Questionnaire UK COVID-19 Inquiry: Module 2 - Rule 9 Request to Birthrights

Reference: M2/R9R/BIRTHRIGHTS/TJS

1. A brief overview of the history, legal status and aims of the organisation or body. Please explain whether the work of the organisation or body is UK wide, or is instead confined to England, Scotland, Wales or Northern Ireland only.

Established in 2013, Birthrights is the UK-wide charity dedicated to improving women and birthing people's experience of pregnancy and childbirth by promoting respect for human rights. We believe that everyone who is pregnant is entitled to respectful maternity care that protects their fundamental rights to dignity, autonomy, privacy and equality. We provide advice and legal information to women and individuals, train healthcare professionals to deliver rights-respecting care, and campaign to influence and improve services and practice throughout the maternity system.

2. A brief description of the group(s) which the organisation or body supports or represents.

Birthrights represents and supports pregnant women/birthing people and new parents. The organisation is led by people with lived experience of childbirth and we put the voices of women and birthing people at the heart of our work.

Through our work we also train and support maternity healthcare professionals and all those working with pregnant women/birthing people (doulas, antenatal teachers etc) in order to empower them to offer rights respecting care.

3. A brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and Spring 2022 as it relates to the response to Covid-19 of (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive.

The response, across the UK, resulted in profound concerns over the erosion of women's and birthing people's human rights during childbirth. Restrictions in maternity services led to women hearing devastating news or even giving birth alone, parents being separated from newborn babies in neonatal intensive care units (NICU) despite testing negative, vulnerable mothers with wounds from birth or who do not speak English being left in degrading conditions on the postnatal ward, and severe limitations on birth choices.

As a result, our organisation undertook the following to represent and support women, birthing people and birth partners (below provides a summary and further details can be found here):

- Between January 2020 and the end of March 2022 we gave advice to 2255 women and birthing people and their families as well as to healthcare professionals. Demand for our advice service shot up by 300% at the beginning of the pandemic and maintained at that level. We also provided up to date resources on our website which included frequently asked questions on all issues pertaining to COVID and human rights in pregnancy and childbirth.
- We wrote to 36 of Trust CEOs and Directors of Midwifery asking them to justify under human rights law why they would not be considering an exception to restrictions for a person who is entitled to reasonable adjustments under the Equality Act 2010, or who was a victim or trauma, or who was a person living with significant/multiple disadvantage. On multiple occasions these letters to the Trust resulted in a reconsideration of the refusal to consider an exception and the creation of a personalised care plan, including additional support and exceptions to restrictions, for the person who was pregnant.
- We challenged the NICU separation and testing policy at University College London Trust, which was no longer in line with national guidance on using testing to keep mothers and babies together as much as possible in the NICU. As a result of our written challenge, the Trust changed their NICU visiting and testing policy to a less restrictive policy.
- We lobbied the Government and NHS England as well as the Scottish Government, the Welsh Government, and individual NHS Trusts and Health Boards to change disproportionate visiting restrictions/changes to services.
- We challenged the Society of Radiographers and Public Health Wales and Trusts about the blanket policies preventing partners attending antenatal scans remotely.
- We commissioned and published legal advice on partners being involved in scans remotely – national guidance achieved as a result.
- We positively influenced national guidance and briefings on face coverings for women in labour, free birth, and triaging of women who decline a COVID-19 test.
- We told the story via the Press and social media of the detrimental and avoidable impact that changes to maternity services and in particular visiting restrictions were having on pregnant women/birthing people and their families, and also on healthcare professionals who often found it very challenging to enforce these restrictions.
- We launched an online awareness campaign on Basic Birth Rights in February 2021 to counter misleading messaging from some Trusts about the impact of restrictions on choice.
- We published a decision making tool to help trusts run a safe and rights respecting maternity service during a pandemic. This was highlighted at all of our Health Professional Training sessions, circulated to all maternity service leaders by NHS England, and presented to the Global Maternity Council.
- We continued to train maternity professionals – reminding them of their duties under the Human Rights Act 1998 and supporting them to make balanced decisions which explicitly weighed up the need to control the spread of the virus against the harm that restrictions caused families and to come to a proportionate decision. The training was moved online.
- We started a number of legal challenges against Trusts or Health Boards that had visiting restrictions that we felt were not legally justifiable in terms of human rights law (leading the organisations involved to change their policy).

