Birthrights submission to the Expert Panel to the Health and Social Care Committee – May 2021

Birthrights is the UK charity that champions respectful care during pregnancy and childbirth by protecting human rights. We welcome this opportunity to submit evidence to the Health and Social Care Committee's Expert Panel for their evaluation of commitments made in the area of maternity services.

As a charity we have had oversight of how these commitments have been made through our representation on the Stakeholder Council for the Maternity Transformation Panel in particular. We are not close enough to the detail of how these commitments have been implemented in practice to comment on issues such as whether the funding for these commitments was sufficient, how far measurable improvements have been obtained and how far this was attributable to the commitments, and whether the commitments were reasonable to make at the time. However what we can offer is our assessment of the impact of these commitments on women and birthing people through intelligence gathered through our advice line, and other pieces of work such as our research into the experience of women facing severe and multiple disadvantage, and our current inquiry into racial injustice in maternity care, as well as a flavour of how healthcare professionals experience these commitments through our training work. We are grateful to the Expert Panel for the opportunity to share our views.

Summary of key points:

- **Targets can be helpful in harnessing energy and commitment and it is understandable for the Government to focus on reducing deaths and brain injuries given unfavourable international comparisons. Progress towards these targets is very welcome, but understanding any unintended consequences or re-prioritisation that has happened is also very important.**

- **Safety in maternity services is about more than physical outcomes. Birthrights want to see an experiential target to urgently increase the proportion of women and birthing people who feel like the primary decision maker in their maternity care. The evidence suggests that progress towards these will aid help achieve physical safety targets as well as ensuring all women and birthing people feel safe in the widest sense of the word.**

- **From our perspective there is an imbalance between the effort and resources that has been put into achieving commitment 1, compared to the other commitments listed, particularly 3 and 4.**

- **There is also a stark contrast between the effort employed to understand a death, a stillbirth or brain injury compared to understanding how women undergo serious intervention without their consent, for example. The NHS needs to develop a culture of learning from ALL incidents of harm.**

- **We are concerned about the increasing trend to hold the pregnant woman/birthing person solely responsible for any increased risk to the fetus, with little acknowledgment of the roles of broader public health and inequality. A healthier and fairer society would help towards achieving the commitments listed here.**

- **Mandatory training for all maternity staff on their obligations to provide human rights centred maternity care, how to practice in a culturally safe and anti-racist way, and how to have choice conversations in practice, is needed.**

- **The stark inequalities in maternal and infant outcomes are well known, but more urgent and concerted action is vital. Racial bias and systemic racism equally impacts on maternity care experiences, causing trauma and posing serious human rights questions. Birthrights would like to see a stand-alone target to reduce the inequalities in outcomes outlined in the MBRRACE report.**

COMMITMENT 1:

By 2025, halve the rate of stillbirths; neonatal deaths, maternal deaths; brain injuries that occur during or soon after birth.

Achieve a 20% reduction in these rates by 2020.

To reduce the pre-term birth rate from 8% to 6% by 2025.

Safety within maternity services

Since these safety commitments were introduced in 2015, and then refreshed in 2017, the commitment to reducing serious mortality and morbidity has been clear. Programmes and tools to ensure lessons are learnt include: Each Baby Counts, the National Maternity and Perinatal Audit and the Perinatal Mortality Review tool, the Early Notification Scheme and investigations by the Health and Safety Investigation Branch. In addition there have been multiple initiatives designed to improve practice such as the Saving Babies Lives Care bundle, the Avoid Term Admissions into Neonatal Units (ATAIN) and the wider Maternal and Neonatal Safety Improvement Programme (previously the Maternal and Neonatal Health Safety Collaborative). NHS Resolution's Clinical Negligence Scheme for Trusts (CNST) maternity incentive scheme has provided the centre with a carrot to ensure that key safety actions are undertaken by individual Trusts. Others are

best placed to comment on what the impact of such a large amount of initiatives at once has been on staff and whether the pace of change was sustainable.

The impetus to reduce mortality and serious morbidity as quickly as possible is understandable and progress is on track which is to be warmly welcomed. Nonetheless achieving further gains towards the target is likely to be even more challenging and therefore we feel this is a crucial point to evaluate any unintended consequences and ensure that targets are focused on improving maternity care in a holistic way.

Impact on service users

Any avoided death or serious injury as a result of this improvement work is a cause for celebration. The independent evaluation of the Saving Babies Lives Care bundle [1] published in July 2018 calculated that 1,106 stillbirths are likely to have been prevented across England between April 2015 and April 2017.

The same report also noted that the bundle had led to an increase in interventions including a 19.4% increase in inductions, a rise in emergency caesareans (9.5%) and a rise in per-term birth (6.5%) among the nineteen Trusts evaluated.

The Saving Babies Lives Care bundle revision 2 attempted to adjust for this and ensure that intervention was only focused on those at most risk, acknowledging that around 700 inductions would be needed around 37 weeks to prevent one stillbirth. How far this has been successful has yet to be evaluated.

Whether an increase in intervention is a bad thing per se depends on the context. Our main concern is that the maternity services context remains one in which women and birthing people are not consistently the main primary decision makers in their care. We call on the NHS to give the same attention given to transforming the culture of maternity services into one of personalised care as is given to achieving these safety targets. Ultimately this will help to achieve the safety targets as well as paying dividends for the 1 in 4 women and birthing people[2] (around 200,000 in the UK each year) who leave maternity services traumatised by their experience.

