

Summary of key issues raised in a Community Event to discuss Coronavirus and the Impact on People with Protected Characteristics

Unequal impact: a response compiled by ARC South London

There has been widespread concern that the coronavirus pandemic and measures to tackle it are having a disproportionate effect on certain sections of the population, some of whom may already experience health inequalities. To discuss these issues, Dr Josephine Ocloo, research fellow and diversity and inclusion lead and Savi Hensman, Patient and Public Involvement (PPI) coordinator for the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South London, organised a Zoom event on 27 April 2020 to gather evidence on the issues raised by the Women and Equalities Committee in its inquiry on 'Unequal impact: Coronavirus (Covid-19) and the impact on people with protected characteristics'. Madelene Boyton and Flavia Bertini of King's College London assisted. Members of the public were invited to be involved, so that a submission could be prepared to submit to the UK Parliamentary call for evidence. It was hoped that whatever evidence emerged, it could also be used to inform the local strategic priorities of the ARC South London to undertake high-quality applied health and social care research, which leads to improved health and social care outcomes for diverse communities in South London and beyond.

The views and experiences of service users, carers and representatives of community organisations working across the protected characteristics [age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership and pregnancy and maternity] were particularly sought.

Fifty-two people took part, broadly reflecting equal numbers of people from White and BAME communities and representing organisations supporting BAME, LGBT+, disability, older people and pregnant mothers and their babies working mainly living or working in South London. Contributors were invited to share views and experiences in conversation and through the 'chat' function on Zoom and they were also invited to add any points they wished to later by email. Others could not attend but contributed by correspondence and, in addition, one organisation compiled views from some of its users.

Who attended

In addition to King's College London staff, groups and individuals that attended included: Joy Beishon, Healthwatch Greenwich; Sarah McSherry, Kingston Centre for Independent Living; Agatha Anyiwo, Wandsworth Older Peoples Forum; Victoria Cabral, Black Thrive; Tutiette Thomas, elected service user Governor at NHS South London and Maudsley Foundation Trust; Emma Jones, Metro Charity; Lizzie Hewitt, South East Cancer Help Centre; Alan Benson, RUILS, Richmond; Michael Turner, Merton Centre for Independent Living; Mars Lord; Virginia Stuart, local patient; Ruth Oshikanlu; Lania Narjee; Kate Mulley; Hiten Dodhia, Lambeth Council; Natasha Smith, Doula and National Service User Representative on the Maternity Transformation programme; Nordia Nelson, Registered General Nurse and Registered Midwife; Lina Duncan, Neighbourhood Doulas; Carly Bond, East London Maternity Voices; Charlotte McClymont, UCLPartners; Fiona Fairclough, Imperial College Health Care NHS Trust; Tisian Lynskey-Wilkie, Cheshire and Merseyside Women's and Children's Services Partnership

Some individuals were unable to attend, but contributed by correspondence, including: Mike Derry, Healthwatch Richmond; Stewart Tight, Bromley Experts by Experience.

Key points which emerged in response to the inquiry's key questions are summarised below and suggestions for key actions:

- 1. How have people been affected by the illness or the response to it**
- 2. If there have been specific impacts on people due to them having a protected characteristic**
- 3. Whether there may be unforeseen consequences to measures brought in to ease the burden on frontline staff, for example relaxing the measures under the Mental Health Act and Care Act**

When the Coronavirus Act is reviewed:

- 4. What needs to change or improve, which could be acted on in three weeks' time**
- 5. What needs to change or improve, which could be acted on in 6 months' time**

Questions 1, 2 and 3

(i) Maternity care

Contributor A noted that pregnant women are a vulnerable group. Coronavirus has dramatically increased fear and isolation e.g. antenatal appointments cannot be done face to face, quite a few appointments have been cancelled, women are scared to come into hospital, birth choices are restricted. In particular, some maternity safety initiatives have been put on hold. So although women are presenting in NHS settings with reduced movements of their babies, they are being sent home.

