**Written Evidence submitted to the Health Foundation by:
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Background:

NHS Voices of Covid-19 is working in partnership with the British Library to create a national collection of personal testimonies to capture the social significance of the pandemic. The research is funded by the UKRI Covid-19 Urgency Call through the Arts and Humanities Research Council and supported by the National Lottery Heritage Fund.[1] Since March 2020 we have interviewed over 200 frontline NHS staff, clinical leaders, policymakers and patients across the UK about the impact of Covid-19 on their personal and working lives and wider communities. The interviews capture over 700 hours of recordings.[2] Oral history gives agency to interviewees to shape the form and meaning of the interview and thus captures personal experiences alongside sense-making and reflection on the narrative that is being shared.[3]

Methods:

The findings reported here come from a selected sample of over 100 interviews held over the period of March to December 2020 with participants representing all four nations of the UK as well as different economic, social and ethnic backgrounds. The purposive sampling reflects the qualitative approach adopted in this research, in which oral history has been used as a main method to obtain rich and textual data. Since March 2020, all interviews have been conducted over the phone due to the Covid-19 pandemic and the restrictions that were implemented as a result. The voice-recorded interviews contain personal accounts of the lived experience of Covid-19 captured in real time and during the first and second waves of the pandemic. They have been analysed for common and recurring themes and organised accordingly. It is important to note, however, that the research is still ongoing, and the evidence presented here has been gathered at pace and therefore should not be taken as final nor complete.

Our evidence on the areas of interest:

Question 1: What was the impact of people's existing health status on their experience of Covid-19?

The interviews revealed that people's existing health status played a role in how they experienced and understood the Covid-19 pandemic. For people with pre-existing medical conditions including recent diagnosis of illness (e.g. cancer) as well as long-term health conditions, the sudden outbreak of Covid-19 caused a significant amount of stress and anxiety particularly at the beginning where there was limited knowledge about this virus. While these feelings were common and shared by the general public, there were some key differences in how the health pandemic affected this group. We note these issues below and link them to the key themes, which have been identified by the Health Foundation as of interest. It is important to note, however, that the participants in this study rarely fitted any single category alone. Instead, we found much cross-over between the groups and themes, with NHS staff in particular holding multiple roles and identities (e.g. keyworker-woman-carer-vulnerable-BAME), which significantly complicate the analysis along the suggested lines. Nonetheless, the points below summarise the key findings under the first question.

1. **Mental health and wellbeing amongst disabled & vulnerable people**

The language of 'disability' is complex as well as conceptually and analytically challenging. It holds multiple meanings and is understood differently by different people. For instance, the participants who were selected into this category rarely self-identify as disabled despite meeting at least one of the official conditions set out in the Disability Discrimination Act (DDA) under which a person is considered to be disabled. Our ongoing research shows that participants mainly think of themselves in broad and interrelated terms as 'vulnerable' rather than disabled, due to age as well as circumstance such as being pregnant, and 'shielding'. For this reason, we have decided to put these two areas together.

The key implications arising from the new virus affecting these groups concern three key areas: mental health (broadly conceived), access to health care including medicines and finally kinship and fraternity.

a. **Mental health and wellbeing**

Health status was a considerable factor in influencing people's perception of risks particularly in the context of their own vulnerability and susceptibility to the virus. The media played an important role in normalising this notion by framing the pandemic in terms of old age and pre-existing health conditions no matter how well these were managed prior to the health crisis. In some cases, previous experience of a health pandemic acted as a trigger for worry. In this instance the interviewee reflected on the associations drawn between Covid-19 and the HIV/Aids epidemic of the 1980s.

> "I think these suggestions of contagion and isolation and restriction of freedoms have been very difficult because it's taken a lot of them back to the early stages of Aids…I think it's brought up a lot of those memories and made people feel quite vulnerable."

The fear amongst the vulnerable groups meant that whole families at times were organised around strict and time-consuming routines including dividing households into 'clean' and 'risk' areas to mitigate the impact of Covid-19. The different practices (e.g. changing clothes, leaving the post for a number of hours, etc.) did not necessarily have any scientific basis rather they were adopted in the hope that this would offer extra protection for the most vulnerable members of the household. It is difficult to speculate on the long-term psychological impact of these 'rituals' particularly on young children who followed them, but it was evident that having some sort of routine and guidelines provided an important mechanism through which to regain a sense of control.

> "I'm not as fearful as when I was when it [Covid-19] first came about. When it first came about, I was terrified but I kind of came to an understanding that if we wash our hands, do what the government say, we're going to be ok, it's going to be fine".

This compliance with rules is particularly interesting given such significant variations amongst other groups. More so, as this particular interviewee was very critical of the overall government response including the confusing public health messaging. However, the point made earlier about the need for clarity in this highly uncertain environment especially for someone who has been identified as vulnerable explains this position to some extent.

