

COVID-19 and Long Term Health Conditions: Interaction with Ethnicity and Migration

Summary of Findings

This research explores the impact of the COVID-19 pandemic on people with long-term health conditions and how this has interacted with ethnicity and migration experiences in particular, through 34 semi-structured interviews, predominantly with participants from an Asian or Asian British background. This research was conducted with the support of UCL as part of the wider CICADA-ME study which was funded by the National Institute for Health and Social Care (project NIHR132914). This report documents:

- Strategies for health management (Chapter 1) and within this, the impact of the pandemic, which predominantly had a negative influence on participants' health and wellbeing (Chapter 2);
- Experiences of support – from professionals (Chapter 3) and from participants' wider social networks (Chapter 4);
- How the pandemic has been used by contributors to re-evaluate their experiences, life, learning and possibilities for the future (Recommendations).

1 Experience of long term health conditions



“How do you find a balance because you’re fighting with two things at the same time - your mental and your physical state you know?” (I49)

- Participants in this study experienced a variety of long term health conditions, most commonly diabetes, high blood pressure and mental health conditions, and most (56%) were managing multiple health conditions. Participants were at different stages of understanding, diagnosis and management of their conditions, which affected their experience. They were affected by loss of function and strength, effect on energy levels, and for some, how they processed the world around them.
- Independently, participants managed their conditions through medication, understanding symptoms and preparing for crises, lifestyle changes, managing stress and energy levels and practical problem-solving.

- The environment supported and hindered these independent strategies in a variety of ways: offering (or not offering) therapeutic experiences, access to services, appropriate space at home, and confidence in moving outside the home.
- Participants discussed the health conditions particularly faced by the Asian community, such as diabetes and hypertension, and the feeling that treatment pathways for these were less clear or streamlined than for other conditions such as HIV+. In managing conditions, there were several experiences of healthcare professionals who had made assumptions about a diagnosis based on cultural background; different feelings of safety in the local area and a positive association with holistic medicine.

2 Impact of the pandemic

- Three quarters of participants said that their health deteriorated during the pandemic. All interviewees with diabetes thought that their diabetes was harder to control, whilst many contributors reported increased anxiety and depression. Many participants' experiences were of an increased demand on themselves and a removal of existing support.
- The majority of interviewees followed the government guidance despite a range of impacts to their physical and mental health. Fear was a powerful motivator for behaviour, plus the awareness for many that they and the people they cared about were particularly vulnerable to COVID-19's adverse impacts.
- For those with limited energy, changes in commitments took a toll on their health, whilst those with stress-related conditions were especially affected by the uncertainty and family conditions. Reduced physical activity affected mobility, blood sugar and physical health.
- There is some evidence that the more general impacts, such as disruption to supplies and increased loneliness, were exacerbated in this population due to shielding or similar precautions.
- Participants saw these impacts within the context of a whole community struggling, often commenting on the impact of the COVID-19 pandemic to the Bangladeshi community in Tower Hamlets.

“I know how hard I had to work through this whole year just to make me this stable.”
(I25)

3 Support from “professionals”

“So for me, whatever attempt or engagement with the system works well because I say. I know what to ask, I know what to do.... [but my parents-in-law] cannot speak up for themselves, they don't get anything. And there is no one there.” (I4)

- Health and social care support was understood to be in a system providing a range of specific services, from medical expertise to practical support. Participants valued speed and coordination within this system, which was evident within some pathways of care. Most often, however, contributors discussed delays to appointments.
- There were three specific impacts of the pandemic on service provision: widespread service closures and backlogs, leaving participants stuck “in limbo”; the increasing use

of phone or online consultation and communication, with mixed consequences for participants; and the reorganisation and movement of some services.

- Access to this system was often through general practice, social services and crisis services. Participants shared stories of difficulties in access, often due to the volume of demand, criteria employed and routes open to them into the system.
- When discussing interactions with professionals, problem-solving, expertise, care and respect, humanity and flexibility were valued.
- Within this framing of professionalised support, who can and cannot access the system became particularly important. People who were most likely to get the support they wanted had help with advocacy, knew their own health and sometimes had to go to extreme lengths to connect different services and correct mistakes made by professionals. People recently moved to the UK, with English as a second language, were especially vulnerable to being left out of service provision.
- Awareness of ethnicity was present in participants' treatment by professionals, particularly in professionals dismissing their opinion and experience.



4 Wider community support

“I think [for] emotional needs it’s quite difficult to ask for help. I mean social support, physical support is easier and personal emotional support, it’s very challenging.” (I34)

- Support outside of professional health and social care organisations largely came from family, close friends and sometimes neighbours, with some powerful examples of informal peer support and support from community organisations and groups.
- These interactions could provide transformative, long-term support but participants were also cautious about the expectations they could place on these supports, especially around providing emotional reassurance. Many relationships had changed through the pandemic and participants often spoke about being unsure about how they would change again as restrictions lifted.
- Community groups, from activity sessions to training to peer support, could play a large role in the interviewee’s life and be a major support to their health and wellbeing through building new skills, improving mood, building a new network and supporting a healthy lifestyle such as with exercise.
- Many community groups and community centres had closed or moved online during the pandemic. Online and phone communication worked even less well for this kind of support.
- Participants focused on the role of culture and sense of community in this wider support. They expressed the large community network existent in the Bangladeshi community, which brought with it a reservoir of practical support, but also in turn a network of demands on their own time and energy.

What does it mean to be in control of your health?

This research has explored the many ways people felt out of control of their health in the unusual and disruptive circumstance of the pandemic – and how they then coped. The strategies they could rely on included self-management, advocacy for their needs, learning, practical support from community, building networks and problem-solving with professionals. There is much potential for building on these supports. From participants' experiences, it is clear that the collective health of society has suffered and that health and social care systems face an ongoing challenge of capacity. In the face of this, turning towards solutions is even more vital.

When asked about the impact of ethnicity rather than disability or illness on their experiences, participants responded in two ways: one group stated that ethnicity played no part in their stories, particularly in what they saw as a “diverse” and “mixed” community of Tower Hamlets; the other had specific examples of different treatment and possibilities based on their own or others' cultural background, ethnicity and country of birth. Explanations of how participants' ethnicity had shaped their experiences ran through each of these themes in nuanced ways; there was particular reflection and concentration on the numerous challenges faced by people moving to the UK.



Recommendations: Anticipating the future

The final section of the longer report explores a range of solutions, with a common theme of inclusion of those who don't have access to supports – particularly due to ethnicity or lack of English – and building empowerment in people with long-term health conditions. There are five categories of recommendations:

- Discover and connect to ways to work outside patient/professional roles.
- Contribute to enabling people to navigate the health and social care system, including connecting people with long-term health conditions to new opportunities.
- Connect discussions about mental and physical health.
- Involve a wider group of people in finding innovative, practical solutions to day-to-day living for people with long-term health conditions.
- Integrate opportunities to anticipate and prevent common needs within the health and social care system.

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For more information about this research report, contact insights@bbbc.org.uk or bbbc.org.uk/insights

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