

# Somali experiences of first wave *Caabuqa*-corona: an analysis of high COVID-19 mortality and infection levels in London's East End, 2020

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## Abstract

This article focuses on the experiences of a minoritised black Muslim community in London during the first wave of the COVID-19 pandemic, 2020. It shows that many Somali families, living in a high-density area of the East End, experienced acutely high infection and death rates from late March. The reasons for this were found to be late lockdown, a top-down community-insensitive public health approach, and the way that many of the work force were in highly vulnerable occupations. However, high rates were then prolonged due to the legacy of historic poverty, housing density and institutional racism. Culture and locally specific responses were less significant factors but overall had a positive impact in mitigation. However, the situation with regard to mental health remains bleak. This research suggests more trained Somali health experts, community sensitive data, trauma informed care, and use of local networks could help reduce future vulnerabilities and health poverty.

## Keywords

COVID-19, Somalis, London, health-inequalities, racism.

## Note on the authors

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## Introduction

By March 2020, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) was at pandemic level in the UK. Cases peaked first in London according to Public Health England (2020).<sup>1</sup> The capital recorded the highest number of deaths every week until mid-April,<sup>2</sup> and the highest rate of diagnosis for men during this period (PHE 2020: 5). However, Londoners did not shoulder these statistical burdens equally. The disparity of COVID-19 experiences between its richest and poorest residents represents one of the most extreme examples of urban inequality in the world.<sup>3</sup>

London's Somali diaspora found itself on the frontline of the pandemic ('*Caabuqa*' in Somali).<sup>4</sup> In April, the youngest recorded British fatality was Ismail Mohamed Abdualwahab, aged 13.<sup>5</sup> One of the first intimate accounts on national TV of the traumatic emotional impact of a sudden death came from the mother of 48-year-old Somali-Londoner bus-driver, Nadir Nur.<sup>6</sup> Simultaneously, as Einashe (2020) reported for BBC, Somalis around the world were grief-stricken by the loss of the father of classical *oud* music, Ahmed Ismail Hussein Hudeid, who died aged 91 years. Somalis bore witness to the unfolding horror on multiple news platforms (Hujale 2020).<sup>7</sup> In May, West London Somali leaders reported how 'our people are among the worst affected by the pandemic'.<sup>8</sup> Death rates continued to be high for six months and the experience remains traumatic for many.

This study offers a micro-history of one British-Somali community in the East End of London, and their experiences of COVID-19 during the first wave of the pandemic. The aim of the research was to generate data; to present and analyse individual experiences; to examine the reasons for health inequalities laid bare by the pandemic; and to suggest improvements in healthcare delivery.

<sup>1</sup>The initial peak ended on 4 April 2020 and happened first in London, East Midlands and West Midlands.

<sup>2</sup>London had the highest number of deaths every week from until the week ending 18 April 2020. Between 20 March and 7 May 2020, there were 9,035 recorded excess deaths in London in relation to previous average death rates, compared to 2,900 excess deaths in South West England. Ibid, 26.

<sup>3</sup>By late March private jets were reportedly being hired and up to £50,000 a month rental offered for UK rural retreats. Dominic Cummings, the then Special Adviser to the Prime-Minister controversially left the city during lockdown, as reported by Green (19 March 2020) and Lewis, Narwan *et. al.* (2020). As Maya Gordon (2020) explored, similar response was recorded during the outbreak of plague in London in the 16th and 17<sup>th</sup> centuries and was called flight.

<sup>4</sup>The 2018 census recorded 105,000 Somalis in the UK but this figure is disputed and often put at nearer 250,000. Official censuses focus on Somalis born outside the UK. But the population is highly mobile and contains third and fourth generation British-Somalis. Moreover, traditional official categories of Black British were not always the self-identifying category Somalis were comfortable with, some preferring Arab. For these reasons, estimates of London's population are particularly inaccurate other than being the largest UK Somali community and are put at around 100,000.

<sup>5</sup>This resulted in a change in Government policy. Then Health Secretary, Matt Hancock told a Downing Street Press Conference that the sight of Ismail's coffin "being lowered into a grave without a member of his family present was too awful." (BBC Online 16 April 2020)

<sup>6</sup>He had no serious underlying health issues other than mild asthma. He left behind five children including a four-month old daughter. The story moved quickly from five London bus drivers dying in five days, to eight dying within a week, as reported by Mohdin (2020a) and Cumiskey (2020). Once more, it was the family members' and the UNITE Union's demands for protective personal equipment produced a change in policy.

<sup>7</sup>'Coronavirus exacts heavy toll on UK's Somali community – A 13-year-old boy from London and a former Somali prime minister among those who have lost their lives too soon'. This was the substance of an article penned by Hujale (2020), published by *Al Jazeera* and covered in the *SomaliTribune*.

<sup>8</sup>Owen Sheppard (2020), *Local Democracy* reporter, 'London coronavirus: Somali leaders say "our people are among the worst affected" by pandemic: West London boroughs are home to some of the UK's biggest Somali communities'. Aamna Mohdin (2020b), in the *Guardian*, 'At least 36 people have died in Church End, a neighbourhood dealing with housing pressures, in-work poverty and racial inequalities'. Another important piece was by William Wallis (2020) and published in *Financial Times*.

## Background

A Somali presence in the UK can be traced back to the rise of Britain's global maritime supremacy in the early 19th century. Somali seamen first worked on sail ships, then steamboats and the merchant navy, sometimes settling temporarily in small numbers in British port cities including London, Liverpool and Cardiff. Restricted shore leave and racism encouraged a pattern of social segregation centred on seamen's boarding houses and cafés close to dockland areas (El-Solh 1991; Mohammed 2021). Somalis contributed to both world wars. Somaliland (Britain) and Somalia (Italy) became one unified country after independence (unusual in 20th-century history of colonial independence). In the 1950s, Somali communities from Somaliland settled in industrial centres such as Sheffield and Manchester. From the 1970s, and with a simultaneous decline in the merchant navy, the numbers settling increased.

The British-Somali Diaspora then grew exponentially from the mid-1980s, primarily due to the civil war, creating waves of refugees (Prunier 2020). In the 1980s, Somalis seeking asylum in the UK dramatically increased from the north (former British Somaliland), as did the numbers of single mothers fleeing the war (Lewis 2021). The collapse of the Somali state in the early 1990s increased refugee flows through the 1990s and early 2000s, and through family reunion schemes. More Somalis from the south (Somalia) continued to settle, many coming from European countries. Thus, the Somali population has risen to an estimated 250,000, with London having the largest concentration (Mohamoud 2011).

British Somalis are often stigmatised, racialised and subject to Islamophobia. Most are Suni Muslims. Many of the younger men are linked in mainstream media to violence, gang culture, and religious extremism. Conflict and destabilisation in Somalia, including terrorism and Al Shabab, are dominant frames through which Somalis are viewed. Yet in reality, many maintain links back home through sending family remittances, making investments and supporting charitable endeavours (Lewis 2021).

Narrow, generic, or erroneous official BAME categories have been especially problematic for Somalis in Britain from the national census downward, due to the single category of Black African.<sup>9</sup> Many Somalis do not identify as black African when prompted. Even if they do, this does not produce Somali-sensitive data. Population figures remain inaccurate, insensitive, and lead to an underestimation of resources needed, often resulting 'in the British-Somali community's experiences being overlooked'.<sup>10</sup> Mohamoud (2011) found a unique 'culture of disadvantage' among British Somalis: being black, an ethnic minority, and Muslim, as well as often having traumatic exit and arrival journeys as refugees.

