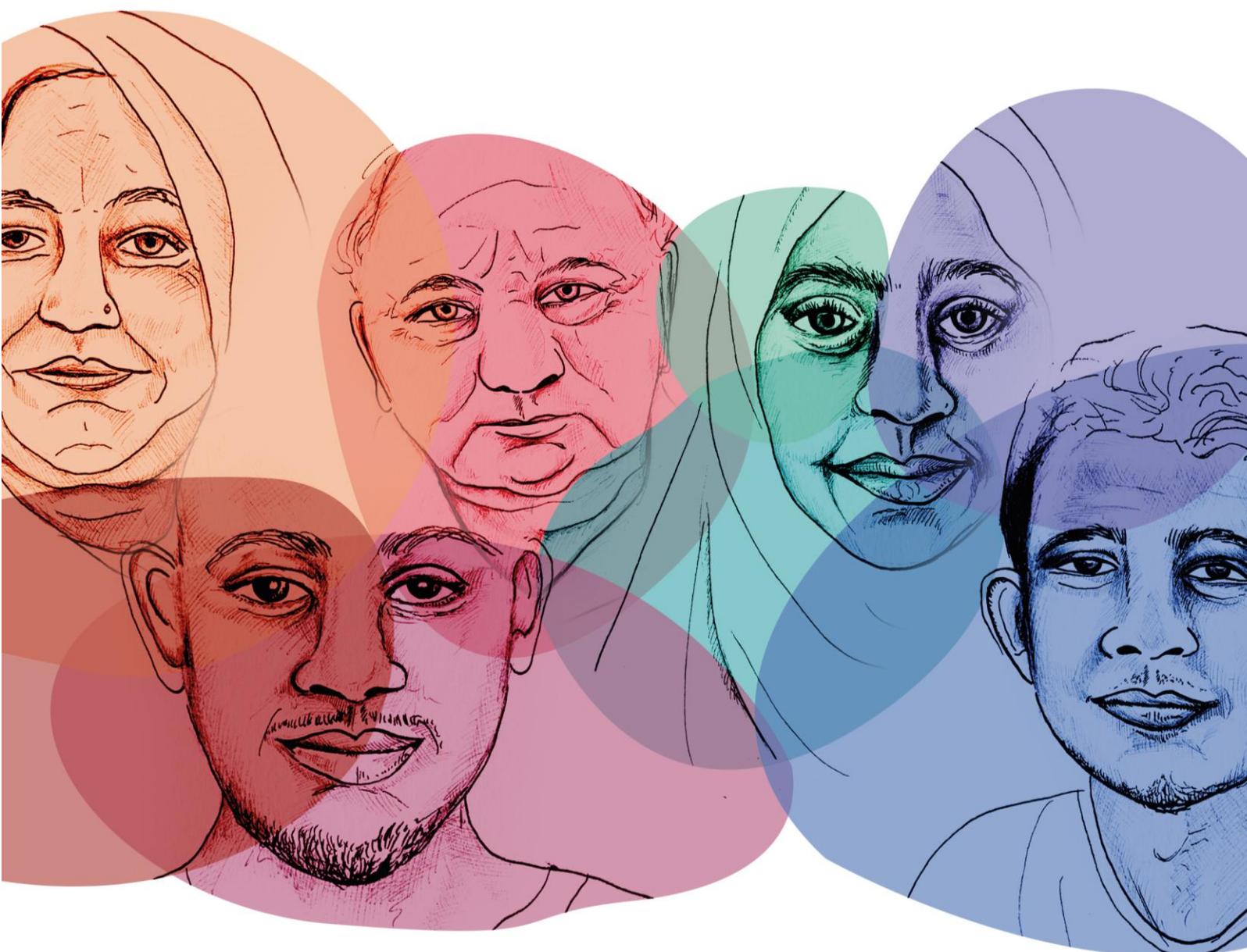
³⁶ <https://www.makingeverycontactcount.co.uk/>

³⁷ [Physical activity and long term conditions insights March 2016](#) (website)

³⁸ Patients and professionals can find more resources on the campaign website www.weareundefeatable.co.uk

What healthy habits could you support someone to develop and/or maintain? What local help could you find to support with this?

For individuals: How well do you understand what is needed to remain healthy? What healthy habits feel more achievable for you? What type of help might you need to build and maintain healthy habits? What can you find locally?



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