Talk, Listen, Change (TLC) COVID-19 co-developing solutions to tackling health inequalities in Luton

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Executive Summary

Background and aim of the project

The disproportionate impact of COVID-19 on the Black, Asian, Minority Ethnic population (BAME)[1] nationally has brought to the fore issues around inequalities. In response to the report on inequalities by Public Health England (PHE), Luton has set an action plan to understand the reasons for the disproportionate impact of COVID-19 on BAME groups and address health inequalities. Within this plan there is a broad action to: 'Work with communities to better understand their needs and co-develop solutions to ensure services meet the needs of the Luton BAME population'.

In Luton, data shows that there has been a disproportionate impact of COVID-19 in the Pakistani, Bangladeshi and Indian population groups (particularly Pakistani) and also in the black African and black Caribbean population. The areas of Luton with the highest numbers of these population groups are also some of the more deprived areas with high rates of health and social care inequalities. The aim of this Talk, Listen Change (TLC) project was to engage in a dialogue with Pakistani, Bangladeshi, Indian black African and black Caribbean community in Luton on their views about the disproportionate impact of COVID-19, tackling health inequalities and co-developing solutions.

This project was commissioned by Luton Borough Council (LBC) to engage in a dialogue (discuss and explore) with Pakistani, Bangladeshi, Indian and the black African and black Caribbean groups in Luton (hereafter referred to as our communities of interest) to better understand their views on the disproportionate rate of COVID-19, the reasons for and impacts of this, how to tackle related health inequalities and co-develop solutions.

This work is part of the work plan of the Health Inequalities Delivery Board, a sub-group of the Health and Wellbeing Board. The findings from this project will be key to informing on-going work of these boards to tackle inequalities in Luton, including the response and resilience to the COVID-19 pandemic. Across Bedfordshire, Luton and Milton Keynes (BLMK) CCG, focused work is also underway to address inequalities and a BLMK Inequalities Board has been established. The findings from the Project will also inform further work undertaken through this group, and provide in-depth insight into the issues in Luton which can be built on through the work at BLMK level.

Aim

The aim was to engage in a dialogue (discuss and explore) with Pakistani, Bangladeshi, Indian and the black African and black Caribbean groups in Luton to better understand their views on the disproportionate rate of COVID-19, the reasons for and impacts of this, how to tackle related health inequalities and co-develop solutions.

[1] BAME is a term that is frequently used in the literature to describe a wide range of individuals, assuming, perhaps, a homogeneity in the experiences of people from different ethnic backgrounds masking inequalities between groups and maintaining white ethnic identity as the dominant privileged norm (Thoburn et al, 2006). We recognise and we argue that BAME communities are not a homogenous group and therefore we have designed this project to focus on the communities that are experiencing a disproportionate impact of COVID-19.

Objectives

The aim was met by achieving the following objectives:

- To discuss and explore views on why Pakistani, Bangladeshi, Indian and the black African and black Caribbean population groups have been disproportionately affected by COVID-19;
- To discuss and ascertain community views on how wider inequalities have impacted on Pakistani, Bangladeshi, Indian and the black African and black Caribbean population groups being disproportionally affected by Covid-19;
- To co-develop solutions to some of the identified issues/barriers;
- To better understand how to communicate with and work with the community to develop shared approaches to tackling inequalities.

Project Design

A mixed methods approach was used to carry out the TLC COVID-19 project.