Contributor A noted the risks for Black, Asian and Minority Ethnic (BAME), women and babies. For Black British babies, the rate of perinatal death is twice as high, for Asian British babies 1.6 times as high as for White women. They don't yet have data on the impact of coronavirus and whether those health inequalities were gradually reducing, but they fear they may start to increase again and we need to monitor that.

Contributor B noted however, *'I have seen and heard of dismissive and unfair treatment of BAME women/ service users coming in now from neighbourhood doulas'*. One of the measures implemented for the coronavirus means that staff aren't allowed on the post-natal ward to support women who have just had an emergency caesarean or traumatic birth. Contributor B said that women have not been given their pain relief on time. There is a perception that black women can 'cope with pain longer' and a perception that Asian women are 'hysterical'. Contributor B has come across Asian women who have been traumatised as they have not been given their pain relief, not been listened to, rang their buzzer in the middle of the night and have been left crying with their new-born baby in their bed. All that was being reported in the news was how wonderful it is that the post-natal wards are quiet, but it was not like that for everyone.

She said that, when doulas had to leave the women for a rest or because of enforced (no companion postnatal) rules, all of the women have said they have been treated badly at times. They have been ignored. Some didn't get pain relief on time. Some rang the buzzer at night, repeatedly and still a midwife didn't come. Some were crying in their beds, with their baby in the bed because they felt unable to get up and down. They reported being afraid and in pain. They felt alone. Some felt it was because they were Muslim or because they were Asian. She said she herself have witnessed verbal and emotional abuse at times of some of the women.

One of the women whom doulas helped during birth was moved to a large residential hostel 8 days after birth. She and her husband and three children are asylum seekers. They were very concerned that it took 3+ months to move them out of there, to accommodation. They told the contributor that there were families with Covid-19 in that building. They had to stay in a small room with all 3 children under 5 years old for weeks on end. Now the mother has signs of Covid-19 herself.

One of the mothers was separated from her baby for 48 hours, having been readmitted to hospital, the morning after being discharged. She was told on the phone that her husband and baby could come into hospital whilst she had a short procedure. This was not the case when she came in and one of the Neighbourhood Doula co-ordinators attempted to advocate for her by phone. Her doula intervened over a period of 3-4 days to communicate with the hospital to remedy the prolonged situation and reunite the baby with the mother.

Email comment - Ongoing racism in maternity services

Contributor B stated, 'The treatment we witness pre-Covid-19 suggests that racial bias is an issue. These same attitudes are present in the current pandemic, yet often without a witness, when the doula is not present. Women that don't speak English at all are often treated badly. These are the stereotypical factors that lead to poorer care and not enough pain relief. For women that already have experienced a lot of trauma in their lives, additional trauma surrounding birth is obviously not a positive experience. We are particularly concerned about the BAME women and families that we work with as we are very aware of the disparities mentioned in the MBRRACE report.'

'We have a broad cadre of doulas of varied ethnicities and able to speak a variety of languages and we have ongoing in-house training so we can offer culturally safe support to the best of our ability.'

Email comment – lack of clarity at birth and in general use of healthcare services

Contributor C mentioned the impact of lack of clear information, for instance – if a partner was to be present at birth –who might be permitted to look after any children if there are no other adults in that household. In general, communications issues, English as an additional language and sensory impairments added to the obstacles for people accessing care.

Zoom chat function: Emotional/psychological safety in maternity services

Contributor D stated, 'I think there's a question of what "safety" means (especially in perinatal care). There's the usual concerns about pregnancy risks, and also now the risk of catching coronavirus. But then there's also emotional/psychological safety. If someone has had a negative experience, or a previously traumatic birth, then they may not be (or may not feel) emotionally safe interacting with some services.'

Different impact of measures on different groups in maternity services

Contributor D suggested, 'I think there are different impacts for some very small groups. For example, access to language line for women in labour has been really problematic. And the only one birth partner rule is then creating a problem if the chosen birth partner cannot act as translator. Similarly, both the no postnatal visitors and the closure of reproductive medicine departments have a different impact on lesbian couples - postnatal visitors where the co-mother was intending to breastfeed.'