Birthrights/Mumsnet survey 2020

2015 was not only the year that these safety commitments were introduced. It was also the year of the landmark Supreme Court judgement in the case of Montgomery vs Lanarkshire. The judgement upheld the right of the patient (in any area of healthcare), to make an informed choice about what is right for them. The decision conferred legal recognition on what had been regarded as "best practice" (as set out in GMC guidance) for many years. The role of doctors and midwives in maternity services is that of a counsellor, facilitating and enabling informed choices. To mark the fifth anniversary of the judgement, Birthrights and Mumsnet carried out a survey to see how far the judgement was being implemented in practice. The survey revealed that **less than half 45% of women surveyed felt that they were the primary decision maker in their own maternity care and 42% said that they did not feel like they were the primary decision maker.**

[1] https://www.e-lfh.org.uk/wp-content/uploads/2020/02/SPiRE-evaluation.pdf
[2] https://www.makebirthbetter.org/

14% of the 1145 women surveyed by Birthrights/Mumsnet felt that their opinions were overruled, and 11% felt there was an attempt to overrule their decisions. 24% said that their decisions and opinions were not respected and worryingly 30% said their decision and opinions were not sought at all.

> *"I was told what was going to happen to me. I had no say in it."* Survey respondent

> *"Staff tended to treat me like a child, telling me what I must do. When I disagreed with their instructions I was met with disapproval and silence. It was a battle."* Survey respondent

The survey showed that some "options" and "choices" were discussed more than others:

- 74% said they were given the opportunity to discuss the benefits of a vaginal delivery, but only 42% said they were given the opportunity to discuss the benefits of a caesarean section;
- 61% said they discussed the benefits of giving birth on a hospital ward, but only 38% said they were given the opportunity to discuss the benefits of giving birth at home, despite NICE guidance (CG190) saying that women who are at low risk of complications should be advised that settings such as a midwifery-led birth centre or home are particularly suitable for them, based on the findings of the Birthplace study – one of the largest ever studies of risks and benefits of giving birth in different setting for women with straightforward pregnancies.

> *"I wanted a home birth, and although it was all agreed weeks in advance they tried to make me go into hospital just before the birth."* Survey respondent

> *After three days of labour, I was told to choose between an emergency forceps delivery or C-section. I knew the risks of a C-section so I opted for forceps. I ended up with a severe prolapsed bladder which is making my life a misery. I had no idea this was one of the risks of forceps and that it apparently happens to lots of women."* Survey respondent

The full survey data is attached as Annex A.

The depersonalised and dehumanised care highlighted by the survey during the antenatal survey, carries through to labour and indeed the postnatal period for many women and birthing people, as we hear every day through our advice line. These quotes are typical:

> *"These events left me feeling that I was not being listened to and people were doing things deliberately without my consent and contrary to my requests. They left me feeling anxious and fearful about the process of what was happening to me. I feel that these events did not help put my body in an optimal state for natural labour due to the increased stress levels and cortisol, which are known to slow/halt the labour process."* June 2019

> *"I had a terrible and traumatic birth experience. I was constantly lied and told that my due date doesn't matter. I was tortuously told that my baby was going to die and had a 3rd degree tear that wasn't taken care for over four hours making me lose considerable amounts of blood. The whole experience has deeply affected my emotional stability. I had a panic attack when going back to the hospital where involuntary movements in my mouth made me break a tooth."* September 2019

"Midwives X and Y were constantly interfering, shouting at me, bullying me by saying my baby should have been born, being hostile, impatient and abusive verbally and physically. They went completely against the NICE guidelines…completely failed to provide a calm, safe and supportive environment for me to birth. Clock watching without considering the individual and the birthing environment is not individualised care and it subjects more women to unwanted and unnecessary interventions that cause more harm and lead to poor psychological and physical outcomes for women." October 2019

"Examination (internal) by the senior doctor was rough and heavy handed. I found the whole process dehumanising. I was asked how much out of ten is your pain, with ten being the maximum pain. I responded that at its peak it's an 8. And they come in waves (like a contraction) "Well, you're not screaming like an 8" was the sarcastic, dismissive and unsympathetic response (from the senior doctor). My pain was not believed to be true or taken seriously." October 2020

Women and birthing people whose safety is most at risk

Evidence shows time and again that disrespectful and dehumanised care is experienced most acutely by groups that already face structural disadvantage.

The MBBRACE report in 2020 showed that Black women are four times more likely to die around the period of pregnancy and birth, with Asian women twice as likely to die, compared to white women. Similarly, Black and Asian women are significantly more likely to experience a stillbirth or neonatal death than their white peers. This clearly shows that maternity services are safer for some women, birthing people and babies than others. Black and Asian women are also at higher risk of illness during pregnancy, which has been brought to the fore in the pandemic: Black pregnant women are eight times and Asian women four times more likely to be admitted to hospital with Covid-19.[3]

These persistent inequities raise serious questions about whether UK maternity services are equally protecting everyone's fundamental right to receive safe, respectful care. Birthrights is currently convening an inquiry into the maternal outcomes and experiences of Black, Brown and Mixed Ethnicity women and birthing people, led by an expert panel of people with lived experience, maternity professionals and birth workers, human rights and clinical negligence lawyers, research and inquiry specialists, and equalities and anti-racism campaigners. The call for evidence is ongoing and has received 200 submissions to date. Early findings include:

- Most people reported they did not feel safe at some point during their care
- Being ignored or disbelieved is a strong theme, especially late in pregnancy or in labour, in relation to pain and to concerns about their own or their babies' safety, in many cases leading to serious injury for women and/or neonatal complications
- Being seen as a nuisance or a "pest" for asking questions about care, even when this related to specific conditions with high miscarriage or other risks

[3] NHS England, 2020, NHS boosts support for Black and ethnic minority women

- Racial stereotypes leading to denial or delay of pain relief, with significant physical and psychological trauma – Asian women seen as "precious" with low pain thresholds, Black women told "girls 'like me' should be stronger"
- Failure to listen to concerns or recognise complications due to skin colour e.g. jaundice in Black babies
- Distress and trauma from failure to respect religious or cultural needs e.g. male healthcare professionals doing intimate procedures, overhearing maternity staff complaining that "people like me" causes issues e.g. needing Halal suitable milk
- Overt racist or other discriminatory language, microaggressions and assumptions rooted in racial stereotypes leading to disrespectful care and distress
- Not being told about options, lack of choice, and feeling coerced into interventions.

