

Learning the Lessons

The Unequal Impact of the COVID-19
Pandemic: Voices of People and
Communities

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Introduction

“We are not all in the same boat. We are in the same storm. Some of us are on superyachts. Some of us have just the one oar.”

— Damian Barr, *Imagine a Country: Ideas for a Better Future* (March 2020)

Initially portrayed as a great leveller it quickly became clear that the impacts of the COVID-19 pandemic were being felt extremely unequally. A quotation from an essay by Damian Barr, illustrated in the *Wall Street Journal* in May 2020 quickly came to be adopted to encapsulate the reality of the pandemic – we were all in the same storm, but not in the same boat.

To those already working on health issues across the UK, these inequalities did not come as a surprise. Warnings about the stark inequalities across the UK had been sounded for decades, and there was work underway in pockets to address it – not least through The Voluntary, Community and Social Enterprise (VCSE) Health and Wellbeing Alliance. But progress was slow.

The unequal impact of the pandemic was the grimly inevitable result of a failure to compensate for historic inequity in how we responded. Without effective mitigation in place, the pandemic exposed and exacerbated existing inequalities making them harder to ignore.

The one positive of this is that it brought welcome attention to the issue of health inequalities creating a unique opportunity for them to be addressed. However, with the WHO having now declared the pandemic emergency over, this momentum is being lost.

There have already been a range of influential reports, drawing attention to data demonstrating the unequal impacts of the pandemic, and examining their underlying causes. We do not seek to replicate this work here. Instead, we want to build on it, by bringing additional insights from the unique group of individuals and organisations in National Voices own network.

To do this, in April 2023 we brought together organisations and individuals with lived experience to share their understandings of the unequal impact of the pandemic and to suggest the key lessons that needed to be learned. This report shares what we heard.

Tapping into insight and experience

At our session in April 2023, we invited participants to come together in an online forum, to share examples from their own experience, and the experiences of the communities they worked with of how the pandemic impacted unequally.

Across two hours of discussion we brought together around 35 individuals, some of whom drew on their own lived experiences of the pandemic, and others who spoke to the insights gathered by the Voluntary, Community and Social Enterprise (VCSE) sector organisations with whom they worked. VCSE sector organisations represented at the event included (not exhaustive):

- Academy of Medical Sciences
- Bassetlaw Citizens Advice
- Carers Trust
- Citizens Advice Eastleigh
- Cloverleaf Advocacy
- Equally Ours
- Friends, Families and Travellers
- Greater Manchester Long Covid Support
- Groundswell
- Hastings – Voluntary Action
- LGBT Partnership
- Macmillan Cancer Support
- Parent/Carer Forum
- Race Equality Foundation
- Renters' Rights London
- SignHealth
- Somali Development Services
- Stroke Association
- Versus Arthritis

As this was a relatively small-scale piece of work, inevitably we did not capture *all* of the ways in which the pandemic impacted people's lives, or all of the groups for whom the impacts of the pandemic were disproportionately felt.

However, the breadth of issues that we were able to explore in a short time and with limited opportunity for outreach, is testament to the rich insight that exists within the VCSE sector and across our network of members and supporters, and to the strength of feeling about the inequitable ways in which the pandemic's impacts were felt.

We know that there is far more insight still to be uncovered across the many communities with whom we and our partners work. We believe that the work we have done here should stand as a model for the Covid-19 Inquiry of how to efficiently and respectfully tap into this rich source of understanding.

Examples of Unequal Impact

Across our discussions, a number of common themes emerged:

Assumptions

It was clear that the pandemic response was calibrated to an assumed “norm” which left those outside at significant disadvantage. Damaging assumptions were made, for example, about the safety, space and suitability of people’s home environments (e.g. that people could safely ‘stay at home’ and could isolate away from family members, and even that they could avoid sharing bathrooms); about people’s work and economic situations (e.g. that people would be able to afford to isolate if exposed, and that people who were clinically vulnerable would not need to work); and people’s digital access (e.g. that people would be able to access online support); people’s sources of information (e.g. that people would find out information from the national news, and could take in written / verbal messages).