The central hypothesis of this research was that, as with other BAME groups, (1) British Somali's were hit hard by the pandemic. The first eleven doctors to die from the virus were from Black, Asian and Middle East backgrounds, as were two-thirds of all health-workers fatalities in

<sup>9</sup>Traditionally in British censuses, 'Black African' as an option has been problematic for Somalis who might have chosen instead 'Arab' or 'Other'. Additionally, Somaliland is not the same as Somalia, but the former is still not an officially recognised separate nationality which can complicate self-identification. As one report (At Home Project for Open Society Foundation 2014: 25) put it, 'Most attempts to classify Somalis are unable to capture their position in relation to nationality/ethnicity and religion/culture. If they are subsumed within the category 'Black African', the differences between Somalis and neighbouring African countries in terms of culture, language, diet, dress and religious practices are not highlighted. However, as Muslims, Somalis worship at mosques alongside Muslims from South Asian and Arab countries, but they do not share other aspects of culture, for example language, diet or dress, with these groups.'

<sup>10</sup>Ibid.

the first month or 71 per cent of all nurses (Kirby 2020). By mid-April, non-white people were twice as likely to die from the virus during this first wave (Croxford 2020). And (2), they may have been at the extreme end of this fact, suffering from a massive lack of basic data on and understanding of the community. Indeed, Public Health England's June 2020 report, on COVID-19 and ethnic disparities, initially classed Somalia as part of Western and Central Africa.<sup>11</sup>

### Methodology

A localised, micro-study was designed to create a snapshot of what happened to British-Somalis in the East End of London, to generate a community-sensitive history of the first wave of the pandemic and suggest explanations for this. Such raw data is hard to come by. Somalis who live in the East End represent one of the oldest communities in the UK. The traditional East End, made up of Bethnal Green and Bow, Poplar and Lime House falls within the large borough of Tower Hamlets. Population estimates from the local authority range from 12,000 to 25,000 (8-10,000 in 1991), although that higher figure has likely been surpassed. This has been evidenced by Camillia Fawzi El-Solh (1991) and, more recently, Joanne Hemmings (2020). It has a history of challenging socio-economic circumstances and a multi-generational population making it an extremely useful case study (El-Solh 1991). As Manish Pareek *et al.* (2020) argued, in order to disentangle the relative importance of an array of complex factors with regard to high BAME COVID-19 mortality rates, prospective studies should quantify 'absolute risks and outcomes' and *consist of 'qualitative studies of behaviour and responses'*.

A mixed method was adopted for gathering sensitive data on the complexity of specific minority ethnic communities' experiences and responses to the pandemic in the light of their particular history, which would come from people and practitioners in those communities. Four main sources were used: primary care anonymised patient records, in-depth interviews, GP testimony, and feedback of preliminary findings from a group of over 100 local council health-workers from the catchment area. All of this data is unavailable and hard to access. To this end we adopted a mixed method approach (after seeking ethical approval and respective permission following established practice on data management). Primary care offered a uniquely rich source, being the only health records to have a designated Somali ethnicity code within their electronic records (council and hospital records do not specify). To this end, Bede conducted a clinical audit of 220 Somali patient records spanning the first and second wave from February 2020 to March 2021. This captured any Somali patient consulting with a GP at the practice during this timeline with symptoms of COVID-19, having had testing, or those on the clinically vulnerable list. It also provided a rare opportunity to examine the social circumstances and medical histories of these patients, which generated a hospitalisation and mortality rate for this group.

Secondly, twenty in-depth interviews were conducted. Half were with patients from within the practice chosen to represent the full range of COVID-19 presentations, from mild symptoms to hospitalisation. The other half were not linked to the practice and did not have a Somali GP, but lived in the area and were community leaders, elders, and/or heads of households. Interviews were semi-structured around a questionnaire made up of five sections which were informed by the results from the patient audit: recollections of the first lockdown; personal COVID-19 experiences;

<sup>11</sup> 'Appendix C: updates and corrections. Correction made on 10 June 2020: Page 54 Corrected to list Somalia in in South and Eastern Africa rather than Central and Western Africa' (PHE 2020: 91).

general health; economic circumstances; and suggestions for how to reduce negative health impacts on the Somali community.<sup>12</sup> Thirdly, Bede had kept a factual diary for the first year of lockdown, recording work life in the practice, unpaid work for her community, and her feelings at the time as a GP on the front-line. This was shared with Lewis and extended in an interview, and was worked into the research findings since it offered a chronology of public health measures related to COVID-19 as they were rolled out, the impact of this on primary care, and the feelings of staff. Fourthly, the authors presented the preliminary findings of the research as part of a training workshop for North East London care providers. Comments and feedback were also treated as primary data in relation to making suggestions for future changes. (This study did not research subsequent waves or vaccination roll outs.)

Challenges faced included conducting research, at times within the second wave COVID-19 restrictions. Meeting people face-to-face or attending Somali community events became difficult. And the authors themselves caught COVID-19 during the research and writing period. Nevertheless, the amount of rich, targeted data collected through multiple channels, when collated, proved highly revealing of trends, perceptions, and issues on a small scale, beginning with the community's traumatic experience of the first lockdown period.

### High death and infection rates during the first COVID-19 lockdown, March–June 2020: 'My community was left broken'<sup>13</sup>

Bede began dealing with worried patients who had been to affected areas in January and February 2020. 'It was a race against time to try to organise our services to be a buffer against the fall out', she recalled. 'I had been working in the East End for several years and knew it would be particularly hardest hit due to the levels of social deprivation, poverty and decades of austerity of public services.'<sup>14</sup> Some elderly Somalis recall initially not being worried, believing that whatever happened would be God's will. Others heard about it first on Somali radio or Somali TV and panicked for their relatives back home. Fatima became concerned when a business associate in China told her about the economic effect of lockdown in Wuhan.<sup>15</sup>

By late February, the situation worsened. On 28 February, a mother came to Bede's practice after her daughter had been to southern Italy. The girl had flu-like symptoms but could not get tested via 111 (NHS helpline) because they had not visited the affected areas of northern Italy at that time. They were left having no way to ascertain if this case was coronavirus. Then the week after, she saw a nursery worker who had developed flu-like symptoms who had managed to secure a COVID-19 test, only to have the guidelines for community testing changed overnight so her test was cancelled the next day. She was advised to self-isolate. 'It was when this patient called the practice back, after hearing her test was cancelled, in floods of tears, not understanding why her test was cancelled, the realisation sunk in that we as GP's had no ability to reassure her one way or

<sup>12</sup> Respondents were either recorded or answers were handwritten. The purpose of the research, its confidential nature, its secure storage, publication goals and data destruction once the research was completed were fully explained before consent was given. Respondents were assured they could stop any time and also ask for the interview materials to be copied to them or withdraw from the research and have their interview destroyed. Everyone was universally enthusiastic about full participation.

<sup>13</sup> Interview 13.

<sup>14</sup> Bede, F. (2020) *Covid Diary* (unpublished, in possession of author).

<sup>15</sup> Interview 15.

the other,’ recalled Bede. ‘It was then that I got a choking feeling of impending doom that this was the beginning of a difficult chapter in all our lives.’

Evidence suggests that by early March the virus reached the community. Many interviewed recalled getting ill in the weeks before lockdown. At this point GPs still did not have personal protective equipment whilst doing face-to-face consultations. On 6 March, Bede saw a patient with a longstanding medical problem. At the end of the consultation, he asked ‘by the way Doctor, I have this cough. Do you think it’s anything to worry about?’<sup>16</sup> With no PPE onsite yet and no GP access to tests, all she could do was to risk assess him and direct him to follow the guidance from NHS 111. ‘I hoped for the best’, she recalled, ‘but all night I couldn’t sleep. I kept tossing and turning, worrying if I’d been exposed to coronavirus.’ From 9 March onwards, her practice (along with many others) switched to telephone/video triage first, and practices were given PPE. However, community testing was still not available and patients with mild suspected symptoms were being asked to self-isolate at home for seven days and only go to hospital if unwell for testing.