"I am British Bangladeshi and English is my first language, but I think there is a stereotype of Asian women in my area that we are tame, quiet and compliant people who have no voice and will be obedient. I have a condition that can cause miscarriage if it is not managed well and monitored, so I felt unsafe when my questions about this weren't answered. It felt like maternity professionals are not used to being challenged by brown women."

"At one appointment, I was kept waiting for several hours to see a consultant, only to be told everyone had gone home, despite me asking three times when I will be seen. When I challenge this I am spoken to at the same time by three white staff who say it is my fault for keeping hold of my notes and that I am aggressive. I am scared to deliver in this hospital. [...] I feel my race means I am seen as less, other, expected to endure more. It led to me being called aggressive by someone who has never before met me – three white staff against one lone black vulnerable female."

"With the birth of my first child, I felt my voice was ignored. My expressions of pain and exhaustion were diminished with comments about how I didn't look like I was in that much pain and how a girl "like me" should be stronger than that. I was told people "like me" don't need epidurals. I laboured for three days, I was unable to keep food down or sleep at all for 48 hours. I was begging for an epidural and shaking with the effort of trying not to push. When I got my first midwife back after several shift changes she was appalled I had been left to continue struggling and had a consultant informed and epidural scheduled within an hour of taking over my care."

The testimony received so far by the inquiry is deeply concerning, but there are examples of rights-respecting and culturally competent care – where "amazing" healthcare professionals listened, were compassionate, and made sure individual needs could be met without judgement or invasive curiosity.

Our joint research[4] with Birth Companions[5] (Holding It All Together, June 2019) also showed that women facing severe and multiple disadvantage are less likely to be offered the same options and choices as other women, and are less likely to give informed consent. This was further exacerbated amongst women who are asylum seekers, facing some of the greatest disadvantage. Too often, despite pregnancy being an opportunity to engage with individuals who might require additional support, women instead report feeling scrutiny and judged. Some women, who may already be victims of sexual violence, FGM, and/or trafficking, are concerned about being charged for maternity services which

[4] https://www.birthrights.org.uk/campaigns-research/severe-disadvantage/
[5] https://www.birthcompanions.org.uk/

puts them off seeking care[6]. Others are worried about social services becoming involved if they decline recommended care, despite it being their right to do so.

> *"…I still don't want to like put a foot wrong or anything like that…I am afraid even to talk to them, or tell them how I feel, or if I have got a complaint or something."* Making Better Births a reality for women with multiple disadvantage, (Birth Companions, October 2018)[7]

Adequate interpretation is essential for enabling women who don't speak English as a first language safe, by facilitating full involvement in their care, ensuring they receive accurate midwifery and obstetric advice, and enabling them to make informed decisions. Sadly, our research, and the experience of organisations supporting women facing disadvantage shows that adequate interpretation is often lacking. This leads to women being unable to give consent as required in law, and in some cases results in explicitly unsafe care.

> *"Some midwives told of significant safety concerns that resulted from mistranslation, such as the case of an interpreter who told a woman to use a tampon instead of a sanitary pad to monitor fluid loss when she thought her waters had broken."* Holding It All Together (Birthrights and Birth Companions, June 2019)

> *"In particular moments when I needed care and support, I couldn't do much because I couldn't communicate"* Holding It All Together (Birthrights and Birth Companions, June 2019)

Recent research[8] has highlighted that midwives feel that they are unable to meet expected standards of care for women who require language support, risking safety, and putting healthcare professionals in an impossible position, feeling "powerless".

Our research with Birth Companions highlighted that the lack of join-up between different healthcare systems (for example, between maternity and mental health) and across different geographical areas presents significant barriers to ensuring women facing disadvantage receive safe and joined-up care. This is particularly the case for those who are living in unstable housing situations, including asylum seekers and recent migrants. These groups are at greater risk of adverse outcomes and supporting them requires going beyond the clinical. Specialist midwifery services offer a vital support to women who are known to be facing difficult circumstances, often going far beyond provision of 'simply' maternity care in ensuring women receive safe and holistic care during pregnancy and in the postnatal period.

In general we are concerned about the way in which risk factors for a stillbirth, such as smoking and obesity for example, are laid at the door of the individual who is pregnant. Often these individuals feel blamed, and under scrutiny without consideration being given to the combined impact of the multiple pressures they might be facing. This can lead to the individual disengaging from care, despite pregnancy being a recognised as a time when individuals are highly motivated to make changes in their lives. **Evidence suggests that if we all lived in a healthier and fairer society, many of these risk factors**

[6] https://maternityaction.org.uk/vawg-report-december-2019/
[7] http://www.revolving-doors.org.uk/file/2333/download?token=P2z9dlAR
[8] https://www.emerald.com/insight/content/doi/10.1108/IJHRH-10-2020-0089/full/html

would be significantly reduced. The role of structural racism and discrimination – both directly in maternity care and indirectly in broader services and society – must be acknowledged and addressed in any efforts to achieve maternity transformation goals.

