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## Title page

“Anxious and traumatised”: users’ experiences of maternity care in the UK during the COVID-19 pandemic

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JS and RB both contributed to study conceptualisation, design, data collection, data analysis, and writing of the manuscript.

### Conflict of Interest

None declared.

### Ethical approval

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## Introduction

The COVID-19 pandemic saw universal, radical, and ultra-rapid changes to National Health Service (NHS) maternity services in the United Kingdom (UK). At the onset of the pandemic, NHS maternity services were stripped of many of the features which previously supported woman and family-centred care. In anticipation of unknown numbers of pregnant women and maternity staff potentially sick with COVID-19, services were pared back to the minimum level considered to be required to keep women and their babies safe. Little was initially known about the SARS-COV-2 virus and its impact on the general population or on pregnant women and their babies. On Monday 16<sup>th</sup> March 2020 pregnant women were advised that it was particularly important for them to follow advice to avoid all unnecessary social contact<sup>1</sup>. Pregnant women who were deemed to be clinically extremely vulnerable, including those with significant heart disease, were advised to 'shield'<sup>2</sup>. The advice to healthy pregnant women was not based on evidence showing pregnant women and their babies were at a greater risk than others but was underpinned by the precautionary principle<sup>3</sup> - 'it is better to be safe than sorry' - often operationalised in light of a paucity of evidence.

Common changes to NHS services included a reduction in face-to-face antenatal and postnatal contact with women<sup>4</sup>, using 'smart devices' for antenatal and postnatal care, a centralisation of services into obstetric led settings, the closure of midwifery units and stopping home births, and restrictions on partner and family visiting/attendance.

By the end of March 2020, just weeks after the introduction of COVID-19 service changes, national maternity support groups were reporting high levels of anxiety among women accessing maternity care<sup>5</sup> and were advocating against the implementation of blanket visiting restrictions in maternity services<sup>6</sup>. As the pandemic, and visitor restrictions continued, evidence emerged of pregnant women and new mothers feeling isolated and lacking necessary support<sup>7</sup>.

COVID-19 maternity risk messaging and service adaptations represented radical and untested service changes in a context of widespread anxiety and uncertainty. At the onset of the pandemic, restrictions placed on birth partners and maternity visitors throughout the UK were stringent and consistent. Subsequently, as more became known about the impact of the virus on individuals and organisations, central advice to the NHS on birth partner and maternity visitor restrictions throughout the UK was relaxed and diversified. Whilst some relaxation of visitor restrictions has occurred, guidance<sup>8-10</sup>, and implementation of such

guidance<sup>11 12</sup>, across geographical regions of the UK now varies. Anecdotal examples of individual staff exercising over-zealous implementation of restrictions continues.

Inconsistencies in the relaxation of maternity visitor restrictions based on service preferences rather than scientific evidence cannot be logical, fair, or justified, and has once again highlighted the challenges of accurately reflecting evidence in maternity public health messaging. The ongoing potential for new emerging variants and local 'lockdowns', and the likelihood that some service changes will become permanent, means it is important we understand the impact that the changes to services have had on users. This can be used to prioritise the return to visitor access and inform evidence-based recommendations on the organisation of maternity services for the 'new normal' NHS.

## Methods

We conducted an online survey to explore user's experiences of COVID-19 public health messaging and 'socially-distanced' maternity care across the four nations of the UK. The study population consisted of women who had experienced pregnancy after the 11<sup>th</sup> March 2020 when the WHO declared a pandemic, whether still pregnant or had a pregnancy ending in a registrable birth, miscarriage, or termination. We collected data between June and September 2020, as this covered the period when stringent visitor restrictions were still commonly in place.

### Inclusion criteria

- Women who are 16 years old and above
- Women who have been pregnant or given birth since 11<sup>th</sup> March 2020
- Women who are living in the United Kingdom

### Exclusion criteria

- Women with insufficient English.

We sought to include experiences of pregnancy during the COVID-19 pandemic regardless of an individual's gender identity, sexuality, ethnicity, religion, or the outcome of their pregnancy. However, the survey was not intended to produce a nationally representative sample of respondents as this was not feasible within the project time scale or budget.

