Women's Health Strategy: Call for evidence

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 call for evidence to inform the development of the Government's Women's Health Strategy 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 looking at decision-making and the ethical challenges of restarting and 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 staff 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. This call for evidence is intended to inform the priorities, content and actions within the Women's Health Strategy. Our response offers a perspective on experiences of maternity services during the COVID-19 pandemic. Our comments reflect the data gathered during the course of our research and our response is underpinned by this data.

We have collected qualitative data by interviewing senior managers and healthcare professionals in four NHS Trusts spread geographically across England. These interviews have explored their 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.

iii. Our research speaks specifically to question six, which considers how we might understand and respond to the impacts of COVID-19 on women's health and women's health services. This is the focus of our response below (we have addressed this question first). Our comments reflect the data gathered during the course of our research to date, 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.

Responses

Question 6: Understanding and responding to the impacts of covid-19 on women's health.[1]

Maternity services: A general comment

Public health priorities during the pandemic have impacted on individual and personalised care. Many healthcare professionals are motivated to do the work they do because they want to offer compassionate care, where 'care' is 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 there is often no treatment needed and care is concerned with supporting both women *and* their close family members through physiologically normal births. Our participants have reported that care, and caring relationships, have been a casualty of the pandemic, with the focus having shifted to infection prevention and control. The incorporation of norms from public health into clinical care have put pressure on the long-established principle that the individual patient's interests are core to clinical management. Infection control policies have, by discouraging close physical proximity and impeding non-verbal communication, prevented emotional and social support at critical times for those giving birth and others (such as partners and close family members).

Our participants described the emotional impact of socially distanced death in hospital and bereavement as worse than before the pandemic. Participants have looked after babies who have died without meeting their grandparents and siblings. We have been told of instances where both parents were allowed to be by the cot together only when care was withdrawn. We have heard how restrictions on visiting have impacted on the shared experiences of other family members. Participants described feeling, as a result, that parents' memories were more likely to be shared with staff. Despite this, where staff would normally offer physical comfort (such as a hug) or other tangible support (such as attendance at a funeral) they have been unable to do so due to infection prevention measures.

Our participants experience caring as a human job that goes beyond the mechanics of delivering medical treatment. The implications of de-humanising care are significant. Our preliminary findings suggest that healthcare professionals have questioned how far *should* care be compromised to prevent viral transmission. Excellent patient care in 'ordinary times' should be holistic, incorporating medical expertise, engagement with the patient's physical and emotional needs, and offering a human response to joy, relief, anxiety, pain or bereavement. One midwife in our research specifically referenced the etymology of 'midwife' – which derives from the middle-English for 'with woman' – as encapsulating the all-encompassing nature of the care that midwives want to offer to their patients. PPE and social distancing literally get in the way of that. An ethical discussion is therefore needed to consider *how* the tensions between the interests of the 'wider community', in terms of infection control, and the patient as the 'first concern' should be balanced.

Policy-makers have, to date, been reluctant to address the fact that 'gold standard' care is simply not possible in the context of a pandemic. In avoiding a discussion about what is 'good enough', we suggest that they do healthcare professionals, patients and their families a disservice. Public expectations of what care should look and feel like under the constraints of a pandemic need to be realistic. If it is not accepted that excellence is about doing the best that can be done in these circumstances, healthcare professionals will be set up for failure. Demoralisation, distress, and other mental health issues suffered by healthcare professionals as a

[1] In making reference to 'women' and 'pregnant women' in our responses, rather than 'people' and 'pregnant people', we are adopting the terminology used by the participants in our research.

result of their experiences of the pandemic are likely to increase the numbers that consider leaving the profession.[2]

Evidence on how COVID-19 has impacted women's health (positive and negative)

Maternity Services

1. **Healthcare professionals and our focus group participants reported that refusing a woman's partner access to her antenatal scans and screening had a particularly negative impact on both pregnant women and their partners or other carers**. Hospital senior managers had, in making decisions about how to provide services during the pandemic, to consider staff safety as paramount. The requirement that staff (and patients) wore PPE was part of the response, but attention had also to be paid to the number and proximity of people in an enclosed space. Typically, antenatal scans are carried out in small rooms, and all of the NHS Trusts participating in our research banned partners from attending them. Our participants indicate that women are still advised to attend the clinical setting alone, but that partners are now allowed to accompany them. The rationale for banning partners during the acute phases was the significantly increased risk to sonographers, who might scan 20 women in a working day. Exposure to their partners as well, particularly in the period before lateral flow testing became widely available, was considered an unacceptable risk to sonography staff. Mitigating the risk to staff, however, created a risk of harm to pregnant women attending for scans alone as a result. Where, for example, a scan revealed complications or bad news, where a woman was suffering from mental health problems, or where the pregnant woman was a teenager, healthcare professionals and focus group participants relating their personal experiences considered the removal of the support of a parent or partner to be damaging.

