All-Party Parliamentary Group call for evidence – learning lessons from the Government's response to COVID-19

Response from the NHS Reset Ethics Research Team

The NHS Reset Ethics research is funded by the UKRI AHRC rapid Covid call .

The project is being conducted by a multi-disciplinary team led by Dr Lucy Frith, University of Liverpool with Dr Anna Chiumento, Dr Caroline Redhead and Dr Carol Gray (University of Liverpool), Professor Heather Draper and Dr Paul Baines (University of Warwick), and Professor Sara Fovargue (Lancaster University).

Introduction

i. This response to the All-Party Parliamentary Group's Call for Evidence concerning the government's response to coronavirus (COVID-19) has been prepared by the members of the multi-disciplinary team running a UK Research and Innovation Arts and Humanities Research Council (UKRI AHRC) funded study. Our research is exploring decision-making and the ethical challenges of restarting and/or reconfiguring NHS services in maternity and paediatrics since April 2020. The team members, from the Universities of Liverpool, Warwick and Lancaster, have expertise in bioethics, law and clinical medicine.

Our project is entitled *'When pandemic and everyday ethics collide: supporting ethical decision-making in maternity care and paediatrics during the Covid-19 pandemic – NHS Reset Ethics Project'*, and is led from the University of Liverpool by Dr Lucy Frith (PI).

The coronavirus (COVID-19) pandemic is causing far-reaching consequences for health systems worldwide. In England, the response to the sudden demand for critical care services was to reorient clinical capacity. Many non-urgent services were suspended, and healthcare professionals and resources were redeployed to acute care. In April 2020, the UK Government declared that non COVID-19 clinical services **must** resume but that capacity to manage subsequent waves of COVID-19 should be maintained. This created a unique 'reset' context in which it became critical to consider how ethical considerations did and should underpin decisions about how to reset health services while new infection control measures were also managed.

ii. Our response presents the preliminary findings of our ongoing research. We suggest that:

a. Risk appetite and risk tolerance are not the only bases for choosing which trade-offs should be made in emergencies. Decision-making in healthcare, particularly in the context of a pandemic, *must also be values-based*;
b. Transparency as to what, and how, values underpin decision-making is crucial to support healthcare decision-makers during a pandemic**.** Our rapid review of guidance published by, amongst others, the Government and the Royal Colleges, found most to be 'ethics-lite'.[1] Healthcare decision-making can (and should) be supported by clarity and transparency with an underpinning *ethical framework for the reset phase of a pandemic*;
c. Transparency, clarity and consistency are equally important in communications with patients and families. Our public focus group data emphasised the importance to patients and families of understanding the reasons for, and being involved in evaluating, changes made to service provision as a result of the pandemic. Participants emphasised the idea that, in maternity and paediatric services particularly, the 'patient' is not just the woman or the child, but the family or wider support network too;
d. The COVID-19 pandemic was characterised by a rapidly changing public health picture. Information-gathering, communication, co-ordination and corrective action were all critical activities in this context. Our data suggests that senior NHS Trust decision-makers came together to co-ordinate regional responses, including mutual aid between Trusts, but that the national response might have benefitted from increased communication with regional decision-makers; and

[1] Chiumento A, Baines P, Redhead C, Fovargue S, Draper H, Frith L., '*Which ethical values underpin England's National Health Service reset of paediatric and maternity services following COVID-19: a rapid review*'. BMJ Open 2021; 11:6 http://dx.doi.org/10.1136/bmjopen-2021-049214

e. The possibility of healthcare professionals suffering mental health conditions linked to *moral distress*, as well as other mental health conditions, should be identified as a consequence of a pandemic. Frontline healthcare professionals' mental health will be affected where failures in co-ordination and communication result in differing regional approaches to healthcare decision-making and healthcare professionals lack practical ethical support.

iii. Our response reflects the findings of our rapid review of COVID-19 related guidance for paediatric and maternity services,[2] and offers a perspective on experiences of doctors, nurses and midwives, working in those specialist services during the COVID-19 pandemic. Our focus is the **reset phase** (described above). We have collected qualitative data by interviewing senior managers and healthcare professionals in four NHS Trusts spread geographically across England. These interviews have explored participants' experiences of making decisions about how best to restore, recover and reset the services that were suspended or reconfigured in the first wave of the pandemic, whilst continuing to offer care for patients with COVID-19.