Large social gatherings continued throughout March. ‘I think I got it before lockdown’, recalled Muna in her 60s. ‘I had this terrible sore throat. I went to an all-day event in a civic centre. Then in the evening there was a Somali event. I was basically inside all day.’<sup>17</sup> There were people from the community in hospital from at least the last week of March. According to some, three big social events had taken place before lockdown. One was in a basement with indoor snooker, cards and so on being played, and ‘lots of men had gone’. They brought the virus home. About 17 people caught the illness from one event. ‘If test and trace had been in place earlier, we would have known much more.’

The most discussed factor about the spread of the virus in March was how ‘It began to hit men first the hardest. They were working on the front line’.<sup>18</sup> Taxi drivers, Uber drivers, hospital porters, street cleaners: these were the occupations most often listed for the major male breadwinner. Younger men were falling ill too and were also working as carers and shop assistants. Men were in hospital by the end of March. Shukri caught the virus around the last week in March. ‘I was sick but not too sick. My nephew had caught it. He was working as a carer.’<sup>19</sup> ‘When the Government started talking about lockdown, for many it was unbelievable. ““This cannot be happening here”, people said. “It is more developed here [UK].” Nothing is unexpected back home [Somaliland], but we had fled to get away from that ... The bad news and the impact seemed limitless.’<sup>20</sup> Mohammed, in his fifties, was working as a taxi-driver and caught the virus early April. ‘I couldn’t get a test as there was no community testing. I wished I could have known earlier and not passed it onto my family.’<sup>21</sup>

The initial high death rates were often remembered as: ‘healthy, middle-aged men were falling sick and some were dying’; ‘the first people we knew died on 29 March’; ‘I knew of two men who caught the virus and died early April’; ‘people we knew started dying by the first week of April. This went on for over six months.’<sup>22</sup> Muna, a community leader, remembered that at one point ‘there were five deaths a day of people known to us .... We know families that got wiped out’. This was when widespread panic spread within the community. ‘People were calling me and asking can

<sup>16</sup> Bede, *Covid Diary*.

<sup>17</sup> Interview 20.

<sup>18</sup> Interview 20.

<sup>19</sup> Interview 16.

<sup>20</sup> Interview 20.

<sup>21</sup> Interview 10.

<sup>22</sup> Interviews 18, 20.

we come and stay with you.’<sup>23</sup> ‘A lot of people withered’, recalled Fatima an East End resident. ‘I knew the impact of the virus was deadly on the community’, recalled Bashir, a community leader in his forties. ‘We know our community. We are experts *by experience* but we didn’t have the data to say it. We knew it but we couldn’t prove it. We felt gas-lighted.’<sup>24</sup>

News spread within the community of hospital deaths. Zhara, in her 70s, had a fever, aching muscles and was dizzy for two weeks, calling her GP on 14 April. She did not want to go to the hospital, but when her breathing became difficult she was admitted a week later. She was given oxygen, then put on a ventilator. Her family remember how she was scared, that she had felt that she had been not listened to earlier, and that the family had little information on her condition. Her English was poor. She died on 28 April.<sup>25</sup> Mohammed too was hospitalised mid-April. He had settled in Bow in 2003 after fleeing as a refugee in 1997, and was in his late 60s. A retired seaman, he lived by himself with family nearby.<sup>26</sup> He felt very alone during lockdown. When he got symptoms, he called a friend who told him to call an ambulance. He spent two weeks in hospital having oxygen therapy. ‘He struggled there’, his daughter remembered, ‘the food was not edible and he was only drinking [fluids]. He couldn’t communicate his needs as there was no translator.’<sup>27</sup> Nevertheless, he was discharged at the end of April and recovered largely thanks to donations of food from a restaurant distributed by the Seamen’s Day Centre. One of his friends died at the same time. In total, he knows eight retired seamen in the area who died.<sup>28</sup>

The initial high rates of men hospitalised and dying made the wider local community less likely to report symptoms or to delay reporting serious breathing problems, for as long as possible, since there was a massive fear of going to hospitals and dying alone. ‘The main story of COVID-19 at the beginning was symptoms like bad flu, you struggle to breathe and if you go to hospital, you are likely dead.’ ‘A friend got ill’, recalled Jawahir. He was admitted. ‘A few days later I spoke to his wife warning her not to allow doctors to place him in induced coma. “Too late” she said, “he was in a coma”. Two days later he passed away ... I know a total of four people that died. The virus took some of my friends. It has been very stressful.’<sup>29</sup>

‘The stories going round in the community were scary’, said Osob, whose recollections were shared by many. ‘People were saying you could drop dead after a small cold ... people avoided going to hospital because COVID-19 has cold symptoms, and every Somali has a herbal mix for that.’<sup>30</sup> Families preferred to take traditional remedies first and/or pray. ‘The only thing to expect at the hospital seemed to be a “coma bed”. Take your chance at home unless the person was finding it hard to breathe was the message going around’. Many interviewees recalled people falling ill or dying in April. Sadia and her husband both caught the virus. He had to be hospitalised after two weeks of being ill at home: ‘we didn’t get access to testing when we needed it and we were scared to go to hospital ... we heard many people in A&E were [lying] on the floor ... and my husband doesn’t speak English ... we worried he could die on the floor without his loved ones around him’.<sup>31</sup>

<sup>23</sup> Interview 20.

<sup>24</sup> Interview 13.

<sup>25</sup> Interview 2 (granddaughter).

<sup>26</sup> He had not been able to work for eleven years initially waiting for his status to be clarified. He had never returned home due to his English not being good enough to complete the passport form.

<sup>27</sup> Interview 1.

<sup>28</sup> Interview 3.

<sup>29</sup> Interview 15.

<sup>30</sup> Interview 16.

<sup>31</sup> Interview 4.

The national news story in early April was the death of the youngest UK victim of COVID-19, a Somali boy. This confirmed to many in the community that hospitals were death machines for Somalis and that it was affecting the community worse than others, arousing further fear and suspicion. ‘I knew of a few Somali children that got very sick with COVID-19’, said Hodan, ‘although they said in the news that children were not at risk of being sick.’<sup>32</sup> Rumours increased when someone went into hospital. ‘You were not allowed to see your people again’ was a common feeling. ‘There was a rumour’, recalled Muna, that ‘people were not being buried properly. We tried to do something about this. We sent a message around from the Council of Muslim Burials that it was OK. People *were* having Islamic burials.’<sup>33</sup>

The pandemic reached its peak death rate in April. ‘As doctors we were on auto-pilot mode, with one setting “go” all the time, trying to fight fires with little armoury’, recalled Bede in interview. ‘It was a frustrating time for GPs. We were largely shut out of the decision-making process, not able to digest nor reflect on what was happening. I was feeling worried for my loved ones and my patients.’ GPs were sharing information, resources and were supporting each other. But Bede remembered feeling, ‘outside of our bubble, we were cut off from those making the decisions despite receiving lists of patients the government wanted us to contact for shielding for 3 months. Most of the names we agreed with but there were some missed off ... I wondered why GPs weren’t involved in the creation of these lists from the beginning as we knew our patients well.’<sup>34</sup> Muna’s experiences were similar in Tower Hamlets:

The information flow was not coming from the top-down. Not down to the middle level. There was a breakdown in communication. Even in August when a test centre was established ten minutes away from her Somali centre, we were not told.... The local authority was not taking responsibility. Even GPs were not responding at the beginning. But then again, it was an emergency. Each had their own problems from the pandemic.

