



**Health Inequalities:  
Somali people's  
experiences of health and  
social care services in  
Birmingham**



**November 2020**

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## Executive summary

**Objective:** We sought to identify the challenges and barriers that impact experiences of health and social care for Somali people in Birmingham both prior to and during the Covid-19 pandemic.

**Methods:** Individual, semi-structured interviews with 17 Somali people in Birmingham. Interviews were conducted over Zoom, WhatsApp and by telephone. Questions explored positive and negative experiences of health and social care services. These included experiences of racism, discrimination and bias, the impact of new ways of delivering services introduced during the Covid-19 pandemic, communication and engagement and ideas about removing barriers and improving services.

**Findings:** Levels of trust and engagement amongst Somali people in Birmingham are being impacted by: negative experiences of health and social care and the challenges and barriers they face when accessing services and experiences of discrimination. Dismissive attitudes of professionals, lack of dignity and respect, poor diagnosis and referral to specialist treatment, cultural and language difficulties, limitations in interpretation support, stigma and discrimination have led to distrust and detachment from health and social care services.

Our findings highlight the following key themes:

- Culture and language barriers have considerable impact on how care is delivered and accessed.
- Trust between Somali people and health and social care services in Birmingham is lacking, leading to caution in seeking treatment and a reliance on alternative sources of care and advice.
- The importance of a diverse health and social care workforce.
- There needs to be adequate access to interpreters/translators that are knowledgeable, reliable and able to explain medical terminology in simple terms.
- The Somali community require knowledge about how the health and social care system works and their rights within it. Different levels of health literacy require active intervention to enable groups such as Somalis to understand their right to healthcare<sup>1</sup>.
- Stigma, discrimination and issues around stereotypes tend to guide the interaction between Somalis and health and social care services. Discrimination has also made people more reluctant to access services. Some participants said they have become accustomed to the discrimination they face and fail to raise it as an issue due to fear of affecting access to services for themselves and their families.
- Many healthcare professionals lack cultural sensitivity and the ability to communicate in a manner easily understood by diverse audiences including persons with limited English and low literacy skills. There is also a need to examine the views and values of those delivering services.
- There should be greater use of appropriate methods for communicating information including translations of materials such as health education and awareness leaflets and signage, alongside use of other languages on TV, radio, newspapers etc. Communication should be geared towards prevention and effective engagement to ensure that people are aware of health risks.
- Opportunities are available for people from the community to be involved in decision-making processes in health and social care.
- Face-to-face interaction with health and social care professionals are important for Somali people. Digital delivery of services has the potential to exclude them.
- The interaction of various inequalities of religion and ethnicity impacts access to care, the quality of care and health outcomes. It is also essential to understand people's experiences of health and social care on a case by case basis and a move away from grouping people under the broad term of BAME.
- Commissioners, Providers (i.e. GPs, trusts), Public Health England, and Birmingham City Council have an important responsibility for increasing understanding of services including preventative services, ensuring diversity in the workforce, ensuring access to community services (e.g. community centres, parks) and ensuring that there is meaningful understanding and identification of BAME communities through data to awareness of health and social care services available to various communities.

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<sup>1</sup> <https://www.tandfonline.com/doi/abs/10.1080/14473828.2018.1434989?journalCode=yotb20>

**Next Steps:** The findings in this report point to numerous ways to improve health and social care services for Somali people in Birmingham. There is considerable work to be done by the health and social care system to improve relationships with the Somali community and also improve experiences of care. There must be an understanding that exclusion of the Somali community in Birmingham comes from a combination of language skills, economic and social circumstances, how services are commissioned and issues in the areas where Somali people live. These inequalities need addressing on multiple fronts.

We will publish this report on Healthwatch Birmingham's website and share it with commissioners, providers and third sector organisations across Birmingham. We will engage with providers of health and social care, commissioners (Birmingham and Solihull CCG and Sandwell and West Birmingham CCG), Public Health (Birmingham), the Health and Wellbeing Board, Health and Social Care Scrutiny Committee, Birmingham and Solihull STP and the Black Country and West Birmingham STP. The key points of this report will be translated and distributed amongst the Somali community in Birmingham.

Our Key Questions to health and social care services are:

- How will your organisation use the findings in this report to improve your knowledge of the issues affecting the Somali community?
- How will your organisation improve its engagement with the Somali community including the involvement in decision-making processes?
- How will your organisation address the issues that have been raised in this report regarding diversity, stigma and discrimination, knowledge and rights, culture and language and trust?
- How will your organisation use the experiences shared in this report to design, commission and deliver improved services for the Somali community?





# Introduction

## What did we investigate?

Covid-19 has exposed and amplified health inequalities in the UK. Various factors, such as level of income, residential area, and social exclusion or specific characteristics such as a disability are linked to the increased likelihood of severe symptoms and death from Covid-19. The Covid-19 pandemic has unearthed further health inequalities based on race or ethnicity. A recent report from Public Health England<sup>2</sup> shows that Covid-19 has had a disproportionately detrimental impact on Black, Asian and Minority Ethnic (BAME<sup>3</sup>) groups compared to others. People in BAME groups are more likely to be diagnosed with Covid-19 and have higher risk of death. The reasons behind this include social and economic inequalities, racism, discrimination and stigma, occupational risk, and higher prevalence of conditions that increase the severity of disease such as obesity, diabetes, Cardiovascular Disease (CVD) and asthma.

Healthwatch Birmingham is well-placed to help local health and social care services understand these issues by listening to and sharing the experiences of BAME groups. Through this process, we can ensure that health and social care initiatives implemented during the pandemic (which are likely to continue during the restoration and recovery phases) do not further widen health inequalities.

This report focuses on the experiences of health and social care of the Somali community in Birmingham. The key question that the project aimed to address was '***What are the key issues for Somali communities around health and social care services in Birmingham (including during the Covid-19 related lockdown into the recovery phase of services)?***' We specifically focused on:

- the challenges and barriers that negatively impact on Somali people's experiences of health and social care (both prior to and during the lockdown)
- the impact that service changes, due to the pandemic, are having on the Somali community
- understanding what could improve Somali people's experiences of health and social care services in Birmingham.

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<sup>2</sup> Beyond the data: Understanding the impact of Covid-19 on BAME communities - [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/892376/COVID\\_stakeholder\\_engagement\\_synthesis\\_beyond\\_the\\_data.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf)

<sup>3</sup> Although we are using the term BAME in this instance, we recognise the debate that has taken place and how the term leads to the 'othering of communities'. We recognise that the term unhelpfully blends ethnicity, geography and nationality and we hope this study will contribute to highlighting the need of understanding issues of health inequality as it relates to ethnicity on a case by case basis. <https://docs.google.com/document/d/e/2PACX-1vQkg5IloeAqMjMF6VW-eIEtEUEgK3GLudW1meE2DILbJPZYPIp0dO3Qwx6YVxBFxOhI1KEp5swpok80/pub>

## Why did we focus on the Somali community in Birmingham?

The Somali community in Birmingham has grown exponentially since the 2001 census, which recorded the population to be 819. Since then the 2011 census recorded 7,765 Somalis as living in Birmingham. However, some current estimates settle at around 40,000. The census number is based on people's own perceived ethnic group or cultural background. This might affect the estimates.

Various research studies have shown that language, culture, social and economic issues can restrict access to health and social care for Somali people. Most of the Somali community live in the most deprived wards of Birmingham. According to the 2001 and 2011 census, the largest numbers of Somalis were in the wards of Sparkbrook, Nechells, Lozells and East Handsworth, Bordesley Green, Soho, Ladywood and Aston. These areas have been classified as having at least 75% of their population fall within the 10% most deprived areas in England. In addition, health conditions such as asthma, diabetes, heart disease and high blood pressure are considered to be prevalent amongst the Somali community and other minority ethnic groups<sup>4</sup>.

We also recognise that multifarious ethnic groups are grouped together under the BAME umbrella with attendant assumptions. A survey of 1000 people from Black, Asian and ethnic minority groups agreed that they do not want to be grouped into a collective term, or reduced to acronyms<sup>5</sup>. How people identify themselves is based on a number of things including migration patterns.