Email comment – asylum-seekers giving birth

Contributor D added that 'access to language line for women in labour has been really problematic, because landline phones are difficult to sanitise, and it can be costly calling many language lines from mobile phones, especially if on a top-up rather than monthly contract (which most asylum seeking women will be on)'

Zoom chat function: Diverse involvement, raising awareness of bias risk

Contributor E suggested that ‘we need more co-production of services with our BAME communities - pre covid I was planning implicit bias training for midwives but unfortunately this is on hold until after covid-19.’

Ongoing racism in maternity services, COVID highlighting long-term inequalities

Contributor F expressed the view, ‘BAME people have always had worse outcomes because of biased treatment in the NHS. Covid-19 is now only highlighting the issues that have always been there.’

(ii) Accessing emergency services

Contributor G noted that she had symptoms of coronavirus and experienced difficulty when trying to get hold of the emergency services. When she rang 111, she was on the phone for two hours feeling really ill and unable to get through. Her brother also had symptoms and called 111. When they called 111 they were told that they probably don’t have coronavirus and so to stay at home and monitor symptoms for the next two or three days and then call their GP. Contributor G felt the coronavirus is affecting the BME community in quite an aggressive way as they have higher blood clotting illnesses, which might be why they have such a significant number of deaths. She thought maybe their conditions were classified as a heart attack or pulmonary embolism, when really, it was secondary to the coronavirus.

(iii) Attending outpatient appointments

Contributor H noted that there is a lot of confusion around outpatient appointments across the board. People are not sure about whether they should attend outpatient appointments. Hospitals are meant to be contacting each patient and that’s not necessarily happening. Some of these outpatient problems are going online, some people are not contacted at all. Some people are only contacted literally the day before their appointments, so there is a huge amount of stress. And now because the messages are coming out around BAME groups being more risk of the coronavirus, BAME groups are less likely to want to go to hospital for any outpatient appointment. The impact is therefore that they are missing quite an important follow up appointment. People are still going to be reluctant to attend an outpatient appointment until it’s clear how they are going to be kept safe from the coronavirus.

Contributor G noted that people are not turning up for their appointment and the hospital is not as busy. We were told not to go to the hospital unless we really have to, a lot of people have still got that in mind. However, things have changed and yet that’s not being passed on and communicated.

Contributor H proposed that we need clear and targeted communication, as the information isn’t getting out and filtering down. It’s completely pointless saying the NHS is open for business unless the government can actually explain to those groups who are already at high risk – how they are going to be kept safe from the coronavirus if they go into hospitals/clinics, have staff been tested, have they already had it? They believed that such information needs to be circulated – not just through the CCGs and hospitals – but also through the voluntary sector, through organisations like Healthwatch or the patient groups, through the cancer networks.

(iv) Accessing medical support for other conditions

Contributor I asked, at what point do we balance the protectiveness and restrictions of the coronavirus with the fact that people are now not coming forward with symptoms for other things. She noted that we are used to seeing so many people coming in newly diagnosed with cancer, and all of a sudden that’s completely dropped, but that doesn’t mean those people aren’t experiencing cancer. They’re just not getting diagnosed because of the fear of going to a GP or health service or hospital. We have to be careful that we aren’t going to experience higher deaths from other issues. Contributor I

proposed that we have to address how to make it more safe for people to still receive medical treatment and/or diagnosis.

Zoom chat function - COVID-19 education in diverse communities

Contributor I said she completely agreed that there has not been enough focus on education of issues around Covid-19.

Contributor J noted that one of the services that have been seen as non-essential is the assisted conception services. Most IVF clinics are shut down temporarily until the pandemic is over. Contributor J highlighted that she was one of those clinicians that decided to return to the front line because her independent services were going to be put on hold. Unfortunately, within 10 days of going back to the frontline, because the community wasn't adequately prepared, half of their team went down with symptoms of the coronavirus.

