Talk Listen Change

COVID-19 health inequalities
creating solutions together

Talk, Listen, Change (TLC) COVID-19.

Creating solutions together to tackle health inequalities in Luton: A shorter summary

Why this project?

Covid has hit black, Asian and minority ethnic people much harder.

We know that Covid has affected Pakistani, Bangladeshi and Indian population groups (particularly Pakistani) and also in the black African and black Caribbean community very badly.

The areas of Luton where many of us from these communities live, are also some of the poorer areas of our town.

The aim of the Talk, Listen Change (TLC) project has been to have a conversation among ourselves, learning to communicate with each other and tackling inequality and building solutions together.

University of Bedfordshire

INSTITUTE FOR HEALTH RESEARCH

Luton

When did we undertake the research?

We worked with our team of community researchers and local leaders during 2020 and the spring of 2021 to inform our communities about the research and to encourage residents to take part.

What we did and who took part

The project was led by Luton Council's portfolio holder for Health and Wellbeing and managed by a partnership between Luton Council's Public Health Team, community representatives, voluntary and community sector representatives, representation from the council's Housing Team, Communications and the Social Justice Unit. We also worked with Healthwatch Luton, and the University of Bedfordshire Public Health Faculty.

We held 14 online group conversations with people from wards most affected by COVID-19 (Northwell, Leagrave, Biscot, Dallow, Saints, and South). These are the most ethnically diverse Wards in Luton.

We also held online interviews with community representatives and key workers including healthcare specialists involved in diagnosing, managing and preventing COVID-19.

We ran a community survey in which 1,053 questionnaires were completed online, on paper or face to face.

Our main communities of interest were people who self-identify as Pakistani, Bangladeshi, Indian, black Caribbean or black African, representing different generations, genders, cultural and language groups, and social classes.

All participants were over 16 years old.

What we learned

Understanding how Covid spreads

All who took part in the research said that they had a good understanding of the risk factors, symptoms and transmission of COVID-19 and they said that their understanding had improved over the course of the pandemic.

Risk factors were understood to be underlying health conditions, individual immunity, age and diet and lifestyle.

> ***Yes I do believe that illnesses like obesity and diabetes have a role to play in the death toll being so high because COVID effects those with underlying health issues. As they already have the weak immune system*** (Black African Male).

Symptoms noted included flu like symptoms: cough, and loss of taste, a loss of smell, fever, temperature and diarrhoea.

Participants understood that touching contaminated metal surfaces, being close to someone who tested positive, and air borne germs shared by coughing and sneezing caused Covid to spread.

Some participants argued that the government had delayed and then limited information about symptoms and transmission of Covid, resulting in many people continuing with work and carry out day to day activities, so contributing to rising numbers of cases nationally.

The majority of participants gave examples of how they had tried to limit transmission but also discussed situations they had experienced or witnessed where this could have taken place, for example employment situations which would put individuals at higher risk.

> ***So at the start of COVID Indian communities especially were not socially distancing and were not taking it seriously, you know, massively gathering in lockdown. We did so much work with our community members that we've made friends with all, we've made contacts with them we've got so much messaging out from the radio, to try and instigate but they didn't want to listen a lot of the time. Slowly but surely they have got so much better and I think that is because of information and also that they have had people with COVID, worst case scenario pass away from COVID. That as sad as it sounds and as bad as it is, is the real message isn't it*** (Indian Male Key Worker).

Some explained that cultural pressures often meant that the hands, face, space rule could not be maintained eg when visiting poorly relatives, attending funerals and meeting with family for condolences, greeting with handshakes.

> ***The problem with our community is that they don't I'm really sorry to say but they don't stop visiting each other…luckily they all survived***
> (Black Caribbean Female).

> ***…It is our Pakhtoon way that if we visit Lidl or Sainsbury, we wear mask but as we visit our shops we don't care. So it is our fault***
> (Pakistani Female).

There was extensive discussion of the impact of living in extended families and intergenerational households, for example practical difficulties in sticking to guidelines.

> ***Normally, in terms of living accommodation, we live with our parents, children, husband and wife. In comparison to English people we have a large family. When one person contracts it, then the whole household catches it. When these lot go to other houses, then they give it to others too*** (Bangladeshi Male).

Having to work during lockdowns and particular jobs were considered factors contributing to Covid transmission.

Some participants pointed out that knew people who did not have the confidence to ask employers to follow guidelines set by the government, feeling that they were at risk of losing their jobs if they complained.

Others explained that attending congregational prayers at places of worship had contributed to the transmission.

Some believed that children and young people were contributing to transmission.
The government's decision to open up schools after the first lockdown was mentioned.