### Recruitment

We disseminated a link to the online survey through existing platforms for expectant and new mothers (e.g. MumsNet and NetMums), and the extensive social media networks of collaborating organisations (e.g. NCT, and Birthrights). We also used Twitter, Instagram, and Facebook's paid-for advertising feature. Finally, we shared details of the survey with relevant local and grassroots level organisations working with specific groups of women and their families (e.g. City of Sanctuary).

### Survey tool

The online survey was developed in collaboration with the project's Oversight Committee which includes clinicians, academics, and patient representatives with extensive experience of supporting women through pregnancy.

The survey asked respondents about their experiences of and opinions on public health advice for pregnant women during the pandemic, and their experiences of antenatal, intrapartum, and postnatal care in reconfigured maternity services. There was a mixture of quantitative and free-text, qualitative questions. The same survey was completed by all respondents, for example, by those who were currently pregnant and those who had already given birth. The number of responses vary for each question, due to missing data and respondents completing questions relating to their own point on the antenatal, intrapartum and postnatal pathway.

The survey was designed so it could be completed in approximately 15 minutes and was hosted by SurveyMonkey.

### Data analysis

We exported the survey data from SurveyMonkey® into a Microsoft Excel® spreadsheet. We then extracted free-text responses and stored them in Microsoft Word® documents. We thematically analysed the free-text data using an approach described by Braun and Clarke<sup>13</sup> supported by Dedoose<sup>14</sup>.

Quantitative data were cleaned in Microsoft Excel® and descriptive statistics generated in Microsoft Excel and SPSS<sup>15</sup>.

### Ethics

Participants did not receive any remuneration or incentive for completing the survey. Ethical approval was granted by the Research and Ethics committee of the School of Social Sciences at Cardiff University.

## Results

We present our findings according to the chronology of the maternity care pathway: communication with women; public health advice for pregnant women during the pandemic; antenatal care; care during labour and birth; and the postnatal period. We also present findings relating to the communication of the latest guidelines and restrictions. Quantitative and qualitative findings are presented simultaneously.

All 524 women completing the survey had experienced maternity care during the pandemic. Most participants were pregnant at the time of taking the survey (n=331, 65.7%), or had given birth during the pandemic to a live baby (n=171, 33.9%). Fourteen participants' pregnancy had ended in a miscarriage, termination, or the death of their baby. Around half of all participants (239, 45.5%) were expecting or had just given birth to their first baby. Reflecting the proportion of women with an underlying or pre-existing health condition (n=129, 26.0%), or a pregnancy related health condition (n=150, 30.4%), 40.3% (n=199) of women reported being under obstetric care.

Participants appreciated that the pandemic represented a rapidly changing situation with new emerging information relating to pregnancy, and the need for the NHS to have adapted maternity services to reduce risk to the public and staff.

### Demographic characteristics of participants

The mean age of the 524 participants was 31.8 years. Most participants were married (68.4%, n=262) or living with a partner (27.2%, 104) and heterosexual (93%, n=356). Participants were predominantly White British (85.9%, n=329). A further 9.4% (n=36) participants were 'White Other', including Irish, North African, European, and Middle Eastern. A minority of participants identified as a range of Asian (3.4%, n=13) and Black ethnicities (0.8%, n=3). Many participants were still working in paid employment with 37.4% (n=177) of the survey participants reporting that they were key workers, 15.2% (n=72) of whom were healthcare professionals. 11.6% (n=72) of respondents were in receipt of or had recently applied for state benefits.

