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University of Manchester, NHS Voices of Covid-19,
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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]

Methodology

Since March 2020 we have been interviewing over 250 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 are a mixture of 150 one-off interviews and recurring sessions with 100 interviewees which together comprise over 700 hours of audio recordings. Voices from all regions of England are represented in the collection, alongside voices from Wales, Northern Ireland and Scotland. The tables on p.13 give more detail of the breakdown of interviewees. Oral history gives agency to interviewees to shape the form and meaning of the interview and thus is adept at capturing experiences and reflections that speak to the plural identities of individuals as citizens, workers and patients. It facilitates sense-making and reflection on the narrative that is being shared and is effective at capturing the scale and depth of the effects and impacts of Covid-19 on every aspect of our lives and communities.[2]

[1] The evidence comes from *NHS Voices of Covid:19: Creating a national collection to document and understand the impact and legacy of a pandemic through personal testimonies*, University of Manchester in partnership with the British Library. The work is funded by UK Research Innovation through the Arts and Humanities Council (Grant No. AH/V00879X/1) and the National Lottery Heritage Fund (Grant No. HG-16-05732). The views expressed here are not necessarily those of the UKRI, the AHRC or the NLHF. We are grateful for the support of many partners including NHS England, Age UK and the Stroke Association.

[2] Stephanie Snow, '"I don't know what I'd have done without this project: Oral History as a Social and Therapeutic Intervention During Covid-19', *Researching in Times of Crisis: Care and Resilience*, Volume 2, Bristol: Policy Press, 2020, pp.33-38.

Our evidence on the policy areas of focus[3]

1. Health and wellbeing

1.1 What effects and impacts has Covid-19 had on physical and mental health with respect to NHS staff?

Covid-19 is a new infectious disease which prior to December 2019 had no established evidence-base to inform understandings and treatments. 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 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.

1.1.1 ***Protecting staff, patients and families***

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% 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.

> *'a third of the swabs come back as false negatives … and there's a real issue with the Covid swabbing … you can have a Covid swab that says you've got Covid, you can also have Covid pneumonitis, which is this inflammation of your lungs, which is quite easily diagnosable on a chest X ray … there is a real issue with bed managers and*

[3] The AHRC sent us the call for evidence on Friday 27 November with a deadline of Tuesday 1 December. Hence the short time has allowed us to provide an outline rather than in-depth response to the areas under investigation. We would be happy to respond with more detail if requested.

nursing staff not being able to get their heads around the fact that it doesn't solely rely on the swab …That is a professional difference where doctors are used to balancing different pieces of information, and coming up with them with a kind of balance of probabilities, diagnosis, and nursing stuff are much more algorithm-based, yes or no, tick or cross'.

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 witin my eyes'. Some staff moved into alternative accommodation to protect families and experienced feelings of isolation and depression; and one interviewee described dividing her house to protect her husband with an underlying health condition and only having limited contact with him in the garden.

1.1.2 *Mental and physical trauma*

Staff worked long shifts which left them physically exhausted and few were able to take all their annual leave which exacerbated 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.

'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 heartbreaking'.

1.1.3 *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?'*

1.2 What effects and impacts has Covid-19 had on the physical and mental health of high risk patients (shielding)?

The government policy of shielding high risk patients has kept patients physically safe but has also exposed some of them to adverse mental health impacts from loneliness, isolation and boredom. Testimonies also expressed people's discomfort with the emphasis put on age as a risk factor.

> *'The hospital said I needed a GP examination. Because I am shielded, I can't go to the surgery so a GP came out in full PPE which was really strange. It was quite an intimate examination but I felt really safe. It was all very different but very efficient'.*

> *'One felt alienated and had to get used to a whole new way of living'.*

From March to June the government advice on implementing shielding policy evolved on a regular basis. In terms of governance, shielding raised issues of difficulties around data-sharing and data-reliability and the confusion for patients as to whether they needed to shield or not created tensions with their primary care providers.

> *'Some of the people that were originally on the shield register we've had to write to this week and say, we've got clear guidelines now and you don't need to be on the register. So they've been self-isolating for three weeks and actually just needed to be socially distancing. So it's been a right mess. It's taken up a lot of practice time and you've got people who need to be on it and don't want to be, and then you've got other people who want to go on it. It's from the sublime to the ridiculous. So yes, we've had one or two [patients] shouting over that'.*

1.3 What effects and impacts has Covid-19 had on the physical and mental health of patients with non-Covid-19 conditions?

1.3.1 *Poorer outcomes for health*

Patients responded immediately to the introduction of national lockdown and government messaging asking the public to 'protect' the NHS by reducing their interactions with health services. The rapid drop in patients presenting caused clinicians to worry about untreated disease and the poorer outcomes for health. We have evidence that patients' fear of

catching the virus prevented them from accessing care and they are now experiencing poorer outcomes as a result.