4. A list of any articles or reports the organisation or body has published or contributed to, and/or evidence it has given (for example to Parliamentary Select Committees) regarding the impact on the group(s) which the organisation or body supports or represents of the response to Covid-19 by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please include links to those documents where possible.

Birthrights in the pandemic: Our impact 2020-2021

Birthrights position statement published at the outset of the pandemic (31 March 2020)

Frequently Asked Questions and answers published on the Birthrights website from 12 March 2020 and updated throughout the pandemic

Evidence to the Health and Safety Select Committee re: maternity care in the pandemic (April 2020)

Issues shared by women, birthing people and healthcare professionals (5 July 2020)

Evidence to the Women and Equalities Committee re: impact of Covid on people with protected characteristics (published July 2020)

Legal advice received on legality of excluding partners from joining a scan appointment remotely (Jan 2021)

Legal advice on legality of self-isolation guidance requiring birth partners and new parents to self isolate (February 2021)

Article quantifying the financial cost of the mental health burden (£17.5bn) created by the pandemic and visiting restrictions in maternity services (July 2021)

Evidence given to the London Assembly about maternity care during the pandemic (at 1:18) (30 June 2022)

Partners still unable to stay after visiting hours in many NHS facilities (published in the Telegraph) (13 October 2022)

Birthrights informed the ASPIRE COVID-19 study and the findings can be found here 2020/21.

5. The view of the organisation or body as to whether the group(s) it supports or represents was adequately considered when decisions about the response to Covid-19 were made by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please also explain the reasons for the view expressed by the organisation or body in this respect.

It is Birthrights's view that the unique needs of pregnant women/birthing people and their families were not sufficiently considered in national, regional and local decision making in response to COVID-19 which caused significant trauma and in some cases death.

There were some positives. We were pleased to see across the UK recognition from the outset of the pandemic or not long after, that birth partners accompanying an individual in labour should be exempted from the ban on hospital visitors. However, even this guidance was interpreted differently by different maternity providers. Some Trusts/Boards were not allowing partners to be present for a caesarean birth for example, or were not allowing alternative partners to be present if the intended birth partner had symptoms of COVID.

The Government's response, across the UK, resulted in the undermining and erosion of women and birthing people's fundamental human rights in pregnancy and childbirth. This included breaches of those rights which cannot be restricted, such as the right to not be subjected to inhuman and degrading treatment. The Government's response facilitated an "infection control at all costs" approach at senior leadership level, where women's fundamental human rights were viewed as a "nice extra" which could be jettisoned in favour of reducing the spread of COVID, even after the vaccination programme was fully rolled out. "Safety" in maternity care became about primarily reducing the spread of COVID. Any holistic view of maternity safety which encompasses staff and families' psychological safety, inclusion, and trauma informed care, all within a human rights framework, was lost.

The Human Rights Act 1998 applies to the whole of the UK and therefore all NHS Trusts and Boards (and their employees) across each UK nation need to pay heed to the underlying principles of:

- individuals having rights which can't be restricted without good reason
- the need to explore all alternative options to ensure restrictions are the minimum necessary to achieve the legitimate aim of protecting the health of others
- the need to review these decisions as the situation changes.

During COVID we saw many of the examples of breaches of human rights at the most basic level. These included:

Restricted access to pain relief, women being left to give birth alone in the dark with no partner at all, plus women and individuals who had recently given birth being left on the postnatal ward without any support to clean themselves, without catheters being changed, and without ongoing access to water or help to lift their baby: Article 3 of the Human Rights Act prohibits inhuman or degrading treatment.