Despite the popular narrative, not all Somali people have come to the UK as refugees. Some originally came to work as mariners and in the steel industry between the 1800s and 1900s. Following the breakout of civil war in Somalia others arrived as refugees to be reunited with their family. Many have come to the UK as EU citizens; mostly from Norway, German, Netherlands or Denmark where they were initially settled. However, amongst the Somali ethnic group, there is a clan system that has led to some experiencing discrimination, deprivation and exclusion from social and political systems. Although Somali people may belong to different clans, the majority are Muslim. Such diversity within the Somali community underscores the importance of health and social care commissioners and providers understanding the differences between ethnic groups and their issues with service provision.

## What are health inequalities?

The King's Fund<sup>6</sup> defines health inequalities as avoidable, unfair and systemic differences in health between different groups of people. However, they note that health inequalities also refer to differences in care that people receive and their opportunities to lead healthy lives. Health inequalities can involve differences in:

- Health status - life expectancy and prevalence of health conditions
- Access to care - i.e. availability of treatment
- Quality and experiences of care which can be measured as levels of satisfaction
- Behavioural risks such as smoking
- Wider determinants of health such as quality of housing.

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<sup>4</sup> <https://lemosandcrane.co.uk/resources/jones%20-%20the%20unexpected%20community.pdf>

<sup>5</sup> <https://incarts.uk/%23bameover-the-statement>

<sup>6</sup> Also see <https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on>

Health inequalities are analysed across four factors:

- Socio-economic factors – income
- Geography – region or whether urban or rural
- Specific characteristics – sex, ethnicity or disability
- Socially excluded groups – such as people experiencing homelessness.

The Health and Social Care Act 2012 requires healthcare commissioners and providers (including local authorities, the Department of Health and NHS England) to have due regard to reducing health inequalities in England<sup>7</sup>. According to guidance<sup>8</sup> for NHS Commissioners on equality and health inequality to “have regard to the need to reduce” means:

- health inequalities must be properly and seriously taken into account when making decisions or exercising functions, including balancing that need against any countervailing factors
- accurate record keeping of how the need to reduce health inequalities has been taken into account when making decisions or exercising functions
- that duty must be exercised with rigour and an open mind and should not materialise as an afterthought in the process of reaching a decision.

Other duties that health and social care needs to take into account are the Equality Act of 2010 and the Social Value Act that also require public sector commissioners to consider economic, social and environmental wellbeing when they conduct procurement for services<sup>9</sup>.

## Methods

We conducted semi-structured interviews with individuals from the Somali community based in Birmingham. Eligible participants were Somali adults (16+ years old) currently living in and accessing health and social care services in Birmingham. We conducted our study with the support of Ashiana Community Project<sup>10</sup>, which supports local people from various ethnic backgrounds to improve their social, physical and economic wellbeing. Ashiana Community Project provided us with a list of 28 service users from the Somali community.

Ten individuals from the list agreed to participate in the study. We recruited seven further individuals through prominent individuals from Birmingham’s Somali community, a Healthwatch Birmingham volunteer from the Somali community and through personal contacts. In total we interviewed 17 people between the 20<sup>th</sup> September and 23<sup>rd</sup> October, 2020.

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<sup>7</sup> <https://www.england.nhs.uk/about/equality/equality-hub/resources/legislation/>

<sup>8</sup> <https://www.england.nhs.uk/wp-content/uploads/2015/12/hlth-inqual-guid-comms-dec15.pdf>

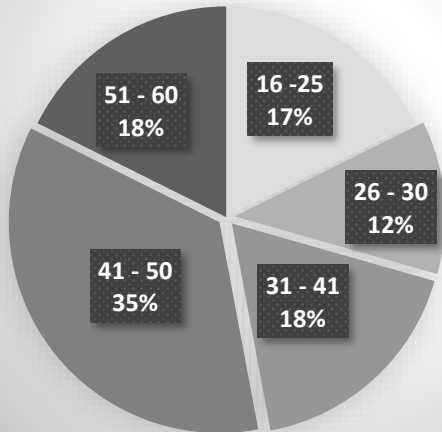
<sup>9</sup> <https://www.england.nhs.uk/wp-content/uploads/2015/12/hlth-inqual-guid-comms-dec15.pdf>

<sup>10</sup> <https://www.acpgroup.org.uk/>

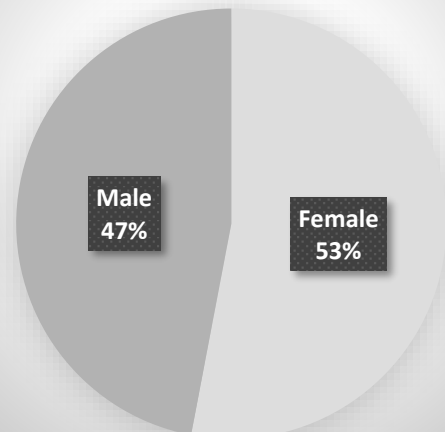


## Demographics of Participants

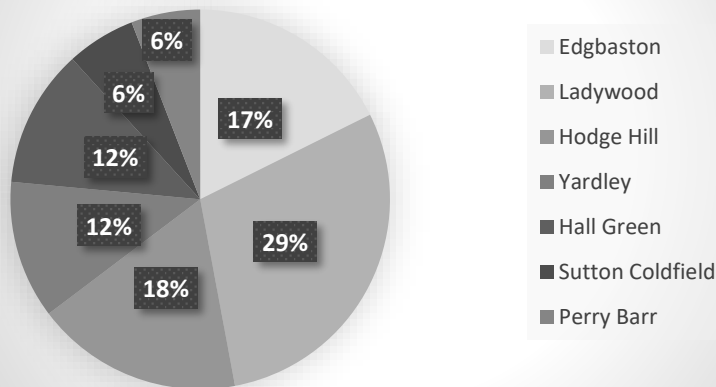
### Age group of participants



### Gender of participants



### Participants by District



We are grateful to all the participants who shared their experiences with us. We would like to thank third sector organisations and various individuals in Birmingham that supported us in accessing participants. Key to our study was Ashiana Community Project, who helped us to gather feedback from the people they support. We would also like to thank individuals from Birmingham Health Champions, The Somali Education and Cultural Centre (Nechells), HADAL (TALK), in particular Yumna Hussain for helping us access participants and our volunteer Salma Abdullah.

## Findings

Most study participants acknowledged the benefits of having access to healthcare services in comparison to services in Somalia. However, it was clear that there are significant health inequalities for Somali people and their access to healthcare is complicated by various issues, most importantly language, trust, and knowledge about the system and rights.

Although the initial intention was to gather experiences about primary and secondary healthcare, social care and public health services more generally, it was clear from the interviews that there was more focus on primary care experiences, followed by secondary care and public health services. Most of the participants had not engaged with social services, with some claiming that the only time social services engage with the Somali community is when they are taking children away. Others noted that their culture meant that they were unlikely to use carers or care homes. Therefore, the experiences presented below are mainly of primary care, secondary care and public health services.

### Experience of accessing health and social care

#### Dismissive attitudes of professionals

Participants said they often felt dismissed and were not heard by health and social care professionals, or that their needs or condition were not taken seriously.

*I haven't used health services that much because I haven't had any conditions that required me to use healthcare. But when I do use it, I don't like it because I don't really feel heard. I am not sure if that's everyone's experience or it's specific to me because I am Somali and Muslim, I don't know.*

*I have realised also that when I am at the GP and I am explaining my symptoms, before I even say a complete sentence or finish saying what I want to say or explain myself, already the GP is prescribing something and he just says go and take that. I have dealt with that a lot.*

Participants said that healthcare professionals (GP, receptionists, consultants etc.) were more dismissive when they were aware that English was not the patient's first language. Most participants believe this is because healthcare professionals know that with limited ability to speak English, patients are unable to communicate effectively and are unlikely to know the system or their rights. This impacts on the quality of service they receive and can lead to people not getting the treatment that they need.

