Maternal Request Caesarean

August 2018



Protecting human rights in childbirth

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Foreword

Transparency about maternal request caesarean is long overdue. We are pleased to share the results of our research and shine a spotlight on the availability of MRCS in the UK.

Since its revision in 2011, NICE Guideline CG132 has rightly recognised that women should always be the primary decision makers in childbirth, whilst also protecting the right of individual doctors to decline to support an individual who requests a caesarean on non-medical grounds. Despite this guidance, Birthrights' advice service now handles more requests for support from women unable to access a caesarean section than any other issue.

The publication of this research demonstrates that nearly three quarters of NHS Trusts do not have written guidelines that clearly commit to upholding a woman's autonomy in this area. Some Trusts have implemented blanket policies that effectively ban maternal request caesareans, running contrary to NICE guidance and potentially in breach of their human rights obligations. Our data, paired with the distressing stories we hear regularly from pregnant women, demonstrates that the majority of Trusts are not consistently providing compassionate, woman-centred care for those requesting a caesarean.

The women we support have endured previously traumatic births, mental ill-health, childhood sexual abuse, or have carefully examined the evidence available and made informed decisions that planned caesareans will give them and their baby the best chance of an emotionally and physically healthy birth and parenting journey. Their decision-making processes and desire for kindness, clarity and control at a transformational and vulnerable time in their lives are no different to those of women we support as they try to access home, hospital or midwife-led births.

Positive birth experiences have repeatedly been shown to be promoted by positive relationships between a woman and her care team and a feeling of control over decisions in pregnancy and birth. Birthrights believes that all women deserve unbiased and personalised pathways in maternity care alongside evidence-based information to allow them to make the best decisions in their individual circumstances. It is clear that women requesting caesareans meet judgemental attitudes, barriers and disrespect more often than they find compassion and support. We are concerned that this lack of respect for patient dignity could have profound negative consequences for the emotional and physical safety of women.

We hope that this report, and the online map that accompanies it, will in the short-term give women information to help them choose a maternity care provider. Most importantly, we want these results to act as a catalyst for transparency and consensus on this issue encouraging national bodies, service-users groups, campaigners and clinicians to come together to promote policy and guidelines on maternal request caesarean birth that truly meet the needs of women.

Rebecca Schiller, Chief Executive, Birthrights

Background

Birthrights believes that human rights values have the power to transform maternity care in the UK. We reach thousands of women and health care professionals through our advice and training, while our research highlights the challenges and inequalities faced by women in maternity care.

Why did Birthrights undertake this research?

Enquiries about maternal request caesarean are the most common reason for women to contact the Birthrights email advice service. A third of our enquiries are now on this topic. Our advice service cases continue to demonstrate that this group of women face considerable uncertainty about whether their request will be listened to, and that practice varies between Trusts.1 Furthermore, intelligence from our advice line has highlighted a worrying trend towards Trusts informing women on booking into maternity care that the Trust do not offer maternal request caesarean and that this is causing women significant anxiety and distress.

NICE Guideline CG132 (revised 2011)² states that women requesting a caesarean with no other indication should be offered appropriate discussion and support, but ultimately, if they are making an informed choice, a caesarean should be offered. The guideline also states that if an obstetrician is unwilling to carry out a caesarean section (CS) the woman should be referred to an obstetrician who will carry out the CS.

Whilst it is not a legal requirement to follow NICE guidance, Trusts should be able to give robust and evidence-based reasons for diverging from it.

The decision of the UK Supreme Court in Montgomery v Lanarkshire Health Board (2015) articulated the requirement for healthcare professionals to have a two way dialogue with a pregnant woman that explored all "reasonable alternatives". Birthrights are concerned that any statement or policy from a Trust, that a caesarean will only be granted on medical grounds may be incompatible with Trusts' obligations to have an open, supportive, twoway discussion that explores all reasonable options. If such a policy is then applied in a blanket way, we are further concerned that such a policy could be incompatible with human rights law.