Suspension of maternity services, including home birth and midwifery-led birth centres: Article 8 (the right to private and family life) protects the right to physical integrity which includes the right to make choices about where to give birth.

Preventing birth partners to be present to support women and birthing people before, during and after labour: Article 8 (the right to private and family life) protects the right to family life, which includes the right to make choices about who is present to support you when you give birth.

Disproportionate impact on women and individuals from disadvantaged and vulnerable groups. This included:

- **racism towards women of colour on postnatal wards**

- **denial of access to a proper interpreter (and so women were unable to exercise informed decision making)**
- **pregnant people living with trauma, or with a disability, or with autism denied their sole birth partner at any appointments, or denied their second birth partner during labour and birth (even when the partners were double vaccinated and prepared to wear a mask and socially distance)**
- **disabled women suffering a miscarriage prevented from having their partner, who was their registered carer, attend for miscarriage treatment with them:**

Article 14 protects people against being treated in a discriminatory manner in the application of the other rights within the Human Rights Act.

Restrictions in maternity services led to women hearing devastating news or even giving birth alone, parents being separated from babies, and severe limitations on birth choices. We have seen this result in significant trauma. Throughout the last two years the first or second highest theme of enquiries on our advice service has remained "complaints - birth trauma". These are women and individuals who wish to make a complaint about their traumatic birth during the pandemic. This issue has continued to constitute 20-35% of our enquiries every month for over 24 months. Recent evidence demonstrates that in some cases the trauma of pregnancy and birth where human rights have been breached will have contributed to maternal deaths.

Below are some specifics:

The Healthcare Safety Investigation Branch (HSIB) national learning report into maternal deaths[1] early in the pandemic suggests that visiting restrictions, in England, were a contributing factor in some of these cases.

After writing to NHS England and Improvement several times a framework on reintroducing visitors in maternity services in England was published on 8 September. Subsequently, guidance was revised on 14 December 2020 which clarified that partners had a critical role in maternity care and should be accommodated, if at all possible. The latter in particular was very welcome, but ultimately decision making was left to individual Trusts. The decision making process and the evidence that fed into this was not transparent and there were few mechanisms for challenging decisions once made. Whilst differing estates and workforce challenges may have objectively justified some variation in local decision making, in our view different appetites for risk, and the power dynamics between those arguing for infection control and those advocating for maternity services users played a significant role. The result was that pregnant women/birthing people faced a postcode lottery with some Trusts in population dense areas, such as Whittington Health NHS Trust allowing partners 24/7 throughout the pandemic on maternity wards while at the same time other Trusts and healthboards in rural areas with much lower numbers of COVID infections, such as Betsi Cadwaldr in North Wales had a complete ban on partners.

[1] https://www.hsib.org.uk/investigations-and-reports/maternal-death-learning-from-maternal-death-investigations-during-the-first-wave-of-the-covid-19-pandemic/national-learning-report-maternal-death-learning-from-maternal-death-investigations-during-the-first-wave-of-the-covid-19-pandemic/

In addition to the postcode lottery that was created by decisions being delegated to individual Trusts but without any real mechanisms to challenge outliers, the other significant issue was the contradictory messages that pregnant women/birthing people and their families were being given. The inconsistencies across maternity services and messaging during the pandemic not only led to a general increase in anxiety[2] but also an increase in freebirth[3], in addition to women delaying seeking care and discharging themselves from hospital early. For example, at the outset of the pandemic, during the first lockdown, the Government's message to the public was "stay at home". This led to a huge increase in interest in home birth, and birth in smaller midwifery led units. Pregnant women were often scared about going to hospital and exposing themselves or their baby to COVID, and/or being separated from their partner. However at the same time, the immediate response of around half of maternity services in England was to centralise their maternity services and withdraw home birth/community birth centres. Once again in some cases this may have been unavoidable due to ambulance response times/staff shortages but it is notable that some Trusts (for example Chelsea and Westminster and South Warwickshire) found innovative ways to actually increase their home birth provision to meet demand.