While normative assumptions were an issue before the pandemic, the problem was notably worse once COVID-19 struck, as guidance was developed and policy made without consultation, and without the involvement of people with lived experience, and without the input of organisations working with different communities. This meant that the usual checks and balances were lost.

A lack of understanding of, or attention to, people’s unequal starting points when the pandemic hit meant little was done to correct for these in the response. This was seen in everything from the failure to recognise how self-isolation requirements would affect people on low incomes and in insecure employment; to the lack of recognition of the impact of the digital divide on children’s education; to the failure to understand how an age-based vaccine roll out would impact people from minoritised ethnic groups.

A failure to meet access needs

Many of the challenges that people faced during the pandemic were a result of failure to translate previously hard-won rights to adjustments to support access to the new ways of working in the pandemic. As a result, people who required adjustments to access work, or services, and activities found they were excluded.

The starkest example of this was the failure to take steps to address people’s lack of access to online and telephone-based services, whether caused by lack of access to digital technologies (whether due to lack of kit, connectivity or skills) or due to sensory or cognitive issues.

Even when we were able to connect online services were not accessible. For example, it was some time before access functions such as closed captioning became commonly used. There was also a failure to recognise that one point of online access may not be sufficient for people with additional needs: one participant described having to use multiple devices in order to engage with online meetings due to the need to use different apps and plug ins.

Inclusive communication

The pandemic required significant amounts of complex and changing information to be conveyed to members of the public at speed, and as such effective and clear communication was more vital than ever. However little attention paid to the need to ensure the communications were inclusive, leaving people who had additional communication needs – for example due to sensory issues, or because they did not speak English as a first language - at significant disadvantage.

A failure to provide information in range of formats – including offering translations to other spoken and written languages, and into BSL, or to offer offline sources of information – also left people at significant disadvantage.

The need for adjustments for those for whom pandemic mitigations – such as mask wearing and barriers – hampered communication, was also ignored. This affected a wide range of people including Deaf people, people with hearing loss, and those for whom a lack of facial cues, and challenges recognising people made communication more difficult.

Those who were not able to access “mainstream” communication channels were left without critical information about the pandemic (in some cases) leaving them less able to protect themselves and others; they more vulnerable to misinformation; and were less able to access vital services.

The importance of trust

There was also a failure to take into account the impact of lack of trust in health systems, and wider statutory services, which exists in many marginalised and minoritised communities. This had significant (potentially life and death) consequences for their access to vital information about the pandemic, to treatment and to vaccination.

Working with trusted organisations was critical to ensuring people could access vital information and support, but there were missed opportunities in this regard. For example:

- Community leaders proved vital to getting public health messaging out and to the roll out of the vaccination programme, but the strength of community networks and the ability of public bodies to tap into these networks varied from area to area.
- In many areas local authorities played a key role in linking health leaders up with local community organisations that could reach into marginalised and minoritised communities. However, this was most effective where it built on pre-existing relationships – and these were not always in place.
- There were missed opportunities to build community outreach approaches in from the outset of the vaccination campaign – these were bolted on later when the data demonstrated lower rates of uptake among some minoritised ethnic communities. However, the delay left space for misinformation to spread, which then had to be countered.

Impact on Voluntary, Community and Social Enterprise sector

Failings in the support offered by statutory services meant that VCSE sector organisations had to step into the gap both to campaign for the support that their communities needed, and to provide additional support. For example:

- VCSE sector organisations working with people with specific long-term conditions had to step in to provide specialist advice around the pandemic tailored to the needs of their patient groups. These organisations often saw significant increases in web traffic and calls to their helplines after each change in government guidance.
- VCSE organisations had to step to support access for many patient groups where mainstream services were failing. Notably SignHealth stepped in to fund the BSL Health Access service from their own reserves, but also many small community groups stepped up to translate health information and advice and facilitate people in accessing vital services including vaccination.
- Community based organisations had to step up to provide basic practical support to people who were not able to access mainstream services, including shopping, health services and care and support; as well as to offer social and emotional support, particularly for those most affected by the pandemic.
- While some of this work ultimately attracted funding from statutory bodies, this was not always the case, and much of this work has not been sustained despite the ongoing impacts of the pandemic – for examples NHS funding for SignHealth’s BSL Health Access service has now ended, without alternative provision in place.