(v) Losing face to face services for Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ+) groups

Contributor K, noted that one of the big impacts is that people are losing face-to-face services. For example, her organisation has a LGBTQ+ mental health drop-in, which has been running for over 20 years, and over 50 people attend regularly every week but now it has stopped. There are some kinds of remote versions of it, but the quantity of people able to participate in those things or wanting to participate isn't as large. For the youth groups, they've noticed that there are people who are not participating online because they may not be 'out' [as LGBTQ+] at home and they may not be as comfortable. People may also not be open about their HIV positive status at home. Even though they have access to remote services and technology, there may not be the level of ease with the way these services operate. Contributor K noted support was needed for people who are disabled, who now have problems submitting benefits claims because they can't meet face to face with welfare officers and are struggling to get the money they need to pay for essentials.

(vi) Access and use of digital technology

There are also issues with people accessing remote groups and technologies because they can't afford to do so, have no recourse to public funds, can't afford their 4G connection, don't have laptops, don't have tablets and are struggling to find food. Contributor H noted that one of the issues that she had come across at her Healthwatch was around people accessing primary health care if you don't have a mobile phone, or if you don't have a smartphone, because now a lot of consultations are being done using digital technology. If you don't have that technology, it's very difficult to know how to actually engage with health services. They had been contacted by people with no recourse to public funds, because there is lot of confusion about what services they can and can't access and different agencies are telling them different things and that has a disproportionate impact on people from BAME communities as well. There is a lack of communication around what people can actually access, in terms of recourse to public funds. There is a whole section of the community that don't have access to laptops or smartphones and can't do the online consultations with GPs, it is just not possible for them. Contributor H also noted that elderly people might not have the manual dexterity as well and will find it quite difficult to use mobile phones because of arthritis in their fingers.

Email comment – Hospital discharge and impact on Elderly communities

Contributor O pointed out the different impact of measures on different groups in hospital discharge. Apparently, some London hospitals are sending elderly patients home who have tested positive to the virus and who also have underlying conditions more prevalent in certain communities, and where multi-generational households may be common, increasing the risks of spread amongst such communities.

(vii) Impacts on BAME Communities

Contributor L noted that one of the issues with the impact of the coronavirus is to do with sickle cell within the BAME community and not understanding how this is affecting people's sickle cell. The other issue is people being too afraid to go and get their medication. E.g. if they are on blood pressure medication, repeat prescriptions and needing to get blood tests for those that are on it, they are afraid to go and get it because they don't want to catch the coronavirus. Contributor L noted as part of her work with pregnant women that more women are wanting to free birth. These are women who have had babies before, they've had poor experiences, so then they're not wanting to engage with services. The communication is challenging under normal circumstances, but it's even more challenging now, with the coronavirus. A lot of mothers just don't know what services are running, in one minute it's there, then it's not. They've not heard from midwives, for example and they are not sure if they should go for appointments. They're too scared to go for scans as well. Women are being treated badly, whether it's through midwives or other staff by the way that they are spoken to, it's quite condescending. Josephine asked if this was for women from BAME backgrounds. Contributor L said that this was for BAME women.

Contributor G noted that her friend has been in intensive care who was admitted to hospital and her husband was sent home and they didn't give him any information about self-isolating. There is a lack of information for BAME communities.

Contributor M reported that many black people felt unsafe leaving their home to even exercise, for fear of being disproportionately stopped by the police and the stigma from the public about COVID-19. In general, lack of trauma-informed approaches and cultural competence plus institutional racism caused additional problems at this time, while underlying health conditions which increased the risk of severe coronavirus had often been made worse by institutional racism and bias, including raised levels of poverty and stress.

Myths around the virus

Contributor N noted that due to the trauma that communities have experienced from authorities, there is hyper-vigilance in sections of the African and African-Caribbean community and there is scepticism as to the cause of why people are getting ill. There are myths spreading and those that believe them are a risk to themselves and their loved ones e.g. one African-Caribbean man has been detained by the Mental Health Act because he believed the virus was caused by 5G. The mainstream media haven't sufficiently given coverage to this to educate people who may have these beliefs. There is a historical distrust of the health care system over decades, so later on we may find pockets of people contracting the coronavirus because of these beliefs and this has not been looked at.