Conclusions on Commitment 1

We know from a multitude of research[9] that women who feel they have a good relationship and are treated with respect by their care team, and remain in control over decisions about what happens to their bodies during maternity care, are much more likely to experience their birth as "positive" and "safe", regardless of how the birth unfolded.

The majority of women and birthing people want a physiological birth but are also willing to accept intervention if necessary.[10] The power dynamic with healthcare professionals needs to be explicitly recognised here and balanced information giving is key.

We remain extremely concerned about information and practices such as booking women/birthing people in for an induction without their consent. Research suggests that the information needed to make an informed choice is only given in a minority of cases (see Jay et al (2018)[11]). Women have recounted to us how, for example, they were told about their induction as if they had no option, or that it would be booked "just in case" or they were told their induction could be moved forward when they did not know they were booked in for one in the first place. This quote is taken from a qualitative study[12] of women who had a prolonged pregnancy:

> *"It never felt that an "offer of induction". There was never any discussion of the pros of this, the cons of that, you need to think about what to do. It was just "this is what we do next". I knew I didn't want to be induced, but I didn't realise I had options!"*

In contrast if women are asking for a maternal request caesarean they are required to undergo several consultations in order to convince healthcare professionals they are making an informed choice.

The Maternity Transformation Programme has always asserted that safe care is personalised care. In other words, birth is a psychosocial event and women and birthing people must feel listened to, with care wrapped round them as individuals. National initiatives have generally made this clear. The second version of the saving Babies Lives Care bundle[13] states that:

> *"It is self-evident that a woman's autonomy is paramount and that care should be delivered in a way which informs and empowers. Women should have access to best practice care and their decision to accept or decline an intervention should always be respected."*

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[9] COOK, K. & LOOMIS, C. 2012. The Impact of Choice and Control on Women's Childbirth Experiences. The Journal of Perinatal Education, 21, 158-168, KARLSTRÖM, A., NYSTEDT, A. & HILDINGSSON, I. 2015. The meaning of a very positive birth experience: focus groups discussions with women. BMC Pregnancy and Childbirth, 15, 251. NILSSON, L., THORSELL, T., HERTFELT WAHN, E., EKSTRÖM, A. 2013. Factors Influencing Positive Birth Experiences of First-Time Mothers. Nursing Research and Practice, 2013, 6.

[10] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5903648/pdf/pone.0194906.pdf

[11] https://www.magonlinelibrary.com/doi/abs/10.12968/bjom.2018.26.1.22

[12] https://journals.sagepub.com/doi/full/10.1177/0959353518799386

[13] https://www.england.nhs.uk/wp-content/uploads/2019/07/saving-babies-lives-care-bundle-version-two-v5.pdf

However in practice, we see that clinicians find themselves at the centre of conflicting messages and priorities, whilst facing limited resources conflicted. This can be for a range of reasons including ignorance:

> *"I was of the understanding that it is my right to decline any treatment or procedure even if this could mean death for myself or my baby. The Head of Midwifery didn't think this was the case and said that she would have to see if she could get something in writing from their legal team before they would be able to allow me to decline a specified potential life preserving treatment."* Birthrights advice line, August 2020

For this reason, **we would like to see all healthcare professionals undertaking training in human rights law and how it applies to maternity care**.

However even where clinicians are aware of the legal position, Nicholls et al (2021) [14] illustrates how clinicians learn to manage busy clinics by framing an antenatal appointment in a clinical way from the outset, leaving little room for a woman/birthing person to share what is important to her/them. Despite the very welcome statement above about respecting women's autonomy, the Saving Babies Lives Care bundle does ultimately require women to be offered support to stop smoking for example, but doesn't really address the insecure employment, inadequate housing, domestic violence or other issues that may have led an individual to smoke. Whilst these issues go significantly beyond the scope of maternity care, it must be recognised that there is no overarching body or collaboration mechanism that is addressing these holistic influences on individuals' lives.

In other cases, rightly or wrongly clinicians may fear the consequences of not following guidelines or protocols, more than they fear the consequences of breaching an individual's human rights. In our own Birthrights training we have been told countless times that midwives/doctors must follow guidelines and cannot facilitate a woman's (out of guidelines) choice because it would be "my PIN/registration on the line", despite the fact that the law requires healthcare professionals to uphold the autonomy of their patients.

Birthrights would like to see an experience measure target to increase the number of women and birthing people who feel like the primary decision maker in their care driving a personalised care transformation, with all the consequent improvements in safety this would bring.

COMMITMENT 2:

The majority of women will benefit from the "continuity of carer" model by 2021, starting with 20% of women by March 2019.

By 2024, 75% of women from BAME communities and a similar percentage of women from the most deprived groups will receive continuity of care from their midwife throughout pregnancy, labour and the postnatal period.

[14] https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-021-03574-2

Birthrights remains fully supportive of these targets given the evidence of the benefits that continuity of carer provides, as summarised by NHSE England on its website here, and highlighted in our research on the experiences of women facing multiple disadvantage.