2. **Yet, banning partners from antenatal scans and screening allowed NHS Trusts to create safe spaces for disclosures of domestic violence or other abuse.** The reduction in, or cancellation of, home visits and other face-to-face appointments led to concerns about women on safeguarding pathways. Midwives are made aware of women who are known to social services or at risk of domestic violence at an early stage in any pregnancy, and home visiting or engagement with women in the community allows midwives to support local safeguarding teams. Banning partners from antenatal scanning appointments for infection prevention reasons allowed healthcare professionals to create safe spaces for safeguarding concerns to be raised at this appointment, whilst home visits were suspended.[3] This vital aspect of healthcare therefore continued despite limited in-person interactions.

3. **Banning partners from hospital prior to delivery had a negative impact on women's experience of childbirth.** Changes to maternity procedures during the coronavirus pandemic permitted the presence of a partner or other support person on the labour ward only when 'active labour' became established. Our participants indicated that strict adherence to this rule meant that, on occasion, a partner or support person was not present for the birth. This not only deprived the woman of the emotional (and physical) support of a partner, but also deprived the partner of the experience of the birth.

   Note: Recognising these impacts, some Trusts relaxed the 'strict' criteria for confirming active labour where other indicators suggested to their satisfaction that active labour had started.

[2] See BMA tracker survey, April 2021: https://www.bma.org.uk/media/4055/bma-survey-april-2021-uk-overall-snapshot.pdf

[3] Note: we do not intend to suggest that this should be a justification for continuing to restrict attendance at antenatal scanning appointments once safeguarding processes/home visits resume.

4. **Neonatal specialists reported that policies banning mothers whose COVID-19 status was unknown, or who had tested positive for SARS-CoV-2, from neonatal wards was extremely damaging both for mothers and healthcare professionals.** Where a mother tested positive for COVID-19, or was self-isolating when she went into labour, the prioritisation of staff and patient safety initially underpinned policies that refused her access to the neonatal ward. The restriction was typically only lifted if care was to be withdrawn at the end of a baby's life. Where the effect of such policies was to prevent a mother from seeing her newborn, particularly where the baby was unwell and its recovery uncertain, mental health consequences for mothers were described. These included emotional withdrawal and an unwillingness to engage with the baby even when access was allowed (for example, at the end of life). Healthcare professionals reported feeling damaged as a result of providing 'bad care'. The relatively fast reversal of these policies did not help healthcare professionals come to terms with the feelings of failure they reported as a result of having to enforce policies they vehemently opposed.

5. **Restrictions on visitors to hospitals had both positive and negative impacts on women's health.** Most hospitals initially limited visiting to one visitor, subsequently relaxing this to allow two named visitors who were not allowed to be on the ward at the same time. A negative lateral flow test for SARS-CoV-2 was also required, when such testing became available. Typically, this meant that the informal support a woman would receive from visiting family members or other carers was not available to her. This was particularly damaging where complications in pregnancy, or during or after delivery, resulted in admission to hospital. Participants talked, for example, about teenage mothers having to choose between their partner and their mother, and women for whom English was not a first language being unable to have their partner and a translator present at the same time.

   On the positive side, however, participants reported that women were able to build relationships with each other more readily when visitors to the ward were limited, allowing for increased informal support. The experience of one focus group member, who felt so isolated in a private room that she rang a relative in the middle of the night, supports the healthcare professionals' view of the benefits of informal support from others on the ward. The fact that wards were quieter and less busy allowed women more opportunities to engage with the ward staff, and to rest. Midwives preferred the quieter, cleaner wards but did not feel, on balance, that the severest restrictions on visitors should continue, although there was some support for continuing to limit the number of visitors, including children. The rationale for this was that the presence of too many visitors can be tiring and stressful both for women on the ward and for healthcare professionals.

6. **Reducing post-natal community visits, and changes in practice for those that continued, had (and continues to have) a negative impact on women and their families.** While the availability of testing and vaccination against SARS-CoV-2 has reduced the risk of infection for community midwives, home visits are still reduced but happen whenever a midwife considers a virtual appointment is unsuitable. In making such a decision, midwives are advised to consider a range of things, including access to the appropriate technology, English language ability, the existence of any safeguarding concerns that would mitigate in favour of a face-to-face appointment and the woman's wishes and feelings. Trusts are guided by their midwives' perceptions of the balance of the infection risk against the woman's need to be seen, which means that practice is inconsistent across England. Where a midwife does attend, PPE creates a barrier to the checks a midwife would ordinarily carry out, and many of these checks will not be 'hands on' in the way that they would have been pre-pandemic (the mother holds the baby). Women who would ordinarily also be visited by a social worker may still not receive those visits in person, but may have a telephone or video call with the social worker while the midwife is

physically present. Participant midwives felt that this increased the attending midwife's responsibility, adding to the overall burden on midwives.

