

## **Miss Joanne Deery- Written evidence (PRT0043)**

I am submitting this evidence on behalf of 2 large groups of women affected by preterm birth as a result of cervical incompetence, in the UK. These groups are called 'Incompetent Cervix UK' (which currently has 2600 members) and 'The UK TAC Support Group' (that has 650 members). These are UK specific groups and members are vetted on requesting to join, to ensure they reside in the UK and their care is applicable to the NHS health system. These groups are on the Facebook Platform and can be found via a search of their names. Incompetent Cervix UK is a group for anyone who wishes to receive support and information on the condition who resides in the UK or Ireland and The UK TAC support group is for women who have had or will have placed a transabdominal cerclage (TAC) to prevent future preterm birth in the UK. I believe that evidence on behalf of groups of this size should be essential to your this call (1)

These groups were formed by myself and a few others over 10 years ago as a source of support and knowledge sharing for women across the UK who were at risk of / or experiencing preterm birth, yet had no one to speak with who had the same lived experience. Although preterm birth is a massive issue, the combined numbers of those effected in smaller pockets of communities tend not to be. Therefore, finding anyone else who knows what you are going through and can be a source of support locally, was very hard to find. (2)

Moving forward to the present day, there are still issues in women receiving the care they should receive in line with current guidelines and I often find myself referring women to specialists via email address when their high-risk pregnancies are not being treated as they should be. This has resulted in treatments being given too late, putting pregnancies at risk and the psychological impact of this for these women is immense. From personal experience it makes you question all medical care you

receive in later pregnancies and all the joy that should come with those pregnancies is replaced by anxiety, fear and uncertainty. (3)

In relation to the topics you wish to cover in the submission, I would like to touch on the ones below if I may.

Variations in care and health inequalities remain vast in spite of the 5<sup>th</sup> element of the saving babies' lives care bundle V2 which was introduced in 2019. This is for a number of reasons but it is primarily due to location of care in my opinion and a lack of knowledge amongst healthcare professionals in smaller district general hospitals. Unfortunately ego can play a part in medical decision making where certain doctors practice a certain way, have always practiced that way and do not look at current evidence and change their practice in line with it. This is seen often in the women of our groups where some have been refused guideline treatments / care as their current medical team do not believe they work. As most evidence-based practice is 'guideline' and not mandated, this continues to affect the care of women at risk of preterm birth for whatever underlying cause. Other barriers such as language also play a part, especially in smaller hospitals as resources for translators are smaller – yet even when no language barriers exist, the problems remain. There needs to be a mandated push for national clinicians to discuss the care of their patients with specialists, with the removal of any personal bias. (4)

There are also issues with prevention if you live in an area where no preterm birth specialist clinics take place or there are issues with funding the right equipment to provide early preterm birth risk detection. Local procurement teams often dictate what tests can be bought for use in trusts and are based on budgets, so this may not always be the best test available. For example – a non-quantitative foetal fibronectin test instead of the recommended quantitative, or a different brand used and so on. The use of cervical length scanning versus not using it is also an issue. Staffing to carry out screening scans and run preterm birth clinics in

secondary care centres is a major prohibiting factor that impedes adequate preterm birth preventative care. Screening by midwives in primary care is also dictated by the capacity of the secondary care teams to follow up highlighted women. For example – it is recommended to follow up every woman who has had a prior emergency lower caesarean section when dilatated at the time of the section. This can be any stage of dilatation I believe, yet my local secondary care trust only has capacity to scan the most high risk of these women and follow them up. So only those that had a full dilatation section and no others yet we are seeing women in our groups losing babies when only dilatated to 7cms and missed for screening. The guidelines are being followed, but only barely. Many factors play a role in effective prevention of preterm birth. In terms of preventative treatments both primary and secondary, this is also very much based on the clinical teams preferred methods and techniques they are familiar with undertaking. Women in East Kent or Cornwall for example usually need to travel to London for the placement of a transabdominal cerclage as it is not practiced any closer, this has implications in itself for women and their families, especially if they have other children with no one at home to look after them while they are away, as this procedure requires at least a one night stay as an inpatient.

(5)

Psychologically women are suffering as a result of preterm birth emotionally and this can affect them for the rest of their lives. One of our members lost 4 babies due to inadequate care decisions and she will now never be a mother as she has passed the age to have her own children. There needs to be better support for women who lose their babies prematurely. I received no support after I lost my 2 babies prematurely and I only hope that in the ten years since, this has changed. (6)

My recommendations would be a national hub for all referrals to be discussed with specialists if it is deemed necessary. I believe Tommy's has recently won a bid to host the national preterm birth research centre

in London and a support network that runs in line with this would be an excellent source of knowledge and support for women. It should not only be the role of groups like ours to provide this for women and families effected nationally, this should be embraced as importantly as clinical care. (7)

Research studies should focus more on using groups like ours for potential participation. We recently helped with a qualitative piece of research where 186 women were asked about their experience of transabdominal cerclage. Our groups hold in one place a pool of patients with lived experience far larger than most areas of the country and this should be made use of more widely, to advance the speed at which research findings take to come to fruition. Whether that be participation or dissemination of findings. Communication is the key to improving outcomes in this area. (8)

Thank you for taking the time to read our submission and thank you again for addressing this issue with the seriousness it requires.

*27 March 2024*