Meanwhile, the government’s ‘stay at home’ message was having serious unintended repercussions. ‘We were confused by the “stay put” message’, said Sadia, as did many others. Bede recalled that the practice was having delayed presentations of medical emergencies. People were also stopping their medicines for chronic illnesses. ‘There was confusion about going to the pharmacy to get them and fear of contracting Coronavirus; fear of hospitalisation and being unable to see loved ones and the possibility of dying alone as visitors were not allowed.’

Death rates in the community continued to remain high especially among the elderly and vulnerable. Limited English was a factor. In the East End and Tower Hamlets, elderly Somali patients often had their grown-up children or friends/relatives or neighbours translating for them, but ‘as the lockdown restrictions were announced and many were shielding alone at their home, often this couldn’t happen. So they had limited access to advocacy services.’<sup>35</sup> ‘I felt sorry for my neighbour’, recalled Osob, an elderly Somali woman whose family was out of the country. ‘She became very lonely, stopped going out for walks and deteriorated quickly. She was admitted to the hospital and died soon after.’<sup>36</sup> Bede found herself taking the initiative to reach the community: ‘I created Somali language videos explaining how they could still get help from their practice and

<sup>32</sup> Interview 18.

<sup>33</sup> Interview 20.

<sup>34</sup> Bede, *Covid Diary*.

<sup>35</sup> Interview 20.

<sup>36</sup> Interview 16.



to continue taking their medications and shared this with healthcare organisations and local authorities in the North East London area as well as on social media such as YouTube, Facebook and Twitter.’

Panic at the start gave way to severe anxiety. Mental health issues grew as did stress from within the home. At the start of lockdown, Muna’s organisation was getting inundated with calls, the majority from people who were living alone, could not speak English and their supplies had run out. ‘They had experienced war and loss of food’, she explained, but that was part of the problem. ‘They were asking “What could have happened? We have already lost everything once. This cannot be happening again, here”’.<sup>37</sup>

Many had to keep working and lived in fear of getting ill and passing it on. Nadifa, a single mother with three children, kept working as a carer. ‘The first lockdown was scary. I still went to work. I was very worried about bringing the virus home.’<sup>38</sup> Grief was also taking its toll on many. For example, Kadija lost her grandparents to the virus in April. Both had ironically returned to Somaliland for the winter for a healthier lifestyle. Her father in his 70s or 80s had always avoided GPs and the hospital unless absolutely necessary.<sup>39</sup> ‘I got very anxious during the pandemic and couldn’t access talking therapies’, confided Sulekha.<sup>40</sup> With six children and two adults in a three-bedroom house, finding privacy was hard. Nimo has complex health issues including diabetes and FGM complications. Lack of physical access to a GP caused her added anxiety.<sup>41</sup> Many spoke of the mental health impact: the effect of not being able to go out and be sociable; of feeling mentally drained and exhausted; of families being on edge, with more arguments. ‘I had to fight hard to prevent the young men in the house from ordering greasy takeaway food.’<sup>42</sup> Mohammed was stressed about money as he was not working. Consequently, his hypertension worsened. He was also unable to exercise at home and his blood pressure increased.

Women as carers particularly found their anxiety rocketing. Dhibla’s daughter developed anxiety, but they were unable to access talking therapies. Her father died of COVID-19 in May in Somaliland.<sup>43</sup> Many women said they had or knew women with diabetes or high blood pressure who worried about their conditions worsening: ‘who would look after the children and their obligations back home if they fell ill?’<sup>44</sup> Some looked after their cousins’, nieces’, or nephews’ children when parents felt sick. Everyone interviewed knew personally at least one person who had passed away in April, usually more after that, and of multiple families who had caught the virus during the first wave.

## Prolonged COVID-19 vulnerability and health poverty

The nightmare was not over. The data reveals that death rates and infection rates were sustained after the peak of the first wave. What role might a diminished ability to stay healthy and fight the

<sup>37</sup> Interview 20.

<sup>38</sup> Interview 1.

<sup>39</sup> Interview 5.

<sup>40</sup> Interview 7.

<sup>41</sup> Interview 8.

<sup>42</sup> Interview 15.

<sup>43</sup> Interview 6.

<sup>44</sup> Interview 17.

virus play in making this community more vulnerable for longer? Analysing 220 Somali patient records produced insightful data on housing, occupation, prior health issues and the incidence of COVID-19. Five determining factors were identified as fuelling the continued disproportionate impact of the virus.

### 1. Long-term comorbidities

There is some evidence that, of the Somali patients registered in the East End practice who contracted the virus, many had multiple, underlying health conditions, conditions associated with communities with compromised self-care and stress-related conditions. Those over 60 and who had come to Britain as refugees confided that they did battle depression. Retired seaman Mohammed explained that, after moving to the UK, he started suffering from depression which initially kicked in when his close relative was killed in 1999 and was exacerbated by having relatives back home. Anti-depressants and talking therapies had not helped him. Some of his friends, also former seaman who lost their jobs, were depressed as well, ‘I would bump into them on Mile End and would worry about them.’<sup>45</sup> Generally living in the UK made him secure but ‘unhappy’ as he missed the weather in Somaliland and the people. This feeling was exacerbated during the pandemic since he had no opportunity to go to the Seamen’s Day Centre and had limited phone contact with his male peers. He felt constantly lonely.

Additional community-specific health issues also emerged, specifically complications from FGM and PTSD from the civil war. ‘I have suffered with depression in the past. I am now better and feel better about life, thank God’, said Osob. A few mentioned the negative impact on their mental health from anxiety about their citizenship. Hayat has diabetes, glaucoma, gallstones and gastritis. She is nearly 60 and came to live in the UK in 2014 from Somalia. She has a three-bedroom flat where she lives with her two adult children and one teenager whom she brought over in 2018. She suffered from anxiety as she waited for her citizenship and did not eat well, ‘as I didn’t have rights to work’.<sup>46</sup>

Hawalin thinks Somalis caught COVID-19 in a different way and have different symptoms because they were so tired. In one East End practice, after a review of 220 electronic records for Somali patient consultations done from March to November 2020, 54 were considered relevant to COVID-19 (meaning a patient was either reporting symptoms and/or had taken a test locally where the results were reported back to the practice, and/or was deemed clinically vulnerable). A third of all patients were aged 25-40, 10 per cent were frontline key workers such as bus drivers, nurses, carers.

<sup>45</sup> Interview 3.

<sup>46</sup> Interview 17.

**Table 1.** The percentage of Somali patients in each age bracket during the clinical audit.

<i>Age of patients</i>	<i>Percentage</i>
0–16	11.1
18–25	7.4
25–40	33.3
40–50	16.6
50–60	11.1
60–70	1.85
70–80	9.3
80–90	1.85
90–100	7.4

Of the 54 patients, 55.5 per cent (30/54) had a test after reporting symptoms and 50 per cent of these were positive (15/30). At this time, only PCR tests (polymerase chain reaction, the gold standard laboratory test for Sars-Cov-2 virus) were being done in the hospital with limited community testing. Although the situation improved in autumn, there was a shortage of testing again once schools re-opened. The most commonly reported symptoms were fever, dry cough, muscle aches, tiredness, headaches, and shortness of breath. Eighteen of 54 patients were categorised as clinically vulnerable with co-morbidities including diabetes, asthma, heart disease, kidney disease stroke, immunosuppression, and severe mental illness.