*[The dismissive attitude] it's not just me who faces it, a lot of people in my house, for example my parents for whom English is not their first language, we have to go and help them when they go to the doctors. I realise that they dismiss and disregard them a lot. My parents are older and my mom is diabetic and she has had a lot of problems with the GP where she has told them continuously to send her medication because she takes metformin which she can't do without. But this is often forgotten and she has actually had to fight with them over the phone and they will say 'We will do it' but won't unless she actually turns up at the GP or brings one of us with her cause her English isn't that great. We think it's because they think we do not know our rights. For instance, my mom was at the*

*GP asking them why her medication was not sent or was not ready again, and it's only when she said I am going to let Healthwatch know if you don't do anything about this (because I have told her about Healthwatch) that the lady switched on her and said I will send this straight away. It is only because my mom could demonstrate that she knows the system and knows her rights that they acted. It's because they think she does know anything and she is not going to file a complaint, cause they can see she can't speak English well and a complaint would be hard to do.*

*Sometimes they look at your language, and if you do not speak very well, they look at you like you are ignorant. Maybe you don't know the law – they don't give you an opportunity to get an interpreter and they don't understand what you mean. They are just looking at you like you are second class. If your language is not perfect, they look at you as a stupid person and that you don't know your rights. It's when you show you know your rights that you get a service. When you are not white, you don't get full treatment. That's what I feel, maybe I'm wrong but through my experience this is what I feel.*

Feeling dismissed and not heard has meant that many people from the Somali community do not visit the GP, especially for minor ailments. Rather they opt to go to A & E with many opting to access private healthcare or going abroad for treatment.

*I have also dealt with not very nice receptionists, always try to dismiss you and disregard you. This has stopped me from going to the GP unless I really really need it. So sometimes, I feel not well but I would rather stay home until it gets serious just to avoid these situations.*

*I work with a Somali organisation and we get parents, old women come in whose English is not great and we have to help them with health concerns. Some have an ill child or disabled child and they tell us that they are not able to get any support from healthcare that they need. That has been a problem in the Somali community that many of them seek medication from outside of the UK. Because they feel like they are not getting the right treatment so they would rather even pay for private medical care or treatment. Cause they feel the GP is not giving them their rights or even giving them a chance to hear them out.*

Throughout our interviews, participants talked about a loss of confidence and trust in the health services.

*The current situation of Somali community in accessing healthcare is so bad that they travel abroad to Germany, Sweden, Denmark, and Belgium for treatment and care. There is a lot of mistrust between the NHS and the Somali community because the doctors here are not listening. People travel a long distance when we have one of the best hospitals here in Birmingham – people say it's because the doctors here are not listening, they are not communicating with me, they don't have time for me.*

*So, when I get a diagnosis or medication from the GP, I make sure I check them to see what they are or I get people I know who are nurses or doctors to check them*

*before I take them. So, there is now the trust issue cause I don't understand how they could have prescribed me the wrong medication previously. Is it done on purpose? Out of fear I have to do a lot of research. So now I know most of my family and friends use natural remedies when they are sick. If it gets worse then you would go to the GP.*

*There is a lot of mistrust between the NHS and the Somali community. First because they don't understand each other due to the language barrier, the NHS does not have the money to invest so as to support the Somali community with translation, help and support. A lot of Somali people don't believe the doctor wants to help them.*

### **Dignity and Respect**

Some participants told us that they do not think many Somali people are treated with dignity and respect by health and social care services. Some linked this to ethnicity and religion including the negative perception of Somalis in the media.

*I don't think Somali people are treated with dignity and respect, you have to understand that we are not just black and Somali, we are also Muslim and with that you have two odds against you. Because Muslims are not perceived very well in the media. So, I do ask myself questions when I can see I'm being treated differently to the white person in front of me - I have to ask myself is it my colour or my headscarf, my religion or is it both? Mistreatment happens a lot when Somalis access healthcare. The sad thing is that we have become immune to it. You get remarks all the time and discriminatory acts all the time in healthcare and other settings, although with healthcare it happens a lot when someone just treats you differently and looks at you differently. Sometimes you think it's the language but no, even I get problems when I visit the GP. So clearly, it's more than about language and also about our religion.*

Other participants believed that in the instances where they are treated with dignity and respect, this is because they can speak English and therefore understand the system and their rights.

*I am treated with dignity and respect because I know the system, I know my rights and I can speak English. If someone disrespects me, I can complain and I know how to complain cause I know my rights. I can also tell them 'Excuse me that's not right'. For example, when I went to hospital and I had my baby, I had an emergency C-section, I gave birth within 15 minutes and within that time they gave me privacy to cover my head cause he realised I am a Muslim. There are many times where I have been treated with dignity and respect.*

*In general, I have been treated with dignity and respect and the service I have received has been sensitive to my needs but it's because I know the language.*

### **Timely and appropriate services that are sensitive to needs**

Participants told us that healthcare professionals were often rushed and tended to give out prescriptions and tell people to take water. They felt that doctors did not take time to listen, understand or check what is wrong with them.

*I do not think the service that I get is sensitive to my needs, or timely. A lot of the time the GP is very rushed; before I even sit down and start talking, before I even finish my sentence, she is already finishing my sentence and giving me a prescription. She will be like, 'Yes I have given you this prescription' and I'm like 'No, I haven't even finished telling you what's wrong with me'.*

*One time I visited the doctor and I had only been there two minutes, told him that I was feeling low, and tiredness, and he told me just to take some water. At no point did he say 'Let's do a blood test' and I told him that. It's only because I mentioned it that he said 'OK you can have a blood test'. He only gave me two minutes and he already made a decision.*

*People just want to be able to have a doctor that is really listening to them not only 'I have 10 minutes' and he gives you a prescription when you say 'I have a migraine'. People travel abroad just to get a proper check, even if they are told you are healthy. At least they know there is nothing wrong because they get a full check-up. If the doctors in UK did that instead of just bombarding people with prescriptions.*

Other participants spoke about the failure to accommodate cultural or religious needs.

*Healthcare needs to be more accommodating to Somali people. I realise that there are a few times where a woman would feel more comfortable speaking to a female doctor and they tell you that it's too late, you just have to see a male doctor. There could be other alternatives - like you could book the person on another day instead of just saying 'Sorry there is nothing we can do'. At least offer the option of rebooking. Otherwise this lady is forced to see a male doctor cause their health is at risk but they are very uncomfortable.*

### **Diagnosis and referral to specialist treatment**

Referral from primary care services to hospital specialists enables patients to receive a diagnosis and access to investigations. Referrals are important as they are an opportunity to improve outcomes for patients. Various studies<sup>11</sup> show that referral rates to specialist services are lower among minority ethnic groups and do not represent the population within local areas. Other research has shown a lower referral rate for people in less affluent compared to more affluent areas. Indeed, an NHS report<sup>12</sup> observed that patients in the most deprived areas are less likely to be diagnosed through cancer screening. In addition, black patients are considerably less likely to be diagnosed through screening.

Participants spoke about their personal or family member's experiences where they were misdiagnosed. They spoke about physical problems diagnosed as mental health problems and being prescribed the wrong medication.

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<sup>11</sup> <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-018-1035-5>, [https://spcare.bmj.com/content/2/Suppl\\_1/A108.2](https://spcare.bmj.com/content/2/Suppl_1/A108.2)

<sup>12</sup> <https://www.england.nhs.uk/wp-content/uploads/2018/03/09-pb-29-03-2018-scene-setter-on-current-trends-health-inequalities.pdf>



*I was getting a lot of migraines which were affecting me. I went to the GP and before I could even finish explaining what was happening, he prescribed me a tablet. After I took it, I noticed a difference in my mood and I was feeling weird - at the time I was at Uni and I wondered what was wrong with me. I told my mom how I was feeling and I never thought about the tablet. She said 'Can you look at the tablet to see what it is?' When I searched for it on the internet, I found out that it was an antidepressant. I couldn't understand what my migraine had to do with antidepressants. All I said was 'I am getting these really bad migraines and I can't sleep at night' and he gave me antidepressants. I realised that that's why I was getting mood swings and feeling depressed so it affected my Uni work all because he gave me the wrong prescription.*

Others described very long delays in getting a diagnosis, and a lack of referral to specialist treatment.