We therefore decided to send Freedom of Information requests to every Clinical Commissioning Group in England and every NHS Trust providing maternity services in the UK between November 2017 and January 2018 to find out:

a) whether they had a written guideline on maternal request caesarean sections

¹ Please note that we have referred to Trusts throughout this report to mean Trusts in England and Northern Ireland and Boards in Scotland and Wales.

² National Institute of Health and Care Excellence (NICE). 2011. *Caesarean section clinical guideline.* (Available at https://www.nice.org.uk/guidance/cg132)

- b) whether this reflected NICE guideline CG132
- c) the number of maternal request caesareans being performed.

We were interested to find out how far policies on maternal request varied across the country, and in particular whether the practice of informing women at the start of their care that maternal request caesarean would not be offered by the Trust was widespread, and whether this policy was being driven by commissioners or Trusts themselves.

Why do women ask for a caesarean section?

The reasons for women requesting a caesarean are not always well understood.

Our own analysis of our advice service enquiries on this issue between November 2016 and May 2018 reveal that a third of enquirers (33%) want a caesarean due to a previous traumatic birth. The second most common reason (28%) for wanting a caesarean birth is an underlying medical condition such as symphysis pubis dysfunction (SPD) - a common problem with the pelvis during pregnancy -, vaginismus or fibroids. These conditions do not always meet the threshold of requiring a caesarean for medical reasons but the impact of these conditions on the women affected is significant, and the thought of having their condition exacerbated by a vaginal birth can be a cause of huge anxiety.

The remaining third is made up of women who simply believe it is the right option for them (16%), often after extensive research into the evidence, or who have primary tokophobia (8%) or who have experienced other trauma in their lives such as sexual assault (6%). 10% did not give their reason for making this request.

Although, this analysis is based on relatively small numbers (83 enquiries in total), it paints a picture of women who are driven to make this request by well thought out reasons or intense fears, and who know they will often face an uphill battle to be listened to.

Understanding the barriers to caesarean section

The additional physical health risks to a woman or baby are often cited as barriers to offering maternal request CS. Birthrights believes that all woman should be enabled to make informed and individualised decisions about their maternity care (including mode of birth). These decisions should be based on information that is balanced, based on the latest available evidence and personalised. Any significant limitations of the evidence should be explained.

We are concerned that many women we support are not being made aware of the quality of the evidence available, are not presented with the full range of risks and benefits, and that women's own values, needs and individual risk-factors are not taken into consideration as part of the decision-making process.

This is particularly important because:

The quality of evidence around this issue is low. Most studies have used mixed caesarean data (i.e. data from both emergency caesareans and planned caesareans) to report on outcomes. Reports from women to our advice service suggest that midwives and doctors can appear overconfident in the outcomes drawn from this data, and do not always explain the limitations of the evidence.

The available evidence on outcomes from caesarean vs planned vaginal birth is not clear cut. A recent large scale systematic review and meta-analysis of "long term risks and benefits associated with cesarean," published in January 2018 quoted evidence from NICE to conclude that "the short-term adverse associations of caesarean delivery for the mother, such as infection,

hemorrhage, visceral injury, and venous thromboembolism, have been minimised to the point that cesarean delivery is considered as safe as vaginal delivery in high-income countries".3 Women need access to this information as well as the legitimate concerns about the long-term outcomes of caesarean birth for the mother and the baby. Women report a tendency for the known risks of caesarean to be emphasised or exaggerated. The small but significant number of women who end up with more serious injuries following a vaginal birth often feel that they were not informed about those risks. More transparency and unbiased presentation of the evidence and its limits is needed.

The risks and benefits of vaginal birth vs caesarean birth need to be personalised.

A recent study by Rahmanou et al of Sydney University showed that the risk of pelvic floor damage from a vaginal birth increased by over 6% with each year of maternal age at time of first birth.⁴ If women are not planning to have any further children then the risks of caesarean for future pregnancies are not relevant. Therefore a 42 year old first time mum pregnant with her first and only expected child may face a different set of risks and benefits to a 23 year old in her first pregnancy who hopes to have a large family.

