

“Everyone is grieving at home on their own”

An exploration of the experiences of the BAME communities in North Kirklees during the COVID-19 pandemic

During the coronavirus pandemic, North Kirklees has suffered a very high number of deaths compared to the other areas of the South West Yorkshire Partnership (SWYP) NHS Trust. In some cases, two members of the same family have lost their lives to COVID-19, and the wider repercussions on physical and mental health have been numerous.

Between September and December 2020, People's Voice Media, the Trust and other local partners have worked with a group of people from North Kirklees to gather stories of lived experience from affected BAME communities, using the Community Reporting methodology. Community Reporting is a peer-to-peer storytelling movement, focused on working with lived experience as a tool for social change. We trained these individuals as Community Reporters and as part of this training, they have learned different storytelling techniques to enable them to share their own stories as audio and video recordings, and capture stories from across their peer networks. Working with People's Voice Media, they have curated these stories into a core set of findings that are evident in this report. Key topics within the stories include mental and physical wellbeing, bereavement, relationships, messaging, technology, faith and spirituality, and support systems. This insight briefing will begin by setting out the key findings of the project, and then link these learnings to recommendations for creative/wellbeing interventions.

“Their anxiety levels are much higher”

Bereavement, mental health and community support in the pandemic

As mentioned in the introduction, North Kirklees has suffered a very high number of deaths due to the pandemic when compared to other areas of the same Trust with, in some cases, multiple deaths in one household. [One storyteller](#) points out that the particular living arrangements of many BAME families – large, multi-generational families living together in one household – have exacerbated things, encouraging the spread of coronavirus and making it difficult for more vulnerable family members to effectively shield. Whatever the causes behind it, the massive sense of loss has had a real impact on the close-knit North Kirklees BAME communities. [One storyteller](#) talks about the devastating effect of losing several close friends within the same month, as well as the sense of loss he felt in not being able to see or touch his elderly father, saying “many times, I was actually in tears.” In this story and others, this feeling translates into a fear of passing on the virus, to those who are elderly or vulnerable, with many people talking about anxiety, fear, and feeling as if they were struggling, with those particular words coming up many, many times. However, it becomes clear that people did not feel they had an outlet for their emotions, with [one storyteller](#), for

instance, saying that because everyone was going through the same thing, they did not feel as if they could share their struggles with others. This, combined with many services closing or operating remotely during the pandemic, suggests that people have been going on without emotional support during a very difficult time. This is reiterated by [another storyteller](#) who says “everyone is grieving at home on their own.” This is compared to the usual grief process for the South Asian community within North Kirklees which would see funerals with hundreds of attendees. The storyteller, a health worker who lost his sister, aunt and father-in-law during the pandemic, tells how he was unable to attend his sister’s funeral due to travel restrictions, and how his aunt and father-in-law’s funerals had limited attendees and then no one at the house afterwards: “We had to do a Zoom get-together.” Naturally, this inability to grieve in the way one is used to takes a toll on mental wellbeing, with people having to deal with their loss alone instead of being supported by wider family and the community. [One storyteller](#), a faith leader who lost two cousins and several friends to coronavirus, says how he has had members of the community crying on the phone to him due to not being able to attend a loved one’s funeral. This really throws into sharp relief the impact the pandemic has had on the traditions of the BAME community in North Kirklees, which can also be seen in other customs such as weddings. These were discussed by several participants, all mentioning how these were scaled down from thousands of guests to just a few from no more than three households, and how different this was to the norm, with couples not allowed to celebrate with the full community as they usually would.

Another element made clear by COVID-19 is **the impact that barriers to support have on people’s access to healthcare**, both physical and mental, leaving them feeling disconnected and unsupported. This is also **exacerbated by language barriers not being taken into account**. This has had an effect on not only those people directly affected by the pandemic, but also those with pre-existing mental health needs who have found their support suddenly difficult, if not impossible, to access. One anonymous storyteller who works for community mental health support services found, like the majority of people, that her normally face-to-face role become work-from-home, predominantly carried over the phone while having to support people remotely. This meant that, due to consent issues, many of the tasks she would normally assist them with (claiming benefits, for instance, or arranging medication with their GP) had to be carried out by the person themselves without on-hand support which, in some cases, was not easy or even possible. One of the barriers identified was that of digital inclusion. She says, “most of my Asian clients don’t have the internet and can’t understand what to do and they will get very upset of the whole issues as I am not there physically to support them.” It also transpires that many websites don’t have adequate translations, so where people could access the internet, they then struggled to find the support they required. These barriers create an additional level of mental distress, adding to mental ill-health rather than helping it. The storyteller describes seeing people who had been making good progress begin to relapse as they were struggling with avoidable anxieties, or even unable to take regular

medications as they were unable to get their usual prescriptions. [Another storyteller](#) who works for an organisation supporting elderly members of the community found that many of the cohort she works with struggled because they prefer face-to-face contact and so are not on social media, don't use debit cards (some even do not have bank accounts) and suddenly found themselves isolated and unable to engage safely in society without support from volunteers. She also mentions the lasting repercussions of lockdown: "As we talk about lockdown lifting, they've [elderly community members] not gone out for so long that they are now nervous about coming out, and their anxiety levels are so much higher."