viii) Impact on those with disabilities

Contributor P noted that she works for a disability organisation that helps people with their direct payments, to be able to access their care independently and so that they can employ their own personal assistants (PA's). Contributor P noted that there has been a lot of mixed messages, depending on where that funding comes from. Still to this day, they're waiting for guidance from the CCG about how people can adapt and change spending with this funding if their usual PA isn't able to support them at the moment, or if they're anxious about having people come into their home who aren't in their family unit. They've also had feedback from people about their anxieties in going into hospital and actually what that will mean for them and if they will be treated fairly because of their disabilities or learning difficulties. There is also the issue of somebody going into hospital with someone who may have difficulty with communication and them not having somebody with them that could help them.

Contributor P from another South London borough stated that disabled people were not having access to their usual care and support and testing for personal assistants was not readily available. There had

been Inconsistent or delayed guidance from the local authority, clinical commissioning group and children's services regarding flexibility of the use of direct payments and personal health budgets during the pandemic and Government guidance was only published on this last week. There were also anxieties regarding priority in terms of access to treatment and lack of adequate support in hospital or home treatment for people with learning disabilities. For instance, the mother of a young woman who has a learning disability believed that her daughter, if she contracted COVID-19, was unlikely to be offered ventilator support if required.

Contributor Q proposed that we would benefit from maintaining flexibility. e.g. there is a difficulty in trying to get assistance for disabled people on public transport, so a lot of people are taking their own personal assistants; however the cost is very high if extra tickets are required. If the government provided free tickets for personal assistants, that would solve this problem.

It was noted that video calls are very difficult for many people; specific access needs, language barriers etc. should be taken into account.

Ensuring access to support services and transport

Contributor Q noted the issue of people who usually get assistance in to do jobs around the house, can no longer let people in. e.g. there's one particular person who has had a fire alarm going off for two weeks, beeping every 30 seconds because the battery is dead. She can't reach it which is frustrating for her. So they are trying to get somebody to assist her. Contributor Q also noted that one of the good things to come out of this is the increase in volunteers. Also, their community self-help group, which has gone from meeting physically to meeting virtually is actually getting lots better attendance and meeting more often to reduce that feeling of isolation. So there are some things that hopefully we can take forward, out of this experience.

In addition the provision of free public transport to personal assistants, if the usual help a disabled person might need is unavailable, would improve access.

Email comments – added difficulties for disabled people in staying safe and receiving essential support

Contributor R reported that people in a South London borough receiving care in the community were being told they will only qualify for personal protective equipment (PPE) if they or their personal assistant displayed symptoms. Care agencies were running out of PPE and waiting up to a week for supplies

Contributor C mentioned that blind people were struggling to socially distance safely and sometimes self-isolating as a result but not getting the support that they would if they were shielded.

Email comments – different effects on children and young people of education mainly at home

Contributor M drew on her background of working in a South London school where 95% of the children are from a BAME background and often disadvantaged, though teaching staff and the senior leadership and governors are mostly white. Children had largely been sent home with little support, despite the possible serious emotional impact, especially since many already had substantial support needs.

Contributor R reported that disabled pupils with special educational needs were not receiving the same level of support and care to take part in education at home, leaving them at a disadvantage compared to their non-disabled peers.

ix) Impact on those with mental health issues

Contributor O noted that she would like to know what sort of existing provisions (and new provisions after the pandemic) are available for people with mental health issues or the mental health issues that will come out from this pandemic, especially for people from BAME communities.

Contributor S noted that one of the most significant negative impacts is the lack of face to face contact with mental health services, not being able to see your therapist or a new care coordinator in person, whether it's individual or groups. Contributor S noted the issue around social distancing, for a lot of people with OCD tendencies, and it can create a lot of anxiety in public, especially if not everybody's adhering to the guidelines as much as they should. Contributor S also noted that you would sometimes think that we are disproportionately negatively affected, but at the same time, because of our histories and past traumatic experiences, we have been through so much that this in a way pales in comparison. For the general public, it would be overwhelming, as they have never had to cope with such severe lockdown restrictions.