From patient records analysed, the hospitalisation rate was found to be at 12.9 per cent. The death rate in this cohort of patients is 5.5 per cent. However, the true numbers are likely to be much higher when we corroborate qualitative data from the interviews and media reports during the first wave, compounded by the fact that while the ethnicity of the person who died is asked for, it is not mandatory for the service to record it (this information is also often not available on death certificates).<sup>47</sup>

Additionally, views of normal health were not positive. Many interviewees suggested ‘Somalis feel healthiest in their 20-40s and that’s about it’, whilst others point out that ‘people in Somalia’ by contrast ‘are usually healthy until they die.’<sup>48</sup> ‘People I know back home’, said Osob, ‘mostly suffer from old age.’ She has back pain, high blood pressure and has had a hip replacement. She feels healthier back home ‘because mentally, I am content. I know the culture, the language and everything feels comforting.’<sup>49</sup> Many women over 40 have arthritis and feel healthier at home in the sun which makes movement easier. Nevertheless, an equal number recorded that they feel happy living in the UK and made the effort to stay healthy especially through walking. ‘My family and I have many opportunities in this country and a freedom to express ourselves’, said Jawahir. Her primary stress is financial and not home-sickness even though she has not been home for thirty years. ‘I love the freedom and the Somali community in the UK’ was a feeling shared by some.

<sup>47</sup> Ethnic group is not recorded when a death is registered. The Care Quality Commission (CQC) who oversee GP surgery and care home inspections have reported difficulty getting ethnicity data after death. They write on their website in 17 June 2020 ‘The ethnicity reported on the death notification form reflects the ethnicity that the provider selects – we cannot be sure that this would be the same as that which the person who died would self-report.’ They add ‘the percentage of forms where ethnicity was unknown, not stated, missing or which could not be analysed (due to factors including illegibility of handwritten forms) was 13.8% in 2020 and 13.4% in 2019. It is possible that the death notifications where ethnicity is not recorded include a higher proportion of people from BME groups but we are not able to determine this’.

<sup>48</sup> Interview 15.

<sup>49</sup> Interview 16.

Significantly, patient records consulted revealed a high incidence of types of illnesses which research has associated with the effects of racism (Paradies *et al.* 2015). Stress associated with experiencing racism (and its emotional drain) has been linked to long-term physical problems, from high blood pressure, weakened immune system, hypertension, higher rates of smoking, alcohol use, drug use, and unhealthy eating habits increase inflammation risking heart disease and kidney disease, and impacting sleep and physiological functioning from middle age onwards (Lewslley 2020). Moreover, as Lo *et al.* (2021) have recently argued, medical comorbidities do not explain the excess risk experienced by racial and ethnic minorities, and support the central role that inequities in the social determinants of health play in COVID-19 infection.<sup>50</sup> They lamented the limited prior investigation of the combined influence of personal and community-level socioeconomic factors on racial/ethnic disparities in individual risk of COVID-19-related illness.

## 2. High density living

East London is well known for its tower blocks and one of the concerns when the pandemic struck was that those living in overcrowded dwellings would be more at risk of being exposed. After Abdul was evicted from his privately rented property just before the pandemic struck, he found himself sofa surfing with friends and family whilst working as a London bus driver. As the pandemic was announced, he became concerned about bringing the virus home to loved ones, especially his elderly mother. Consequently, he began living in a hotel which he described as ‘rammed with people’ and having ‘very little personal space to relax after a long shift.’<sup>51</sup> Sulekha believes her family’s healthcare could be improved by better housing: ‘we are a big family of eight, six kids and two adults, and we live in a three-bed’.<sup>52</sup> Also ‘they live in multi-generational homes with communal living.’

Poor housing and over-crowding were mentioned by several interviewees. ‘How do you self-isolate in a flat with three bedrooms for ten people?’ asked Muna. ‘Men brought the virus home and then it was impossible to keep away from it.’<sup>53</sup> Of the primary care patient records reviewed, the majority of patients were found to live in one- to two-bed flats with the living room converted to an extra bedroom. On average there were 4.7 people living in each flat.<sup>54</sup> ‘Our homes are often high-density – five or six people sharing three rooms’ said Bashir, ‘this created a domino effect.’

This research confirms the link between health and housing that has been argued for elsewhere. The Centre for Ageing Better in partnership with The King’s Fund (2020) found that 18 per cent of homes in England are in a ‘non-decent’ condition, or not meeting the Decent Homes Standards. However, when wider aspects of housing quality beyond these minimum criteria are included, the percentage of households that create risks to health is likely to be considerably higher. These homes are occupied disproportionately by older people, those with existing health conditions, people on lower incomes and those from ethnic minority groups. Research done by Public Health

<sup>50</sup>They argued that, ‘Even after accounting for personal contact with COVID-19, occupation as frontline HCW, and comorbid conditions, community-level socioeconomic factors still mediated 16.6% and 7.7% of the excess COVID-19 risk compared to White participants in Black participants in the US and the UK, respectively.’

<sup>51</sup>Interview 11.

<sup>52</sup>Interview 19A.

<sup>53</sup>Interview 20.

<sup>54</sup>Data compiled from 220 Somali patients who contacted the practice during the first wave.

England and the Centre for Ageing Better (2020) also found that some groups are more likely to live in poor-quality housing than others. Thus, disproportionate number of deaths from COVID-19 in BAME communities can be explained in part by the conditions in which people live. More research is required looking at the intersection of multi-generational living and of overcrowded accommodation in the generation of health inequity.

### 3. Fragile incomes

Sadia echoed many views that ‘more Somalis were catching it and dying getting to the hospital often too late’ because ‘not only is there over-crowding but they were doing manual work.’ Over half of respondents stressed how a large proportion of men and women do a lot more front-line manual work like bus-drivers, shop assistants and nurses. Incomes plummeted for many families if the man was the main breadwinner and could not work or passed away. Some had rent to find. As Muna explained, some households in low socio-economic bracket only had one phone in the house. They would have had to share it. Those who needed foodbanks suffered because ‘the foodbanks were not enough. Families were only allowed to visit some of them four times.’<sup>55</sup>

Many had little savings to fall back on (if any), having endured long-term financial hardships since the 1970s. Some of the elderly recalled the importance of accessing services at the Seamen’s hostel due to being thrown into dire straits after the decline of the dock industry. Mohammed remembered many of his peers accessing their services when they became homeless. As they got older, they found it harder to access work and housing, and developed mental health issues.<sup>56</sup> However, in the East End, the impact of years of austerity led to cuts to public services, carers provision, and mobility supplements. Additionally, the recent benefits system overhaul (with the introduction of the Universal Credit) has created a perfect storm of worsening social deprivation. Many families were already shouldering financial shortfalls well before the pandemic with very little capacity to withstand further financial shocks. Their ‘fragile incomes’ were a direct consequence of changes in the benefit and social care system. Dhibla, who is disabled and lives with her four children, had her care package cut by six hours during the pandemic and then ‘without her knowledge a further five hours was reduced’.<sup>57</sup>

Many had no choice but to keep working in high-risk jobs, and this was one vector of transmission. Zamzam reported she had to do overnight stays as a carer with recently discharged elderly COVID-19 patients, despite there being no test done on return to the community to confirm they were negative. Many women like Zamzam were also caring for their children during the day when the schools closed and their partners were working.

Many interviewees were on ‘fragile incomes’ directly as a result of their frontline work, creating a vicious circle. Hayat had to keep working as a cleaner to support her son back home in Somaliland, who was looking after his sick father. Moreover, they reported that financial stress was further causing depression. Osob, in her 60s, after bringing up her own children, adopted her brother’s two sons, and has chronic hip and joint pain. She, like others, often feels sad because of the ‘poverty struggle and the teenagers with nothing to do on the streets’.<sup>58</sup>

<sup>55</sup> Interview 20.

<sup>56</sup> Interview 3.

<sup>57</sup> Interview 7.

<sup>58</sup> Interview 16.