### Public health advice

The vast majority of respondents, 89% (n=429) either agreed, somewhat agreed, or strongly agreed that pregnant women should practice stringent social distancing. However, 40.8% (n=122) of women said that they found the advice somewhat unclear and confusing, and 16.7% (n=50) said it was very unclear and confusing. Women cited the precautionary principle when explaining why they thought stringent social distancing was important for pregnant women:

*"As the virus is relatively new to us I think it is important to social distance. Just there is not enough data or evidence as to what impact it could have to a pregnant woman. Although some pregnant women have tested positive and given birth with no issues I don't think it is necessarily indicative of how it would progress should I catch it myself. So to me it is not worth the risk."*

However, they also reflected on the practicality of restrictions, and the negative impacts of stringent social distancing:

*"I understand the importance of social distancing, and I have remained at home throughout lockdown, but my husband is a key worker and has been going into work, having contact with lots of other people, meaning I've still been at risk yet I haven't even been able to meet with my immediate support network (parents) which has been hugely upsetting and distressing during what should be a happy time for us."*

Several respondents reflected on how the communication of evidence/the paucity of evidence on pregnant women being at greater risk of COVID-19 was poor. There was also widespread confusion over the recommendation for stringent social distancing, with many

women overinterpreting advice as an instruction to ‘shield’, which had far-reaching impacts on wellbeing:

*“It is unclear to me whether pregnant women are at greater risk (some stories in media about death of mothers and sickness in new babies, but very little explanation of whether this is widespread and why that might be). The difference between social distancing and shielding has not always been clear.”*

### Antenatal care during the pandemic

#### Pragmatic and positive

A small number of women provided comments indicating they were pragmatic about changes to care and partner involvement:

*“It has been nice to sit in the car and wait rather than in a waiting room. I have felt very alone and unsupported when it comes to having important scans though. I am looking forward to the postnatal ward being a bit quieter as I found the number of visitors a bit overwhelming last time, however my husband will have to leave after my c-section and won’t be permitted to come back until I’m being discharged. The midwives have been amazing. I really commend them for all their hard work at such a difficult time.”*

#### Women attending alone

Over 92% of women (n=421) had experienced restrictions on partners attending antenatal care appointments. A high proportion of participants, (83.3%, n=379) had experience of having an ultrasound scan during the pandemic. Many of these women found attending alone to be distressing, particularly when a problem was identified, if they had experienced a previous pregnancy loss, or if the care was unscheduled.

*“Having my 20-week scan alone, being told there was a problem with the baby was awful. Communication was poor with the sonographer and the consultant, and I was extremely distressed after 2 miscarriages in the past. Then having to relay the information to my partner whilst sobbing on the phone. Every appointment since had been awfully distressing.”*

The survey did not specifically ask about use of private care but several women commented on accessing private scans so their partner could attend without restrictions.

*“We have been lucky enough to be able to afford 2 private scans, which means he has been able to be there for some. This has cost us around £750 in total. We are lucky, many people cannot afford this.”*

Women found attending emergency antenatal care alone particularly distressing. They described having to attend when bleeding in pregnancy, for reduced fetal movements, and in other situations when they could be informed that their baby had died – all without a partner for support.

*“Awful. I was told at a routine 12-week scan that I’d had a missed miscarriage. I was on my own and my partner was in the car. I had to go through a very difficult scan alone and then also had to relay that information to my husband. It made an already difficult situation much more challenging.”*

#### Virtual antenatal care

Receiving some antenatal care by virtual means was common with 51.8% (n=243) of participants having experienced ‘routine’ check-ups with a midwife by phone or video calls. A lower proportion of participants, (29.4%, n=138) had experienced a virtual appointment with a doctor. Very few participants (4.2%, n=17) reported having difficulty with the technology required to access virtual care, but only 12.9% (n=31) considered their needs were entirely met by this mode of care delivery, and 23.3% (n=56) felt their needs were not at all met.

*“It has felt very hands off. I’ve had two very brief phone calls. Whilst I have been pregnant before, it ended in miscarriage very early, so this feels like the first time I’ve been properly pregnant. As I haven’t been through the NHS antenatal care pathway before it feels a bit daunting with so much uncertainty and so little contact.”*

For some participants they were concerned that reduced care may have placed themselves or their baby at increased risk:

*“A lot has fallen through the cracks. My local midwives seem very overworked/understaffed. I didn’t see anyone until I was almost 30 weeks. Before that, I had a phone booking appointment and both 12 and 20-week scans. No other phone calls - nothing. I also didn’t get diabetes testing despite being high risk due to family history.”*

#### Confidence in accessing services

Many women reported still having some aspects of care delivered in person. For example, 34.9% (n=159) of respondents reported having appointments with a doctor or consultant. When asked how confident they felt about accessing services in person, 56.5% (n=257) of respondents said they felt confident about accessing services in hospital, and 45% (n=205) felt confident about seeing their GP. Conversely, 35.8% (n=163) said they felt unsure or very unsure about accessing services in hospital, and 37.6% (n=171) felt unsure or very unsure about seeing their GP. A worrying minority of 11% (n=50) women said they had missed an antenatal appointment, with the most cited reason being *“I was worried about getting COVID-19”*.