Our survey showed that:

Knowledge of how Covid is caught was significantly related to education status.

Types of employment, use of public transport, living in densely populated areas and living in overcrowded accommodation were the highest reasons for the disproportionate impact on some communities.

Wearing facemask, washing hands frequently, avoiding public spaces and avoiding contact with those affected were seen as the best actions to reduce transmission.

Barriers to getting tested for Covid-19 and reasons for vaccine hesitancy

Overall, participants felt that the testing for Covid had worked well once test centres had been established but identified some barriers to members of their communities using the service. These included ease of travel, stigma associated with testing positive, fear of being hospitalised, and hesitancy around testing and vaccines.

Some explained that friends and family living alone had experienced problems getting to test and vaccination centres.

Others explained the role culture plays in putting off seeking help for medical and health issues, giving examples of situations they had seen where people self-medicated and even died at home rather than going to hospital.

The majority explained that they had or would opt to be vaccinated but gave a number of reasons for being unsure within their communities. Explanations centred on accessibility and availability in Luton, doubts about vaccine effectiveness related to the pace at which they had been developed and rolled out, a perceived lack of information about vaccine ingredients, getting Covid after being vaccinated, conspiracy theories and suspicion about government intentions.

> ***I didn't get the vaccination. Every new medicine or vaccination needs more trials and enough time to investigate and compare the pros and cons. At the moment scientists are only focusing on the benefits but the disadvantages will surface later times. I believe that these vaccinations are new and I think they didn't get many trials. I booked an appointment to get the vaccination but I couldn't make it due to an urgent trip. I postponed it again due to Ramadan. After that, some of the research from European studies came out and I postponed it until further studies. Three members of my family got vaccinations*** (Somali Female).

Most of participants said concerns about the vaccine had reduced over time as new information emerged, and was supported by respected members of their community, often through videos on social media.

Some participants said that their communities would be more inclined to be vaccinated if they needed to travel internationally.

Covid information and community action

Participants explained that they got Covid information from various places, for example the government, NHS and council websites, schools, news channels, the internet, staff intranets, leaflets from local community organisations, community and religious leaders such as imams and mosques, pastors and churches and Mandirs and Gurdwaras and Giyani.

Some Muslim participants mentioned mosque radio programmes transmitted directly to congregations, community radio stations, and informal networks such as WhatsApp groups, from family, particularly younger members of families fluent in English and friends.

There was overall agreement that Covid information was accessible and acceptable but mainly for people with a good level of English language.

Some participants explained that sticking to guidelines was not consistent within communities, extended facilities and even friendship groups. It was made more difficult in multigenerational households where older members of the family, for example grandparents carried out child minding for working children, households with key workers and people living alone who needed to leave the house for food and medicine.

Informal networks

All participants discussed informal community networks and how they had been useful for sharing Covid information, especially for members of the community who had a poorer level of English language. Participants discussed the reliance on information circulated through 'trusted' community media channels, community organisations and by religious figureheads.

Many acknowledged that communities had mobilised to support vulnerable members but explained that they did not have the resources to reach all of them. They expressed disappointment that the government had not done more to support the most isolated and marginalised within their communities.

There was discussion about misinformation, particularly on social media, relating to vaccination.

Feeling targeted

Some people felt 'targeted' by media reports during the lockdowns. They explained that negative messages 'blaming' Black, Asian and minority people for increasing numbers of Covid cases spilled out on social media and workplaces. They acknowledged that not all members of their communities were following the rules but that they had also witnessed the general public flouting them.

> ***You know where I live it's a predominantly white area, I was in a group in the community, people were saying things like look oh it's in the minorities. It's them they are putting us in the lockdown because they are visiting each other. I had to get off the group because it was so upsetting. I was like when you guys were at the beaches, nobody said anything. As soon as it's the black people or Asians visiting they were blaming us. We are going to go into another lockdown because of you people, because you guys can't stop visiting each other*** (Black Caribbean Female).

Impact on mental health

All of our participants knew of friends or extended or immediate family members who had caught Covid and almost all had either lost someone or knew someone who had lost friends or family.

Discussions focused on the effect of loneliness and isolation on mental health in communities but especially the elderly, children and young people, bereaved members of the community and those supporting bereaved families with last rites.

Participants said that there was a lack of understanding on how to recognise and support someone experiencing mental health in all communities. Muslim participants explained that mental illness was rarely acknowledged and often attributed to black magic or the evil eye.