7. **Women feel that, despite the increase in the use of technology to support 'virtual' care, they have not always been able to contact healthcare professionals during the pandemic.** While some women have felt very supported by their healthcare providers throughout their pregnancies, some have not. Focus group participants report widely differing experiences, from being given personal contact details by a specialist nurse, to having to do lots of 'detective work' to find a way of contacting a consultant's secretary for advice. Most participants understood the need to prioritise staff and patient safety, but many felt that communication could (and should) have been better during the pandemic.

8. **Our focus group participants had not been consulted about the changes made to local maternity services.** Although some trusts report having co-produced policies with their local Maternity Voices Partnership groups, women did not feel involved in changes to maternity services. Where changes to services were publicised by Trusts, our focus group participants described confusing differences between, for example, a Trust's website and its Facebook page. Participants felt, though, that the co-construction of virtual services with service users would be welcome. They felt that remote access to healthcare offers many benefits (including, for example, reduced travel costs and less time off work to attend the hospital).

Evidence on how COVID-19 has impacted women's health services, including innovation in service delivery

Maternity services

9. **Support for homebirths was withdrawn during the early stages of the pandemic. Senior midwives participating in our study report policy changes** during the first wave of infection as a result of the pressure on emergency ambulance services.[4] Support for homebirths was suspended in some areas and pregnant women were advised that they would have to deliver in a hospital setting. This was because the ambulance service was unable to guarantee a sufficiently prompt response time to allow for safe transfer of a labouring woman to hospital in the event of complications. The period for which homebirths were suspended was short lived (around a month), but it is an example of the impact on some women's health services of problems in other parts of the health service. While, in the scheme of the wider impacts of the pandemic, this might be easily dismissible, it directly impacted on the delivery choices available to the women who gave birth during that period.

10. **Community hubs and virtual booking for antenatal appointments.** Service delivery changed for community-based antenatal visits in some areas. Initial information-gathering was done remotely (either by telephone or other virtual appointment) and the first face-to-face visit offered at a community hub. This reduced exposure for community midwives to families in their homes, and reduced the need for women to attend visits at the hospital (although they could choose to do so). Participants report that this change in service delivery was popular and a hybrid offering is likely to continue. Focus group data indicate, however, that participants' experience of community hubs was not entirely positive (for example, accessing them was difficult for some women), although they could see the advantages if the service could be offered with more flexibility for women who were unable to travel to the hub.

[4] And see the BMJ Blog from April 2020: https://blogs.bmj.com/bmjsrh/2020/04/02/home-birth-covid-19/

11. **'E midwife' services were offered by some trusts, via Facebook or telemedicine platforms.** Responses to these virtual offerings from healthcare professionals and service users were mixed. Healthcare professionals were concerned that safeguarding was more difficult when it was not clear who was listening to the consultation, or who might be in the room with the woman but choose to remain unseen and unheard. Our participants were also aware that virtual services might not be accessible to women who lacked the appropriate devices or connectivity, and that care needed to taken to ensure that face to face appointments remained available where necessary.

    The 24/7 availability of online interpreting / translation services to Trusts was seen by our midwife participants as a positive innovation. Their experience during the pandemic was that these services increase the support Trusts can offer to women whose first language is not English, and avoid the waiting time women typically have to endure where there are difficulties in accessing appropriate face-to-face translation/interpretation services. They reported that the availability of translators in different time zones across the world had increased the availability of support at unsociable hours in the UK. Where a translator attends virtually, there are, of course, no social distancing consequences – so a partner, or the designated number of visitors, can still be with the woman.

12. **Making accommodations: a general comment about innovations in service delivery.** Where changed practices continue to be used as the reset of the NHS continues, it will be important that attention be paid to issues that have been experienced by women, their family or carers, and healthcare providers, as difficult, or ethically problematic, during the pandemic. In the context of extreme pressure on services, or a wave of infections sufficiently worrying to justify a national lockdown, changes in practice can be justified that would not be justifiable in 'usual' circumstances. It will be important to ensure that unsatisfactory ways of working do not become 'normalised' as the infection risk reduces. Collaboration with women, and the co-creation of policies and procedures for maternity services, will be critical.

Concluding comment

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. Our research activity is continuing, and the responses above are therefore informed by our findings to date. We would be pleased, if it were to be of assistance, to report on subsequent findings, or to expand our response as our project progresses.

NHS Reset Ethics research team
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