Continuity of carer was one of the recommendations of Better Births that presented the opportunity to put the "Transformation" in Maternity Transformation Programme given its power to make a difference positively or negatively to women and their families:

> *"The care I've had throughout my high -risk pregnancy has scared both me and my partner. We are putting in a complaint about the lack of continuous care (im 33 weeks pregnant and still have no named midwife, I also have had had nearly 10 different drs at "consultant" appointment, and I will not meet my named consultant until planned c section, if then.) This lack of continuous care has meant most aspects of my care have not been done because each health professional we see we are seeing for the first time and there is no follow up and no one to contact to check on test results, referrals, medications etc. Things have gotten to the point that I don't feel safe having my twins here"* Birthrights advice line, December 2019

17.3% of women were receiving continuity of carer in March 2019[15], and NHS England have been rather coy about progress since then. Given different starting points and staffing challenges, Trusts were given rather wide leeway in terms of what models should be adopted, when national implementation guidance was issued in 2017. We were pleased to see that continuity was defined as across the three phases of the maternity journey (antenatal, postnatal and most importantly labour and birth as well). However midwifery teams could be between 4-8 meaning that while some women and birthing people have truly had the opportunity to develop a relationship with a named midwife, with other members of the team as back up, others have seen a different midwife for nearly every antenatal appointment. This has led to huge variation across England. The situation is even more complicated for women requiring consultant led care.

It is disappointing that the latest CQC maternity survey in 2019[16] found that more than than half of women (54%) said that none of the midwives involved in their postnatal care had been involved in either their antenatal care or their labour and only 28% of women said they saw the same midwife every time during their postnatal care.

Once the pandemic hit, we observed anecdotally that Trusts that were further ahead in introducing continuity of carer models were much better placed to keep in touch with women and birthing people, particularly women and birthing people facing severe and multiple disadvantage than those who did not have these models in place.

Birthrights would like to see progress on this commitment firmly prioritised and implemented as quickly as possible. Once existing targets are close to being met, new targets should be set. The ambition of Better Births was to offer continuity of carer to all women, not just 51%.

Given the inequalities in outcomes experienced by Black and Brown women and birthing people and also pregnant individuals from socio-economically deprived background, we

[15] https://www.england.nhs.uk/wp-content/uploads/2020/03/better-births-four-years-on-progress-report.pdf
[16] https://www.cqc.org.uk/news/releases/many-women-have-positive-experience-maternity-services-some-care-continues-fall-short

are pleased to see continuity of carer being prioritised for these groups. However, implementation of continuity for these groups also appears to have varied widely.

Offering continuity of care to these groups is a good start but it will not result in culturally safe care if the underlying structural issues are not addressed. Women and birthing people need to know that the individual practitioners looking after them will listen to them, treat them with respect and keep them safe whether within a continuity of carer model or not.

Initial findings from the inquiry on racial injustice in maternity care indicate that racial bias, stereotypes, assumptions and microaggressions are pervasive. While there are some examples of good, culturally safe care, the weight of testimony to date shows that many people face harmful attitudes based on their race, religion, culture, appearance or the white, eurocentric lens through which most practitioners have been trained. Continuity of carer can only succeed for Black, Brown and Mixed Ethnicity women and birthing people if it is accompanied by action to acknowledge and tackle systemic racism, at a policy, practice and individual level. **Anti-racism training should be a core part of ongoing learning and improvement.**

Birthrights would like to see a stand-alone target to reduce the inequalities in outcomes outlined in the MBRRACE report, in addition to the target to introduce continuity of carer for 75% of Black, Brown and Mixed Ethnicity women and birthing people.

COMMITMENT 3:

Ensuring NHS providers are staffed with the appropriate number and mix of clinical professionals is vital to the delivery of quality care and in keeping patients safe from avoidable harm.

We fully agree with this statement.

1 in 10 midwife posts were unfilled prior to the start of the pandemic, which doubled to 1 in 5 once the pandemic took hold. The UK WHELM study (Hunter et al, 2018)[17] showed that 83% of midwives were showing signs of burnout and that a staggering 66.6% had considered leaving the profession in the last 6 months. The two top reasons were: 'Dissatisfaction with staffing levels at work' (60%) and 'Dissatisfaction with the quality of care I was able to provide' (52%). A very recent survey[18] published in August 2020 by the RCM showed that 87% of midwives had to delay going to the toilet due to lack of time, 77% skipped meals and 53% reported feeling dehydrated all or most of the time.

A 2018 report[19] on the Obstetrics and Gynaecology workforce showed that 9 out of 10 maternity units had unfilled middle grade doctor gaps and a 30% attrition rate for trainees was typical. Obstetric and Gynaecology trainees reported more undermining

[17] https://www.rcm.org.uk/media/2924/work-health-and-emotional-lives-of-midwives-in-the-united-kingdom-the-uk-whelm-study.pdf

[18] https://www.rcm.org.uk/media-releases/2020/august/midwives-missing-meals-and-loo-breaks-to-keep-services-running/#:~:text=Midwives%20are%20missing%20meals%20and,College%20of%20Midwives%20(RCM).&text=During%20a%20typical%20working%20week,don't%20have%20enough%20time.

[19] https://www.rcog.org.uk/globalassets/documents/careers-and-training/workplace-and-workforce-issues/rcog-og-workforce-report-2018.pdf

behaviour/bullying than any other speciality. The same report highlighted the human cost of the blame culture within the NHS (to both doctors and patients). More recently, a 2020 study[20] found that 18% of obstetricians and gynaecologists reported symptoms of post-traumatic stress disorder after exposure to trauma at work, with the rate higher for doctors from minoritised backgrounds. The research also found the "culture in obstetrics and gynaecology was identified as a barrier to trauma support".

The NHS Staff survey[21] also highlights significant concerns about the culture of safety within the NHS with only 59.7% staff reporting that they feel staff who are involved in an error, near miss or incident will be treated fairly, and only 71.1% of staff surveyed feel confident that their organisation would take action to prevent an error, near miss or incident happening again. The case of Dr Bawa-Garba[22] demonstrated how individuals can be personally blamed and left unsupported if anything goes wrong even if they are doing their best in very challenging circumstances, suggesting that there is still significant work to do to build a learning culture within the NHS.