Who were our participants?
X14 focus groups with people from our communities of interest who were living in the wards most affected by COVID-19 (Northwell, Leagrave, Biscot, Dallow, Saints, and South). These are also the most ethnically diverse Wards in Luton.
X8 interviews with community representatives who were from our communities of interest and were identified by the community living in Luton as representing community views.
X9 interviews with key workers from our communities of interest living in Luton. Key workers were healthcare specialists were people involved in diagnosing, managing and preventing COVID-19.
Community survey: 1053 questionnaires were completed.
Participants were 16+ years old.
Our communities of interest were people who self-identify as Pakistani, Bangladeshi, Indian, black Caribbean or black African and reflected, self-ascribed identities, generational, gender, linguistic, national and social class differences.
Ethical approval was obtained from the University of Bedfordshire Ethics Committee.
All participants were recruited purposively.[2] We created TLC branding for publicity and recruiting participants.
The project took place during the COVID-19 lockdowns and therefore focus group discussions and interviews took place over Zoom, Skype, Microsoft Teams or FaceTime. The community survey was available to complete online and was also disseminated, in some cases interviewer administered and collected by the TLC Community Researchers.

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[2] Purposive sampling refers to prospective study participants being selected based on the particular objectives (or purpose) of the study. The characteristic of the sample should enable the objectives of the study to be met (Ritchie and Lewis, 2012).

The Findings

All discussions were audio-recorded and transcribed. We used the Framework Approach to analyse the focus group discussions and the interviews[3] and the data from the community survey was analysed to provide descriptive and comparative statistics.[4] The open text comments on the community survey were analysed using qualitative content analysis.

Views on the disproportionate impact of COVID-19

Asked about the reasons for the disproportionate impact of COVID-19 on their communities our focus group and interview participants said that:

Views about risk factors, symptoms and transmission

- All participants 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 period of the pandemic.
- Risk factors were identified as: 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 discussed included: flu like symptoms: cough, and loss of taste, a loss of smell, fever, temperature and diarrhoea.
- Transmission was explained using examples of touching contaminated metal surfaces, being close to someone who tested positive, air borne, coughing, sneezing.
- Some participants argued that the Government had delayed and then limited the information related to the symptoms and transmission of COVID-19 resulting in many people continuing with work and carry out their day to day activity which resulted in the rapid transmission of the disease and contributing to rising numbers of COVID-19 cases nationally.
- The majority of participants gave examples of how they had tried to reduce transmission but also discussed situations they had experienced or witnessed where transmission could have taken place contributing to increasing numbers of COVID-19 cases e.g. type of employment which would put individuals at higher personal risk and chance of transmission of COVID-19.

[3] A thematic Framework Analysis approach was used to analyse the data (Ritchie and Spencer, 1995, Mason 2017). This involved a detailed familiarisation of the data, identification of the key themes to form a coding frame, indexing the material according to the coding frame, and interpreting the findings in the context of other research and policy and practice considerations (Silverman, 1993).

[4] Categorical variables for all explanatory variables were analysed using Chi-square Goodness of Fit analysis and Fishers Exact Tests. Adjusted standardised residuals (ASR)'s were calculated to indicate the importance of the cell to the ultimate chi-square value which took account of the overall sample size. Therefore, when reporting the results, the ASR values were used to indicate significance i.e., ASR values of 3.09 (p<.001), 2.6 (p<.01) and 2 (p<.05) will signify significance, with anything below 2 deemed non-significant (p>.05). A binary logistic regression analysis was conducted with socio-demographic variables alongside knowledge of symptoms and transmission entered as explanatory variables. All statistical tests were completed using IBM SPSS Version 27, two-tailed significance was assumed at p<0.05.

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 COVI, 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 participants explained that cultural pressures often meant that the hands, face, space rule could not be maintained e.g. visiting poorly relatives, attending funerals and meeting with family for condolences, greeting with a 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/ intergenerational households on the transmission of COVID-19 e.g. difficulties of adhering to guidelines when living in multi-generational (often overcrowded) households.

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).