A woman brings her own values and needs to this decision and may be broader that purely clinical factors. And an individual who has faced trauma in her past may never disclose the reason for wishing to have a caesarean section.

Women with complex social needs may face more significant barriers within the current system. Women who feel they need to comply (for a range of reasons such as

social services involvement), or who are unable to advocate for themselves (for example women who don't speak English as a first language, or have learning difficulties) may be more likely to agree to proceed with a vaginal birth that feels unsafe to them, even if they are not reconciled to it.

What about the rights of healthcare professionals?

One in four babies in the UK is born by caesarean and obstetricians perform caesareans on a daily basis. Nevertheless, the NICE guideline is clear that any individual obstetrician can decline to undertake a maternal request caesarean they do not feel comfortable with. It is important that doctors are able to decline to undertake maternal request caesareans which they believe run contrary to their Hippocratic oath to "do no harm".

We are confident that the current guidance protects doctors and have yet to be contacted by any healthcare professionals who feel pressured into performing a maternal request caesarean. All the written guidance we have been able to access creates the impression that individual obstetricians are strongly supported in their right to decline.

However, Birthrights has been contacted by healthcare professionals who are prevented by their Trust from offering women the personalised care they feel they should be offering and are required to refer women requesting a caesarean without a medical reason elsewhere.

In addition, we also know of obstetricians who will support maternal request caesarean even if their Trust policy is not supportive. However we also know that in these cases it is sometimes a matter of luck

³ Keag OE, Norman JE, Stock SJ. 2018. 'Long-term risks and benefits associated with cesarean delivery for mother, baby, and subsequent pregnancies: Systematic review and meta-analysis'. *PLOS Medicine* 15(1): e1002494. (Available at: http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002494#pmed.1002494.ref004)

⁴ Rahmanou, P, Caudwell-Hall, J, Kamisan Atan, I & Dietz, HP. 2016. 'The association between maternal age at first delivery and risk of obstetric trauma'. *American Journal of Obstetrics & Gynecology*, 215, 451.e1-451.e7. (Available at https://www.ajog.org/article/S0002-9378(16)30117-X/fulltext)

as to whether women wanting a maternal request caesarean are matched with consultants who are prepared to support that request.

would fall to £84 per birth. NICE judged that this was not significant enough to influence the decision-making process.

What about the cost?

The increased costs of caesareans to the NHS is frequently cited as a barrier to maternal request caesarean. However the economic modelling set out in the full version of the 2011 update of the NICE guideline on caesarean section⁵ found that, without taking any longer term impacts into account, a caesarean cost around £700 more than a vaginal birth. If the costs of treating urinary incontinence (disregarding other forms of damage caused by vaginal birth) were taken into account, the cost difference

How do MRCS policies make women feel?

"I do not want a fight, I am simply an anxious woman requesting a caesarean section and requesting some certainty around my situation."

"It is still so very sad that I cannot have my baby at my local hospital near to my family and support network. I am also very scared about the journey and what would happen should I go into early labour."

"At my first scan, which should have been a happy occasion, I was filled with dread when the technician said the baby was growing well as all I could think about was how I would give birth to this baby and how it was getting larger with each day that passed without my having secured the caesarean"

"A c-section is not my idea of an ideal birth; it's the option that I find least terrifying, the lesser of two evils."

"I feel that my concerns were not listened to, my knowledge of SPD with my own body and the previous trauma my body had suffered along with the recovery time were ignored. I was made to feel like a number rather than seen as an individual."