We welcome the recent announcement of £95m for maternity services and the fact this funding will be recurring as a very positive step forward. However we are concerned that this may only fill a third of the current midwifery vacancies, for example. We hope that others will be able to comment on whether this funding is likely to help plug the current gaps in staffing of maternity units in the longer term.

COMMITMENT 4:

All women to have a personalised care and support plan by 2021.

Firstly we believe that this is an intermediate goal on the journey to achieve the overall target of ensuring all women receive personalised care. Ultimately there is no point women and birthing people having a plan if it does not change how they experience care. There is also no point having a plan if they are not truly supported to make a plan that reflects their wishes for their care.

Progress on this ambition has been woefully inadequate, not least because the Montgomery v Lanarkshire judgement endorsed existing GMC guidance in place at the time that Sam Montgomery was born in 1999 that recommended that it was best practice for doctors to have a dialogue with their patients about the risks and benefits of various reasonable options and to support them to make informed choices about their care. And yet, as the results of our survey with Mumsnet survey show, only a minority of pregnant women and birthing people feel they are in control of decisions around their maternity care. This was confirmed by recent research by Nicholls et al (2019)[23] which found that there was a culture of "expected compliance" in maternity services and that women did not always experience consent as a choice.

[20] https://obgyn.onlinelibrary.wiley.com/doi/abs/10.1111/1471-0528.16076
[21] https://www.nhsstaffsurveys.com/Page/1085/Latest-Results/NHS-Staff-Survey-Results/
[22] http://www.pulsetoday.co.uk/news/gp-topics/gmc/bawa-garba-timeline-of-a-case-that-has-rocked-medicine/20036044.article
[23] https://pubmed.ncbi.nlm.nih.gov/31129561/

Our research has shown that women facing disadvantage and disabled women are even less likely to be supported to make choices in their care. Some reported being completely unaware that they were able to make choices about their care. Disabled women reported being classified as 'high risk' and having choices limited or denied on this basis, without any understanding as to the specific reasons.

> *"I was told I was a health and safety risk."* Dignity and respect during pregnancy and childbirth: a survey of the experience of disabled women (Birthrights and Bournemouth University)[24]

> *"I wasn't allowed to go to the low risk centre, despite my disability not affecting my capacity to give birth."* Dignity and respect during pregnancy and childbirth: a survey of the experience of disabled women (Birthrights and Bournemouth University)

Better Births recommended that all women should have a personalised care budget; the transfer of money, even if notional, being the "transformative" element, providing some clout to the longstanding idea that women and birthing people should be able to choose where and how they gave birth. This element of Better Births has been dropped and it has taken five years to issue guidance on personalised care and support plans[25]. The contrast with the immense effort put behind achieving the safety targets under commitment 1 is stark.

Given what women and birthing people tell us every day about how their experience maternity care, much more progress is needed to create a culture of personalised care in maternity services. Despite the lack of pace to date, we hope that the recent guidance will provide renewed focus. We particularly welcome the explicit recognition in the guidance of clinicians' obligations to uphold the human rights and autonomy of the individuals under their care. However the guidance on its own will not be enough. Birthrights helped to author the Institute of Personalised Care e-learning module on personalised maternity care which is a positive development. But training and attention at the local level will be needed to ensure clinicians know how to facilitate informed choices, and are encouraged to support women and birthing people whatever choices they make. Once again this comes back to culture which is why Birthrights is keen to see the introduction of **an experience measure target to increase the number of women and birthing people who feel like the primary decision maker in their care.**

Birthrights is pleased to be working with NHS England and NHS Improvement, the Royal Colleges, service user representatives and others on a new tool called IDECIDE which will provide both healthcare professionals and women with a framework to aid informed decisions especially during labour. The tool will include a short "how did you find this conversation?" experience measure survey, sent at an appropriate interval after the birth, to ensure that healthcare professionals can continue to improve the way they conduct choice conversations even in the most challenging of circumstances.

Learning from past mistakes, in the context of a no blame culture, is absolutely key to quality improvement. Therefore we would like to see the same effort put into learning

[24] https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-018-1950-7
[25] https://www.england.nhs.uk/publication/personalised-care-and-support-planning-guidance-guidance-for-local-maternity-systems/

from where personalised care and support planning has not gone well, and women don't feel listened to, and in the worst cases feel completely violated. We concur with the CQC that:

> *"Trusts who encourage a culture of learning and openness alongside a willingness to listen to and prioritise the needs of the women using their services are more likely to deliver care that is not only safe, but person-centred and empowering."* CQC briefing on safer maternity services[26]

At the moment investigation into informal and formal complaints is highly variable, and is dependent on staff at all levels of the system being able to accurately recognise when a human rights violation has occurred.

Evidence we have seen shows that senior healthcare professionals are often not aware of women's legal rights, for example to give informed consent and also to withdraw it. PALS have little clout with senior clinicians and the NHS as a whole is still some way off adopting a learning culture.

And when women challenge these attitudes, regulatory bodies and the Ombudsman are often not able or willing to help, or pass the buck to another body.