*I have a friend of mine who was very sick, he has been going to the doctor for two years and they could not give him a diagnosis. He was hospitalised during Covid at Queen Elizabeth and they still could not tell him what is wrong. Just the beginning of this September, he paid to go abroad to Germany and he came back last week with a diagnosis. He didn't come back with a bag of medication. He was happy, met the doctor five times and told him what is wrong and how to manage. Here he could not get a doctor to sit with him for 30 minutes to talk to him. I have seen so many people go to Germany to get an operation and not even see their GP cause they say 'These people are undermining me, they don't talk to me and dismiss me'.*

*I don't encounter many problems. But if I tell you about my parents that's a different case. My parents are very old - 85, they don't speak English very well and they have problems getting through to NHS services. Sometimes they need checks at the hospital but the GP never gives you a referral. My mom had a problem and they hadn't diagnosed quickly, the problem they diagnosed three years later. I knew that was the problem she had. Another scenario, my mom had an accident in an ambulance cause they did not let her wear a seatbelt. The ambulance was involved in an accident then she hit somewhere. That resulted in problems with her knees and could not walk properly. It took four years for them to refer her for a knee replacement yet they knew the problem she had and that she could not walk. If they had referred her quickly she wouldn't have had the pain she had for years.*

*I remember my sister had a problem when she did not speak the language and for years and years she struggled. My sister was suffering from a tumour for years and all the doctor would say is 'Take this depression tablet'. 10 years they gave her depression tablets. No real checks or investigations were done. 10 years down the line they found out she had a brain tumour. So, things like that some health services when they see the patient does not speak the language, they just try to close the cases quick. They don't give them the right help because that person does not speak English and would not know any better. They believe that you don't know your rights and don't offer you any extra help. Now my sister is*

*getting help but it's too late now because things like that you need to catch them early so it is affecting her now. 10 years she has been visiting her GP and for that long she had no support and there is no other explanation. Other than the fact that when you don't speak the language, that's it you don't get the help you need. Instead of offering extra help like an interpreter they are just pushed to the back saying they won't waste time or energy on that person.*

For others, it was that they were not offered the full range of evidence-based treatments, with the doctor often prescribing medication and failing to offer psychological interventions for mental health concerns or access to x-rays.

*I was translating for another Somali lady who has been taking medication for mental health for 10 years and not once have they ever sent her for therapy. That is the problem when you can't speak English and you don't know your rights.*

*A lot of the time you do not get the treatment you need. For instance, my mom had a lot of pain in her arm and they kept giving her anti-pain medication to suppress the pain with no real checks to see what was really wrong with her. That is all she wanted to know. What is wrong with me? She really had to fight to get an x-ray as the pain was getting worse.*

One of the respondents noted that poor diagnosis was common amongst the Somali community.

*In general, usually minority groups often get misdiagnosed. I don't know what the issue is whether there is a language barrier. For me I had a misdiagnosis and I know it happens to many other people in my community. I am not sure what the reason is, why minority groups have a high percentage of misdiagnoses for serious issues. If it happen to my mom or another Somali family they wouldn't know because there is a language barrier there. I used to go to the GP for the same problem and they didn't know what it was. They just used to say 'Maybe it's a chest infection, we can't diagnose you with anything now, just take this medication and you will be fine. Just make sure that you are eating well and drinking.' I kept going to see them and one day they just randomly came up with the diagnosis that I have TB. All the doctor did was see that we are from Somalia and therefore it should be TB. That's the first thing they said was 'You are a Somali family so there must be a history there'. That's a big problem that they diagnose you with something for no particular reason other than that you are Somali. They label us that just because we are from Africa then we have a certain disease instead to doing proper checks. Yes, they might be right that there are a lot of cases of TB in Africa but that was not my case.*

## **Appointments**

Participants told us about negative experiences around appointments. They noted that the appointment system made it difficult for people from the Somali community to access services.

*You have lots of rules and regulations, you have to call them early in the morning on the phone, you spend one hour on the queue and then you still don't get what*

*you need. Another problem is the GP secretaries and receptionists, because you call there and you are having to beg for help. Especially when they know that English is not your first language. They undermine you, ask you questions where you have to give a diagnosis and tell them what's wrong with you. Yet they know that you can't speak English very well. For most people for whom English is not their first language, don't have enough English to express themselves and diagnose themselves. They don't give any consideration of this. This makes people more frustrated.*

*Sometimes, I get the issue that when you go to the doctor and you complain about headache, sore throat or something else, the doctor will say 'Let us deal with one issue at a time'. I didn't come for only one issue, I came to receive treatment and I'm telling you that I have temperature, sore throat, stomach pain and I need you to address all these things. But the doctor will say 'I can only treat one thing at a time' and that I can only have a maximum of 10 minutes with the GP. So, I need different appointment for different things. Someone with already a barrier like language and they do not know their rights, what is going to happen to that person? Most of the GPs do not have translators so what happens when you have to keep coming for one condition at a time, you can't have help.*

Another concern is the lack of availability, which leaves people having to call the GP several times on different days in order to get an appointment. This is especially difficult if they need an interpreter or translator.

*When you call, they say 'Call tomorrow morning'. You call in the morning you are in a queue and then they say there are no appointments. Call again tomorrow. For someone with a language problem, who needs another person to help them, how can they do this daily? I say 'Why you can't just give me an appointment even if it's in the next month?' I think, who makes these rules to make appointments difficult.*

## **Challenges and barriers in experiences of health and social care**

### **Cultural and language difficulties**

Language was singled out as the most significant issue excluding Somali people from health services in Birmingham. Even Somali individuals with good English found it difficult to understand complicated health terminology. In some cases, many are not able to read well. Inability to speak English means that people are unable to express what they are suffering from clearly with healthcare professionals.

*A lot of the older people do speak English, even though it is broken and like my parents understand when I speak English and they speak broken English. They just need more time to express themselves and formulate the sentences. All they need is time to really say what is bothering them. A lot of the time I have seen my parents speak English, although it's broken, they can speak but they are never given the chance to really speak. So, when they go to the GP, the GP doesn't even take time to listen and just tells them it's this, so this puts them off and they just go like 'OK'. They don't get to explain themselves. It is important that when people meet with the GP that they are given the time to really explain themselves*

*and the GP can then come with their solutions. Otherwise the GP just assumes they know what they want to say when they have cut them off and they have not finished explaining themselves or come to the point. This happens a lot even to me, who can speak English, before I have explained they are already writing a prescription and telling me this will resolve it. So, you can imagine how hard it is for someone who can't really speak English.*

There is a perception that inability to speak English has often dictated how healthcare professionals engage with them. Some said there is a belief that lack of English equates to a lack of knowledge about the healthcare system and the various rights enshrined in the NHS constitution<sup>13</sup>.

*I feel like they will only take you seriously if they know that you know your rights ... I have noticed that when I go to the GP or hospital, if they know that I do know my rights then they tell me 'OK we will do this and do that' and so on. If you don't know anything then they try to feed you what they want. That's the challenge for my parents cause English is not their first language, they do not know their rights, what they can have or not have so they can easily be told that we don't do this or we don't do that unless someone else tells them.*

Some participants pointed out that when healthcare professionals are aware of their lack of or limited language skills, they know that it will be difficult for them to go through the complaints process. A majority of participants considered the ability to speak English vital for accessing, understanding and navigating the healthcare system.

*Ourselves as Somalis we need to learn the language and learn our rights. Once we know our rights then nobody can overstep that. We need as a community to try to learn our rights.*

*The major problem is the lack of understanding of the services within the community because of the language barrier.*



### Lack of interpretation or translation support

Most participants viewed interpretation and translation support as inadequate for Somali people. Even where translators/interpreters exist participants were concerned about the quality of the service. They spoke about the many dialects spoken within different Somali communities as well as the absence of some healthcare terminology in the Somali language. For instance, words such as depression, stress and anxiety do not exist in Somali culture or language. It is therefore important that interpreters are able to explain and enable individuals to understand.

Most participants highlighted the importance of having good interpreters that are able to not only translate but explain medical terminology and concepts.

*We need interpreters who are experienced and understand medical terms and how the system works. We just don't need any interpreter. We need an interpreter who can translate what the doctor is saying but also with enough knowledge to explain it in a way that the patient can understand.*

In some cases, participants told us that interpretation responsibilities have been left to the younger Somali generation. Although this is useful, it becomes a problem when young people are in school, at work or in university, leaving many individuals without support. As one respondent noted:

*It's really hard as a child to have to see your parents in that much pain, you don't know what to do and you are speaking to these people and they are not listening and your mom is not getting the treatment they need. So, you can imagine when we are in school, university, working and stuff, our parents are suffering or struggling at home unable to get healthcare cause there is no one to support them. They cannot understand each other with the GP so cannot get the help they need. So, when they come home, they feel like they haven't expressed themselves properly. We can't always be there. So, there is not that access for them like someone to translate for them, hear them out and someone to just understand them. Every time they go to a healthcare professional, they are always being shut down and not listened to.*

### Stigma and discrimination

Issues around cultural stereotypes are also important. Mass media messages and a popular belief that migrants affect opportunities and service availability for UK born citizens generates a climate of exclusion. Participants told us that there are many myths and beliefs about Somali people in health and social care that affects their engagement with services.