> '*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'.*

1.3.2 ***Separation from family/friends***

Intense distress was caused to patients, families and friends from new restrictions imposed on visiting in order to stop disease spread. One interviewee's daughter was admitted to Intensive Care after a drug overdose on the very day the unit closed their doors to patients. She was allowed to be with her daughter on admission in the morning but when she returned in the afternoon the doors were locked and it was then five months before she saw her daughter again. This led to patients having no physical contact with families for several months and having to rely on staff supporting them to use digital means such as mobile phones and WhatsApp to connect to family and friends. Staff also limited their usual social contact with patients.

> *'I just felt sad on the ward. I could just see people sat in their beds, lying, just knowing they hadn't had a conversation with anyone all day'.*

1.4 How has Covid-19 changed experiences of end of life care and bereavement for staff, patients and families?

Covid-19 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'.*

We see the main policy challenges and longterm impacts arising out of this area 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.

2. Communities, culture and belonging

2.1 How has Covid-19 affected public perceptions of and attitudes towards the NHS?

2.1.1 *Support for the NHS and 'heroes'*

The government's strategy placed the NHS at the centre of their response to the crisis, using the strapline 'protect our NHS'. It prompted immediate outpourings of love and support for the NHS which manifested in 750,000 volunteers signing up, the weekly Clap for Carers, fundraising and charitable giving to Association of NHS Charities, and donations of food and other goods to NHS staff from local and national companies. NHS staff initially welcomed these initiatives which boosted morale in the early period. However, over time, interviewees told us that they felt increasingly uncomfortable about the weekly clap and donation of goods. The key tensions arose from the way in which framing NHS staff as heroes produced a counter-narrative around the idea that heroes could be sacrificed for the greater good.

> *'The narrative that's been created about NHS staff being heroes just creates a narrative where it's okay for NHS staff to die. In hero films, it's okay for the hero to die as part of the greater good. I don't think that's fair'.*

> *'we've looked after some people and possibly saved their lives, but that's our normal job … I'm not a hero … I have found being cast as such, very troubling, because I can't live up to that expectation … to hold [staff who have died] up as a hero is … disrespectful of the fact that they were just somebody that went to work and got sick, and died'.*

Many staff iterated how they were continuing to do their 'normal' work, albeit in extraordinary circumstances but they did expect the NHS as their employer to keep them safe by providing appropriate PPE and infection control systems. Testimonies expressed anger at the disjuncture between the public clapping and public behaviour around following social distancing rules. The public clapping on Thursday 7 May compared to the non-adherence to social distancing at social events to mark VE day on Friday 8 May was a common example.

2.1.2 *NHS as cohesive social force*

Criticisms of the government handling of the crisis are distinguished from the NHS itself and instead, there is much evidence of the pandemic strengthening the place of the NHS in British identity and culture.

> *'I feel proud to be part of an institution whose sole purpose is wellbeing and health promotion …. I feel part of a team, there's a great sense of solidarity … I feel part of a big family whose ultimate sole purpose is to get people through it, and actually, the way that we came together as an institution is phenomenal'.*

> *'[the NHS] is a massive lifeline … when you see other countries, and you see they're charging whatever pence for a bit of cotton wool, and however many pence for a needle … we've just got that automatically at our fingertips, that if you're not well, you are treated, and it doesn't matter how much money you've got, it doesn't matter*

how little money you've got, it doesn't matter…there's no differentiation between anything. Everybody's treated the same in the NHS. You all get the same treatment, no matter what your circumstances are, and I think that's an absolutely fab thing, and I'm proud to be part of the NHS'.

'people have started actually enjoyed coming to work because it feels like they make a difference. … this actually made us all realise, including patients, what the NHS is actually about, and what it was created for'.

'If you look at what's happening in America … I think people are thankful that, okay, we might not have the PPE, it might still be stuck in Turkey or whatever, but it's a coordinated response … I don't think any other country in the world has got that advantage'.

The power of the NHS as a socially cohesive force meant that government strategy focused on clustering initiatives such as volunteering around the NHS and adopted a 'top-down' approach. This proved ineffective and revealed a lack of understanding about how things worked at local level.

'For instance there has been this 'Army of volunteers' that have been recruited to work with the NHS, and as laudable as it is and it is wonderful that loads of people have put themselves forward, immediately you knew that was not going to be able to cope because you can't organise that centrally… if resources had been put in locally to enhance local groups it would have been off the ground and running by now … [central government] don't understand what goes on locally because they have never had to experience it - they are not in touch with local services and don't know what local voluntary organisations and charities do … it seems like rather than go to them, a new empire needs to be set up because that adds onto this NHS centralised brand.'