We have also held focus groups with members of the public local to some of our participating NHS Trusts and with experiences of interacting with maternity or paediatric services during the pandemic. These groups have explored participants' experiences of decision-making in their local Trusts, the extent to which they felt involved in changes made to the way services were offered during the pandemic, and what they felt might have been done better.

iv. Our comments reflect the data gathered during the course of our research and our response is underpinned by this data, recognising that this is a qualitative study that produces rich data on the lived experience of our participants and not large-scale quantitative data.

Response

1. **Values based decision-making is a key aspect of managing healthcare services during a pandemic**. Fairness and transparency, openly stating and defending the values and principles that underpin Government decision-making and policy, are always important but become crucial in the context of a public health emergency. Policy decisions of the kind that must be made in response to a public health emergency require collaborative engagement between scientists, political and policy decision-makers and, where possible, the public, but also, and crucially, (bio)ethicists. The process of making political and policy decisions requires the consideration and weighing of various, often competing, perspectives and considerations. It is not possible simply to 'follow the science'.

2. **Transparency as to what, and how, values underpin decision-making is crucial to support healthcare decision-makers during a pandemic.** Pandemics—and public health emergencies more generally—reinforce approaches to ethics that emphasise or derive from the interests of communities. Accordingly, in the acute phase of the coronavirus pandemic, attention was focused on saving as many lives as possible, although notably the emphasis was on patients with COVID-19 and there was a lack of emphasis on saving lives threatened by non-COVID-19 illnesses. The focus was typically on infection prevention and control measures and on the approach that should underpin resource allocation *between* patients with COVID-19 in the event that demand for life-saving equipment were to outstrip

[2] See note 7.

supply.[3] Guidance on ethical responses to questions of this nature relating to the acute phase of a pandemic is readily available. In the UK, the Pandemic Flu Ethical Framework guided decision-making.

The **reset phase,** however**,** incorporates elements of recovery *and* of re-imagining future health services. It operates alongside and continues after the crisis phase, and must, therefore, mediate the tensions between the ethical orientations of 'usual' and 'crisis' phases, operating to balance the values of both patient-centred care and public health. This mediation between patient-centred care, underpinned by clinical ethics, and public health concerns, underpinned by public health ethics, presents ethical challenges that characterise (and are unique to) the reset phase. The decision-making context is challenging, with emerging evidence and uncertain outcomes, rapid adjustments to healthcare policies and practices, and uncertainties around personal risk. In the context of emerging variants of SARS-CoV-2 and further waves of COVID-19 infection, as well as the substantial backlog of cancelled and delayed care, it is clear that the reset of the NHS will continue for some time. **No nationally recognised ethical framework exists to guide decision-making in the reset phase.**

The absence of an ethical framework leaves healthcare decision-makers in a difficult position. Whilst a plethora of rapidly changing guidelines was promulgated during both the acute and reset phases of the coronavirus pandemic, our rapid review of guidance published by, amongst others, the Government and the Royal Colleges, found most to be 'ethics-lite'.[4] While key ethical principles were referenced, sometimes only in passing, many sources failed to operationalise them. We defined 'operationalisation' as applying ethical principles to specific situations, considering how predictable ethical dilemmas might be managed, or offering suggestions as to how, in practice, ethical principles might be balanced against one another. Guidance lacking this dimension leaves healthcare professionals without a coherent ethical framework to support decision-making. In the context of the reset phase, characterised by rapid change and uncertainty, consistently interpreting and applying broad-brush ethical guidance to practice becomes impossible. Regional differences in approach exacerbate this uncertainty. Where national guidance lags behind regional decision-making, a coherent and operationalisable healthcare response to a pandemic is difficult to achieve. **A clear ethical framework to underpin healthcare decision-making is therefore required.**