*There is a lot of people committed to doing their job well (in health and social care). But sometimes there might be misunderstanding and something like a myth about a community. Mostly if you go to any office or public office such as healthcare, people they say, without hesitation, that Somali community likes to be by themselves, they don't want to integrate. That is something that pushes the Somali community away from using public services, especially the health services sometimes.*



*There is a stigma already in the GP about Somali people. Their culture is not respected. For instance, ladies have come to me to tell me that they have issues with some GPs. They are being told that they cannot have any more children because they already have four children. They are being told 'You don't need to be pregnant again'. That decision belongs to the person not the doctor, receptionist or nurse. If there is no health risk then that is their choice.*

*I used to help with English language and translating for Somali people especially the elderly when they access healthcare. I picked up two things: there is a perception by healthcare professionals of the Somali people and there is a stigma attached to Somali people where people see us as pirates and also GPs believe that Somali people go to the GP for a lot of things. Which is not true. So, a lot of people say to me that 'There is no point for me to go to the GP because the GP always thinks I'm lying about my illness. The doctor does not trust me, when I tell the doctor that am feeling like this, they do not show me that they trust what am saying'. That is wrong to have that perception. I have seen many GPs in Small Heath who have that perception. Quite surprisingly some of those GPs are from other ethnic minority groups and I have seen Somali people suffer and they hate to go to the doctor because of the undermining tone.*

*The funny thing is when I go to the hospital or GP, as soon as they see you are Somali, they assume you don't speak English, you are unemployed and most believe you are an asylum seeker – they will always ask you if you have papers to be in the UK.*

*Some healthcare professionals believe that Somali people just like to go the doctor. But nobody goes to the doctor just for fun. You trust the doctor and you think when you go there your life will be saved.*

Participants spoke about the overt and hidden discrimination they face when they access health and social care services.

*I do definitely feel discriminated against when I attend my GP. Sometimes it is very obvious that I am being discriminated against. For example, I used to notice when I attended my GP, that when you go to the receptionist and the people who are in front of me who are white are treated well, very welcoming attitude - 'Oh yes, please come forward' with a smile. When it's your turn they won't even give you eye contact, they are busy with their computer and will coldly ask you 'What it is you want?' It's happened with me a lot of the time, with my sister, my mom, almost every Somali I know. We know that when something like that happens, where you are ignored, it has to do with our skin colour or our religion. It couldn't be anything else, because what else differs us from other people?*

*In the most deprived areas of Birmingham, I have seen direct discrimination in waiting rooms. If for example, three nationalities are sitting in the waiting room and one is Somali, what I have picked up is that always Somali women and children are neglected in making appointments.*

Other participants noted that they face discrimination on multiple fronts, demonstrating how various inequalities of religion and ethnicity can interact and position individuals. This impacts access to and the quality of care as well as health outcomes. This also highlights the importance of understanding people's experiences on a case by case basis and moving away from grouping people under the BAME umbrella. As these participants explained:

*Sometimes the difficulty is going to come for example, I am black and I share all the experiences of black people but am also Muslim as well. I have got two things that many people don't have. The person who is just Muslim cannot experience the black issue and black people who are not Muslim will not experience the Muslim issue. For example, when Muslim wear their clothes and people see them, they have already made a decision about you. Some people ask 'Are you Somali?' when I say 'Yes' people will say 'Please don't take us from our country cause you people are pirates'. It's another stigma that when they see a Somali person, they say 'Look, the pirates are here'.*

*Asian culture is not the same as African culture. Just because you are Muslim Pakistani or Muslim Bangladeshi does not mean you are the same as Muslim Somali. Religion and culture are two different things. Always they say 'You are Muslim and you are the same as either Pakistani or Bangladeshi' but these are different. Black Muslims totally have different values, experiences and at the same time if you are black and Muslim, it is worse than if you are black Christian. You find many black Muslim people hide their religion because of the stigma attached.*

Despite facing discrimination, most of the participants told us that they fail to raise the issue due to the fear of affecting the service they or their families receive.

*A lot of the times when an older Somali mom or dad comes to the GP, this happened to me personally, I have gone with my mom to the GP and she has not been treated well by the receptionist or the doctor, she will say 'Just leave it'. They believe that if they argue or complain that they might withhold the service. They will let people treat them badly so that they can get the treatment. It shouldn't be like that and this makes me angry. You know people are scared to complain because of how this will affect them and their children. So what they will do is deal with this for years. They are thinking 'My health comes first, my family and children come first therefore I'm not going to raise this issue'. For example, like this interview I'm doing with you, it will be hard to find people to speak cause they think if I share my experiences it will affect me.*

### **Wider factors that contribute to challenges and barriers for Somali people**

It has been well established that the social, economic and environmental conditions in which people live have an impact on their health. People told us about the lack of access to ESOL classes that used to enable people to learn the English language, closure of leisure centres and libraries in their local communities.

*Before the ESOL classes were completely free but now these have been reduced and can only be provided at a college. Therefore, large numbers of people cannot*

*access these classes. Education is therefore another challenge or barrier that Somali people are facing.*

*Of course, the council needs to support communities and continue to provide ESOL courses in the local community. You now have to travel to do ESOL courses. There is a lack of funding for communities. There are some structural barriers for people that make it difficult for them to integrate.*

*There is no library in Nechells therefore nowhere to get intelligence. I have lived here in Nechells for five years and there are no community centres, no one that can help us. For this whole community we only have that little park in the middle, nowhere for people to exercise. Physical activity is important.*

Others spoke about the impact of Covid-19 on the Somali community, leading to a loss or reduction in household incomes.

*Covid has made community lives very hard. People are struggling economically and financially. Self-employed people are struggling and we have had to support them with getting money through the furlough system. Many lost money because they did not know about the scheme and did not have information.*

As this participant indicated, it is important that the health and social care system takes a holistic approach when addressing issues of health inequality and addresses issues such as housing or lifestyle impact on health.

*There just needs to be more community support to help people to open up more and show that healthcare can help them. At the same time support should not just be healthcare because other things like poor housing impact people's health and are more at risk of other conditions and poorer quality of life. There is need for co-ordinated support. Show people how lifestyle affects other areas of life like health.*

### **New ways of delivering services during lockdown and the impact on Somali people**

In order to respond effectively to Covid-19, the health and social care system has had to prioritise services. This has resulted in substantial changes to what services are still available and how services are delivered and used. For some this has meant replacing face-to-face services with telephone, online or video services<sup>14</sup>. We asked participants what their experiences of accessing health and care services were during the lockdown, especially the use of digital technology. Some said these new ways of accessing services made their experiences better and also enabled them to keep safe from contracting the virus.

They noted that their experience was positive because of their ability to speak English and that they had access to either a smartphone or computer. They noted that other Somalis have limited English and no access to a device to enable them to access online

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<sup>14</sup> Murray, R., Edwards, N., and Dixon J (2020) Delivering core NHS and Care Services during the Covid-19 pandemic and beyond, <https://www.kingsfund.org.uk/publications/letter-to-health-and-social-care-select-committee-covid-19>; Lewis et al (2020) Understanding and sustaining the health care service shifts accelerated by Covid-19, <https://www.health.org.uk/publications/long-reads/understanding-and-sustaining-the-health-care-service-shifts-accelerated-by-COVID-19>

consultations. They also spoke of people not having the financial means to have credit for their phones to enable them to make a call or use video. Others spoke about illiteracy in using online and digital services.

*Most of the Somali community you can say are uneducated about using digital services. Because they learn in the Somali language to use the phone of the olden days. They don't know how to use these smartphones. These are the barriers they are getting in terms of accessing health services, social services and Covid19 services.*

A majority of participants said that it was already a problem for the Somali people when you could only book GP appointments online or over the phone. They argued that these new ways of delivering services have made the Somali people invisible in health and social care services. As one participant said “*You know how healthcare was struggling to see Somali people now with these virtual online or telephone service delivery, you can't see them at all. Online services have made it worse for them. This applies to all BAME groups*”.