In deprived communities, where the VCSE sector generally has less capacity, people were less able to access the support they needed.

As well as identifying these core themes, we also heard about the experiences of specific groups and communities upon which the impact of the pandemic was particularly devastating.

People in poor housing and experiencing homelessness

The core ask of people in the pandemic was to “stay at home”, so almost inevitably those who were insecurely housed, or whose housing was unsuitable or unsafe were disadvantaged. While some steps were taken to address the most visible issue of street homelessness, issues remained.

Key issues to which participants bore witness for those in insecure housing included:

- **Unfair treatment by landlords:** illegal evictions; people in joint tenancies (the most common form of tenancy, especially among those aged 35 and under) found themselves “jointly and severally liable” for rent, with one tenant left responsible while others moved out.

- **Challenges in isolating or shielding:** People in shared accommodation often struggled to isolate or shield, due to having shared (and often overcrowded) facilities. Where people felt vulnerable in their tenancies, shielding and isolating could be particularly challenging – for example we heard one Covid-positive migrant worker avoided seeking help and support from those in his shared house, because he feared he may be evicted for being sick.
- **Challenges accessing services:** People who were insecurely housed or in poor accommodation often faced additional challenges in accessing services as they moved online as they often lacked access to reliable internet connections, and lacked private spaces from which to make phone or video calls.

People experiencing **homelessness** were recognised as a vulnerable group during the pandemic, and the issue of rough sleeping was brought into focus in the pandemic, with the swift implementation of the “Everyone In” policy. However, the implementation of this policy was not consistent and not everyone offered a bed as part of this scheme had a positive experience. We heard:

- The speed with which “Everyone In” was implemented meant there was widespread variation in the programme – whereas some people gained access to a holistic package of support, others just got a roof over their heads. In some areas people in temporary accommodation were connected to wider services including drug and alcohol treatment, and support from the health system for the first time. But this was not consistent. A key factor was whether there were already positive working relationships between housing and health and the VCSE in the local area.
- In some areas, where little support was provided, some homeless people found themselves abruptly evicted, or found themselves without access to necessities, such as alcohol for those who were dependent. Where no onward support was provided some people found themselves returned to the streets after the initial pandemic period.
- The wider disruption to community-based services had a serious impact on people experiencing homelessness – with libraries and day centres closed, and public transport services limited, people lacked access to sources of warmth, access to digital services and Wi-Fi and hygiene including toilets and showers. Even where basic services were provided, opportunities for social connection were lost.
- In some areas the pandemic led to more flexible approaches – for example issuing more flexible methadone scripts – which worked better for people experiencing homelessness – but, again, there were inconsistencies and in some cases these services have not been continued after the pandemic.
- The processes around Test and Trace and the vaccination programme were ill-suited to the need of people experiencing homelessness and insecure housing. For example, the reliance on digital technology for booking tests and appointments and for on online and traditional media for

communicating information around eligibility did not work for people who were digitally excluded due to a lack of skills, kit and/or access to data, or who lacked a secure home.

- The reliance on General Practice in the vaccination programme failed to take account of the low levels of GP registration among people experiencing homelessness. In areas where there were existing inclusion health services, and outreach programmes these issues could be overcome, but access to these practices is patchy.
- The challenges of the pandemic came on top of the pre-existing health inequalities faced by people experiencing homelessness – they have significantly worse health than the general population, and experience earlier onset of long-term conditions and the interaction of physical health conditions with mental health issues and drug and alcohol addiction issues. People also experience barriers to accessing health services, including refusals to register people without a fixed address, the impact of shame and stigma, and lack of support for people with dual diagnosis. The pandemic perpetuated and exacerbated these existing inequalities – often making it harder for people to access treatment – for example with the move to remote delivery in mental health services.