> ***I think there's a lack, there's a major lack of education on how to help somebody with mental health issues or the signs, but cos there's no education we don't know how to help. Mainly I think more cultural otherwise somebody with mental health issues you sort of tend to stay away from them*** (Bangladeshi Female).

Participants said that lack of face to face contact with members of the family and GPs was a significant factor in poorer mental health, especially for elderly.

The role of religion as a coping strategy

Some participants spoke about communities feeling protected against Covid by God but overall, religion was discussed as a coping strategy for managing Covid.

Our community survey indicated that the most common barrier to getting tested was lack of transport.

Participants also claimed a lack of understanding of what to do. English fluency was an issue. Fear of possible pain or discomfort also put them off.

Most participants said that they would have the vaccine if given safety, if it protected the wider community, or if it was a requirement for work. Fewer than 9% stated that they would definitely not accept the vaccine.

Participants who were Indian were significantly more likely to definitely accept the vaccine with black African and Kashmiri more likely to definitely not accept the vaccine.

The reasons for not accepting vaccines were found to be mostly related to lack of trust in safety, side effects, a mistrust of government or a perceived lack of need.

More evidence regarding effectiveness and safety would reassure them to have vaccine

Views on how inequalities have influenced the disproportionate impact of Covid

Participants acknowledged that existing wider inequalities experienced in our communities were contributing to the disproportionate impact of Covid.

There was considerable discussion about the types of employment and financial pressures to work during the lockdowns which put some at a higher risk of infection. Some pointed out that many key workers are women, in part-time or low paid employment and live in relative poverty. They did not have the choice to self-isolate.

> ***I think the main reason was Somali people's jobs were at the frontline, mainly bus drivers, taxi drivers, care workers, and similar jobs. They were vulnerable to being infected with the coronavirus. They couldn't work from home…*** (Somali Female).

> ***So look at all these people they are at the front line, and sometimes we're bottom of the system were we have to do the cleaning, we can't sit at home and say look the government is going to give me money, because they don't. They didn't pull through so people had to go to work. We are not the rich community who can sit back and say I've got a bit of money coming in we actually have to work*** (Black Caribbean Female).

Participants pointed out that the initial government guidance and support for key workers was poor and significantly contributed to the disproportionate impact of Covid.

Some participants also argued that Asian business were too relaxed when testing employees because they were concerned about going out of business and did not like spending extra money, for example on sanitisers or temperature guns. So employees that were infected continued to work, unaware that they were transmitting the disease to fellow workers and customers.

Participants also discussed how poor living conditions and overcrowded homes contributed to infection.

> ***So if you look at the housing conditions it is overcrowded compared to some other white folks*** (Bangladeshi Female).

Participants argued that existing high rates of chronic conditions contributed to a higher prevalence of Covid in our communities of interest.

They discussed a lack of vitamin D as a possible reason for the disproportionate impact.

Our participants argued that there was a great deal of community suspicion surrounding the way in which members of their community were treated compared to their white counterparts with Covid, and that there was a lack of confidence to complain.

Some participants also said that South Asians had poorer outcomes because the expertise for managing patients with chronic conditions and Covid was inadequate in hospital.

Community stakeholders who were involved in supporting bereaved families with the last rites expressed anger that bodies arrived at the Mosque morgue without having catheters removed, causing further distress.

Key workers discussed their experiences of working in health and social care during the lockdowns and recounted experiences of discrimination related to being expected to work in unsafe conditions and availability of PPE.

> ***… Yeah, definitely not being listened to maybe. Because as an Asian person maybe there is some kind of, there is racism in place in the NHS, there would be racism where you know you're not taken as seriously as you're white, you know white patients*** (Bangladeshi Female Key Worker).

> ***I think most of those tubes could have been removed. I think I felt that because this individual has no family and maybe they do not understand from then Islamic point of view that why if you are saying you are at risk to remove these, someone is going to remove them*** (Pakistani Key Worker).

Participants discussed access to vaccination centres in the context of access to health care services generally, especially GP surgeries during the lockdowns.

Key workers also discussed the challenges to accessing GP services.

Communicating with communities and tackling inequalities together

Participants highlighted the limited availability of interpreters in hospitals and how this impacted on the hospital experience of patients during the restrictions, where family and friends were not allowed to visit and support with communication between patients and staff.

They discussed the importance of messages being delivered by members of the family, community and religious figureheads and the increased likelihood of sticking to guidelines this way.

Some participants explained that information is transferred orally within our communities rather than by passing on written materials. Participants in FG12 and FG8 discussed the importance of using community and friendship groups to disseminate information.

Some participants mentioned the importance of messages being delivered by members of the family, community and religious representatives and the increased likelihood of adherence to messages.