- The type of employment/jobs and having to work during the COVID-19 lockdowns was considered a factor contributing to the transmission of COVID-19
- Some participants pointed out that they know of people in the community who did not have the confidence to request employers to follow standard operating procedure (SOPs) set by the Government and also felt they were at risk of losing their jobs if they complained.
- Some participants explained that attending congregational prayers at places of worship had contributed to the transmission of COVID-19.
- Some participants said that children and young people were contributing to COVID-19 transmission. The Governments decision for opening up schools after the first lockdown was also mentioned as a reason for increases in COVID-19

Our community survey indicated that:

- Knowledge of routes of transmission 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 this disproportionate impact

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

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

- Overall participants felt that the testing for COVID-19 had worked well once test centres had been established but identified some barriers to members of their communities accessing the service: travel to test centres, stigma associated with testing positive, fear of being hospitalised, testing for COVID-19 and vaccine hesitancy.
- Some participants explained that friends and family who lived alone had experienced problems getting to the COVID-19 test centres (also the case for COVID-19 vaccinations).
- Some participants explained the role culture plays in contributing for delays in help-seeking and gave examples of situations they had witnessed where people were inclined to self-medicate and in severe cases die at home rather than going to hospital.
- The majority of participants that took part in the interviews and focus groups explained that they had or would opt to be vaccinated but gave a number of reasons for vaccine hesitancy within their communities. Explanation for vaccine hesitancy centred on access and availability of vaccinations in Luton, doubts about the efficacy of the vaccinations which was related to the speed in which vaccines had been developed and rolled out, information about vaccine ingredients, getting COVID-19 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).

- The majority of participants said that concerns about the vaccine had dissipated over time as new information emerged, and was endorsed by respected members of the community through videos on social media.
- Some participants said that their communities would be more inclined to be vaccinated if it became a requirement for international travel.

COVID-19 information/messages and community adherence

- Participants explained that they received COVID-19 related information and messages from various sources: the Government website, NHS website, schools, news channels, the internet, local council website, work staff intranets, leaflets produced by local community organisations, community figureheads, religious figureheads e.g. imams/Mosques, pastors/churches and Mandirs and Gurdwara's/Giyani. Some Muslim participants mentioned Mosque radio programmes that are transmitted directly to their 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 an overall consensus among participants that the COVID-19 information and messages were accessible and acceptable but for participants with a good level of English language fluency.
- Some participants explained that adherence to those messages was not consistent within communities, extended facilities and even friendship groups. Adherence 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 individuals lived alone and needed to leave the house for food supplies and medication.

Informal information and support networks

- All participants discussed informal community networks and how they had been useful for disseminating COVID-19 information and messages especially for members of the community who had poor English language fluency. Participants discussed the reliance on information and messages circulated through 'trusted' community media channels, community organisations and by religious figureheads.
- Participants acknowledged that communities had mobilised to support vulnerable members of their community but explained that they did not have the resources to reach all vulnerable people. Participants expressed disappointment that the Government had not done more to support the most isolated and marginalised within their communities.
- There was discussion about the misinformation circulating particularly on social media related to the vaccination.

Feeling targeted

- Some participants discussed feeling 'targeted' by the media messages during the lockdowns. Participants explained that negative messages 'blaming' BAME groups for increasing numbers of COVID-19 cases spilled out on social media and the workplaces. They acknowledged that not all members of their communities were following the COVID-19 rules but that they had also witnessed the general public flouting the COVID-19 rules.
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> *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 and/or extended or immediate family members who had contracted COVID-19 and almost all participants had either lost someone or knew someone who had lost acquaintances, friends or family to COVID-19.
- Discussions focussed on the effect of loneliness and isolation on the mental health of the community but especially the elderly and children and young people, bereaved members of the community and those supporting bereaved families with last rites.

- Participants discussed 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 usually 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 the lack of face to face access to members of the family and GPs was a significant factor contributing to poor mental health especially for elderly.

The role of religion as a coping strategy

- Some participants spoke about communities feeling protected by God against COVID-19 but overall religion was discussed as a coping strategy for managing COVID-19 outcomes.