People with long-term conditions

As the entire health system pivoted towards managing the COVID-19 pandemic people with existing long-term conditions bore a significant burden as access to the support and treatment upon which they relied to maintain their health and wellbeing became significantly harder or disappeared:

- Services upon which people relied were withdrawn or moved to remote delivery – these did not work for everyone or every condition.
- Many faced delays to elective or routine treatment, leaving people coping with ongoing pain – for example routine joint replacement surgeries were cancelled for two to three months, leading to backlogs which remain today. Communication with patients was poor during this period, adding additional stress to the experience of waiting. In a survey by Versus Arthritis during the pandemic around 40% reported issues getting access to care, and one in two were in such significant pain that they couldn't do things around the home. 50% of respondents reported having physiotherapy and podiatry appointments cancelled.
- Some people delayed seeking support for ongoing or new conditions due to fears of infection leading to the exacerbation of their conditions – late diagnosis of conditions such as cancer had significant impacts, although the NHS made attempts to counter fears and encourage people to come forward were not always effective.
- Some people struggled to use services – for example we heard of a patient with a suspect melanoma who was asked to send photographs for a remote

consultation but struggled to gain accurate images and as a result went undiagnosed.

- Many people with long-term conditions – who were already disadvantaged in the labour market – lost their jobs or were forced to stop work due to fear of infection.
- The challenges posed by the pandemic came on top of the existing disadvantages faced by people with long-term conditions. There is a significant social gradient to long-term conditions with people in deprived communities and people on low incomes more likely to acquire more long-term conditions earlier, and there are significant inequalities in access to treatment and support – for example women are less likely to receive treatment for MSK conditions and people from minoritised ethnic groups experience worse outcomes from some treatments. The pandemic amplified and exacerbated these inequalities, with those already disadvantaged facing even greater impacts.

Clinically Extremely Vulnerable groups

In the early waves of the pandemic, significant numbers of people with long-term conditions were asked to shield.

- These groups experienced extreme isolation – some had to live away from their families and loved ones, even staying in garden sheds, trying to stay safe while family had to go to work, school.
- Poor data meant that some people who were vulnerable to COVID-19 were not included on lists, while others who were not vulnerable received letters asking them to shield. These data inconsistencies also impacted people's access to support with basic services.

While for some people the advent of the COVID-19 vaccine reduced their vulnerability to the virus to the extent that they could resume a "normal" life, a small group, including people who are immuno-suppressed, remain extremely vulnerable to COVID-19. For these people the pandemic is still ongoing:

- This "hidden 500,000" are still impacted by lack of access to safe health care, education, therapeutic treatments and to wider society and feel that they have been forgotten.
- The removal of pandemic mitigations including mask wearing and distancing, and the failure to improve ventilation in public spaces suggest that the needs of clinically vulnerable individuals are not being prioritised.
- While patients have come together to [advocate for their rights](#), they face an uphill battle to be heard.

Carers

The pandemic had significant impacts on people who provide unpaid care for friends and family members.

- Many carers were forced to take on additional caring responsibilities as paid-for care services were withdrawn and many groups and activities upon which carers relied for themselves and their loved ones were closed down or moved online.
- Even when care services were available, many carers were uncomfortable letting additional people into their homes given the risk of infection, so had to take on more responsibility to protect their loved ones.
- Carers reported feeling significant loneliness and severe impacts on their mental health.
- Carers were particularly affected by the wider economic impacts of the pandemic – for example, they were significantly more likely to be made redundant.
- Young carers faced a range of challenges as set out in this [report](#) – many found themselves taking on additional responsibilities with less support. The closure of schools had a significant impact on young carers who were left trying to juggle schoolwork at home with additional caring responsibilities. The impacts on young carers' mental health were significant.

Too often carers' needs were not taken into account in the pandemic response. For example, carers' organisations had to push the Government to give clear advice around being able to leave home to provide care. Carers experienced being prevented from attending medical appointments with their loved ones. Carers were also overlooked in the vaccine prioritisation – with organisations having to push to ensure they were given priority access, having initially been left out of JCVI considerations.

People from minoritised ethnic groups

There is clear evidence that the impact of the COVID-19 pandemic fell disproportionately on people from minoritised ethnic groups. This has been evidence across the literature, and these realities were reflected in our discussions:

- We heard personal stories of the significant impact on people from minoritised communities – for example one woman spoke of losing multiple family members, and experiencing repeated COVID-19 infections. Others spoke of barriers to accessing services – for example services refusing to allow a family member to attend appointments to provide translation support for people who did not speak English as a first language.
- We heard testimony of the significant levels of trauma left by the pandemic, from losing loved ones, often having been unable to be with them when they died, even when they were relied upon for translation.