3. **The possibility of, and the reasons for, healthcare professionals suffering mental health conditions linked to *moral distress*, as well as other mental health conditions, should be identified as a consequence of a pandemic.** The findings of our qualitative interviews with healthcare professionals suggest two key issues are important in considering what lessons might be learnt from the Government's handling of the coronavirus outbreak so that the UK's response may be improved in future. These both relate to 'care', and the nature of what health*care* means in the context of the reset phase of a pandemic:

   a. **'Silver standard care'**

   Our research has explored the tension between clinical and public health ethics during the reset phase. We have found that providing so-called 'gold-standard' care – usual care – has often not been possible. Healthcare professionals are providing the best care they can in the circumstances; care that is limited by infection control measures in how it is delivered, what can be offered, and the length of waiting

[3] Baines P, Draper H, Chiumento A, Fovargue S, Frith L.'*COVID-19 and beyond: the ethical challenges of resetting health services during and after public health emergencies*'. Journal of Medical Ethics 2020; 46:715-716.

[4] Chiumento A, Baines P, Redhead C, Fovargue S, Draper H, Frith L., '*Which ethical values underpin England's National Health Service reset of paediatric and maternity services following COVID-19: a rapid review*'. BMJ Open 2021; 11:6 http://dx.doi.org/10.1136/bmjopen-2021-049214

times. The reset phase requires the continuing care of patients infected with COVID-19 (and those suffering from long COVID), as well as the recovery of services that were suspended during the crisis phase, and the redesigning of services that cannot be offered in the usual way. The continuing ability of the system as a whole to function becomes the objective. Patients, therefore, must expect to receive care that treats their clinical needs, 'good enough' care, what could be termed 'silver-standard' care'.[5] **There is a pressing need to acknowledge the reality of silver standard, or 'good enough', care**. The concept, and language, of excellence should specifically **not,** in the reset phase**,** be used as a standard to which healthcare professionals are expected to aspire, save insofar as excellence is regarded as being concept specific – so an excellent pandemic response might be one that embraces the 'good enough' or 'silver standard' care that circumstances allow.

Given the unnecessary stress that results from a mismatch between 'the message and 'the reality', there is an obligation to ensure that this is made obvious both to patients and to healthcare professionals from the outset. Patient and public information must be clear as to what is possible with the reasons for these decisions – including the underpinning values - simply and clearly explained. Our public focus group data indicates that patients are able to understand, and willing to accept, 'good enough' care when they understand what that means, and why it is necessary. What is 'good enough' must also be reinforced clearly and transparently in professional guidance. If it is not, healthcare professionals are set up for failure, and their efforts to date demonstrate that they deserve better than that. As the reset phase continues into what might be described as the 'post vaccination new normal', the Government and policy-makers must prioritise how to make compromises in standards of care fairly and transparently. This should include considering how to balance COVID-19 care and non-COVID-19 care, and at what point (and how) to resume an aspiration to higher standards and possibly 'gold-standard care' (whether or not gold-standard care can be considered to have been the prevailing standard prior to the coronavirus pandemic).

b. **Care and Caring**

Our research has discovered that the caring aspects of treatment - an essential component of patient-centred *care* - have been an immediate casualty of the reset phase, due primarily to the continuing requirement for strict infection prevention and control measures. We understand care as embracing the interpersonal relationships between the patient (and their family) and the healthcare professional, and as an ethically important dimension to healthcare delivery. Our participants, for example, reported that while treatment delivered wearing personal protective equipment can largely meet a patient's clinical needs, there are significant barriers to offering or demonstrating *care*. Care from behind a mask or a ventilated hood is experienced differently by both healthcare professionals and their patients. Accordingly, it is clear that balancing public health concerns with the 'human' aspects of patient-centred care is a crucial difficulty for healthcare professionals during the reset phase. It is here that the distinctive ethical tensions arise for healthcare professionals and decision-makers aspiring to 'gold standard care' in a 'silver standard' context. Our research suggests that healthcare professionals are burdened by their experiences of offering treatment that they feel is ethically lacking because it fails to attain the relational, caring, and *human* dimensions of health*care*.