Similarly the serious restrictions that were placed on freedom of movement were rationalised by vulnerable people with serious health conditions probably sooner and more willingly.

> "Like with shielding and everything else, I've taken, we've taken it all very seriously right from the start because I know it's for my benefit, I know it's for our family's benefit at the end of the day. We all want to be together at the end of it".

Another consistent theme, in line with the official government message, has been around a sense of responsibility for our own health in order to protect the NHS. Many older respondents mentioned being extra careful, not wanting to be a burden and being 'sensible'. This was also the case for people with pre-existing health conditions who were aware that the NHS became also a place of 'contagion' which needed to be avoided.

> "I really think it's my responsibility to be as sensible as I can. I was going to start riding my bike again [...] but I thought if I'm going to fall off my bike and end up hurting myself, I'm going to end up in hospital."

The extent of the pressure that affected the mental health and wellbeing of these vulnerable groups varied, albeit it was consistent in terms of the sources, e.g. mass media coverage, public health messaging, confusion around guidelines, home-schooling and in some cases difficulty accessing medication and healthcare (covered in the next section). Significantly, though, existing health status was not always the major source of stress and worry particularly once safe-guarding practices were adopted.

> "It's been very stressful. The most stressful part about it is the pressure that we get from the education side for the children. It's a lot of work when you haven't been trained to teach. So that's been extremely, extremely stressful."

What is also interesting is that some people reported improvements to how they felt as well as to the level of activity and interactions they did under the lockdown conditions. It is difficult to be certain why this was the case, but it is possible that the idea of 'vulnerability' acquired a different and extended meaning under the lockdown shifting attention from strictly physical aspects to other societal challenges (e.g. food security) that were increasingly reported by media. Likewise, there was some noted improvement in the diligence of care provided at home that paid more attention to the overall wellbeing and safety of patients.

At the same time, other groups not considered vulnerable were reporting difficulty with sleeping, recurring nightmares, and exhaustion which featured heightened and prolonged states of anxiety. Although, many of the coping mechanisms adopted by the interviewees involved healthy activities such as exercise, taking up new hobbies, walking and gardening, others were less safe, for instance excessive drinking and eating.

b. Access to medication & health care services.

At the start of the lockdown, some vulnerable groups reported a range of difficulties in accessing medication. For example, some prescription drugs suddenly became unavailable or had to be sourced from another location delaying the whole process. In other instances, people had to queue for long periods of time and often more than once a week if not all medication was available the same day. Volunteers, neighbours and other social networks were mobilised to provide vital assistance. Likewise, many appointments were cancelled, rescheduled and in some cases not attended at all, because of fears of contracting the virus in the place of care. There is already a significant amount of evidence that is emerging in this area.[4] Our findings also highlight the danger of rationalising and normalising this absence of

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[4] https://www.england.nhs.uk/2020/04/help-us-help-you-nhs-urges-public-to-get-care-when-they-need-it/ - accessed 10 December 2020.

care by vulnerable and older groups on the basis of increased risk in accessing primary and secondary care, as well as by evoking emotions and feelings around responsibility to the NHS, and a duty to protect others.

The period just before the national lockdown has also been significant in shaping people's perceptions of risk associated with Covid-19. For instance, one interviewee observed that a lack of clear and visible procedures in one of the largest cancer treatment centres in Europe (The Christie) led them to question the severity of the virus.

> "[...] Just before the lockdown, if coronavirus was mentioned in the Christie it was because I mentioned it. The waiting rooms were still full. The corridors were still full. I was acutely aware of trying to keep that distance and it make me duck into to the side corridors to avoid people [...]. And standing up because I didn't want to be sitting down on a waiting room chair. Then desperately hunting [pause]...There's always lots of bottles of hand gel but these were mostly empty. It felt as if [...] they were not driving that change. And it made me feel like, maybe I'm a bit oversensitive, maybe I'm being over cautions".

The rapid drop in patients presenting caused clinicians to worry about untreated diseases and the poorer outcomes for health.

> "I really want my patients to come forward, and they're not coming forward enough. And we know, therefore there are people with serious conditions that are just being left, because statistically, that has to be the case. We are seeing maybe 10% of the number of people with suspected cancer symptoms that we would normally see".

> "[a 48 year old patient] who has now got deformities to his hands, and his hands will never go back to normal shape, because he's left his symptoms for months and months. … he's already destroyed some of his joints … he was still too worried about coming in. … another guy who has mental health problems, and he's just been deteriorating at home and had arthritis related to some bowel disease … was really actually very unwell. And his present presentation was because he had joint pain. In fact, he had a really bad problem in his abdomen that needed surgery urgently".