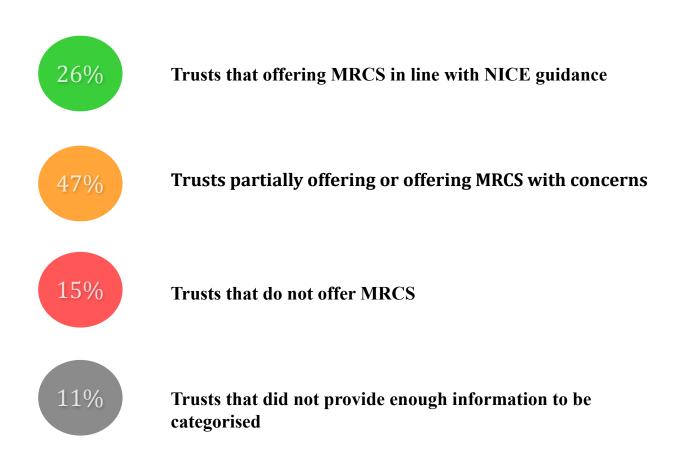
⁵ National Collaborating Centre for Women's and Children's Health. 2011. *Caesarean section November 2011 NICE Clinical Guideline*. (Available at: https://caesareanbirth.files.wordpress.com/2017/01/2011-cg132-nice-caesarean-section-update-full-version-guideline.pdf)

Summary of results

What did our research tell us?

We wrote to 206 CCGs and we received 187 responses – a response rate of 91%.

We wrote to 153 Trusts providing maternity care and received 148 responses – a 97% response rate. This survey therefore represents a comprehensive snapshot of Trust policies on maternal request caesarean section.



Visit $\underline{\textit{birthrights.org.uk}}$ to see a map showing the rating for every Trust. Please note that due to rounding these percentages add up to 99 rather than 100%

Analysis

Trusts

We asked every Trust offering maternity services in the UK to tell us:

- how many maternal request caesareans they carried out between April 2016 and April 2017 with no other significant medical, obstetric or psychological indication;
- to provide us with any Trust guidelines, staff guidelines or patient information leaflets on MRCS;
- to explain how they complied with NICE CG132 1.2.9.5.

Out of the 147 responses we received we concluded that **39 Trusts (26%) offer MRCS**.

These Trusts are committed to the spirit of the NICE guidance (at least on paper). They had a written policy that made clear that, if appropriate support has been offered and a woman is making an informed decision, based on an understanding of the risks and benefits of all options, that they will offer maternal request caesarean. If an individual obstetrician is not comfortable with carrying out the surgery they will refer to a colleague who "will" carry out the caesarean section within their own Trust (or in one case "seeking input" from outside the Trust). Trusts that looked after over 2,000 women that had carried out no MRCS in the year data was requested for, were excluded from this category even if their policy appeared to support it.

70 Trusts (47%) partially offer or offer MRCS with concerns

This category includes Trusts where we could not be sure whether a woman would

ultimately be offered a caesarean section if she wanted one. We defined this to include:

- Trusts that said they offer MRCS but had no written guideline. We recognise there is no requirement to have a written guideline but feel this indicates a thoughtful and consistent approach to the issue
- Trusts who said they offered MRCS but had carried out none between April 2016 and April 2017 (if the Trust had over 2000 births per year)
- Trusts that had a policy to request a second opinion but it was unclear what would happen if the second opinion was a "no"
- Trusts that always required the permission of two consultants (10 Trusts in total)
- Trusts that mentioned referring women to another hospital as part of their process
- Trusts that seemed to have an incomplete guideline (for example where the guideline only dealt with maternal request caesarean section stemming from a mental health issue),
- Trusts that suggested that a compulsory mental health appointment was required for the CS to be offered.
- Trusts where the policy was not to make a decision until after 36 weeks,
- Trusts where the CS would not be scheduled until after 40 weeks
- Trusts where we had any other concern about the policy/process described.

A number of Trusts in this category gave a combination of the reasons above. This category covers a large range of Trusts from those which seemed to have a very supportive process but no written policy, to those who were very close to being categorised as not offering maternal request caesarean.

22 Trusts (15%) do not offer MRCS

This includes all Trusts that had an explicitly stated policy not to offer MRCS. Some of these Trusts did go on to explain that they might be offered in exceptional cases. This category also includes Trusts (overseeing more than 2000 births a year) who did not clearly state whether they offer maternal request CS but where the number of MRCSs carried out was zero. We have included Trusts in this category that told us they did offer maternal request CS while also sending us information they gave to women which directly contradicted this.