- Despite the fact that people from ethnic minorities were over-represented in many “frontline” jobs during the pandemic – including health and care work, public transport and retail roles – we heard that people from ethnic minorities did not feel they were being celebrated when the nation “clapped for carers” or celebrated its frontline workers.
- The experience of the pandemic has seriously impacted people’s trust in public institutions. One participant said that they felt like a minority for the first time during the pandemic.
- Pre-existing barriers to accessing services, including a lack of support for people who do not speak English, and a lack of digital skills and connectivity exacerbated the impact of the pandemic among some people from minoritised communities, as services moved online and many sources of formal and informal support became less accessible or closed altogether.
- Many people from minoritised ethnic groups found their employment impacted by the pandemic.
- The higher levels of infection mean there is now a substantial burden of Long Covid among people from minoritised ethnic groups.
- The UK’s pandemic response was not informed by the reality of the lives of many Black and minority ethnic people. When the Government asked people to “Stay at Home, Protect the NHS, Save Lives”, it failed to take account of what this would mean for people from minoritised ethnic groups. For example:
 - The emphasis on “staying at home” placed an unequal burden on the UK’s black and minority ethnic populations who were more likely to be living in over-crowded accommodation and more likely to be in jobs where working from home was not possible.
 - The focus on working from home as means of avoiding exposure to the virus disadvantaged people from ethnic minority communities, because they were disproportionately employed in frontline roles and in roles that could not be done from home – they faced a double cost – either seeing increased exposure, or losing work. The impact of the UK’s weak system of sick pay was disproportionately felt in minoritised communities.
 - By Feb 2021 people from the two most deprived income groups – in which people from ethnic minorities are over-represented – were more likely to be going into work than working at home. Between Dec 2020 and Feb 2021 this group were much more likely to be using public transport. These factors significantly increased their exposure to the virus.
 - People from ethnic minorities were also more likely to live in homes in which isolating proved challenging due to overcrowding.
 - People from ethnic minorities were also disproportionately impacted as a result of where they lived. The COVID-19 pandemic primarily

impacted urban areas, where ethnic minority communities are concentrated (for example 98% of black people in the UK live in urban settings).

- “Saving lives” among people from ethnic minority communities proved more difficult – Black and Asian people were significantly more likely to die in the pandemic. Several participants said that they felt that the reasons for this increased vulnerability were still not fully understood.
- Despite this the COVID-19 vaccination programme was rolled out without reference to these racial inequities. The decision to vaccinate based on age meant that in the early stages of the programme very few people from ethnic minorities were eligible: of 4.6m people aged over 80, only 140,000 are Black.
- These racial inequities – in housing, income levels and working environments – were well understood prior to the pandemic yet this evidence did not inform the pandemic response.

People from Gypsy, Roma, and Traveller communities

The needs of people from Gypsy, Roma and Traveller communities and other living nomadically were also neglected in the pandemic response.

For example, guidance around handwashing was not suitable for people without access to running water, and guidance on distancing and isolating did not take account of people’s living arrangements.

Refugees and asylum seekers

Refugees and asylum seekers bore a significant burden during the pandemic, as a result of a combination of poor accommodation; lack of access to health services; language barriers and restrictions in access to support services. Some of the key challenges to which our participants bore witness included:

- Lack of access to digital services, and quiet spaces in which to access online services.
- Disruption to vital educational support, including language learning.
- Lack of familiarity with and trust in health services.
- Language barriers resulting in lack of access to basic information around the pandemic / systems for testing and self-isolation / vaccination programmes.
- Fear of formal / statutory services leading to reluctance to seek help with ill-health and access testing and vaccination programmes.

A lack of face-to-face support services was a particular challenge for many refugees and asylum seekers who have experienced significant trauma, as they often need additional time and space to build up trust in professionals.

Disabled people

Disabled people were additionally impacted by the pandemic as key services upon which they relied – including health services, care and support provision, and community groups and activities - were withdrawn or became less accessible. As noted above, it took some time for adjustments to be made to facilitate access to online services and in many cases services remained inaccessible throughout the pandemic. Some services, including day services and activity groups, which closed down in the pandemic, have not re-opened.