It is also relatively common for women to tell us that their notes or part of their notes have gone missing, if they are raising a complaint. This not only limits the investigation by the Trust, but also limits any opportunities for the woman to take the complaint to the Ombudsman or to regulatory bodies if appropriate. In some cases, investigations into complaints have discounted witness evidence from birth partners, as they were deemed to be "guests" of the birthing person, and therefore "unreliable".[27]

A's case demonstrates the issues. A has a heart condition, and other medical conditions which require special consideration. A reports that:

> *"The delivery was traumatic mainly because not a single member of staff involved would listen to anything I had to say."*

A explains that during her labour:

> *"Vaginal examinations were performed to place a foetal scalp electrode and take foetal blood sampled but I was not even warned they were about to take place let alone asked for consent."*

A had been clear throughout, and this was recorded in her notes albeit apparently not in the "correct" place, that she did not want an instrumental delivery but wanted to proceed directly to a caesarean delivery, if the need arose as she was concerned this would inflame another long term medical condition. She eventually consented to a caesarean under general anaesthetic. As she was being given the anaesthetic she could hear the two doctors discussing whether to attempt a forceps delivery or a caesarean and urgently told them that she didn't want a forceps delivery she wanted a caesarean birth:

[26] https://www.cqc.org.uk/publications/themed-work/getting-safer-faster-key-areas-improvement-maternity-services
[27] https://www.bloomsburyprofessional.com/uk/womens-birthing-bodies-and-the-law-9781509937578/

"I cannot begin to explain the terror of being trapped on an operating table and not being able to move or scream and being told that someone is going to cut into you and perform a procedure that you have refused both in writing and verbally."

The doctors carried out a forceps delivery which has left A with a chronic pain condition, significant psychological trauma. Due to the medication she is on and in unable to manage without, A is unable to have further children:

"I am still in pain everyday and expect to be for the rest of my life."

The reaction of the system to this violation where the law has been broken is just as shocking. After some delay, the Trust commissioned reports from an independent obstetrician and an independent midwife which were both critical of the Trust's response. The consultant obstetrician's behaviour was judged to be "below that one would expect of a consultant obstetrician" at the time. The Nursing and Midwifery Council (NMC) declined to investigate as there were no other complaints against the midwives involved. The Parliamentary and Health Service Ombudsman (PHSO) had originally said it would investigate if A was not satisfied by the Trust's independent investigation but then said the complaint was out of time, despite the fact that the initial complaint had been submitted within a year. The General Medical Council (GMC) did look into A's complaint but found that the test of doctors "posing a risk to patients" or "undermining the public's confidence in doctors" was not met. An appeal requested by A and by Birthrights found that the original GMC investigation may have been flawed but the result would have been the same. Some of the comments made by the GMC's own expert witnesses, lay bare attitudes that are very common amongst obstetricians:

"When the doctor inserted the speculum inside the vagina to access the scalp. the expert felt it would be reasonable to assume the patient provided some sort of consent (as she would have had to open her legs to allow access."

"Even if A's account was accepted, I consider it unlikely that our Expert or any other independent expert would conclude that Dr X's actions in going ahead with the vaginal examinations and foetal blood sampling fell seriously below the standard expected."

This is completely at odds with the GMC's own guidance on intimate examinations[28] which Birthrights has raised with the GMC.

"The expert noted that the patient may have previously said that she wanted to undergo a c-section instead of a forceps delivery – but the expert felt that it was important to recognise that the doctors were thinking of the baby's best interests."

This is despite the fact that law in this country firmly supports the right of a woman with capacity to make decisions about her body even if it endangers her own life or that of her baby[29], and that a baby does not have separate rights until it is born.

"The expert acknowledged that it could be argued that the doctors performed a rotational Kiellands forceps trial against the patient's wishes"

[28] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/intimate-examinations-and-chaperones
[29] See MB (1997) and S v St Georges 1998

We understand the doctors concerned have reflected on their practice and contributed to making changes. Nevertheless the message given out by the system as a whole is that undertaking a major procedure without consent is not a serious issue.

This is in sharp contrast to the investigations that would have taken place had there been a death or a brain injury to the baby.

Birthrights is clear that significant improvement is needed in the way serious human rights abuses are investigated in maternity care. Indeed all incidents where women have not been listened to should be adequately investigated so that lessons can be learnt and implemented. This will not only prevent significant psychological and physical trauma but also could ultimately reduce the risk of a death.

We would be very happy to discuss any element of this submission in more detail with the Expert Panel.

About Birthrights

Birthrights champions respectful care during pregnancy and childbirth by protecting human rights. We provide advice and legal information to women and birthing people, train healthcare professionals to deliver rights-respected care, and campaign to change maternity policy and systems. We are a charity, independent of government and the NHS. https://www.birthrights.org.uk/

Contact: Maria Booker, Programmes Director, maria@birthrights.org.uk

Birthrights/Mumsnet survey – published September 2020

Top lines

- 68% felt they had the information they needed to make informed choices when it came to decisions about their care or about planning for birth, but
  - 43% said the information they were given was not tailored to their individual situation, and
  - 61% would have liked more information from maternity services to help make decisions about their care and planning for birth
  - 49% felt they needed more support in making decisions about care and planning for birth
- 53% say their opinions and decisions about birth planning were respected
- Over one-third - 34% - said they were not asked or supported to make decisions about their care, and 30% say their decisions about birth-planning were not sought or respected.
- 14% say their birth planning decisions were overruled, and a further 11% say there was an unsuccessful attempt to overrule them
- 58% were aware that legally, an expectant mother is the primary decision maker about her care and the midwives and doctors' role is to advise her and to support her; 42% were unaware. Less than half (45%) said this reflected their experience; while 42% said it did not.