The rapid switch by the NHS to online or telephone consultations was particularly challenging for low socio-economic communities. Two major aspects to this were limited IT skills and limited online facilities at home. ‘I don’t have IT skills and struggled with online. My friends who usually help me were self-isolating so at times I felt alone’.<sup>59</sup> This was experienced by women of all age groups, not just the elderly. Sadia was unable to do online booking without her children helping her. Some reported difficulty in accessing appointments and information. Some reported they were not told there were changes in how to request to see a doctor. One woman had to keep calling on behalf of her daughter. She was given a link but that did not work for her.<sup>60</sup>

#### 4. Being elderly

The prior health service neglect and isolation of many elderly Somalis was also a factor increasing and sustaining virus vulnerability. ‘The elders didn’t understand the severity of it if they did not have anyone to explain it’, explained Bashir, ‘and a high number of our parents have high blood pressure and so on making them high risk. Day after day at the start I heard this elderly person had passed away. That person has passed away the day after. Then in just 24 hours my father passed away. How did this happen I asked.’<sup>61</sup> Abira reported that, ‘there is limited services for elderly women in Tower Hamlets’, and that her mother ‘wasn’t listened to’ when she had COVID-19 symptoms. Two weeks later she died in the hospital.<sup>62</sup> Mohammed who had lost many of his retired ex-seamen friends to COVID-19 argued that only an increase in Somali medical staff would prevent this from happening again, ‘to assist older people like me with language and cultural barriers’.<sup>63</sup>

Many respondents stressed how the elders were affected badly with ‘no connection to community services and accessing information’.<sup>64</sup> Some were left lonely, isolated and with limited food, often not knowing about community initiatives as they were not IT literate and could not attend webinars or have social media accounts where most of the information on community initiatives was being shared during the pandemic. As Bashir explained, ‘Elders particularly distrusted hospitals before but with the rumours of people dying they became very anxious about being on their own. I would always go with my father to see the doctor. He knew Somalis tend to be looked down on because of knife crime and people’s lack of understanding about the community.’ ‘People, not just the elderly, distrust the system’, added Dirie.<sup>65</sup>

Evidence suggests other non-technical barriers to engaging with the NHS. One was no previous experience of using it or a negative previous experience. Many elderly respondents or their children recorded how they would never go to a doctor or a hospital ordinarily unless it was absolutely necessary. ‘My grandfather did not want to go to hospital even after he got sick with COVID-19. He had poor experience with hospitals. He would stay away from doctors and the NHS. He denied

<sup>59</sup> Interview 1A.

<sup>60</sup> Interview 7.

<sup>61</sup> Interview 13.

<sup>62</sup> Interview 3.

<sup>63</sup> Interview 3.

<sup>64</sup> Interview 16.

<sup>65</sup> Interview 14. With an increasing ageing population, the impact of a lack of elderly health care can only get worse The Centre for Aging Better has calculated that in 20 years’ time, one in four people will be over 65.

the virus was serious to start with and would never have gotten vaccinated.’<sup>66</sup> Some say the longer they live in the UK, the more likely they are to call a GP if they are worried about anything, perhaps reflecting the way in which the horn of Africa doesn’t have established primary care services

The paucity of Somali GPs was an added issue: ‘I have never seen a Somali GP. For example, Mohammed insisted he would never have gone to the hospital with COVID-19 had he not had ‘access to a Somali-speaking GP’. ‘This’, he explained, ‘made all the difference’, and stopped him from listening to ‘fake news going around that people were not to go in, as patients were dying on the hospital floor with no access to family members’.<sup>67</sup> ‘My Somali GP did videos in Somali helping us understand COVID-19 better’.<sup>68</sup> Jawahir, a mother of three in her 40s, echoed the widespread sentiments of interviewed Somali women: ‘It would have helped to have access to trained Somali medical professionals for advice’. She added that, ‘I have never visited or been treated by a Somali GP or health worker’.<sup>69</sup> Hayat confessed that throughout lockdown, ‘I was dreading having a phone call with a doctor as I usually have a Somali translator at the medical centre or I bring my own if not available.’<sup>70</sup> She and her group of female friends on WhatsApp got around this by getting access to informal information from trained Somali professionals on Facebook. This was crucial to enabling her to understand complex terms in her mother tongue. A few did say communication was getting better. Some were extremely grateful for the healthcare. Mohammed, who has type 2 diabetes, hypertension, depression, kidney stones, cataracts and prostate cancer, suggested successful treatment through having easy access and dialogue with his GP. He is grateful for living in Britain, the NHS and to the medical staff who have helped him.

## 5. NHS barriers and racism

Nevertheless, the issue of NHS access for Somalis was a recurring theme. The language barrier in accessing medical help was raised almost universally, often on behalf of the elderly or a parent. Over half of all respondents recorded issues with dealing with receptionists or in reception areas. ‘There are no Somali speaking receptionists’, was a repeated criticism. ‘They speak too fast’, and at least if you see them in person, you can read their body language. A common barrier was navigating a receptionist on the phone. Talking about her and her father’s experiences, Hawalin explained, ‘There’s a lack of Somali interpreters to access the NHS but once they book you an interpreter the GP is helpful but the services in Tower Hamlets need to have Somalis in mind. Often this isn’t relevant like at reception desks.’

Others tell of relatives always spending hours in waiting rooms for their appointments as they ‘couldn’t read the digital appointment sign and missed their slot due to language barriers. More Somali receptionists would have helped as we have an oral culture and many don’t read in any language’.<sup>71</sup>

<sup>66</sup> Interview 5. He later died of covid.

<sup>67</sup> Interview 3.

<sup>68</sup> Interview 4.

<sup>69</sup> Interview 15.

<sup>70</sup> Interview 17.

<sup>71</sup> Interview 3.

However, Sadia would go to her GP nine times out of ten. ‘I was lucky. My own GP speaks Somali so was able to help me. I was able to have video calls during the pandemic. ‘There aren’t so many Somali speakers. I just wish there were more on reception and at the hospital’.<sup>72</sup> Some elderly interviewees remarked they could not understand because of the poor English of others and that the NHS ‘had a lot of foreigners’.

Many admitted language had always been a barrier to getting healthcare. ‘I can’t speak English well and have never been able to give feedback to any service. This is the first time I have been included in feedback or research.’<sup>73</sup> Suleka’s mother only speaks Somali and ‘she would have benefited from public health information that was language specific’.<sup>74</sup> ‘I know’, admitted Osob, ‘I would probably have better and easier access to health services if I could speak for myself fully in good English.’ She uses basic phrases and gestures to ‘get by’, but she feels ‘there are some things I am not saying to an interpreter.’ Significantly, a common view was a belief that in relation to *other ethnic minorities*, the health service has ‘less Somali focused community health initiatives and more racism affecting access to services’.<sup>75</sup>

Racism as a barrier to accessing healthcare was cited directly by many. Bashir discussed ‘structural racism’ within the police, the council, while making a FOI request or the NHS. ‘People distrust the system; they are always apprehensive. I know people who for that reason, if they can, go to Germany for healthcare. When people died early on in hospital and there was no communication, that fuelled the distrust already there’.<sup>76</sup> Dhibla explains how, as a wheelchair user and being Somali, she faces racial and verbal abuse. She feels she ‘sticks out like a target’.<sup>77</sup> She is repeatedly the subject of hate speak – ‘a sponger’ or ‘go back home’. Abira articulated that how society views Somalis is an inhibiting factor when approaching the NHS: ‘they are going to kill me as a Somali’; ‘because I am Somali they might kill me’. It was a view expressed by a quarter of interviewees.<sup>78</sup> Osob’s remarks reflect what many conveyed: ‘I have met individuals in medical centres and at hospital appointments who seem not very nice. It crosses my mind sometimes that they may not like Somali or black people.’<sup>79</sup> Even Somali trained medical workers speak of experiencing racism within the NHS.<sup>80</sup>

Microaggressions were commonly reported on a person-to-person basis. Hayat commented on her experiences with staff at medical centres. ‘I have sensed they might be racist in the past’, she says and ‘this can make me feel uneasy. Are they racist or just having a bad day, I always wonder. God knows.’<sup>81</sup> Hodan tells of a GP surgery in the area saying it was full but people believed ‘they didn’t want to register Somalis anymore’.<sup>82</sup> It may well have been the case the practice was full (practices are seldom allowed to close their lists by the commissioning groups or GP federations they belong to). But the way racism is identified or how people feel badly treated is indicative of a

<sup>72</sup> Interview 4.

