Written evidence submitted by Catherine Williams (MSE0079)

**Summary**

- it is common for people to be sure what 'safety' in maternity 'is' without having considered their 'thinking frame' – their biases and assumptions, and the values they are guided by
- respectful, human rights-based care is safe care – that encompasses 'clinical safety', research evidence, and other important factors that are often disregarded
- beware the belief that 'machines that go ping' are key to safety improvements
- unbiased presentation of information from research is important for thinking about and discussing safety in all contexts: NICE has published the national standard for presenting data to adult NHS service users, which is useful for everyone
- the Birthrights letter to the Maternity Review and this Lancet paper are key resources to inform the framing of work of this Inquiry

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1. I have been a service user advocate in maternity for more than 15 years. I have volunteered with and supported Maternity Voices Partnerships for many years and became an antenatal educator and a lay representative in policy settings, and in some maternity research, en route. I have visited many services as a lay reviewer, and spoken with many midwives and doctors, as well as many service users. Over a period of years, I came to the view that fear of litigation – fear of making catastrophic mistakes in care - tends to control NHS service provision, and the decisions that women are 'allowed' or denied. Indeed, that it puts women on a 'conveyor belt' of check-list-based care that can, perversely, get in the way of the human conversations between women and carers, and between professionals, that are real 'teamwork'. Teamwork, with the mother at its centre, that is not wholly defined by fear and 'risk talk', can hold and manage 'risk' in a way that respects the fact that things can go wrong, but will not necessarily do so, and has plans to minimise and manage risk, and to respond as needed in a changing situation.

The death of any mother, any baby, is tragic; and avoidable harm that is not fatal can cause a great deal of suffering. Any compassionate person wishes to see harm and death avoided. The difficulty is that some deaths and some harms are unavoidable, and that the pursuit of 'zero' avoidable death and harm may in itself lead to unintended harms.

I am, at times, concerned that high-profile campaigns for 'greater safety', particularly those based on tragic cases with a human face, rather than epidemiology, receive (very understandably, and with very human care for individuals) so much attention within maternity, the press and wider public domain, that at times it can be difficult for thorough analysis of all the issues be heard, and to also influence public policy and clinical practice.

A thorough analysis will include weighing up the likely unintended consequences, as well of the benefits, of proposed actions or clinical practice changes to address a specific risk or care outcome.

2. Recent campaigning for automatic referral of all term stillbirths to the coroner is an example of this. The loss of any baby is a tragedy. Learning from avoidable loss and minimising avoidable deaths is essential. However, the potential human rights implications for women inherent in this proposal are serious – as the submission by the charity Birthrights to the consultation explained. What might

seem a ‘sensible’ or ‘obvious’ measure (automatic referral to the coroner) is not straightforward at all.

3. How can maternity care be made safer? (In what way(s) does it need to be? Always, the question or assumption before the ‘obvious’ question’ matters. What is the evidence? And how should the evidence be read in an international context? What is different/particular to the UK system, if anything?) I have come to understand, as a lay person reading research evidence and commentaries, that safety is not necessarily a given result of using more and more machines and technology. An enduring problem in maternity, some commentators argue, and I share the view, is the valuing a particular technology - using a ‘CTG’ machine for continuous electronic monitoring of the fetal heart during the woman’s labour - despite it being introduced into practice without proper research or evaluation, evidence over time that it causes harms, and yet it appears to be no more useful than intermittent auscultation of the fetal heart rate with a hand-held device (to summarise in simple terms, for brevity.)

4. Please – Committee Members – do not assume that more electronic surveillance of the fetus during birth, and use of CTG machines in particular, is a good thing. Nor that ‘failure to read the trace properly’ is in fact, in many cases, the explanation that it might appear to be. CTG is a deeply flawed screening test – and ‘more’ is not always better. To illustrate some of the issues:

- a blog from a well-known lay commentator (contributor to the national reviews *Changing Childbirth* and *Better Births*, and a member of the Maternity Transformation Stakeholder Council) explaining briefly some of the issues with over-reliance on technology, and a focus on labour and birth care at the expense of addressing the causes of the greatest proportion of stillbirths

- a blog which is one of a series by an Australian obstetrician and academic with a PhD in the topic, explaining why we should be thinking hard about use of CTG (rather than hand-held ‘intermittent auscultation’ devices)

5. But we’re forgetting someone here. When we speak of safety, whose safety? Where is the woman, the birthing person? And who gets to decide how to make trade-offs among the various risks that birth (like any activity in life) entails? Does she? Or is that the role of her care-providers?

6. A woman is not merely a container for growing a baby. Mother and baby are legally one until the moment of birth. Her right to accept or decline treatment (providing she has mental capacity, as in any situation where an adult is offered treatment) is absolute. Even if to decline treatment will result in a stillbirth.

(Think back to the proposal about referrals to the coroner above – and be aware that in the United States there have been reported abuses of the human rights of pregnant women – in States where the fetus is *de facto* prioritised over the mother – that include forced caesarean sections. A woman is not a mere container: that the baby grows in her is biology, and others must reconcile themselves to her right to autonomy and self-determination. However much they – perhaps the father; perhaps a midwife or doctor with a strong ethical drive to help and save – want her to accept certain treatment, which she has an absolute right to decline. In a society committed to women’s human rights, that is.)

7. Thinking about human rights and ethical duties is complicated, and needs time and care. Similarly, what ‘risk’ is, what ‘safety’ means, and who gets to define it, and options for women, is more complicated than it first seems: there is a very strong tendency in maternity services worldwide to

frame safety in terms of intervention to save life, mother and baby; but all interventions have potential harms, and over-treatment (iatrogenic harm) is a well-documented consequence of over-treatment in maternity care. I recommend to Committee Members that you read, as contextual information to the evidence that you receive, this 2017 Lancet paper about arriving at the right balance between under-treatment and over-treatment – read here.