Interesting lines

- Lots of variation in which birth modes women feel they were given the opportunity to discuss - eg:
  - 74% felt they were given the opportunity to discuss the benefits of a vaginal birth but only 42% who felt they were given the opportunity to discuss the benefits of a caesarean birth;
  - 61% felt they were given the opportunity to discuss the benefits of giving birth on a labour ward but only 38% who felt they were given the opportunity to discuss the benefits of a home birth
- Fewer women said they were given the opportunity to discuss the benefits to them of a home birth (38%) than giving birth on a labour ward (61%)
- Lots of interest in finding out more, with 83% saying they were keen to do their own research to help them make decisions about their care
- 65% would have liked more personalised information from maternity services

Survey of 1145 women in the UK who have given birth at least once. Survey dates:

During your pregnancy, did you feel you had the opportunity to discuss the BENEFITS to you of:

Giving birth on a labour ward **Yes** 61% **No** 39%
Giving birth at a birth centre/midwife-led unit **Yes** 49% **No** 51%

Home birth **Yes** 38% **No** 62%
Vaginal birth **Yes** 74% **No** 26%
Instrumental birth (ie forceps or ventouse to assist delivery) **Yes** 37% **No** 63%
Caesarean birth **Yes** 42% **No** 58%
Induction **Yes** 53% **No** 47%

During your pregnancy, did you feel you had the opportunity to discuss the RISKS to you of:

Giving birth on a labour ward **Yes** 36% **No** 64%
Giving birth at a birth centre/midwife-led unit **Yes** 39% **No** 61%
Home birth **Yes** 45% **No** 55%
Vaginal birth **Yes** 44% **No** 56%
Instrumental birth (ie forceps or ventouse to assist delivery) **Yes** 37% **No** 63%
Caesarean birth **Yes** 51% **No** 49%
Induction **Yes** 41% **No** 59%

Overall, when it came to decisions about your care or about planning for birth, did you feel you had the information you needed to make informed choices?

Yes 68%
No 32%

Overall, when it came to decisions about your care or about planning for birth, which of the following would you say best describes your experience regarding the AMOUNT of information you received?

I was given too much information 1%
I was given the right amount of information 39%
I wasn't given enough information 30%
Sometimes I was given the information I needed and at other times I was not 30%

To what extent do you agree with the following statements about the information you were given when making decisions about your care or about planning for birth?

The information given was tailored to my individual situation **Net agree** 36% **Net disagree** 43%
I was not asked or supported to make decisions about my care **Net agree** 34% **Net disagree** 48%
I had all the information I needed to make an informed decision about all aspects of my birth **Net agree** 49% **Net disagree** 34%
The information was difficult to understand **Net agree** 10% **Net disagree** 68%
The information was easy to understand **Net agree** 69% **Net disagree** 8%
The information felt biased **Net agree** 42% **Net disagree** 31%
The information felt unbiased **Net agree** 32% **Net disagree** 38%
The information given seemed generic and didn't adequately address my individual situation **Net agree** 52% **Net disagree** 28%

Did you feel comfortable asking questions about the information you were given and about options for your care?

Yes 52%

Sometimes 39%
No 9%

How much did you want to do your own research in order to make informed decisions about your care?

Net 'keen' 83%
Net 'not keen' 3%

If you did do your own research, why was this?

I prefer to seek my own information 65%
The information I was offered was not personalised to me 39%
I didn't have enough time in my appointments to find out everything I needed 30%
I had concerns about the information I was offered 21%
Other 16%
I didn't trust my midwife/doctor 10%

Where, if at all, did you look for official health advice and evidence-based information from health professionals?

NHS.uk 69%
Patient information leaflets given to me 50%
Other 39%
On an app my maternity notes were on 9%
Did not look for additional official health advice 9%

If you did look independently for official health advice and evidence-based information from health professionals, were you able to find the information you were looking for?

Yes, I found the information I was looking for 88%
No, I did not find the information I was looking for 12%

Would you have liked more information from maternity services to help you make decisions about your care and planning for birth?

Yes 61%
No 39%

To what extent do you agree or disagree with the following statements?

I feel that I needed more support in making decisions about my care and planning for birth **Net agree** 49% **Net disagree** 33%
I would have liked more information that was relevant and personalised to me from maternity services to help me make my decision **Net agree** 65% **Net disagree** 21%
I was happy to follow the advice of my midwife/doctor so didn't need any further information **Net agree** 30% **Net disagree** 35%

To what extent do you agree or disagree with the following statements?

Whenever I needed to make a decision about where or how to give birth, I felt that I understood the benefits and risks of all reasonable options **Agree** 55% **Disagree** 25%
Knowing the information I know now, rather than what I knew at the time, I would make different choices about my maternity care **Agree** 43% **Disagree** 43%

If you would have liked more or different information from maternity services, how would you have liked access to this information?

More time to discuss in person with a midwife or a doctor 85%
Online tools or apps (eg risk calculators, decision aids) 49%
Patient information leaflet (hard-copy) 29%
Patient information leaflet (online) 35%

When it comes to your opinions and decisions when planning your birth, which of the following would you say applied in your case? Please tick all that apply.

My opinions/decisions were respected 53%
My opinions/decisions were not sought 30%
My opinions/decisions were overruled 14%
There was an unsuccessful attempt to override my opinions/decisions 11%

Legally, an expectant mother is the primary decision maker about her care and the midwives and doctors' role is to advise her and to support her to make an informed choice. Were you aware of this?

Yes: 58%
No: 42%

Legally, an expectant mother is the primary decision maker about her care and the midwives' and doctors' role is to advise her and to support her to make an informed choice. Do you feel that this statement describes your experience of planning for birth?

Yes: 45%
No: 42%