Other individuals told us:

*New ways of delivering services has made things more difficult. Like my mom is diabetic and also has arthritis and has a lot of pains in her arm. She had difficulties getting services pre-Covid, during Covid, she can't even get half the services she gets and she needs for her diabetes. We have had to constantly call them and fight for the service. So, it has really been more difficult. My mom had to seek for medication outside of the NHS cause her health was under threat and she did not know what to do.*

*Since the lockdown happened, the GPs and NHS got a good excuse not to do what they need to do. For example, at my GP, if am ill, I have to go on the website, fill in a form about my illness and diagnosis, so many questions you have to answer and that takes 20 minutes. Then you have to write in 100 words what is wrong with you and describe your symptoms. A couple of days ago, we needed an appointment for my wife who needed a referral to Queen Elizabeth that was scheduled before the lockdown. The receptionist redirected me to the website. I had to tell the receptionist that my wife couldn't fill the form because she does not have good English. The receptionist said they did these forms to make it convenient for the doctors. I said 'Are you kidding, you are making it convenient and comfortable for the doctor? What about the people who are sick, who make it comfortable for them?' But she wouldn't budge. We just had to go onto the form and did the best we could. My wife is not a doctor and I'm not a doctor, so we did what we could. So, what hit me is, what about the people for whom English is not their first language? Some of them don't even have internet at home and do not even write in English. So, we are becoming since the lockdown a digital community and we consider that everyone in UK has access to computers, phone or internet. Even those that do have access are only looking at the pictures on the internet, they can't really read English or write in English.*

Some were concerned about the ability to carry out a proper diagnosis using digital means.

*In my experience, since it's not face-to-face, I feel like the diagnosis will not be correct and appropriate. Because if I want to see the GP due to chest pain, how do you diagnose that over the phone? I do understand the need for it now because of Covid. It's just made it harder to access services.*

*If a person says I have to use the phone or video to diagnose my condition and there is a language barrier, already there is a problem. Again, if the person is illiterate in technology this is difficult. When you meet the doctor face-to-face you can explain to the doctor and point to the place where you are in pain. You can say that my head is painful, or my stomach or my legs. I can point to the problem area and the doctor can see. But when you say to me that 'I am going to call you' that makes Somalis keep away from GP appointment. That makes them say 'I don't want the doctor appointment because it will be a telephone conversation and I don't have the capacity to make the doctor understand what my problem is'. So what's the point in booking an appointment? So, they would rather go to A & E.*

Other participants pointed out that there is a need to consider culture and religion when using digital technology in accessing healthcare. There are also issues around the translation of online information, for instance when booking an appointment online before you access an interpreter/translator.

*Everything is online, Zoom or WhatsApp. Even if you have access to these things, you then have cultural and religious issues where people don't want their picture to be shown on the phone. How do you diagnose the person? What about the confidentiality for the person who is not sure how videos or pictures will be used in the future? I am really concerned about digital online things we are developing in this country. Members of the Somali community will disappear or suffer because of that.*

*If there is a second wave, GPs will be closed and it will be difficult to get into a hospital, so I think if you book an appointment online there should be a way of translating it for the community so that they can understand it. They might have a translator on the other side but beforehand there is information you have to go through that people can't access.*

Most of the people we spoke to were concerned about the impact on the Somali community of using digital technology beyond the pandemic. One respondent challenged health and social care services to compare consultation rates pre-Covid-19 with current rates to see how much this has affected the Somali community.

*If healthcare continues to deliver services in this way where you can hardly get a face-to-face appointment - then this will impact the Somali community a lot. Unless we get people from the Somali community who can support them otherwise this will worsen people's conditions. If you look at the GP records to see the number of Somalis who are booking appointments now compared to before Covid-19, you will see that the number has reduced. If I am not going to the dentist*



*where am supposed to go every six months or to the GP where am supposed to go once a year then what will happen is my condition will become worse and the doctor will not be able to control it.*

*The way these services are being delivered will impact Somali community more than coronavirus has because the Somali community cannot survive with the digital delivery of NHS services. We need to have face-to-face access. We didn't have before coronavirus good access to healthcare. If we develop more on the side of digital delivery system the Somali community will not survive. There will be a lot of health issues and problems.*

## **Communication, Information and Engagement**

### **Communication and information related to Covid-19**

Participants told us that there was not enough information for the community concerning Covid-19. Where information existed, it was not accessible to the community and as a result there was a lot of misinformation circulating.

*In terms of information, there was a lot on social media and our parents watched the news and we would translate for them. So we had to look it up, the information that we needed and what we needed to do. For families with a non-English speaking person that could translate for them were completely blind to what was happening, what they can access, what they can't access, how to protect themselves.*

*Not enough information on Covid has gone to the community or even about managing their conditions such as diabetes. It is really not accessible for people and not in a way that they can understand.*

*I know my Somali community like to get close to each other, hug each other, shaking hands - there is no information or information through radio in Somali language to help them understand about Covid and the dangers. There is no information in a language that the community can understand about what to do and what not to do. It should be Birmingham City Council and health services helping people to understand in their own language.*

*There is need for more information, full information provided to the Somali community - because there is inadequate information. There is a lot of misinformation going around about different issues such as Covid, diabetes etc. Everything on radio is English, the news on to TV is English so they are relying on the neighbour who is not educated and does not understand the issues - they just say that 'I heard this' and 'I heard that' with no real information or facts. There is a big gap in information about health and social care...the support to our community has always been on financial support, this bill or that bill or legal issues. But nothing about educating people on their health and healthcare services.*

## Communication and information about medical conditions

Some participants said that even though information is given to the patient when they are diagnosed with conditions such as diabetes, asthma, or high blood pressure, it is often inadequate and not communicated in a format the patient can understand.

*There is not enough information about different conditions. For example, myself it is only when I was trained as a health champion that I found out all the health and social care information I need. I never noticed before I had been trained that there was all this information. It is a shame because it is people from our communities that suffer from different conditions - diabetes, high blood pressure, asthma. Yet we don't have information, cause it is on the net and our people don't have access to that information. Even for me to take out that information from the net, I don't have money to do that - can't pay for internet etc. I don't have anyone to support me get that information. Even if I got that information, I need someone to help me understand it. That's why most of the people are dying cause of lack of information. Right now, I know 7/10 people that have died due to Covid to my knowledge, there might be more, and all these had diabetes or high blood pressure. They can't survive unless they get good information.*

*My mom got diabetes about six years back, of course when you get things like that and the doctor diagnoses you, the doctor informs you. I have noticed a lot of things with that - the information that they share with you is very fast and minimal. They just tell you this is what you have and rush through it. The patient leaves with no information packs, leaflets or any information on how to handle their condition. All you had was a two minutes conversation with the doctor sprinting through the information so you don't remember half the stuff. So my parents have come home and said the doctor said this and when I ask further, they can't even remember the words that the doctor used and we will have to figure it out or my dad has to book another appointment so that we can go and ask what it going on.*

Participants spoke about the long-term impact on the NHS of the failure to provide adequate information and advice about various conditions, and how to manage them and prevent them.

*The thing that I'm concerned about is diabetes amongst Somali people. It can't be treated by a bag of metformin. They need information and advice about managing their condition. There is a bad diet amongst the Somali community. In the long run it starts to affect the NHS financially. I have diabetes as well and I have never been advised about how to take care of myself, how to eat well. There is no information about diabetes management in a language I can understand. Information about these things is not accessible to people from the Somali community, no diet support and it is difficult for the elderly to read a leaflet about the conditions they are struggling with. Even harder for people who can't speak English. What they need is information in a Somali language, or maybe they need a Somali nurse or someone who can interpret.*

*We need health education about the food that we eat. We are using a lot of sugars and that's the main thing causing diabetes in the community. We take a lot of*

*sugar with our tea, add sugar to juice, breakfast chapati we add oil and sugar, and tea and sugar, this is causing problems. Need to change how Somali people look at food and more help with exercise for young and old. Physical activity is important.*

*When people go to the GP or hospital and they get diagnosed with like diabetes, the doctor will give them information on how to handle it. They probably need family members to translate for them any documents given. I think what's missing is the other side of it, the preventative side. Many Somali people don't have enough information about what they are prone to and how to avoid it. There are many diseases that we are prone to and there is not enough information. No preventative messages that are helpful to the community. We only know about conditions when it happens to us or someone we know.*

Participants recognised that difficulties in understanding medical terms cuts across various ethnic groups. However, they noted that this is more difficult for people for whom English is not their first language. They suggested that:

*There needs to be some information that someone goes home with and translation. Even those of us who speak English struggle when the doctor rushes through things and uses terms that are difficult - they use medical terms that if they are not explained to you then you won't understand what's going on. I have sat with a doctor and he is using 10 different medical terms and I don't understand what is happening. I have to keep asking 'what this means and what does that mean?' Imagine for the person for whom English is not their first language, they are not going to understand. I think for things like that people need information packs or links to information so that they can go off and read by themselves or get someone else to support them.*

## **Engagement**

Engagement between health and social care services and the Somali community was seen as lacking. The participants' views show that there is a relationship between their experiences of care, limited language skills, the barriers and challenges faced and exclusion and engagement.