The initial lack of action on behalf of the government, followed immediately by a series of different policies and guidelines which were constantly changing, left some groups confused. This was evident in relation to shielding where many people ended up interpreting the policy typically in the way that meant they were either shielding for unnecessarily long periods of time or when they were not required to do so.

c. Kinship and fraternity

The sense of responsibility extended to other areas, often with members of the family taking further precautions to protect the most vulnerable in their household. In many cases, partners, children and other family members already did a significant amount of informal

caring but the pandemic further exacerbated these dynamics. There were some positive and unintended outcomes from this with people reaching out more to friends and family via the phone and increasingly zoom and other virtual platforms. Initially, this activity was seen as a vital substitute for face to face communication, however, over an extended period of time the level of enthusiasm subsided, particularly amongst the groups who were using the same tools for work. Increasingly people were reporting high levels of exhaustion and tiredness. However, informal networks proved vital for vulnerable groups both in terms of mental health as well as at the more practical level with many becoming more dependent on food parcels, interactions with 'strangers' to access some necessary resources such as medication, as well as to mitigate against isolation and loneliness. In our study, we received many reports of new food banks being established by informal groups of individuals rather than as part of established charitable organisations. This may prove difficult to quantify and therefore more research is needed to ascertain the extent of the problem around food security during and post Covid-19 pandemic.

Question 3: What was the impact of government and societal responses to the pandemic on people's health?

In this section we draw attention to the impact of government and societal responses on key workers. Specifically, we report on key findings in the area of mental and physical health and wellbeing over the first and second phases of Covid-19 pandemic. We also record the change to practices in caring for patients including the greater reliance on digital communication. Together these findings highlight the cumulative impact on the NHS which is already facing significant workforce shortages that could limit the ability to respond to future pandemic, as well as to recover from the current one.

The biggest impacts on the physical and mental health of NHS staff have been caused because of the ways in which Covid-19 cut through the core values and paradigms of care. For a generation of NHS staff who had little experience of earlier infectious diseases such as TB and smallpox, it was the first time they felt that caring for patients posed a direct threat to their health. This extended into concerns about themselves as a vector of disease and the broader threat to the health of their family. It is also important to recognise that Covid-19 occurred at a point when the NHS had significant workforce shortages and staff were already reporting high levels of stress.

> "I don't want to infect doctors and nurses and healthcare workers in ICU [Intensive Care Unit]; putting them at risk of dying in order to save me. This is the first time I have ever been in the situation where I'd be really worried that my colleagues are going to die".

Personal Protective Equipment (PPE) was intended to protect staff from becoming infected by patients, but the shortages of PPE combined with a mistrust of government advice about

the specific levels of protection needed in different clinical situations caused staff huge psychological distress.

> "the [resuscitation] trolley might not have your [size] mask on it and then you've got a decision to make about, do you try to resuscitate that patient? Or do you just stand there with your hands crossed because you haven't got the right mask? … I've never worked anywhere where my health is at risk, let alone being asked to make a decision between myself and the patient".

Infection control processes in some hospitals were not effective as the movement of patients from Covid-19 to non-Covid-19 areas was determined by the patient having a negative swab. The 30 per cent false negative rate of the test meant that patients in non-Covid-19 areas could subsequently test positive and spread the infection to other patients and staff. In some sad instances, patients who were in hospital with non-Covid-19 conditions caught the virus and died and staff spoke of their anger about these unnecessary deaths. Testimony around how these decisions were made revealed tensions between nursing and medical decision making processes: nursing assumed test results were accurate, even if the patient was symptomatic, but medical staff took account of symptoms and other diagnostic results alongside test results before deciding which areas patients should be moved to.

Many staff described the steps they took to prevent contaminating their families from changing clothes and footwear before entering the house, to limiting physical contact with children and partners: 'they want to come and run and hug me … I walk away with tears in my eyes'. Some staff moved into alternative accommodation to protect families and experienced feelings of isolation and depression.

a. Mental and physical trauma

The long shifts that staff was required to work left them physically exhausted with few able to take their annual leave further exacerbating the situation.

> "I don't think most people realise the conditions people have to work in … I don't think people realise what it really is like, it is hellish … things will go back, people will forget. And I keep taking photos … the other day I just took a picture of my scrubs, completely sodden with sweat, I just did that because it's so surreal. I've never, I've never worked in such conditions".

The impact on psychological well-being cannot be overstated. Interviewees testified to their fear, anxiety, low mood and stress which manifested as sleeplessness, nightmares, visual flashbacks to difficult situations and burnout. The scale and pace at which this pandemic unfolded is unprecedent and it is likely to have long-term implications on staff wellbeing but also the wider environments in which they operate.