Later in the summer of 2020, when people were allowed to go out to shops, pubs and restaurants and indeed were encouraged to "eat out to help out", those expecting a baby were incensed that partners were not allowed to attend a scan, or maternity appointments with them, or be present on the postnatal ward after the birth. The uplifting of social hospitality restrictions was completely inconsistent with the tight maintaining of restrictions in all maternity settings, even out-patient appointments. This gave rise to the #ButNotMaternity campaign which Birthrights played a leading role in.

In addition, the messages about whether pregnant women and birthing people should be treated as a clinically vulnerable/high risk group, and messages on vaccination changed over the course of the pandemic. This created confusion and as such resulted in, for example, putting some pregnant women at risk in the course of their employment and a lower take up of vaccination.

Scotland

We were contacted about a number of issues in relation to changes in maternity services in Scotland, at the outset of the pandemic, particularly in relation to the withdrawal of home birth services. We came to understand that equity is a strong guiding principle for service provision in Scotland and that there was some reluctance in some areas to provide more restricted home birth services if not available to all. In addition, partnership working between the Scottish Government, employers and staff representatives required local guidance on issues such as lone working, going out to someone's home etc before agreement could be reached.

However the guidance issued by the Scottish Government in July 2020 meant Scotland's maternity services were the most open to partners than the other countries across the UK.

Wales

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[2] https://www.birthrights.org.uk/2021/07/27/covid-19-maternity-mental-health-17bn/

[3] See for example https://kclpure.kcl.ac.uk/portal/en/publications/between-a-rock-and-a-hard-place-considering-freebirth-during-covid19(22248544-6a9f-400f-acde-f39c69c12cf2).html

The Welsh Government produced guidance as to the visiting arrangements that should be allowed in maternity services depending on the local risk assessment of the threat from Covid-19. However the reality was that most Health Boards in Wales maintained ,for many months, two hours of visiting on maternity wards (we legally challenged two Health Boards who offered less) when it was not clear why longer visiting could not be facilitated as per other parts of the UK. We wrote to the Welsh Government and met with the Senior Midwifery Officer who assured us that this was a priority but no action was taken for some time.

Northern Ireland

In our view the Northern Ireland Executive did not take the needs of pregnant women/birthing people into consideration as for many months new mothers and their babies could only be visited once a week on the postnatal ward. The guidance then changed to give discretion on visiting to the healthcare professional in charge of the ward making it very difficult for individuals to know what to expect and also for outside organisations to assess what visiting was being permitted and whether proportionate decisions were being made.

6. Whether the organisation or body raised any concerns about the consideration being given to the group(s) which it supports or represents with (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive, when the Government(s) and/or Executive were making decisions about their response to Covid-19. Please provide a list of any such correspondence or meetings with the UK Government, Scottish Government, Welsh Government and/or the Northern Ireland Executive, including the dates on which the body or organisation wrote or such meetings were held, to whom the correspondence was addressed or with whom the meeting was held, and any response received from the UK Government, Scottish Government, Welsh Government and/or Northern Ireland Executive addressing such concerns.

Letter to NHS England raising concerns about the proportionality and transparency of decisions being made – April 2020

Response from NHS England to letter of 23rd April

Letter to NHS England asking them to issue guidelines to Trusts to relax restrictions in maternity services – August 2020

Letter to NHS England from coalition including Birthrights asking for clarification that partners should not be treated as visitors. (October 2020)

Letter to NHS England published in the Mail on Sunday signed by over 100 MPs, academics and organisations repeating demand that partners should not be treated as visitors (November 2020)

Letter to NHSE and to the Department of Health and Social Care asking them to change the self-isolation guidance on the back of the legal advice received

Letters to the Secretary of State for Health and to NHS England asking for a clear roadmap for ending visitor restrictions in maternity in England (April 2021)

Response to letter to Matt Hancock from Nadine Dorries (24 June 2021)

Scotland

Our Programmes Director met with Ann Holmes the Chief Midwifery Officer for Scotland on 15 June 2020 to discuss the withdrawal of home birth services and the issue of second birth partners not being treated as visitors. New guidance was issued in July 2020 which permitted more than one birth partner and which put Scotland ahead of the other UK nations in this area..