Our community survey indicated that:

- The most common barrier to getting tested was reported as accessibility issues (travel and lack of transport).
- Participants also stated a lack of understanding of what to do (instructions/language issues). There were also perceptions of pain/discomfort when testing which put them off.
- 41.5% of participant's stated that they would have the vaccine if they receive information about safety (24.7%), if it protected the wider community (8.9%) or if it is a requirement for work (16.1%). A total of 53 participants (8.9%) stated that they will definitely not accept the vaccine.
- Participants who were Indian were significantly more likely to definitely accept the vaccine ($p<.001$) with black African and Kashmiri more likely to definitely not accept the vaccine.
- The reasons for not accepting vaccine were found to be mostly related to lack of trust in safety /side effects/ mistrust of government, lack of need.
- More evidence regarding effectiveness and safety would reassure them to have vaccine

Views on how the wider inequalities have impacted on the disproportionate impact of COVID-19

Asked about the views on how the wider inequalities have impacted on the disproportionate impact of COVID-19 our focus group and interview participants said:

- Participants acknowledged that existing wider inequalities experienced by our communities of interest was contributing to the disproportionate impact of COVID-19.
- There was considerable discussion on the type of employment and financial pressure to work during the COVID-19 lockdowns which put them at a higher risk of contracting COVID-19. Some participants pointed out that many key workers are women, in part-time employment and in low paid employment and therefore live in relative poverty and did not have the choice or were required to work during the lockdowns rather than self-isolating.

*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-19 on our communities of interest.
- 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 like sanitisers or temperature machine. Consequently employees that were positive continued to work unaware that they had COVID-19 and transmitting the disease to fellow workers and customers.
- Participants discussed how poor living conditions and overcrowded homes contributed to the transmission of COVID-19.

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

- Participants argued that the existing high rates of chronic conditions contributed to the higher prevalence of COVID-19 in our communities of interest.
- Participants discussed a lack of vitamin D in our communities of interest communities as a possible reason for the disproportionate impact of COVID-19.
- 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-19 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-19 was inadequate in hospital.
- Some 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 and explained this caused further distress.
- Key workers discussed their experiences of working in health and social care during the COVID-19 lockdowns and recounted experiences of discrimination related to being expected to work in unsafe conditions and availability of PPE.

… Yeah, defiantly 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 especially GP surgeries during the COVID-19 lockdowns.
- Key workers also discussed some of the challenges to accessing GP services during the lockdowns.

Views on how to communicate with communities and co-develop solutions to tackle inequalities

Asked about their views on how to communicate with communities and co-develop solutions to tackle inequalities our participants said:

Approaches to communicating/delivering messages

- Participants highlighted the limited availability of interpreters in hospitals and how this impacted on the hospital experience of patients during the COVOID-19 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 adherence to messages.
- 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.

More messaging and support for the management of health and lifestyle factors

- Participants discussed the importance of improving health literacy/messages for self-care, health and fitness for 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 disseminate COVID-19 health messages. She also explained that these type of groups could be tapped into by Luton Borough Council.

Creating more opportunities for a dialogue and equitable opportunities

- Many participants pointed out that the 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 lower education were significantly less likely to have access to computer or internet access/smartphone.
- Participants aged 65+ 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 directions which LBC can take to respond to our selected communities and improve engagment, COVID-19 related messages and tackle wider inequalities in health.

Our communities said	We recommend Luton Borough 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.	See 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 disseminate health and wellbeing messages.
Use informal information and support networks and groups to deliver key health, exercise and wellbeing messages. A lot of information is passed on by word of mouth.	Recruit and train community members/representatives as health and wellbeing champions tackling issues of health, exercise and overall wellbeing for prevention of chronic diseases. Continue to use the COVID-19 Champions approach
Use more 'trusted' community media channels, community organisations and religious figureheads to disseminate key health, exercise and wellbeing messages.	Have discussions about how to manage cultural pressures around social mixing.
We need more mental health support post COVID-19.	Develop/introduce a COVID-19 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 pathway/services in Luton. Engage with religious groups and establishments to discuss ways to address mental health issues and the dominate

	community narratives around witchcraft and black magic.
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 on 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 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.