She goes on to say how much of the support in the community has come from charity organisations both local and national because they were much more agile than larger institutions, in particular the Local Authority and the NHS. "They couldn't mobilise as quickly, perhaps as some of the charity organisations and the small faith groups and things like that who were really able to mobilise much quicker." This is in contrast to how her own organisation quickly assessed all of its volunteers to see who was low risk and then redeployed them on pandemic-specific tasks, such as delivering shopping, organising entertainment packs, and doing pharmacy runs. This idea of **support coming from within the community itself via grassroots organisations and faith groups**, rather than from central and local government institutions was a running theme through many stories. [One storyteller](#), for instance, who works with a local food bank says how he has spent lockdown delivering food and hygiene packs, with hygiene packs in particular demand as people forgo toiletries in order to buy food. [Another](#) says how the government should have put resources into local interventions, saying "we should have gone house by house, mosque by mosque." It also emerged through the gathered stories that **some schools in the area have recognised their own roles as community hubs and have been offering support, help and advice for both pupils and parents**. [One mother](#) spoke about her experience of lockdown and how she struggled with many different aspects including emotionally. When talking to the school about her son, she told them about her own struggles: "The school staff made weekly phone calls to check on him *and* on me. ... There was genuine concern and confidentiality and the school phone calls provided was very supportive and positive." However, it is clear that the schools can only help students and their immediate families (and even this stretches their resources), so there are large gaps in who they are able to reach, which are not necessarily being filled by other institutions. This suggests that community-based organisations are perhaps best placed to deliver the health interventions needed.

"If members of the government aren't following the rules strictly, then we won't" **Mixed messaging and institutional racism**

The pandemic has both highlighted and exacerbated existing structural and systemic issues and inequalities within our society. Within the stories gathered and discussions

around them, it was clear that systemic racism is an on-going issue that impacts greatly on specific groups of people's health and wellbeing by creating and exacerbating inequalities. One of the main findings that several storytellers mentioned in one form or another is that **fake news and mixed messages from the government, mainstream media and social media is causing confusion, anxiety and distrust** among BAME communities. The way people from these communities are spoken and written about, has made them feel targeted by both the virus itself and the measures laid out to prevent its spread. This has left much of the community disproportionately disadvantaged and living in fear and mistrust for most of the year, which is severely impacting mental and physical health. [One storyteller](#) says, "Nowadays, I just don't know who to believe," succinctly summing up the feeling of being marginalised to a point where people don't know if the system is working for them or against them. This has been further aggravated by the Government's handling of the COVID-19 pandemic and the mixed messaging throughout. [One storyteller](#) states that "the government has been inept in its messaging," blaming this for the sense of denial within the local BAME community: "A big majority of people [in North Kirklees] were in denial of COVID. Then they were in denial of the steps they needed to take to protect themselves." The storyteller, who works in healthcare, worries that this is translating into denial of the vaccine which, at the time, was just becoming available. [Another storyteller](#) discussed the way it seems as if it's one rule for those in power, and another for everyone else and how this made people less inclined to follow the rules: "If members of the government aren't following the rules strictly, then we won't." In reference to government decisions and messaging, he adds, "One word would be 'confusing.'" He also mentions how early on in the pandemic, the government refused to close borders, making it seem as if things weren't that serious, potentially creating complacency. This is emphasised by [a storyteller](#) who says, "I think I didn't, kind of, really take it as seriously as I probably should have done at the start." She goes on to describe her early attitude as "nonchalant" although points out how that has since changed through experience. This is not the case for everyone, however, [one young storyteller](#) says how during the second lockdown there are more people out and about: "People are just over it." Statements like these demonstrate the fatigue, confusion, and disenfranchisement many are feeling in the North Kirklees.

[Another storyteller](#) pointed to the local lockdown in the North of England – announced late on the night before Eid – as being targeted against Muslims, and tells how non-Muslim people approached him at work, unprompted, to tell him they believed the same. This experience suggests the government's messaging and actions have appeared to noticeably hit some communities harder than others – particularly BAME communities. This sense of being targeted has been compounded with further measures. The introduction of a test centre in a specific area, for instance, raised suspicions as it felt as if it was aimed at the majority Muslim community according to [one storyteller](#). And now, with the vaccine being rolled out, there is further confusion. As one anonymous storyteller says, the "problem with the vaccine is we have no information on ingredients - are they halal?" They say that information is not

forthcoming and along with anti-vax messaging on social media, is likely to inhibit vaccine take-up among the BAME community, potentially creating further health issues.

Another point that came up in the stories was the places in which people in the North Kirklees BAME communities seek support and how these have been affected during the coronavirus pandemic. **The closure of places of worship has had an unprecedented effect on the community, with impacts on both mental and physical wellbeing.** For Muslims, their mosques are at the centre of their lives, so their sudden, long-term closure has left many people cut off and isolated. [One storyteller](#) points out, “people who have gone to the mosque all their lives, now you don't see them, they're stuck in their house.” An anonymous storyteller, meanwhile, sees the closure of mosques as something of a missed opportunity. While she understands the health need for the cancelling of gatherings, instead, they should have been given information and powers to liaise with the local community so that knowledge is being disseminated by a source the community views as trustworthy. This would have helped ease feelings of suspicion and helped the community feel included rather than marginalised.