Many healthcare professionals are motivated by the possibility of offering compassionate care, where 'care' is understood to be a relational, multi-directional activity. 'Care', in the context of healthcare services is often broader than 'treatment', and this is particularly true for maternity services, where

[5] Horne, S. James, R. & Draper, H. (2021). Reconsidering triage: a panel presentation giving ethical, historical and medical perspectives on planning for mass casualty events in military and civilian settings. Conference presentation, 10th ICMM Workshop on Military Medical Ethics, Zurich, April 2021.

there is often no treatment needed and care is concerned with supporting both women *and* their close family members through physiologically normal births. The implications of de-humanising care are therefore significant. How far should care be compromised to prevent viral transmission? Public expectations of what care should look and feel like under the constraints of a pandemic need to be realistic. Equally, where understanding of a new disease increases as the pandemic progresses, as it has done during the reset phase of the coronavirus pandemic, ethically operationalisable guidance should allow for flexibility in decision-making where the risk of infection in particular circumstances is known to have reduced.

Crucially, there are implications too for failing to *care for healthcare professionals*. As well as opening the door to moral distress, a failure to support and protect frontline healthcare professionals might create a work-life *imbalance*, such that the personal and relationship costs of working in healthcare outweigh its rewards, and people will choose not to do it.

4. **If lessons are to be learnt from the Government's handling of the coronavirus outbreak so that the UK's response and preparedness may be improved in future, the APPG's recommendations to the UK Government must require that attention be paid to the ethical dimensions of decision-making for healthcare professionals and organisations.** We set out below a brief summary of our key findings.

a. Healthcare professionals have lacked structured ethical support in the absence of an ethical framework tailored to the unique public health/clinical ethics tensions characterising the reset phase. This has meant nationwide consistency of decision-making has been/is lacking. This, in turn, increases pressure on local decision-makers.

b. Infection prevention and control measures impacted on the nature and quality of 'care' that healthcare professionals have been able to offer. It is crucial that transparent communication manages public expectations of what is possible during a pandemic to support 'good enough' or 'silver standard' care. If 'usual' care is the benchmark, healthcare professionals will be set up for failure *and it is crucial that the system is designed to care for healthcare professionals as well as for patients and their families*.

c. Infection prevention and control measures discourage close physical proximity and impede non-verbal communication, both of which impact on emotional and social support for patients at critical times. Within a hospital setting, these measures begin with policies designed to reduce footfall. Designated visitors are allowed on paediatric wards – but only one at a time. Someone attending for an emergency antenatal scan must attend alone. Those giving birth may have a birthing-partner present but only when active labour has been confirmed. A rigid interpretation of the criteria for confirming active labour, coupled with the time it takes to don full PPE, can result in a birth partner missing the birth. The existence of these measures, and having to enforce them, causes difficulties for healthcare professionals and opens the door to moral distress. The impact on healthcare professionals of being unable to offer '*caring'* treatment must be recognised.

d. Further work is required as to what 'ethics support' might help healthcare professionals. The next phase of our research will explore the perspectives of healthcare professionals and inform the design of such materials. The need for support of this nature should be built into the Government's pandemic playbook to specifically inform the design of its response the next time.

Concluding comment

Our research activity is continuing, and the responses above are therefore informed by our findings to date. Our research is a small qualitative project, but demonstrates themes that could be explored to ascertain prevalence by quantitative methods. We would be pleased, if it were to be considered helpful, to report on subsequent findings, to expand our response as our project progresses, or to submit oral evidence.

NHS Reset Ethics research team
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