8. I note that your call for evidence seeks comment on *'advice, guidance and practice on the choices available to pregnant women about natural births, home births and interventions such as C-sections…'.* Language is a minefield in maternity, as people with differing views seek to frame things to variously narrow or broaden both philosophical perspective and discussion about practical possibilities in care. I will use the phrase I have picked out to illustrate this:

- a reference to 'natural birth' is often a signal – in the press or a published opinion piece – that the author is sceptical that birth without intervention is sensible, advisable, or even possible. It is noticeable to the 'informed reader' that you select this phrase to use, along with 'home births'. Selective reference to home as an option for place of birth often signals, in press and commentaries, 'how could that ever be a sensible choice for any woman?'
- the call mentions home birth and caesarean birth, and not the other possible places of birth, and modes of birth, all of which have risks and benefits. A more neutral list would perhaps have referred to *'place of birth (home, midwifery unit or obstetric unit) and mode of birth (vaginal birth without intervention, assisted birth or caesarean section)'*
- you will note, of course, my careful choice of increasingly intensive care setting/degree of intervention, starting with the primary care and with birth without intervention – a deliberate choice: whether biased or positively seeking not to lead, nor to establish by implication what is normative and what is not, I leave you to consider. Such are the inferences – of bias, or of intentional neutrality, that different phrase can – and frequently do – give rise to. Acceptance – or not – of any publication can be affected by its language, which may seem innocent to some stakeholders, and alienate others.
- Language does actually matter in reality: in my view, it reflects values and thinking models – and these things do matter. It is important to move beyond merely 'labelling' any given approach to childbirth though, and to ask why people hold the views that they do. The measured, compassionate – rather than emotional – approach of US psychologist Paul Bloom, who is 'against empathy' (and in favour of both compassion and critical thinking) – offers one approach to considering complexity of this sort.

9. Please consider your own assumptions and biases – we all make and have them - as you consider my evidence, and all of the submissions made to the Inquiry. Where did you learn about birth? What are your assumptions? Do you know the evidence on place of birth for women at low risk of complications, for example? For many people, including quite a few midwives and doctors, this evidence, and the NICE recommendation derived from it, is a challenge to their assumptions and beliefs.

- section 1.1 of NICE CG190 Intrapartum Care - brief, readable, available here

10. What those giving birth value and want as options is very important, and their experiences of care are, collectively, important evidence about what is good, what is not working and what could be improved in care. In Maternity, the NHS Maternity Voices Partnerships provide a route for women, birthing people and families to be involved in co-producing quality improvement of services, and monitoring quality, including reviewing numbers of complaints, and information about the themes from complaints, as well as looking at the service 'dashboard' with the professional MVP members.

Co-production of service changes and quality improvements is one way to address our 'collective understanding' of pregnancy' labour and birth in society, because it involves information-sharing and 'thinking together' by service users and healthcare professionals. There are opportunities in the work that many MVPs do together, for example, to create or improve local pregnancy and birth service information resources for women and families

11. Many sources and voices tell women about birth, not just the NHS, of course, and there is good practice and poor practice in the mix from all types of source.

- There is recent research evidence from NPEU and other UK University teams on the information sources that women refer to; what influences their thinking about place of birth; and how birth and place of birth is presented in the press.
- These studies provide important contextual information for this Inquiry, because how care-providers, women, and birthing people conceptualise 'risk' and 'safety' affects what is deemed safe – without reflection, necessarily, on how these ideas have been arrived at. Where do prevailing ideas about safety and risk come from? What is an 'acceptable' or 'unacceptable' level of risk, and who has determined the thresholds? This 2015 paper from the Professional Standards Authority, on the role of risk in regulatory policy, illustrates how thoughtful it is necessary to be about conceptualising risk (and touches the point that 'zero risk' is not a real world possibility.) This 2004 paper remains interesting.

12. How can we have better conversations about health matters including how we women choose to birth, and how to improve and promote safety in childbirth? It would make a huge difference to discussion of risk and safety in maternity if most people would follow the example set by the National Perinatal Epidemiology Unit in a number of its publications, and comply fully with the evidence-based recommendations of NICE CG138 1.5.24 on presenting – and contextualising – data

- absolute figures (not relative risk), standard denominator throughout, frame it both ways – how many affected per 1000 and how many unaffected per 1000 – people have different views about risk – unbiased data presentation is key to unbiased information sharing and discussion of options that the woman can decide between
- too often, information giving is not of the highest quality (for many reasons, being brief here, but some that are system-related, and some that are due to the biases and preferences of individual midwives and doctors - in my view, after years of working with women, and midwives, and doctors, and talking through experiences and issues from many perspectives)
- a recommendation from this Committee that following the NICE national standard on presentation of numbers and information should be the norm could make a significant different to the quality of discussion among policy people and clinicians, and most importantly to how information is given to women – as in these national NHS leaflets on planning place of birth, for healthy women at low risk of complications.

13. Human rights are an essential basis for safe health care. Before you even begin to consider the topics highlighted in the call for evidence, I hope the Committee Members will have an opportunity to consider together how the Inquiry is framing the issue of safety as it reviews the evidence and begins to draft a report: I commend to you, as both a thinking framework and as a structuring framework for your report and findings, this letter to the Maternity Review from human rights charity Birthrights. It talks about quality and safety – '

'*The assessment of high quality, safe maternity care goes beyond measures of mortality or morbidity and encompasses multiple outcomes…'*

14. I look forward to reading the findings and recommendations of the Inquiry.

Catherine Williams, September 2020

The views expressed in this submission to the Inquiry are personal and not attributable to any organisation with which the author is or has been associated.

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