17 Trusts (11%) unknown

This category covers those Trusts that did not provide enough information to be categorised.

We wrote to all Clinical Commissioning Groups in England and asked them to:

- advise how many maternal request caesarean sections with no obstetric, medical or significant psychological reason were paid for by the CCG between April 2016 and April 2017.
- advise how many maternal request caesarean sections carried out primarily for a psychological reason were paid for by the CCG between April 2016 and April 2017
- advise on any guidance, policies or contractual agreements the CCG had in place with Trusts setting out in what circumstances the CCG would pay for maternal request caesareans.

Pressure from commissioners (Clinical Commissioning Groups (CCGs)) seems to have an influence on Trust policies in some areas although this factor alone does not explain the results.

We found 26 CCGs out of 206 (13%) in England who we identified as not being supportive of maternal request caesarean.

The six Clinical Commissioning Groups based in South East London (Bexley, Bromley, Greenwich, Lewisham, Lambeth and Southwark) have a shared "Treatment Access Policy" which states that: "Caesarean section is only available for clinical reasons. Elective Caesarean section for nonclinical reasons, including maternal request, will not be funded on the NHS unless prior approval has been obtained. Such approval will only be granted if such an elective caesarean section is justified using recently published NICE guidelines. Applicants will have to document carefully how the case fulfils those guidelines." A certain amount of ambiguity over the NICE guidelines is demonstrated here, as the NICE guidelines suggest that maternal request caesareans should be funded by the NHS as long as appropriate discussion and support have been offered. Trusts in South East London have all been classified as "red" (apart from Kings College Hospital NHS Foundation Trust who have recently updated their policy in light of the London-wide tokophobia toolkit).

In addition we are aware of a cluster of CCGs around the Thames Valley who are not supportive of maternal request caesarean. The Clinical Commissioning Groups, whose main provider is the Royal Berkshire (Newbury & District, South Reading and Wokingham), appear to support the Royal Berkshire's policy of referring any woman making this request to other providers and state this is in line with NICE guidance. Chiltern CCG also appears to support the policy of its main provider (Buckinghamshire Healthcare NHS Trust) of encouraging women to go elsewhere or explore private options. Swindon CCG states that its policy is to promote natural birth

and states that maternal request caesarean will only be funded for a psychological reason if two consultants agree.

The Derbyshire Clinical Commissioning Groups (Erewash, Hardwick, North Derbyshire and South Derbyshire) are governed by a Derbyshire-wide policy on procedures of low clinical value which includes maternal request caesarean as an intervention that will not be routinely commissioned.

There is a further group of CCGs (Cannock Chase, Stafford and Surrounds, South East Staffordshire and Seisdon, East Staffordshire and Wolverhampton) which also share a policy which lists when caesareans will be funded. The list does not include maternal request as a reason which implies this would

have to be funded via an individual funding request.

Other CCGs categorised as being unsupportive were Dartford, Gravesham and Swanley, Hull, Kernow, Merton and North West Surrey.

Telford CCG has recently changed their policy to not routinely commissioning maternal request caesarean.

A number of CCGs who gave an unclear answer about caesareans needing to be clinically appropriate in line with NICE guidelines have been given the benefit of the doubt in our analysis. We believe that the number of unsupportive CCGs may well be higher than 26.

What does a good maternal request caesarean guideline look like?

Birmingham Women's Hospital co-designed their pathway with women. During this process they learnt that women's and healthcare professionals' concerns about the existing pathway were actually very similar. These concerns included: women having to discuss the request a number of times, a delay in the decision for caesarean, women feeling judged, and concerns about the quality of information women were being given.