The failure to take account of disabled people's rights, under the Equality Act and in Human Rights legislation to equality was reflected throughout the pandemic in:

- Failure to provide appropriate adjustments to support disabled people's ongoing access to services – for example online services were often accessible to people who were blind; telephone services were not accessible to people who were deaf or had hearing loss (see below).
- Attempts to apply blanket Do Not Attempt Resuscitation orders to the records of people with learning disabilities – which demonstrated that clinicians did not value their right to life. This has caused ongoing trauma and loss of trust which continues to impact people's willingness to engage with health and care services.
- Withdrawal of care services which left many disabled people without the support they needed to maintain their dignity and wellbeing.

Deaf people

As noted above the pandemic brought with it a need to communicate significant new and rapidly changing information, and at the same time introduced a range of mitigations which hindered face-to-face communication. The actions of the Government demonstrated a lack of attention to the needs of Deaf people – with measures put in place, at best, as an afterthought:

- No BSL interpretation was in place for regular government COVID-19 briefings – leaving Deaf people – many of whom do not speak English as a first language, and often have lower literacy levels – reliant on sub-titling. This approach contrasted to that of other countries where BSL interpreters appeared regularly alongside political and health leaders making key pandemic announcements. FOI requests from the "Where's the Interpreter" campaign found that no planning for BSL interpretation had taken place.
- The lack of direct access to information about the pandemic put Deaf people at additional risk during the pandemic – for example hearing perpetrators of domestic abuse on Deaf people were able to exploit Deaf people's lack of access to information.
- People who use BSL often lacked access to up-to-date information about the pandemic, leaving them at greater risk of exposure, and without the information they needed to recognise symptoms and seek support. We heard of one Deaf man who, worried about his symptoms, called an ambulance only for people to arrive in full PPE and with no access to BSL

translation. He was then transferred to hospital and asked to consent to being put on a ventilator if needed, via a written note that explained that there would be a 30-50% survival rate. This case prompted the charity SignHealth to set up a 24-hour BSL Health Access service to provide interpretation via video call. This was initially funded from the charity's reserves, and then via the NHS. However, funding has now been withdrawn without an alternative in place. The service proved vital during the pandemic, not just for people impacted directly by COVID-19 but because it filled a long-standing gap in communication support for health care for people who use BSL.

- Access to pandemic health services were severely impacted with 87% of Deaf people in a SignHealth survey saying they found it difficult to communicate with Track and Trace. People struggled to get access to wider health services – with people struggling to access face-to-face appointments even when they were needed to meet people's communication requirements.
- Deaf people also faced challenges in accessing wider services due to mask wearing and the introduction of barriers. Very little was done to ensure that there was clarity around the need for adjustments to support Deaf people's access and so charities had to step in to campaign for better access.
- Deaf children – particularly those from hearing families – were disproportionately affected by the closure of schools which meant the loss of opportunities to use BSL. This impacted their mental health.
- Deaf students were also impacted by the move online which significantly impacted their education.
- Deaf people's employment was affected – particularly those who worked in health settings for whom use of PPE was a significant issue and who sometimes struggled to find interpreters who were willing to face the additional risks of exposure in health settings.

LGBTQ+ People

LGBTQ+ people faced a number of additional challenges in the pandemic which were not taken into account in the pandemic response. For example:

- People who were forced to "stay at home" in places where they were not "out" faced significant mental strain. There were also practical issues for example if people did not have the privacy they needed to discuss personal circumstances with health professionals, or other service providers.
- The lack of access to community spaces was a particular challenge for LGBTQ+ people who are more likely to live alone and lack support from family.
- When NHS services pivoted to treating COVID-19 this led to delays for trans and non-binary people in accessing treatment and surgery. There are ongoing backlogs in support for transition and this can have a significant impact on people's mental health and wellbeing.