> ***…the imams have said a bit, you know on the speakers from the mosque to reach out to the elderly. Because a lot of elderly listen to the imam and doctors more than their children. My mum personally is influenced by the imam, she trusts what she hears on the (masjid) mike (transmitter)*** (Bangladeshi Female).

One participant discussed the value of a diverse workforce in meeting the needs of the community it serves, including overcoming language barriers.

Participants discussed social media (WhatsApp groups, Facebook), radio stations and YouTube. These were seen as important mediums for disseminating key messages to our selected communities.

Participants discussed the importance of improving health awareness for self-care, and prevention of chronic conditions.

Participants discussed that messages about health and fitness for prevention of chronic conditions must be supported with facilities that create more equitable opportunities for our selected communities.

Some Muslim female participants argued that there were not enough single-sex exercise facilities available to them in Luton.

> ***…I think the facilities that are available out there it may not be appropriate to go out to exercise in those facilities because they're either mixed or not available. Some places do offer segregation however it may be at an odd time you know they're not busy like eight or nine in the evening…there is a lack of facilities*** (Bangladeshi Female).

One participant explained how she had established a women's wellness group and that she used this platform to share Covid health messages. She also explained that these type of groups could be tapped into by Luton Council.

Many participants pointed out that the TLC project was the first time that they had been asked to engage in a discussion about the health, social and economic inequalities impacting their lives. They welcomed the opportunity and some said that the experience had been cathartic. All participants valued 'being listened to' and suggested that LBC should create more opportunities for dialogue with communities.

Some participants argued that there should be more support from LBC to address wider inequalities

Our community survey results indicate that:

Participants with a lower education level were significantly less likely to have access to computer or internet access or a smartphone.

Participants aged 65 or more were significantly less likely to use internet and social media.

The most regularly used sources (multiple times per day) included WhatsApp (28.4%), national TV (19.3%), family members (17.5%) and friends (16.6%).

Doctors and/or healthcare providers were viewed as the most accurate source of information (33.5%), closely followed by health apps (30.9%).

Participants were asked to what extent they felt the different sources of information raised issues which are relevant to them, their family and their community. The most popular source included national TV (11.1%), health apps (19.0%) and local TV (9.6%). Newspapers and radio were also viewed as relevant sources.

Implications of the project findings and future actions

In this final section of the report we summarise what our communities said and recommend actions which LBC can take to respond and improve engagment, Covid related messages and tackle wider inequalities in health.

Our communities said	We recommend Luton Council
We feel targeted and blamed.	Take a strategic asset /partnership approach. See communities as assets and genuine partners which will create trust. They know the problems and what the solutions are.
We live in multigenerational households and younger people pass on information to elders.	Call on younger members of households, especially those living in multigenerational households, to deliver COVID-19 and health and wellbeing messages.
We need more COVID-19 and health and wellbeing messages in community languages.	Translate written material into community languages but use more social media and audio-visual methods to share health and wellbeing messages.
Use informal support networks to deliver health, exercise and wellbeing messages. A lot of information is passed on by word of mouth.	Recruit and train community members as health and wellbeing champions, tackling issues of health, exercise and overall wellbeing for prevention of chronic diseases. Continue to use the Covid Champions approach.
Use more 'trusted' community media channels, community organisations and religious figureheads to share health, exercise and wellbeing messages.	Have discussions about how to manage cultural pressures around social mixing.
We need more mental health support after Covid.	Develop post Covid community mental health interventions to improve mental health literacy. A targeted mental health intervention to support community elders and children and young people. Improve knowledge of mental health care services in Luton. Engage with religious groups and establishments to discuss ways to address mental health issues and community narratives around witchcraft and black magic.

Our communities said	We recommend Luton Council
We need more exercise opportunities for women and community elders. Use spaces familiar and accessible to us.	Carry out a review of access to good quality sports facilities. Increase visibility and availability of exercise facilities and create affordable opportunities.
We have to work - no choice because we are in low paid jobs.	Increase awareness about the access to financial support for those that need to self-isolate
We need more access to test and trace	More community based access to test and trace e.g. places of worship.
We live in multi- generational households which causes increases in transmission of COVID-19.	Arrange dedicated accommodation where people can self-isolate.
We do not have access to healthcare, we feel we are being discriminated against as employees and patients and we do not feel respected. Diversify the workforce (including LBC) to break down language barriers and understand different cultures.	Review practice and create opportunities for cultural competency and unconscious bias training. Diversify workforce making health and social care services more accessible and respectful.

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Thank you for reading

To find out more please email
public.health@luton.gov.uk

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