#### Care during labour and birth

In keeping with a common move to centralise maternity services into hospital obstetric units, and amidst concerns that ambulance services may not be able to cover maternity calls, many women planning birth at home or in midwifery units were informed their plans



would need to change as these options were no longer available. Like in antenatal care, some women who could afford private care overcame restrictions in the NHS by employing an independent midwife.

*“I was extremely disappointed that home birth services were stopped. It presented a completely problematic situation if you had children already as your partner would either have to be with you OR them, or you broke social distancing and had someone at home / they went elsewhere. We used an independent midwife for a home birth in the end so that we could avoid this problem”*

An aspect of change women reported as particularly distressing was that partners were only permitted entry into the maternity unit once established labour had been confirmed. This resulted in women in labour needing to enter maternity units alone when in pain and anxious. Women who were being cared for in different Trusts/Health Boards reported a variation in policies on when partners could join them:

*“These restrictions have caused great distress between me and my partner as this is our first baby and we wanted to do everything together. Also, hospitals have put restrictions on birthing partners and my hospital doesn’t let a partner in till 7cm. As this is my first baby my anxiety through the pregnancy has been horrendous.”*

*“Husband missed the birth as wasn't allowed in until I was 4cm so waited at home, but I progressed so quickly that he didn't get back in time. Gutted.”*

Once in labour 14.5% (n=26), of participants were required to wear a mask or other PPE. For 31.6% (n=56), the wearing of PPE by staff was considered to have had no real impact on them, and 22.6% (n=40) of participants felt safer due to staff wearing PPE. However, 19.2% (n=34) of women felt it made communication more difficult, and 13.6% (n=34) of participants found the wearing of PPE by staff to be unsettling or scary.

## The postnatal period

### Hospital postnatal stay

Changes to postnatal visiting policies were reported as almost universal, with 88.4% (n=176) of participants stating there had been changes to their Trust or Health Board’s policies. Around half (49.9%, n=67) of the participants who had stayed in hospital after the birth of their baby felt that staff had been too strict with the implementation of visiting arrangements. Generally, women did not feel they went home before they were ready, but many reported being unhappy whilst in hospital.

*“It was awful to be alone after giving birth... I had my twins 12 weeks early via emergency C-section and then my partner had to go home and I was left in a side room, with no husband*

*and no babies. I was only allowed into NICU for 2 hours and my husband and were not allowed to visit together. It was terrible.”*

Overall, participants reported negative feelings towards policies of restrictive visiting on postnatal wards, with 71.9% (n=77) reported feeling lonely, 43.7% (n=60) being very unhappy and 57.5% (n=77) feeling they needed visitors to provide practical help not provided by staff.

There were some positive consequences to visitors being prohibited from visiting postnatal wards, with 52.2% (n=70) of women agreeing the postnatal wards were peaceful and 49.7% (n=66) stating that they enjoyed the time just with themselves and their baby. Fewer, 29.1% (n=39), said they enjoyed talking with other mothers on the ward. One woman described many of the distressing aspects of hospital postnatal care experienced by participants:

*“I was unprepared for the post-natal stay in hospital and what the visitor restrictions were. I had a horrible experience on the post-natal ward as due to the lack of visitors I felt isolated, unsupported and overwhelmed. The staff were so busy, so often when you rang for help it took a long time for someone to come to you. As such you only rang the bell when you really needed it. I was unable to pick up my baby initially so if she cried or needed me I had to rely on the midwives or catering staff to pass her to me. Staff lacked time to explain things relating to my care and recovery beyond the basics. There was no time or space for emotional support. I cried through one of my procedures because it meant I was required to stay in hospital for an additional 24 hours. The midwife did not ask why I was crying or explain why the procedure was necessary. I was not offered support to have a shower until the midwife who helped me deliver checked on me when she started her shift 24 hours later. She was very angry that I had not been offered this on the ward. I was never offered support to shower again during my 5 day stay. When I was more mobile even going to the toilet (which was extremely stressful and painful due to my injuries) was difficult because no one would sit with the baby while I went to the bathroom. So I was extremely worried about the baby the whole time I was in there. Once home I heard babies crying every time I ran a tap in my bathroom for several days. No one supported me with breastfeeding. My partner was incredibly distressed at home on his own with no support. Small things like not being able to reach your bag to get snacks, headphones, phone charger etc also made my stay unpleasant. After a difficult birth, being responsible for a newborn for 24 hours a day for five days was utterly exhausting and overwhelming and meant that I slept for only 4 hours in that whole time period. I was readmitted to hospital with a secondary infection 10 days later.”*

#### Postnatal care at home

While hospital based maternity services were identified as essential needing to be protected from staff redeployment<sup>16</sup>, this was not extended to community midwifery or health visiting services until October 2020<sup>17</sup>.

In many areas of the UK, home based postnatal care in the community was reduced during the pandemic, with 82.9% (n=141) of participants having been informed they would receive fewer in-person visits from midwives and health visitors. Where home-based visits had been replaced by virtual appointments, 28.4% (n=25) of participants felt these had not met their needs at all - an even higher proportion than in antenatal care. In particular, 36.7% (n=54) of participants reported that they had not received any support with infant feeding<sup>1</sup>.

With visitors to homes from friends and family severely restricted, new mothers reported a mixture of emotions. While 74.7% (n=115) reported feeling overwhelmed, and 79.8% (n=122) 'lonely and isolated', 79.5% (n=120) had also enjoyed having quiet time with their baby and partner; and 62.5% (n=95) considered it had been 'peaceful without visitors'.

The majority of women reported they were confident that they could contact their GP, midwife or health visitor for help - around 10% did not have confidence of this support.

*"My post-natal support hasn't been great after the first week. I feel like I've pretty much been abandoned and left to it. My health visitor spoke to me once for 5 minutes and I've never heard from her again. Luckily I have close family to speak to but I worry for those who don't have the support. I also had an emergency c-section and my 6 week check cancelled so I have no idea if my scar is normal and whether I have healed properly."*

*"Postnatal care has been awful. Health visitor called me and talked through what was clearly a checklist. I said I had been deeply anxious and traumatised by the ward and she completed a meaningless questionnaire with me. She did not ask me any questions that didn't come from a checklist, it felt entirely pointless and bureaucratic. I have not felt supported at all by any of the postnatal care - all of my support has come from family and friends, which has been wonderful, but the system has completely failed me. I do not feel listened to and do not feel that there is any real support in place, just questionnaires and tick-box checklists to make it look like a response has been given."*

## Communication

Many participants had informed themselves on the rapidly changing guidance relating to pregnancy and birth from the RCOG but reported frustration at the lack of direct communication from NHS organisations and individual midwives, often compounded by a lack of continuity in carers.

*"I am really surprised that I've had no direct contact from my hospital trust. When I registered as being pregnant, they took my email address and phone number so they could have set up an email programme or text service like my GP surgery has."*

*“As experienced as my midwife is, I don’t think she had read the latest RCOG guidance regarding risk to myself and unborn baby.”*

## Discussion

### Strengths and limitations

The survey captured important information on the experiences of women receiving NHS maternity care during the pandemic. Our participants did not represent the diversity of UK maternity service users. It is reasonable to assume that for maternity service users who cannot communicate easily due to language barriers, other communication difficulties, or for those who experience marginalisation or social disadvantage, COVID-19 restrictions are likely to have had a disproportionately negative impact on their care and maternity experience.

The online survey was self-selecting. Many positive birth stories have been shared on social media during the pandemic and it may be the case that the experiences of those who responded to the survey were not typical.