Learning the lessons

We explored the lessons that needed to be learned from the COVID-19 pandemic, and the actions we wanted to see recommended by the Covid-19 Inquiry. The key messages from our communities were that we must:

Build on what worked

While there was much that went wrong during the pandemic, there are some examples of positive practice upon which we can build. Some of the common elements of positive practices across all groups include:

- Effective partnership working across sectors, as organisational boundaries came down and people worked together towards a common aim – supporting collaboration needs central to planning for future pandemics – this requires ongoing work to build relationships now.
- Flexibility and trust – the necessity of the pandemic meant that in some cases bureaucratic barriers were lowered, placing greater trust in individuals and in communities to get things right – from more flexible scripts for methadone users, to more unrestricted funding for VCSE organisations – this greater trust and flexibility was positive and should be built upon.
- Meeting people where they are – where health authorities worked with local trusted partners to bring vaccination clinics into local community venues, uptake significantly improved. We need to build upon this learning to bring more services into the places people already are, where they are comfortable and have established relationships of trust.

Work in coproduction with people with lived experience

Key to achieving the change we want to see will be shifting the way that power is shared across society, so that people with lived experience of the unequal impacts of the pandemic are able to describe the challenges that need to be addressed and to be part of developing the solutions:

- We need a clear commitment to ensuring that the people who are most affected by the pandemic are in the room when we are working out how to avoid its impacts. Coproduction is an ongoing process and requires resource, expertise and commitment.

The key areas for action, identified in our discussions were to:

Recognise the pandemic is not over

- For many people – including those who are immuno-compromised or otherwise extremely vulnerable to COVID-19; those living with Long Covid; and those coping with ongoing trauma from their experiences during the pandemic – the pandemic is far from over and yet the gulf between their

experiences and the experiences of the majority grows ever larger. The Inquiry must recognise those for whom the COVID-19 pandemic will cause ongoing disadvantage and propose solutions that address their ongoing realities.

Find the facts

- We still need to better understand why some groups were so much more vulnerable to the virus than others – for example why people from Black and Asian backgrounds were more likely to die. We also need to understand why so little action was taken to address the glaring inequalities that were faced through the pandemic – and why fundamental rights and duties under equality and human rights laws appear to have been overlooked.
- The Inquiry needs to forensically unpick these differential experiences, to give these communities answers. Without them the trauma of the pandemic will remain.
- Hearing directly from the groups most affected – for example directly from people from minoritised ethnic groups – will be a critical part of this.

Address inequity now

- It will not be enough to simply create mechanisms for equality impact assessment / equality proofing future pandemic response, if we want to avoid unequal impacts of future pandemics, we need to address longstanding inequalities now.
- We need to address inequalities in housing, employment, education, as well as taking action to address health inequalities directly. The pandemic demonstrated clearly that these issues are interconnected.

Rebuild equitable health systems

- The pandemic exposed the pre-existing weaknesses of our health and care system, not just in terms of its overall capacity, but also in terms of its reach into the marginalised and minoritised communities. The challenge for the future is not only to rebuild our health systems, to make them more robust for the future, but to do so with equity at the heart.

Recognise the core role of the Voluntary, Community, and Social Enterprise sector

- The VCSE sector played a critical role during the pandemic in supporting people who were under-served by mainstream services, and ensuring the people had the information and support they needed to get through. They need to be adequately resourced to play a role in both service delivery and strategic decision making in communities.
- Ensuring VCSE organisations have parity of voice and decision making within Integrated Care Systems (ICSs) will be critical. ICSs need to provide resource to support VCSE organisations to engage in strategic leadership, and to

support engagement with people and communities, as well as to enable service delivery.

Reach all communities

- At the same time the VCSE sector needs to challenge itself to do better in engaging with some groups experiencing inequalities - through assertive outreach to under-served communities and through building partnerships across organisations.

Learn lessons around trust

- The pandemic demonstrated the vital importance of trust in health emergencies. Trust comes from investing the time and space in building ongoing relationships.
- We saw in the pandemic that people often did not have trust in statutory bodies, so working with trusted intermediaries with whom relationships were already established proved vital to ensuring that people got the information and support they needed. These lessons need to be learnt in the long-term.
- Partnership is one vital tool in ensuring that people can access support via channels they trust, but there also needs to be recognition of the need for public institutions to build trust. This is hard work and requires honesty and openness around what has gone wrong before and a long-term commitment to listening to people and building relationships, through open and honest communication and regular feedback.