Researchers helped clinicians and service users to design a new pathway using experienced-based co-design. As a result BWH's guideline uses language that recognises the woman as the lead decision maker, such as "If a woman has decided on CS" and "at every appointment re-confirm (not challenge) decision". It is respectful to the woman's decision-making process and tackles the topic thoroughly. The guidance is also transparent about the low quality of the evidence on this subject.

As a result of this pathway women will have made a decision with the clinical team by 24-28 weeks which allows her to enjoy the rest of their pregnancy knowing she has been listened to. We felt this document was one of the best examples of a maternal request caesarean guideline.

A healthcare professional's perspective

Simon Mehigan, a Birthrights' Trustees, and now Director of Midwifery at Pennine Acute Hospitals NHS Trust, used to run a clinic in a large teaching hospital for all women requesting caesareans for no perceived medical reason.

Over the course of 3 years, Simon saw over 500 women. Simon very quickly found that reassuring women very early on that their request for a caesarean would be honoured if that's what they wanted, led to a much more open conversation about possible options. A couple of women informed Simon that being told "no" by consultants had made them more determined to have a caesarean section because they were not prepared to let someone else make decisions about their birth.

A de-brief of a woman's last birth was often helpful, in opening up the possibility that things could be different this time round. However women were more likely to be open to other options early on in their pregnancy and Simon found that the later these conversations were held, the less open women were to discussing alternative options. Simon also found that once a decision had been made a line had to be drawn as women found it very stressful to have to revisit that decision every time they saw a healthcare professional.

After meeting Simon, 85% of women opted to have a vaginal birth of their own accord and 70% of those women had a vaginal birth. The plans of care that Simon put in place often focused on having an uncomplicated birth with a low threshold for caesarean. However some women simply felt a caesarean birth was right for them and could all explain rationally why they wanted to birth their babies that way:

"In over 20 years as a midwife I have yet to meet a woman that has made irrational decisions or choices. They have always been the right choice for that women based on her individual circumstances."

Call to action

Birthrights would like to see:

Every trust embracing the human rights principle that every woman has the right to make an informed choice over what happens to her body during pregnancy and birth.

Too many Trusts have a policy that does not recognise the women as the primary decision maker in birth. The role of healthcare professionals is to ensure that a woman has all the information and support she needs to make an informed decision, and then to support that choice.

The most important principle underpinning section 1.2.9 of NICE guideline CG132 is that a woman must lead decisions about how she gives birth. This principle should be threaded through every maternity policy and guideline, including those on maternal request caesarean. The guideline concludes that maternal request caesarean it is a reasonable option to offer women taking into account both the benefits and risks and the cost of the intervention. Whilst the right of individual doctors to decline is protected, they do not have the right to prevent women from making that decision. Nor should a decision-making process add unnecessary and lengthy periods of anxiety to a pregnancy.

Birthrights believes that public confirmation from NHS England that choice in maternity care includes the informed choice of maternal request caesarean would be an important step forwards.

Urgent clarification from NICE that larger NHS Trusts referring women to another NHS Trust to access MRCS are not complying with guideline CG132

Public clarification from NICE around transferring women to other Trusts is needed.

There are a small number of Trusts who believe they are complying with the NICE guideline on maternal request caesarean by referring women to another Trust. We do not believe this is the case. Minutes of the Guidance Executive Meeting on 11 October 2011, supplied to us by NICE, describe Ben Doak, Guidelines Commissioning Manager, explaining that the new guidelines meant that "if an obstetrician was uncomfortable with this decision, then another NHS obstetrician within the same unit will be asked to carry out the caesarean section". NICE have informed us that at a subsequent meeting (minutes not available) that the wording "in the same unit" was loosened in response to concerns about whether this was feasible for small Trusts, although the intention remained the same. Where Trusts are really too small to genuinely offer an option to refer to a supportive consultant within the same Trust, pathways to consultants in other hospitals should be agreed, and women not just left to navigate on their own, but for the majority of Trusts referral to other Trusts should not be necessary. We are not aware of any Trust with a policy of referring women elsewhere that has carried out a proper assessment of the impact on women of such a policy, which we know has a huge impact on women and their families trying to juggle jobs, other children, interactions with other medical specialities etc. We would welcome clarification from NICE on this issue.