### Discussion

The early stages of the COVID-19 pandemic saw widespread adoption of the precautionary principle for pregnant women at the individual and organisational levels. Our findings show that, overall, individual women were happy to adopt a precautionary approach and stringent social distancing in the context of a relatively unknown pathogen and in an environment of extreme anxiety and uncertainty. In fact, our findings suggest that women themselves *over-interpreted* guidance to mean they should ‘shield’ as opposed to ‘socially-distance’ in line with much of the general population. This suggests that when knowledge of risk related to pregnancy is uncertain, for many women, the principle of ‘it’s better to be safer than sorry’ is acceptable. Whilst most women were supportive of a precautionary approach in public health advice for pregnant women during the pandemic, they were acutely aware of the negative impacts and unintended consequences. They cited practical difficulties stemming from a lack of support from family and friends, and negative impacts on their own mental health as two of the most pressing issues. Women recognised that at the outset of the pandemic there was limited evidence on the impact of the virus on pregnant women and their babies and identified a need for a stronger evidence base so they could make their own judgements about their own risk profile.

Similarly, the decision to adopt a precautionary approach was also made at an organisational level. At the onset of the pandemic, services were required to make rapid and drastic changes and forced to consider how to manage with unknown numbers of sick women and staff. NHS maternity services rapidly adapted and incorporated radical changes to maintain a safe level of service whilst reducing infection risks to women, babies, and staff. Our findings add to a growing body of evidence highlighting potential<sup>18</sup> and detailing<sup>7</sup> the negative impact of radical service reconfigurations on women and their families. The

survey found that the widespread changes to services caused unintended negative consequences including essential clinical care being missed, confusion over advice, and distress and emotional trauma for women. COVID-19 restrictions have resulted in women feeling their antenatal care to be inadequate and has also come at great emotional cost to users, including the separation of parents at miscarriage diagnosis. COVID-19 restrictions appeared to have exacerbated previously reported failings in hospital based postnatal care<sup>19</sup> to meet the needs of women, many of whom have restricted mobility following regional anaesthesia and operative births. Women reported feeling isolated and sad on postnatal wards, but also frustrated and upset by a lack of staff to help them care for their new baby. There is growing evidence of the physical impact of the virus on pregnant women<sup>20</sup> and the longer term impacts of stringent visiting restrictions on perinatal and longer term mental health warrant investigation. Continued restrictions imposed by overly cautious services need to be reconsidered urgently and a more nuanced, evidence-based approach to caring for women during the continuing pandemic must be prioritised. Following our survey, the widespread vaccine hesitancy fuelled by the lack of clear messages dispelling any link between COVID-19 vaccination and fertility further highlights how potentially unclear public health messaging can result in unintended negative consequences.

Finally, our findings suggest that the pandemic has precipitated a concerning extension of a 'two-tier' system within maternity care in the UK. Whilst partners were not permitted to attend NHS scan appointments, women who could afford private scans were able to access a service where their partners were still welcomed. Similarly, those who were able to employ an independent midwife were able to continue with their plans for homebirth. Others have suggested that the COVID-19 pandemic has reinforced existing inequalities<sup>21</sup> and our results indicate that this worrying trend is also manifesting in maternity services.

## Conclusion

In response to the COVID-19 pandemic maternity services made radical changes with an aim of maintaining a safe level of service, whilst reducing infection risks to women, babies, and staff. As the risk from new variants remain high, even where widespread vaccination is available COVID-19 risk messaging and physical distancing arrangements in maternity care will need to be continued for some time. Compared to at the beginning of the pandemic, when stringent measures were implemented with great urgency, there is now greater availability of PPE, understanding of the virus, knowledge of arrangements that can protect women and staff whilst facilitating partners and essential visitors and, in the UK, widespread vaccination. All maternity services should ensure they have clear lines of communication with women to keep them updated on changing care and visiting arrangements. Continuation of the stringent COVID-19 service restrictions within maternity services, implemented at the pandemic outbreak, are now unjustified, and services should ensure that opportunities to provide safe face to face care and access for birth partners and visitors are maximised.

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