'I've certainly never had anxiety like that in my life before … and I never wish to have it again … fear with a capital F is the biggest thing that's affected me negatively'.

Many staff testified to the 'cognitive dissonance' that they were experiencing compared to their normal work. The sheer numbers of critically-ill patients, new infection control processes, and new treatment procedures (eg. proning - moving patients from backs to fronts to relieve respiratory distress) together created what one interviewee described as 'a new kind of busyness'.

When NHS staff became critically ill from Covid-19, colleagues cared for them and the subsequent deaths were horrific. So too was the emerging evidence that BAME communities were disproportionately affected by the virus.

'[the] high mortality rate, which has been absolutely devastating for people like me to watch, in people who have returned out of retirement to help with the crisis, and of course, some of those, by their very age, are high risk, and that's been heart breaking'.

b. Second wave – exhaustion and frustration

There is a discernible difference in staff response to the second wave. Many describe how the fear has abated somewhat and there is better access to PPE. Nevertheless, morale is very low and staff who are now being asked to cope with the backlog of patient care whilst also treating Covid-19 patients are experiencing exhaustion. In primary care, for example, staff are faced with the logistics of mounting a Covid-19 vaccine campaign on top of their usual winter pressures. There is also a strong sense of frustration that had the crisis been better handled by the government then the second wave would not have been so intense.

'[in the first wave] the main feeling was this is the right thing to do. Let's do it. And now, I think … second time around, it doesn't look quite so appealing in terms of … if the government had handled it better would we be having so many cases? Should I be paying the price of someone else's incompetence?'

c. The impact of digital consultations

The Covid-19 pandemic has also changed experiences of end of life care and bereavement for staff, patients and families. It has disrupted many of the best practices around dying and end of life and the social rituals of funerals and community farewells. Families have had to say goodbye to loved ones through digital means; patients have died alone and the distress for families and carers is enormous.

"There was a wee elderly gentleman who had no family with him … he was unconscious, and we took a phone into the room and the son said goodbye over the phone … and we're watching the gentleman deteriorate over the next half hour, and I was like, I'm just going to go in and sit with him, 'cause you can't leave somebody dying on their own, and the staff were like but you can't … I went into the room, I did have full PPE on, I was totally protecting myself, protecting my family. The

gentleman passed away about five minutes after I went into the room, without his family round about him. … That's draining for a nurse, because you want to provide the best care that you can for these patients … so these wee souls were dying with a stranger holding their hand, or, in some cases, nobody holding their hand".

Even when patients recovered, they described their experiences as frightening.

"I must be honest, I was frightened. I said to [the doctor]," if you put me to sleep can you promise you will wake me up?", and he said, "no I can't. You are on your own, your family isn't with you – you are with all these people that you don't know … it is lonely". I didn't feel lonely but I felt frightened".

The rapid move to digital consultations consolidated initiatives that had begun several years previously in a matter of days. Clinicians rapidly adapted to the changes although there was little formal learning support.

"you're doing it within a week with no guidance on how to carry it out except your common sense … usually that would have been protocolized and there would be instructions on how to open the conversation, and how to close it, and how to make sure you haven't missed non-verbal cues and all that kind of stuff".

There were mixed messages in terms of positive and negative impacts. In many instances, remote consultations were welcomed by clinicians and patients and enabled swift access to treatment without risking safety. Certainly, they saved everybody time in travel and waiting. Less positively, patients needed access to technologies and this risked reinforcing existing health inequalities. There was also strong concern expressed that however well remote consultations were managed, they could not replicate holistic and humanistic approaches to caring for patients. The absence of touch and human interaction was seen as many as cause for concern about the need to care for patients holistically, not just in response to a specific symptom. This was expressed as a difference between care and treatment.

Relatives and staff developed new soft skills through the need to communicate on the phone about the ongoing condition of a patient, their discharge home, or having to break bad news.

Conclusions

In summary from the evidence presented above, we see the main policy challenges arising out of these areas as follows:

- Addressing the cumulative physical and mental stress of NHS staff in the context of significant workforce shortages that could limit NHS' ability to respond to future waves of Covid-19, successfully address the backlog of work, and/or prepare for future crises.
- Supporting bereaved families who have not been able benefit from normal support.

- Mitigating the poorer health outcomes which may be exacerbated by future waves of the pandemic causing the NHS to suspend services and patients to delay seeking treatment.
- Addressing the disproportionate impact on BAME communities within the context of the longer histories of racism and discrimination within the NHS.
- Addressing the lack of trust and compliance in public health messaging that could limit the effectiveness of public health influence on public behaviour in future crises.
- Seeking balance between the benefits of digital technologies in healthcare and the value of human interaction and touch.
- Addressing issues of access to digital technologies so that no community is disadvantaged.