<sup>73</sup> Interview 4.

<sup>74</sup> Interview 8. For many there are the same issues as in the mainstream: not enough time in an appointment when you get one. If you have multiple health problems, as many have, then they find time is too short.

<sup>75</sup> Interview 4.

<sup>76</sup> Interview 13.

<sup>77</sup> Interview 6.

<sup>78</sup> Interview 3; Interview 6.

<sup>79</sup> Interview 16.

<sup>80</sup> For an insight into the wider problem affecting staff at all levels in the NHS, see Babla *et. al.* (2021).

<sup>81</sup> Interview 17.

<sup>82</sup> Interview 18.



disconnect on a deeper level. Perceived racism, including from other minority communities employed in the NHS, from South Asia for example, can be as detrimental as actual racism in creating barriers to healthcare (Stanley *et al.* 2019).

## The role of cultural and local factors

This research found the role of East End Somali culture in exposure to COVID-19 and transmission were lesser contributing factors. Anecdotal evidence and some of this research suggests that cultural responses in some places likely spread the virus and made some people more vulnerable to infection. Some respondents admitted they had not been worried initially by the news of the virus and its impact, since it would be God's will whatever happened, and that Allah would protect them. 'We sometimes downplay things until it's too late as a community', was a general verdict. There was some evidence that this may have led to laxity from men socialising at the start of the pandemic. 'Men carried on going to cafes' in some places, confided Fatima. 'One woman I know rang the police to tell them men were congregating in a shisha bar. I thought "yeah, go girl"'.<sup>83</sup>

Another potential vector was the cultural response to death. The mourning tradition is very communal with relatives and friends visiting to comfort the bereaved. With high number of deaths at the start, meeting up to grieve and turning up in family homes continued, according to some interviewees. To attend in-person or to 'mourn from the phone' sparked many arguments, dividing some, before it became more acceptable to set up WhatsApp groups or speak on the phone. 'The way we Somalis socialise in groups, inside and usually talk in close contact', remarked Hodan, 'made it difficult for many to adapt to COVID-19 restrictions ... also I know our people sometimes downplay our symptoms ... we have a stigma problem which means people can be less honest about health issues'.<sup>84</sup>

Yet, outweighing these negative culture-based impacts feeding into a disproportionate impact of COVID-19 particularly early on, was evidence of the much wider positive impacts of other cultural responses, which helped mitigate the impact of some of the factors raised in the first two sections of this paper. Long-established Somali cultural hubs such as the Seaman's Day Centre proved a lifeline to the elders. Other established and well-respected community organisations were also well-placed to swing into action. Some diverted funds into supplying food. Many became active in explaining the virus, translating the guidelines into Somali and above all, addressing fake news. 'When we saw the community was being influenced by misinformation', said Bashir 'we stepped in to explain, translate and inform'. As Dirie explained, many people had no previous engagement with the health system and there was distrust fuelled by the high death rates in hospital and no communication. Community organisations that had respect and presence were turned to, and they functioned as bridge between the community and the health sector in some cases.<sup>85</sup> We became 'community health champions', using social media to communicate in Somali, making sure the elders did not fall through the net, and collecting data about what has happening on the ground. Other local responses included writing and recording language-specific public health information from Somali speakers and trained Somali health practitioners that existed, which was

<sup>83</sup> Interview 15.

<sup>84</sup> Interview 18.

<sup>85</sup> For example, Coffee Afrique (2021) organised vaccination pop-up clinics. Another respected community organisation functioning as an information hub and lifeline for many in Brent was SAAFI.

done in Tower Hamlets and the wider East end including neighbouring Newham. On balance, the past neglect and distrust of ‘the system’ has fostered coping mechanisms based on operating as a group to survive – ‘we only have each other’ and ‘we go at it alone’ – which undoubtedly prevented the first wave impact from becoming more deadly.

## Mental health

Finally, evidence gathered in this research suggests the first lockdown’s negative impact on mental health was experienced much earlier and with more intensity. Nearly half of respondents mentioned concerns about this and lack of treatment. Family members soon struggled with mental health, said Osob. For example, one of Osob’s nieces lost custody of her children due to a mental health breakdown. Nasir struggled to get talking therapies in Somali. He suffered with PTSD from the civil war and was living in an overcrowded hostel in Tower hamlets. He remarked, ‘I constantly worried about getting COVID-19. I have no one other than my mother and siblings to talk to. The pandemic has made it harder as there are longer waiting lists for everything’.<sup>86</sup>

Tower Hamlets is considered a borough with high levels of mental illness. During 2014-2019 the then Tower Hamlets Commissioning Care Group (North East London CCG as of April 2021 and NHS East London July 2022) had reported on their website<sup>132</sup> that Tower Hamlets has the fourth highest proportion of people with depression in London, as well as the fourth highest rates of patients presenting to their GP for the first time with symptoms of psychosis. Tower Hamlets also has the highest rates of psychosis in east London, according to GP registers. A Somali-speaking therapist was difficult to access or not available at all for patients in Tower Hamlets.

Sulekha experienced a lack of specialist health services for Somali young people first-hand. She is in her 20s and became very anxious during the pandemic but could not access the talking therapies.<sup>87</sup> Elba, who is 28 and unemployed, repeated that there was a lack of mental health services for Somali patients. Having mental health problems herself from FGM and PTSD, she has always felt unable to connect with the therapy services in Tower Hamlets.<sup>88</sup> Mowlid, in his 50s has a brother with mental health problems. ‘There is no Somali-speaking therapists in the borough and he has been in and out of hospital with poor mental health’.<sup>89</sup> Jawahir talked of hearing of some stories about ‘lack of trust for medical professionals in talking about anxiety and depression.’ She explained how there are concerns that, ‘the children will be taken into care if they [parents/guardians] reveal their issue to GP or health workers.’<sup>90</sup> Osob tells of how she has ‘not had a good service from the mental health department in my area.’ Her adopted teenage son needed support, but she said it came late, was not well thought out. This late reaction and not being proactive may have contributed to his breakdown: ‘I think they are quick to deem a young man aggressive.’<sup>91</sup>

<sup>86</sup> Interview 19A.

<sup>87</sup> Interview 7.

<sup>88</sup> Interview 9.

<sup>89</sup> Interview 10.

<sup>90</sup> Interview 15.

<sup>91</sup> Interview 16.

## Discussion

This raw data offers a number of important insights into healthcare and a minoritised community. First, the role of practical barriers. The operational protocols of healthcare facilities, such as opening times and referral pathways in some cases, did not serve the Somali community as well as they had hoped. This was compounded by limited language skills of elderly and vulnerable Somalis, not having language specific public health information, lack of specialist mental health services, inadequate social care packages, difficulties navigating the changes in the benefits system and low levels of IT literacy to access the change to online services.

Secondly, a lack of trust, from perceived or actual racism, of local healthcare services and in the NHS in general. A triad of a lack of consistency, compassion and transparency, each one had a mix of top-down and bottom-up factors. There was a belief that services on the ground were overwhelmed, closed and/or not welcoming of Somalis. This compounded the physical changes to appointment booking systems to online and facility closures. Government public health policy being inconsistent and/or not properly communicated to patients in a timely manner was given as a reason for a lack of trust. Also, a lack of compassion from frontline staff had been reported from inpatients on hospital wards creating an obvious cause of lack of trust in the short term. A top-down more insidious cause attributed was a longer-term lack of interest taken in understanding the community in general before the pandemic. This included a lack of acknowledgment or research of pre-existing vulnerabilities and health concerns in the Somali community when devising public health policy.