Recommendations

Based on the insights gained from the stories, the following recommendations should be taken into account when devising creative and cultural interventions to support the wellbeing of BAME communities in North Kirklees. Ideally, wherever possible these interventions should be delivered by the grassroots and community groups, helping them to expand their existing work.

1. **Language:** Where possible, activities and services should translate their marketing and also the delivery of their activities into the first languages of the people they are working with. We understand that not all activities have funding to translate everything into the various local languages which instantly brings up access barriers for people for whom English is a second language. One way to resolve this would be to create a set of easily identifiable and understandable visuals that can communicate basic information and make people more aware of what creative and cultural activities they can get involved in locally, as well as how they can support their wellbeing.
2. **Communication and Linking In:** The stories have shown that schools occupy a trusted role as a community hub. These spaces and existing relationships of trust that exist at them can be used to promote (and potentially deliver) creative activities. Additionally, creative interventions and projects should work with local mosques, other places of worship and community leaders to help to ‘spread the word’ about what activities are available and act as a bridge into services. More so, a designated outward-facing BAME support role that connects people from

within the BAME communities into creative and wellbeing activities could also support inclusion. Ideas such as these, will help to open-up access to existing wellbeing and creative interventions to people from BAME communities who may otherwise not know they are available or not feel they are for them.

3. **Digital inclusion:** Digital exclusion was a key issue from the stories. To support people to develop the digital skills needed to access wider healthcare services and other information, wellbeing activities could think about how they could include digital learning and literacies in their interventions in creative ways. This could include creating digital art using web-based applications. Such techniques provide people with the creative outlet that will support their mental health, while at the same time developing the core skills they need to navigate online services. When doing this, creative interventions should do a 'digital audit' of the people they are working with and ensure everyone has adequate access to digital technology and the internet to participate.
4. **Sense-checking and pro-active inclusion:** Creative and wellbeing interventions should be actively ensuring that their activities and work is prepared for cultural differences, cultural sensitivities, and language barriers, as well as addressing whether it has any internalised or structural racism, and allow opportunity for the appropriate learnings and changes to be made. One way to do this, would be to co-produce a checklist or evaluation framework with different members of BAME communities in the area and, across South Kirklees, gain buy-in from different creative projects and organisations. This would create a set standard for pro-active inclusion, but it is important that it is not be a tick-box exercise. Therefore, buy-in during the co-production phase from relevant creative and wellbeing interventions is vital.
5. **Addressing Structural Racism:** It is clear from the stories that structural racism is one of the issues that detracts from BAME communities' health and wellbeing. While this may seem a big topic for creative, cultural and wellbeing interventions to address it is important that each part of the North Kirklees infrastructure plays its part. Small actions can be just as important as larger ones. For example, creative activities should use a range of images in their marketing that reflects the diversity of the people they are seeking to engage with. This visually shows people that the activity is for them. Another idea could be to have more BAME representation in the people delivering the activities, and supporting people from BAME communities to set-up their own creative and wellbeing activities – providing the necessary resourcing and support for them to do this. Equally, thinking about the different types of activities that might engage different communities would be beneficial – this could include seeing cooking as a creative activity, using different styles of dance in dance classes, and showing examples of art from a diverse range of artists in art classes. These very practical actions can not only support the wellbeing of the participants, but

can enable creative activities to play a role in addressing structural racism in society.

The piece of work also shed light on some broader recommendations worthy of note, which fall less into the category of creative/wellbeing interventions, but more broadly into healthcare interventions. These include:

- **Schools:** Work with schools, parents and pupils to co-create drop-in sessions that capitalise on the trusted role of schools as community hubs. These sessions would allow parents to access relevant healthcare information and guidance from professionals, but in a trusted, safe setting. This will require funding to help with schools' already over-stretched resources.
- **The inclusion of mosques:** Local mosques and other places of worship should be included in health and wellbeing messaging as they know their local community best and are trusted by the BAME communities. This could include co-production sessions between local NHS and local community/faith leaders to create accessible messaging regarding coronavirus, vaccines and more general mental and physical health. This would aim to reduce fear, anxiety and mistrust, as well as boosting take-up of the coronavirus vaccine when it is more widely available. Local community and faith leaders should be trained and given funding to work with the local people in order to disseminate the information directly to those who need it, filling in the gaps that schools are unable to get to.

Conclusion

The recommendations in this report are largely focused on mental health, structural racism, inclusion and accessibility, enabling the Trust to reach those it has not been able to yet reach. It also aims to build confidence in the Trust among the North Kirklees BAME communities. In many cases, it builds on foundations already in place, such as the grassroots and community groups, local mosques and schools, elevating and expanding the services they provide, rather than starting from scratch. All of the recommendations are made in the spirit of true co-production, where the community is not just listened to, but also given power and control to shape the Trust into what they need it to be in order to remove health inequalities and ease pressure on the NHS.