*I don't think health services engage well with the Somali community otherwise we would see change that reflects our culture and way of living, we would see healthcare professionals coming to see us. When they have been hospitalised, people often come back saying really we have been discriminated. There is no one there defending our values and culture. It's only when people see that you can speak English and you mention some agencies and they see you know your rights and they treat that person better. When they think you don't know your rights, they will walk all over you.*

*There is no effective engagement with the Somali community and not enough information to really guide the community to manage various conditions such as BP, asthma etc. Because if you go to the GP all the leaflets are there but mainly are written in English. It is not always necessary that they translate all of them but if they can just have a sentence in Somali saying what the leaflet is about then you can take it home and someone can translate for you. They are not*

*engaging. You will sometimes see these in Urdu and in Arabic but never seen any leaflets in Somali even in areas where there is a high number of Somali people. Nothing about conditions like diabetes or obesity. Even the doctors can just say this leaflet is about this and take it home for someone to help you translate, that person is likely to take it home than if they don't know what is inside. I don't think they have engaged the community as such.*

*Health and social care does not engage with people from Somali groups. I have never been consulted on anything taking place in healthcare.*

*When it comes to social care, for instance the support provided by Birmingham City Council and we look at social inclusion, the Somali people are not included at all. BCC does not have any connection in its services with the Somali community. The only contact is when they take children from Somali mothers. We are an isolated community and we are not invited to any meeting concerning social care. We are invisible to them and we are becoming invisible to healthcare and this will continue.*

Participants stated that engagement with the Somali community should not be one-off and should be a two-way process. Those engaging with the community need to demonstrate the changes made following engagement. Others told us that the focus of engagement should go beyond the stigma that is attached to the community.

*Also, for health and social care to work with Somali community organisations in Birmingham. They have to be informed – don't just engage with Somali community when you need them what about when they need you. For example, you are interviewing me today because you need me but what about when I need you? All organisations who are health and social care providers, we don't know how to contact them, when we knock their doors, their doors are closed to Somali community. They only open them when they need you and contact you.*

*Working with the community needs to go beyond one-off projects. Engagement needs to be continuous not just based on one problem and we need to see that there is change after the engagement. Otherwise people lose interest.*

*When healthcare engages with the Somali community the focus is on the stigma that is attached to us. So, they will focus on FGM, something that happens in childhood and has nothing to do with why am accessing the GP at that moment.*

## **How can communication and information be improved for Somali people?**

Although participants indicated that leaflets, workshops, and translated materials would be one of the best ways to communicate, they noted that there is a preference for oral communication over written information within the Somali community.

*The best way of communicating is through leaflets, translating materials and we need workshops that focus on different communities. Doctors and other healthcare professionals know that each community has conditions that they suffer from or is high within that community. So, if they know that Somali people suffer from this condition, like diabetes, there should be workshops, events within*

*that community in a language that people can understand. Somali people love information and they would 100% attend a workshop to get the information they need to manage their health. A pamphlet is good but oral communication will improve the knowledge and people in the Somali community like to ask a lot of questions. When we have had workshops like we had with Healthwatch you could see how eager people were to ask questions. Even though English is not their first language you could see the women asking so many questions because this is how they get information that they can understand. It would be amazing, if healthcare really understood what conditions affect which groups and in which areas and bring information to them - that's how they learn.*

Some cautioned that even though workshops or seminars are good, it is important to recognise that health is a private matter. There is therefore a need for various means of engagement.

*Somali people use word of mouth a lot and this can be used. We have a joke amongst ourselves that you can't see a Somali person with a newspaper in their hands cause we don't read or buy newspapers, but we talk to each other. We gather in Small Heath to find information orally. We need people who can hold seminars to talk more generally about health issues. However, understand that health issues are private things, people don't always want to share how severe their sickness is. Most Somalis are very cautious about the information they share about their sickness, some even denying they are sick. What we also need is our second generation who have grown up in this county, have been educated in this country - we are now having young Somalis that are health workers, nurses, doctors. What the NHS needs to do is employ Somali health professionals in areas where there is a concentration of Somali communities. Maybe at the GP, public health, local health centres – maybe these can help these communities. I will trust this person more than sitting in a seminar with so many other people. I can share my health concerns with this person as it's private more than in a seminar or workshop.*

Others stressed the need to ensure engagement is in an appropriate and accessible format and the importance of communicating with the Somali community in a language they can understand.

*If they are spreading news about Covid or diabetes or any disease that black people are prone to, it would be good if it was in our language. It would be good if it was in a Somali language the same way they do with Urdu etc. Most Somalis only know how to read and write in Somali.*

## **What would improve Somali people's experiences?**

Participants said having a simple process for processes like making a complaint would improve their experiences. They indicated that if Somali people could vocalise their issues and share their experiences with services then maybe they would not be treated how they felt they currently are.



*For the Somali community, everything in healthcare is a long process that people don't understand. For instance, the processes for complaints is long. So, for the Somali community with a language barrier and English is not your first language, that whole process is a struggle. It's like I can't go through that so let me just leave it. So, a lot of Somali people have been mistreated in a lot of healthcare settings but they would disregard the whole thing cause they feel 'I can't do this or that, I can't file a complaint' so they just forget about it.*

Participants also told us that it was important for people to have knowledge about the health and social care system and to know their rights. It is therefore important to improve Somali people's understanding of the NHS and social care services and that people know how to share their views about them. People spoke about better support from Birmingham City Council for Somali-led community organisations and organisations like Healthwatch Birmingham that can help hear the community's experiences. One respondent said that they had never been asked to share their experiences of health and social care until they participated in this research.

*We need to help the Somali community by better funding for projects like Healthwatch to help them reach the right communities and right people including the elderly. This problem is not affecting only Somali, there are other ethnic groups suffering, age groups suffering. I have never seen anyone who has ever asked the Somali community the questions you are asking me today. I have tried to connect with the NHS to discuss these types of issues. I hope that your project will shed a light on issues facing minority ethnic groups and the Somali community.*

*The main responsibility for ensuring that people from the Somali community are getting health and social care services falls on Birmingham City Council. They should be resolving these issues, look at the communities that are there and make sure that they are receiving services. The council also needs to make sure that community organisations they are engaging in order to support the community are actually still working. These organisations should not just be there to help us with how to pay or bills, we need support with more than bills. Somali community need support and advice for health issues, education and financial support.*

Some felt that that improved support for Somali-led organisations would help health and social care services to address issues of mental health; an issue that is not easily acknowledged within the community.

*There is the issue of mental health in the Somali community. They do not address it or treat it. The Somali family would rather keep the mental health issue within the family and it gets bigger and bigger. There is a stigma attached to mental health in the Somali community. There is something that healthcare can do to support the Somali community with mental health issues. At the moment there is a mental health Somali organisation in Birmingham led by a certified psychotherapist and it would be useful for healthcare to link up with such organisation that are led by other Somalis. They understand the community and the issues affecting them.*

Education was considered important for both Somali people and health and social care professionals in terms of Somali people learning the English language, and understanding how the health and social care system works and their rights.

*Education is the main key. For example, ESOL learning is only delivered in colleges what about community centres? If we teach Somali community ESOL in their centres, it will be better cause if you tell them to 'Go to the college' that's very hard. Education through the Somali community centres and also educating the Somali organisations that provide support to Somali groups. Training for the Somali community on language and rights, what they are entitled to etc. But also need to train health and social care professionals to remove the stigma that is attached to Somali people. Just because they see one or two people that don't want to integrate, this does not apply to every Somali. Integration does not mean that I will leave my culture or religion and they need to respect this.*

*Have transparent and educated people in healthcare who have the knowledge about different people in Birmingham like the Somali community. People have to have the knowledge that people are different, diverse, and multicultural.*

Participants also spoke about the importance of health and social care professionals being retrained to better understand people's needs and issues around discrimination.