Distrust worsened for those in authority following conflicting testing arrangements and public health messaging about masks in the first wave, and governmental delays in addressing the claims of disproportionate numbers of BAME deaths. Trust itself can now be considered a social determinant of health, especially in BAME communities. Recognising this, in April 2021 the Government set up the NHS race and health observatory to research and recommend improvement to ethnic health inequities, including trust, but this requires long-term transformational change not just within the NHS (Naqvi & Chinembiri 2022).

Thirdly, vulnerability to COVID-19, mental health and economic inequity are interlinked. Poor health more generally and COVID-19 more specifically, increased acute illnesses and also worsened symptoms of COVID-19 lasting more the 12 weeks, known colloquially as ‘Long Covid’ (Department of Health and Social Care 2021). This in turn affected people’s ability to be gainfully employed and thus impacts people’s sense of wellbeing and mental health, in turn increasing those deemed ‘economically inactive’ (ONS 2022). More GP support is needed. But deprived areas like the East End often receive less funding for healthcare despite greater needs. This was termed the ‘inverse care law’ by Julian Tudor-Hart (1971). A recent study by Nussbaum *et al.* (2021) concluded that the gap between the number of GPs per patient in richer and poorer parts of England is widening. Nationally, the number of GPs per patient has fallen for all practices, but has deteriorated most in deprived areas since 2015. In the case of mental health, this can have a huge, hidden cost, keeping people economically inactive, but also increasing their risk of related physical illnesses such as diabetes and obesity (Avila *et al.* 2015).

Narrowing health inequalities requires a culturally sensitive, and as Abdulkadir Mohamed Ali (2020) noted, a bespoke approach ‘to build up future resilience for the Somali community’. This is a long-term goal and needs multi-agency collaboration. With this in mind, this preliminary research became the basis of a training webinar in November 2021 with health and social care staff in

Tower Hamlets. Challenges faced were multi-factorial in origin, such as longstanding lack of funding, but a consensus emerged that future policies needed to be sensitive to three factors: the long-term history of this particular community in terms of health disadvantages; their specific cultural and circumstantial challenges to engaging with mainstream emergency and routine health directives; and the range of highly individual responses within such communities.

This research suggests that these are more likely to be surmounted, through the training and funding of more British Somali healthcare workers from receptionists to GPs, nurses and mental health workers from their local communities if possible, in this case the East End, and working with respected community groups with a track record in advocacy and data collection through evidence-based partnership models.

Future bespoke services especially in primary care would require more Somali people in patient participation groups, so they can help practices connect better with the Somali community. Additionally, they can also aid in the creation of more research on the Somali patient journey through the NHS from primary care and beyond, examining barriers to healthcare, and looking at the intersecting identities of being vulnerable, Muslim, Somali, black. It is imperative for local councils and integrated care boards in diverse areas like the East End to have Somali as a separate ethnic category in all data collection.

Another positive lead came from evidence of how social media enabled the support of its local multi-generational families, including quick and direct responses to vaccine hesitancy that resonate with local people. WhatsApp and Zoom were used to share information on topics ranging from mental health to money advice (Ala *et al.* 2021).<sup>92</sup> Support for learning English would reduce the cost of translators and increase agency over health. It is crucial if sensitive or stigmatising issues like mental health or domestic violence are to become less silenced. In the case of Somalis, coming forward for help is often curtailed by fear of being ostracised from the community and of how they would be treated by the authorities from what many see as an increasingly hostile political environment to immigrants.

Finally, this research suggests how the effect of trauma needs to be mitigated. ‘The refugee legacy’ has been postulated by Yusuf Sheik Omar (2020). In conversation with Mohamed Ismail, Omar listed cultural factors, poverty, the refugee legacy, rumours and frontline occupations. Aweys O Mohamoud studied Somalis growing up in Britain a decade ago and found a ‘culture of disadvantage’.<sup>93</sup> Adding to racism, Islamophobia strengthens the case for Trauma-Informed Practice. This is grounded in an understanding of and responsiveness to the impact of trauma that emphasises physical, psychological, and emotional safety for everyone, and that creates opportunities for survivors to rebuild a sense of control and empowerment (Hopper *et al.* 2010). The evidence base for Trauma-Informed Practice is increasing, especially from its success in other countries.

This research provides some evidence on reported COVID-19 experiences including themes of perceived racism in the NHS, the role of poverty, deprivation and generational factors in the higher rate of BAME deaths from COVID-19 reported in the ONS statistics. However, more research is required to tease out the nuances, such as the extent to which each of the factors plays a role in morbidity and mortality more generally, to help plan for future public health policy. For instance, more research is required on the specific and distinct contributions of the different streams of fragile

<sup>92</sup> Work has started in this area.

<sup>93</sup> House of Commons debate pack, Number CDP-0140 (2021) by David Torrance, Sally Lipscombe, Douglas Piper, Yago Zayed, Paul Little, 8 September 2021.

incomes and the intersection of multi-generational living and of overcrowded accommodation in the generation of housing inequity. These factors are more broadly referred to as ‘the social determinants of health’ and have been extensively researched. Sir Michael Marmot (2006), in his report to the World Health Organization found life expectancy is shorter and most diseases are more common further down the social ladder: ironically his report was updated and republished a month before the pandemic broke out.

Additional frameworks for improving healthcare have long been available (Williams 2012b). Moreover, the Health and Care Act 2022 created statutory integrated care systems (ICSs) in every part of the country, as recommended by NHS England. This included the establishment of integrated care boards (ICBs) and integrated care partnerships (ICPs) in July 2022 (NHS England 2022). The change from health focused clinical commissioning groups (CCGs) to ICBs in England (integrated care boards) offers a substantial opportunity to narrow health inequity by utilising multi-agency working, including local authority, public health, community and voluntary sector, as well as health (primary care and secondary care).

## Conclusion

This micro-case study has revealed how the Somali community in the East End was acutely affected by governmental, public health and institutional shortcomings such as the late lockdown. Secondly, high infection and death rates lasted longer due to the intersection of historic socio-economic and health inequalities that include racism. The impact on mental health has also been dramatically worsened. Whilst specific cultural norms may have increased exposure (such as multi-generational living and a word-of-mouth style of communication), overall community responses on the ground helped to mitigate the dire situation many found themselves in. Finally, suggestions were made about effective, locally-tailored strategies for reducing health inequalities, reducing barriers and racism in the NHS, addressing cultural barriers and the social determinants of health.

For many Somalis living in the East End, the COVID-19 pandemic was a perfect storm that severely tested and sometimes shattered their coping mechanisms and halted the masking of their underlying precarious health. For some, the experience of COVID-19 has had some positives. Quite a few women reported an increased awareness concerning their wellbeing and diet. Additionally, the huge impact of Somali trained GPs and health practitioners has been highlighted and the crucial intermediary role of community champions and cultural hubs. However, overall, many families are still struggling and living in fear of the future, especially as we embark on a chapter of domestic and global economic recession post pandemic and concern over the fall in living standards this will bring.

Ironically, the first major research on poverty in Tower Hamlets was carried out in the 1880s by social policy pioneer Charles Booth (1887). A Booth-like approach to gathering clinical research data on poverty and related health vulnerabilities is overdue (Getachew *et al.* 2021). It offers great hope for the future provision of bespoke, culturally competent, accessible, good quality healthcare for the most vulnerable and disadvantaged in society and could lead to a paradigm shift in healthcare standards resulting in health gains for society as a whole.

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