We have much evidence of how the coming together of individuals and communities created a step change in feelings of social connectedness and solidarity.

'there's a massive shift in people's sense of solidarity and their sense of ethical responsibility to one another. And I think the wave of people that we had approaching us at the beginning, wanting to volunteer, help out with [name of the organisation] – I think that is an amazing thing to see. And it looks like it's happening around the country'.

'The number of people who have volunteered to get involved not only locally but across the country has been a massive positive … People getting out of their way to help others that is a very positive hope for the future'.

2.2 How has Covid-19 affected public trust and confidence in public health messaging

Attitudes to public health messaging throughout the crisis have broadly shifted from supportive in the early period to increasingly critical with current testimonies expressing frustration at the 'confusion' of the tiered system, the relaxation of rules over the Christmas period and the differences between nations. Dominic Cummings' travel to the North East

during lockdown in April was identified in many testimonies as having high negative impact in public adherence to social distancing rules.

> *'[public health messaging] it was completely undermined by Dominic Cummings' behaviour and the government's subsequent defence of him. So you saw very, very quickly, the disintegration of people sticking to the numbers … I know of loads of friends, who are just not sticking to the rules anymore … I don't have much respect for the messaging … the messaging is kind of irrelevant now, because nobody's sticking to it anyway'.*

> *'the whole spilt of England, Wales, Scotland and Northern Ireland with their different sort of rules and stuff just doesn't make any sense to me whatsoever'.*

There is much evidence of people interpreting the 'rules' differently and interviewees express anger at the risky behaviour of neighbours/colleagues whilst also feeling uncomfortable about reporting it to the police. Interviewees also expressed mistrust in the government's use of science as a basis for policy and the wider transparency around the crisis.

> *'I don't know how explicit I can be. I think it is a shambles, a total shambles and I despair. What else can I say?'.*

> *'Some days [public health info/briefings] it's quite informative but other days it just seems to drag along about the same old stuff. It's not much new information. It seems very slow. It kind of feels they are not telling us the whole truth, if that makes sense. Maybe it's just me being paranoid?'.*

We see the main policy challenges and longterm impacts arising out of this area as follows:

- 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.
- Building capacity onto existing networks and benefiting from detailed expert local knowledge rather than creating new structures.
- Supporting the volunteering infrastructure to mitigate against the impact of Covid-19 on local communities.

3. Knowledge, skills and employment

3.1 How did knowledge of the new disease spread across the health and science community?

During January and February 2020 as Covid-19 spread from China to Europe, social media became a key means of disseminating new knowledge about a previously unknown disease. It was the first time that a global pandemic of this scale had access to global media platforms and enabled knowledge to spread rapidly across nations and communities. Particularly for the UK, the videos of the overwhelming numbers of Covid-19 patients seeking care in Italian intensive care units were a decisive factor prompting clinical leaders to prepare and plan for the first peak of the virus in the NHS.

> *'We've never had anything like this in this country. You know, in my lifetime, most of us would have assumed that things like PPE would just be readily available … [it] all developed almost in parallel with the world's media. So I think doctors were in an odd position where we were probably gleaning nearly as much information from watching the news and media as we were from medical sources'.*

3.2 What effects and impact has Covid-19 had on digital skills?

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. Policymakers were hugely supportive of the rapid uptake.

> *'We've been frustrated for years with the slow uptake of digital technology and just like a flicker of a switch, Covid has driven changes to the way we do things. Video consultations are now commonplace … Unbelievable to think that the members of the public – patients – are no longer required to sit in the waiting rooms and wait for their appointment and sit face to face with the clinician. [...] In terms of digital revolution Covid-19 has transformed healthcare'.*

Less positively, patients needed access to technologies and this risked reinforcing existing health inequalities although some primary care providers ran volunteer schemes to support the learning of digital skills. 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 by 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.

> *'How important it is I think for a doctor to be able to sit next to your patient; give them a smile, give them a hello, explain what's going on and know that this is as important as giving them another course of antibiotic.'*
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> *'They're definitely benefits to be able to work [digitally] but what I'd say is that I think it's a shame if it's the case of doing it to save money and save time. What you lose is really this human side of what it is to be a doctor. I suppose I don't want to be a robot'*.

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.

> *'because I had to call families more just to update them on how their relative was doing, I think I learnt a new set of skills … [I] learnt a lot more actually about this patient than I would've done if I hadn't picked up the phone'.*

We see the main policy challenges and longterm impacts arising out of this area as follows:

- 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.

Breakdown of data sample by community and year of birth