Email comments: lack of mental health support at a time of heightened stress

Contributor T described how his mental health peer support group had been unable to meet and voluntary activities had ceased at a time when some members were dealing with bereavement, others were anxious about older relatives or were themselves older people at physical risk

Contributor U reported that many people had had all their mental health appointments (community services, GP, therapy etc) cancelled. There was a lack of information about the 24/7 crisis line which was meant to be in place and she heard that people who have had to contact the line more than once (due to not having other support available), were being fobbed off under a 'fair use' policy.

x) Impact on travelling communities

Email comment – Specific effects on Travelling communities

Contributor V suggested the need to consider Travelling populations with regard to keeping track of Covid-19 cases, ensuring suitability of resources and accessibility and supporting re-settlement post Covid-19 if required, since these communities are transient in their locations.

Questions 4 & 5

An overarching comment received by email after the meeting was that an Equalities lead for the coronavirus response at government level was required.

Key areas for improvement identified by contributors included:

- **Ensuring physically and emotionally safe maternity services, particularly for sections of the population most at risk such as BAME mothers and babies who have higher rates of death, including countering racism and poor treatment;**
- **clear and targeted information for diverse communities, including for people with sensory impairment and non-English speakers, and improved access to emergency, outpatient and other health services, taking account of concerns among many BAME people of being at higher than average risk from the coronavirus and concerns from those with disabilities about unfair treatment and access to ventilators;**
- **Also addressing false information and myths about Covid-19 that can leave communities most at risk less likely to seek medical support and which might also encourage false assumptions or stereotypes against communities who are seen to be impacted by Covid-19**

- addressing health challenges for people with sickle cell and other long-term conditions more common in particular population groups that may be made worse because of Covid-19;
- considering possible effects before discharging older people with Covid-19 from hospital, into communities where certain health conditions are more common and where there are multi-generational households;
- ensuring adequate social care for disabled people, with safe levels of PPE and testing and support with transport;
- recognising that digital technologies are not equally accessible to all, including those with no recourse to public funds, and providing alternative means of communication when face-to-face support would usually have been offered;
- meeting varied mental and other health needs when the usual activities are unavailable, including for long-term service users, LGBTQ+ people and children not receiving the support they would have when at school. Engaging with and funding the smaller organisations that work more closely with specific communities can be helpful in addressing diverse needs.

Further areas for action were also examined.

a) Local and voluntary sector mobilisation

Contributor W noted the lack of local mobilisation, and that the local and voluntary sectors needed to mobilise at this time. There's a lot of people out there that could potentially share a lot, but the government didn't put money into mobilising locally, early enough. She is part of a team that's distributing food to people and has felt very isolated. The media are not covering it. There's not been an emphasis on putting money into the local authorities or local charitable sectors to do that work. Contributor W noted that there was a huge response for volunteers in the NHS, thus how do we take that forward? Health services are operating with as much strain as those in the community.

Contributor H noted that the other issue is around local groups and volunteering groups in her South London borough where there is a huge amount of duplication. They're all doing the same things. It's quite difficult as well, because the individual actually might prefer to go to their local mutual aid group or the local volunteer group rather than go through a service that's being funded by the Council as well.

Contributor H proposed that there needs to be a lot more engagement with service user groups, with patient groups, with the voluntary sector and with individual users. Before the pandemic, there were lots of meetings, committees, engagement forums, patient/user groups, service-user groups, and literally overnight these have shut down or been cancelled. Thus, a lot of decisions are made without any insight on the impact that it's having on patients and service users. Those channels need to be opened up asap and the decision makers need insight from those people that are using the services.

Josephine noted that she is working with the mental health policy research unit and has been helping a small group to put together a list of online resources for mental health. That list went up to 80 references. Therefore, if people know of good local resources that are really good for providing support at this time, then it would be good to identify them.