Furthermore "Maternal request on its own is not an indication for caesarean section" was a phrase found in a number of policies, often followed by the wording in the current NICE Guideline CG132. In fact this phrase is taken from the 2004 guideline (CG13 now out of date) and is at odds with the revised guideline (CG132), which implies that if women are making an informed choice, then maternal request **is** on its own is an indication for caesarean. Again, clarification and raising awareness that this phrase is no longer part of the NICE guidance would be helpful.

A better understanding of the diverse reasons women ask for maternal request caesarean

Our Freedom of Information campaign revealed that many Trusts had a pathway in place for dealing with anxiety and/or tokophobia. The pan-London tokophobia toolkit published in January 2018 is a welcome additional resource on this subject.6 However some Trust policies on maternal request caesarean appear to be based on the assumption that all maternal request caesareans are motivated by a fear of childbirth, as opposed to a rational reading of the evidence and how they apply to an individual's circumstances, or concern as to the impact on another physical health condition, for example. Some women have told us that they are surprised and concerned to be treated as if they have a mental health issue, if this is not what is driving their request.

Furthermore, while a debrief of a previous birth is often helpful, for women with post-traumatic stress disorder following a previous traumatic birth, interventions that focus on re-living the birth risks further traumatisation. Some women with a history of trauma may not feel able to disclose the reason for their request, despite those reasons being compelling. Therefore a one-size-fits-all pathway is not appropriate for maternal request caesarean.

The vision of individualised care set out in "Better Births"⁷, "Safer Maternity Care"⁸ and other policy documents is essential here, as is more research and debate about best-practice.

Unbiased, evidence-based and up-to-date information for women

We welcome the commitment from RCOG to review their patient information leaflet on maternal request caesarean.

Women need balanced information that differentiates between risks of planning a caesarean birth to a woman and her baby compared to a planned vaginal birth and also explains what is known about longer term outcomes for both mothers and babies for each mode of birth.

Healthcare professionals need to be transparent with women about the differences in how this information applies to different individuals and about the limitations of the evidence available.

Pathways that are co-produced by women and healthcare professionals, so that they feel supportive to women rather than heightening anxiety.

Trusts such as Birmingham Women's have already shown the way in terms of codesigning a pathway that takes into account the needs of both women and healthcare professionals. Many other Trusts offer individualised care planning. We urge other Trusts to follow their example and to ensure service-user involvement includes the experiences and voices of women with complex health and social circumstances via Maternity Voices Partnerships.

An agreed nationwide method to categorise and record maternal request caesareans consistently in every NHS Trust's maternity statistics.

⁶ Pan-London Perinatal Mental Health Networks. 2018. *Fear of Childbirth (Tokophobia) and Traumatic Experience of Childbirth: Best Practice Toolkit.* (Available at https://www.healthylondon.org/wp-content/uploads/2018/01/Tokophobia-best-practice-toolkit-Jan-2018.pdf)

⁷ The National Maternity Review. 2016. *Better Births Improving outcomes of maternity services in England A Five Year Forward View for maternity care*. (Available at https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf)

⁸ The Department of Health. 2017. *Safer Maternity Care. The National Maternity Safety Strategy - Progress and Next Steps.* (Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/662969/Safer_maternity_care_-_progress_and_next_steps.pdf)

Without agreed definitions of maternal request caesareans and no comparable national data it is difficult to develop an accurate understanding of numbers and hard to develop a better evidence-base on the short and longer-term outcomes in these births. We hope that NHS England will take up this issue as it reviews national data collection.

Next steps

These FOI results are a clear indictment of the postcode lottery facing women in the UK who, for a wide range of reasons, feel a caesarean birth is right for them. We hope that they provide a transparency that has hitherto been missing around the differences in policies and processes between Trusts at this moment in time.