*The view of Somali people needs to change and the language healthcare professionals use to speak to or speak about Somali people needs to change. I witnessed a doctor telling a 75-year-old Somali woman - 'How long have you been in UK?' When the woman replied that she has been here 10 years the doctor said 'Why don't you speak English? We should not get you an interpreter'.*

*We need workshops with people from Somali groups, awareness amongst social and healthcare services about Somali people - let them become aware that lack of language does not equal illiteracy. They know things but there is just a language barrier. This needs to be addressed – there should be leaflets to advise professionals on how to support people with language barriers.*

*The issue I would underline again is understand the society and the community, don't come with your agenda, preconceived ideas or stereotypes. Somali people are not what everyone thinks they are. For example, I was interpreting for one Somali person at the GP. She had a medication from the Netherlands and went through some blood tests here and the medication was changed a little bit. Then she asked questions about her blood, why she changed the medicine so she had full awareness about her condition. The doctor actually changed the medication back. Despite not speaking English, the lady knew a lot. Not speaking English does not mean that people are ignorant. Awareness and understanding of the Somali community*

## Employment

The lack of ethnically diverse health and social care professionals in communities with a large Somali population was seen as the reason for poor communication, lack of trust and

low satisfaction with services. Participants believed that recruiting people from the Somali community into health and social care roles would help address some of the issues faced by the community.

*There are no Somali people in public sector positions, no Somalis represented on boards, education sector of BCC or health sector, community groups. We have difficulties that other communities have but they have representatives working in various healthcare services that we do not have. There is no one representing us, who understands our culture, our system of living - no one defending our rights.*

*The only exit we have or solution is to have Somali community representatives in health and social care, otherwise things will continue to worsen.*

*To overcome some of the barriers Somali people face, we need to have - especially in the areas where Somali people live or are concentrated such as Nechells, Small Heath and Bordesley Green - equal opportunity in employment. For example, to have GPs that represent the diversity of the community. Have a Somali speaking GP, nurse and receptionists in areas where you have a high concentration of these groupings. When people do not speak the language, you have to have an interpreter and this costs a lot of money and that could be the reason that we are unable to access interpreters for everyone. So, having healthcare professionals from Somali backgrounds would help and save money.*

The Kings Fund<sup>15</sup> has argued that GPs as an employer have a key role to play in tackling health inequalities within the communities they serve. They note that GPs are small businesses, and can therefore have some control in how they operate as employers.

*They should employ people from the community into NHS services. There are not a lot of Somali people in health and social care services - the GP should make sure it employs people who reflect the community it is serving. The GP should employ someone from the Somali community in areas where you have a large number so that they can speak to the people and explain to them. If you look at the police, they are always looking for Somali people to help them in their work but the NHS never does this. The NHS needs to do the same in order to have the ties they need.*

*If you look at all the posts in healthcare and social care you will not find a Somali person. We need Somalis in some of these positions especially in GP and A&E where the main contact is - in areas where you have more Somali people. You need to show people that you can see them. A lot of Somali people are educated now but you hardly see them in these positions, maybe midwife.*

Trust was an issue that was repeatedly mentioned by participants. For many Somalis, the relationship with healthcare professionals is an important one, where they expect the professional to provide the best possible care, to work in their best interest and outcome. One participant said “*you know in certain countries like where I am coming from, you rely on doctor or teacher. If you go to the doctor, you think he or she will be a saviour and*

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<sup>15</sup> [https://www.kingsfund.org.uk/sites/default/files/field/field\\_document/health-inequalities-general-practice-gp-inquiry-research-paper-mar11.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_document/health-inequalities-general-practice-gp-inquiry-research-paper-mar11.pdf)

*you are in safe hands. But here that is different so you will be surprised when the doctor has no sympathy or empathy or takes another attitude because of the way you speak or don't understand the system". Therefore having people they can trust in health and social care was also important.*

*You need people who are able to influence effectively. People that Somali people can trust. Trust is a big issue for Somalis and you need to bring people that they can relate to.*

*The main point I want to make strongly, they need to employ someone who speaks Somali. The Somali community tends to live in certain areas and go to one GP. The area where I live there are at least 80 families going to the same GP but there is no Somali working there. They need to employ a Somali person in reception. If a Somali receptionist explains to someone that this is what is happening, you can't access that at this time and it had nothing to do with you, it will be received better. The patient will understand more and is more likely to trust that person.*

## **Interpreters/Translators**

Participants spoke of a need to improve access to interpreters/translators. The lack of interpreters/translators has meant that people have to use non-professional interpreters, usually family to support them. People also spoke about the importance of not only improving access, but the reliability of the interpreters' knowledges.

*The main thing is the language barrier. If we can just increase interpreters to make it easier for people to access them and easier to communicate. Someone can speak some English but when you really want to communicate how you are feeling or your condition with the doctor then you need an interpreter. Otherwise it is difficult for the doctor to diagnose you and give you a prescription to ease your pain. It is therefore important that there is a third party in the room explaining more to the doctor.*

*At the moment there is a lack of understanding and people are not getting the treatment that they need because there are not enough translators within the hospitals and GPs.*

## **Improved access to community centres**

Participants said improved access to community centres would help health and social care providers to engage with the Somali community on various issues including prevention.

*To improve communication – about Covid, conditions such as diabetes, asthma, high blood pressure – there is need for a community office in Nechells or in areas where there is a concentration of certain ethnic groups to share information. If they can do it during elections where we have cars with big speakers telling us in our language about different things...they can do it for educating us about our health. Covid-19 – there should have been such cars going around and educating people. That's their responsibility, the community doesn't know. There should be community centres where people can be taught especially by other Somali speaking people who are educated well. The thing with Somali is that we do not*

*like reading, we like listening to information, someone really explaining to you. We are not watching news in that way, even when we watch the news we are not understanding everything, maybe 60% we are not understanding.*

## Conclusion

Negative experiences of health and social care amongst Somali people in Birmingham, the challenges and barriers they face when accessing services, and experiences of discrimination are impacting the level of trust and engagement. The issues affecting the Somali community in relation to health and social care are multiple and complex relating mainly to their interaction with professionals as well as between issues. Dismissive attitudes of professionals, lack of dignity and respect, poor diagnosis and referral to specialist treatment, cultural and language difficulties, limitations in interpretation support, stigma and discrimination with their corresponding assumptions have led to distrust and detachment from health and social care services. Improved communication, information and engagement; improved knowledge about the healthcare system and the rights of individuals; education and training for both Somalis (English, rights) and health and social care professionals (cultural, stereotypes and discrimination), access to adequate and knowledgeable interpreters/translators; diversity in recruitment to health and social care roles in local services such as GPs are some of the issues that improve the experiences of Somali people in Birmingham.



## Appendix 1: What is Healthwatch?

Local Healthwatch were established in every local authority area across England following the Health and Social Care Act 2012. Our key role is to ensure those who commission, design and deliver health and social care services hear, and take into account, the public voice. Healthwatch Birmingham listens to and gathers public and patient experiences of using local health and social care services such as general practices, pharmacists, hospitals, dentists, opticians, care homes and community-based care. We hear these experiences via our Information and Signposting Line, our online Feedback Centre, and through our community engagement activity led by staff and volunteers. You can read more about the work of Healthwatch Birmingham here:

<https://healthwatchbirmingham.co.uk/about-us/>

### **How do we select the issues we collect evidence about?**

Some of the issues we hear about from patients and the public may require deeper exploration in order to present a comprehensive report to those who commission, design and deliver health and social care services in Birmingham. Members of the public select these issues as part of our Topic Identification and Prioritisation System. By involving members of the public in decisions about our future activities, we ensure we are operating in an open and transparent way. It also ensures that we understand the public's priorities.

### **Who contributes to our evidence collection?**

We explore selected issues with the help of our volunteers, Healthwatch Birmingham board members, patients, members of the public, service users and carers. They share relevant experiences, knowledge, skills and support. Healthwatch Birmingham also talks to key professionals providing or commissioning the service we are investigating. This helps us to form a deeper understanding of the issue from the perspective of these professionals, and encourages them to take prompt action to implement positive changes for patients and the public.

### **What differences do our reports make?**

We follow up our reports to see if our findings have made services better for patients and service users. We hold service providers and/or commissioners to account for changes they stated they would make in response to the report. If Healthwatch Birmingham finds no improvement, we may decide to escalate the issue to Healthwatch England and local regulators. We also monitor the changes to see if people experience sustained improvements.

### **How to share your feedback about the issues heard in this study**

If you are a service user, patient or carer, please do share your experiences with us via our:

- Online [Feedback Centre](#) here.
- Information and Signposting line on 0800 652 5278 or by [emailing us](#).