Groups and networks providing support and advocacy to BAME communities and other organisations experiencing inequalities currently face unprecedented pressure (even risk of closure): the depth and breadth of contributions highlighted the value of ensuring that they are adequately resourced and actively involved in decisions affecting health and wellbeing.

b) Ensuing representatives of BAME communities can involve relevant others in consultations with health professionals

Contributor X, a local GP, noted that many in the BAME community rely on family members to be their advocate to make sense of health information. Therefore, there should be a quid pro quo and there should be an alternative offer to accompanying a relative for their appointment. He proposed that the health services needed to be much more proactive to provide an alternative to the relative being there in person and as nurse, doctor, health care provider, to connect them through What'sApp to the person that would have been there accompanying them.

c) Diversity monitoring, testing

When testing becomes more available, it was pointed out, it is important to ensure that members of BAME communities have equal access to it. Additionally, given the higher representation of BAME communities affected by the coronavirus, stepping up training for unconscious bias was really important currently.

Zoom chat function - Diversity monitoring, testing

Contributor X noted that once testing takes off (and it will), we need to make sure that there's no ethnic disadvantage, no reluctance to come forward for testing in some ethnic groups. Perhaps we could push for ethnicity monitoring for all testing.

Contributor Y thought this was a good idea but thought that there may well be a lot of suspicion especially considering the history of being Black and how tests are administered and how Black people have been experimented on

Contributor Z noted the issue of racism, that we have an inherent bias which we need to work on and stereotyping/assumptions could be escalated during this pandemic. She asked if people are going to be running away from her now because black people are affected more and are more at risk? Thus, we need mandatory training for everybody regarding inherent bias?

Email comments – Recognising mistrust, monitoring equalities

Contributor O pointed out that, when a vaccine has been developed, fears around safety may be higher in some communities: issues of trust need to be addressed.

Contributor U urged that any data being collected centrally, e.g. testing rates, PPE access, mortality, should include a breakdown by protected characteristics where possible.

Contributor O noted that fears around vaccine safety may be higher in some communities: trustworthy information is needed.

Contributor U urged that any data being collected centrally, e.g. testing rates, PPE access, mortality, should include breakdown by protected characteristics where possible.

d) Mitigating effect of lockdown on mental and physical health of disabled and older people]

Suggestions from service users of a local cancer help centre included mental health support for those experiencing symptoms in lockdown, whether or not an existing service user.

The possibility of a photo-card scheme was raised, to allow those at risk or high risk from the coronavirus to exercise more safely in certain areas of parks at certain times when others would not be admitted, unless carers/support staff.

e) Dealing with death and bereavement

Contributor A's organisation supports bereaved parents and families and there is a massive impact on most parents who've lost a baby. Individuals who become pregnant again within the next year have extreme heightened anxiety.

Several contributors noted that family members had died since lockdown and that the normal traditions and rituals carried out by BAME communities could not be practised. This prevented the closure process and created additional emotional and mental health burdens. Though bereavement is not, in itself, a mental health issue, being unable to process this adequately can be highly damaging.

There needed to be more support and flexibility for funerals and the normal grieving processes, taking account of specific needs, beliefs and customs.

Contributor I also noted that the way bereavement is experienced now is extremely different and she queried if there is a way to provide some form of PPE just for a family member to say goodbye. What do we do to support our BAME communities who can't do the things they would normally do when someone has passed away?

Public involvement and diversity, including in research

Contributors highlighted the importance of giving those most affected by the pandemic, and changes resulting from this, greater influence over decisions, including on research. To quote from the Zoom chat function, 'There is something going forward about identifying what work needs to be funded and commissioned in the near future'; and 'What does consultation mean? How can we change the script?'

Contributor Y noted that diverse/vulnerable communities aren't leading the research and their voices aren't deciding what is happening and the research that is being produced is seen through a particular lens. Therefore, the research and the decisions need to be co-produced with those diverse communities who are often more likely to be impacted by the issues.

Contributor E expressed complete agreement with Contributor Y 'about workforce representation in the top tiers, it needs to happen. We have our BAME academics and researchers but this is still a small number and I would welcome more support for BAME researchers.'

The meeting ended with a video of the song "Rise Up" by Andra Day, a reminder of the human realities behind statistics on the experiences of various sections of the population in difficult times but also of the strengths and important insights and resilience within diverse communities.