Wales

Letter to Welsh Government from Birthrights and other #ButNotMaternity coalition members asking them to revise guidance on visiting in maternity units (November 2021)

Response from Welsh Government (December 2021)

Northern Ireland

Our Chief Executive presented at a meeting of the All Party Group on Women's Health on 4 December 2020 on the impact of the visiting restrictions in maternity services in Northern Ireland.

We also had correspondence with individual Boards in relation to their restrictions.

Legal challenges

Legal challenge to aTrust in England for separating a baby from her parents for ten days because another parent on the unit had tested positive despite both parents of the baby concerned testing negative (details not published). The isolation period ended before agreement was reached.

In wales, we undertook the following:

- Legal challenge to Betsi Cadwaladr for not allowing any visiting on the postnatal ward (June 2021). Board subsequently amended their policy to allow visits of two hours by appointment.
- Legal challenge to Cwm Taf re: no visiting and then one hour visiting on the postnatal ward (Sept 2021 to March 2022). Board subsequently increased visiting to two and a half hours.

7. A brief summary of the views of the organisation or body as to any lessons, if any, that can be learned from any consideration which was given to the group(s) that the organisation or body supports or represents by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland

Birthrights informed the ASPIRE COVID-19 study. The outputs from the study included lessons to learn from how maternity services both in the UK and in the Netherlands responded to COVID. These can be found here.

We feel that even after the rollout of the vaccine programme, infection control was prized above all else. Nowhere near enough attention was paid to perinatal and postnatal mental health, specifically

to the fact that having a baby is a significant, life changing event, when many expectant parents inherently feel more vulnerable and anxious . This became even more prevalent when testing and vaccinations were available but largely restrictions were not lifted in accordance. The strong evidence around continuity of carer, the safety of home birth especially for second time mothers, the benefits of companionship and how to prevent birth trauma and promote family bonding was too often not considered

Individual Trust Risk assessments and a continued review of the maternity services guidance and policies should have been undertaken. Key is the need to involve service users (pregnant women, birthing people, and birth partners) in what communications are disseminated and guidance provided in any future pandemics, This is essential in reducing conflicting messages, confusion and inconsistencies.

While there was an exemplary response to the crisis by many NHS Trusts, there were inconsistent, disproportionate and inhumane responses by others and we saw a number of Trusts making unlawful blanket decisions without taking into account women and birthing people's individual circumstances.

All NHS Trusts and Health Boards should engage in mandatory training on the Human Rights Act in order to understand how the laws and principles laid down by that act apply at all times to NHS public healthcare and specifically how they relate to the provision of maternity care. All staff, from student maternity care workers, to Board Chief Executives should feel confident of the basics of the Human Rights Act and the basic birth rights of all pregnant people in the UK, in order to ensure that their professional decision making is underpinned by the legal framework on human rights. All NHS Staff should understand that human rights are an integral component of safe, personalised maternity care, be aware of how and when the rights must flex (and where that can never happen), and know where to go to escalate concerns and to receive further support and advice on human rights.

National, regional and local decision making structures should be examined to ensure they support transparency and proportionately. Mechanisms are required to reduce unwarranted variation in how national guidance is interpreted locally.

In the same way the public sector equality duties impact assessments (PSEDs) have largely been published to show to the public how the Government has fulfilled its duties we would suggest the same is undertaken for how the human rights duty is fulfilled.

Personal Data

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