Build connections across communities

- We saw that the pandemic response was most effective when people and organisations were well connected across communities, so that organisations could work together easily and people knew how to, and had, access to ready sources of support.
- Building connections across communities should therefore be a priority – this will take time, and resource, and a willingness to engage with people on the issues that matter to them, rather than around a pre-determined agenda.

Improve data

- We need to act now to improve the data available to inform pandemic planning and pandemic response when the next one arrives.
- We need to close gaps in data around marginalised and minoritised communities – for example data on LGBTQ+ people, carers and people who receive care, people living in institutionalised care, people from Gypsy, Roma and Traveller communities etc.
- We also need to improve the data we collect and share around people's health and care needs to improve the ability to reach those who may need additional support or who may be particularly vulnerable to future pandemics.

Improve accountability

- We need to ensure that there is clear accountability for meeting the needs of marginalised and minoritised communities during pandemics. It should not fall to charities and campaigning groups to speak up for the rights of minorities, to fight for the support people need and to fill gaps. Instead, there must be clear accountability for meeting equality duties and securing access.
- Inevitably mistakes will be made in pandemics, but there need to be clearer mechanisms for checks and balances in policy making – the default should be to listen to more voices during a pandemic, rather than fewer. Bringing more people around the decision-making table and creating mechanisms for feedback when things go wrong is critical.

Take a rights-based approach

- Taking a more explicitly rights-based approach not only during pandemics, but to policy-making more broadly has the potential to protect against such unequal impacts in future pandemics.
- The Inquiry needs to consider the ways in which decisions made during the pandemic appeared to value people's lives differently – and should reemphasise the intrinsic right to life which is afforded to all, including those from minoritised ethnic groups, to people with learning disabilities and to people whose conditions make them particularly vulnerable to infection.
- Ensuring people have rights to legal redress where things go wrong will be an important way of ensuring that people's rights cannot be infringed.

Make communication inclusive

- The pandemic demonstrated the vital importance of being able to share information quickly and efficiently with all populations, and demonstrated how quickly misinformation can spread in a vacuum – improving the inclusivity of government and other core communications channels, and building more effective routes for sharing information with all communities, will be vital.
- This should start with ensuring that basic requirements around accessible and inclusive communication are met – for example ensuring that all NHS providers meet the Accessible Information Standard.
- Establishing a baseline of communication techniques, with checklists for basic accessibility requirements (including BSL interpretation for key communications) will be vital.
- We should consider the role that emerging technologies could play in rapidly supporting more accessible communications – for example AI.
- We also need action to ensure that people more routinely have access to communication support, particularly in accessing health, care and other vital public services. Improving the collection and use of data around

communication needs will be vital on an ongoing basis and would give us tools to improve pandemic response.

Build new models which are pandemic-proof

- We need to think about how we can build new, accessible, inclusive models which will be more “pandemic-proof”. When planning work, housing, and study we need to ensure that the lessons of what worked and did not work from the pandemic are built in.
- For example, given that we know how vital digital technology can be during pandemics, it makes sense to think about how to build full inclusivity into the new models we are developing to support remote learning in schools and remote delivery of services. Although some people will always prefer face-to-face contact, we know in pandemics this is not always possible, so we need to act now to develop remote learning / working / service models that do not exclude.

Conclusion

The COVID-19 pandemic amplified and exacerbated inequalities across the UK. The failure to apply an inequalities lens to the pandemic response meant that people who faced existing disadvantage and marginalisation were heavily impacted by the pandemic.

There are lessons to be learned, and first among these is that we need to ensure that the people who are most affected are in the rooms where decisions are being made and are able to participate on an equal basis.

We commend the lessons learned to the Covid-19 Inquiry and hope that they will recommend the actions we have identified. But we also hope that action can be taken now.

During the pandemic we heard a lot about the commitment to reducing inequalities, and addressing inequity. We are concerned that this discourse has since gone quiet. The insights we gathered through this engagement processes demonstrate that we must not allow this to happen.

This small-scale engagement programme enabled enormous insight to be gathered and digested. We hope that the Covid-19 Inquiry will commit to working with us to build on these insights, developing further opportunities to gather rich insight and explore experiences, so that lessons can be learned.

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