There is still work to do to explain this divergence and a national debate to be had about the level of evidence available, what best practice looks like, and how to take forward the calls to action identified in this report.

We are committed to working with NHS England, The Royal College of Obstetricians and Gynaecologists, the Royal College of Midwives, Clinical Commissioning Groups, Local Maternity Systems, Trusts/Boards, user representatives and other organisations with an interest using all available legal and policy options available to make progress on this issue and to ensure that all pregnant women wanting a maternal request caesarean get the respectful treatment they deserve.

Birthrights, August 2018

Annex 1: Trust categories

How did Birthrights categorise Trusts?

When categorising Trusts we largely relied on the response and guidelines provided. When certain elements on the response were unclear we took a holistic view of the tone and wording of all documents supplied in deciding on a category.

However, only Trusts with a written guideline on maternal request caesarean have been classified as "green". We felt that this provided some evidence to an ongoing service-wide consistent approach on maternal request caesarean.

For Trusts of a reasonable size (over 2000 births) who said they offered maternal request caesarean, or weren't clear about whether they offered them or not but told us that they didn't perform any between April 2016 and April 2016 then the zero figure provided has been taken into account when deciding on the category.

All the information provided to us by Trusts has been made available on our website via our interactive map so that individuals can make up their own mind about the responses, as well as being guided by our analysis.

What does this mean in practice?

This means that a Trust like Liverpool Women's which seem to have a very good pathway for maternal request caesarean but has no formal written guideline that references its approach has been classified as an amber.

Similarly the Princess Alexandra Hospital in Harlow, Essex would have been categorised "green" based on the policies supplied, but also said that it carried out zero MRCS between April 2016 and April 2017. It has therefore been categorised as an amber.

Gloucestershire, Ashford and St Peters and County Durham and Darlington have all been categorised as "green" despite using the phrase "maternal request caesarean is not on its own an indication for caesarean" because they all went on to quote the revised NICE guideline (CG132) process in full including having a written commitment to ensuring women were referred to an obstetrician who "will" carry out the CS.

Why did Birthrights not take into account the number of maternal request caesareans performed by Trusts?

Only 61% of Trusts (91) that responded were able to provide a figure of how many maternal request caesareans they performed. Many of these Trusts have said that they are not sure their figure was reliable. Trusts not supplying a figure often said that they would need to go through individual records manually to supply a figure.

We do not believe that maternal request caesareans are recorded in a consistent way across Trusts and therefore we have chosen not to rely on these figures to inform our analysis with the exception of where Trusts have said they perform zero maternal request caesareans.

Were Trusts who said they followed NICE guidelines automatically categorised as green?

No. The NICE guideline seemed more open to interpretation that we had anticipated. Most Trusts said they complied with NICE, even those we categorised as red, and were referring women making this request to other Trusts. Therefore Trusts needed to explain their understanding of NICE and what pathway they followed, however concisely in order for us to analyse their response. Trusts that demonstrated an understanding of, and commitment to, the revised NICE guideline were categorised as green (unless they had over 2000 births and

carried out zero MRCS). Trusts that simply said they followed NICE and nothing else were categorised as "unknown".

Why were Trusts categorised as amber?

39 Trusts of the 70 Trusts in this category did not show a clear commitment to ensuring a woman would definitely get a caesarean if she continued to want one. Many Trusts did not specify what would happen beyond a second opinion. For example Barnsley's policy states "in all cases the Consultant retains the right to decline to perform a caesarean section with no clinical indication. If this is the case the Consultant Obstetrician will either refer the woman to a Consultant colleague for a second opinion or refer the woman back to her General Practitioner to arrange referral to another hospital for a second opinion."

10 Trusts in this category required the permission of two consultants or had an otherwise burdensome/resource intensive process in order for a maternal request caesarean to be arranged, regardless of whether this was wanted by the woman or whether it was appropriate to her situation. For example East and North Herts require a woman to be counselled by two obstetricians and be reviewed by the consultant midwife.

2 Trusts (Bedford and Milton Keynes) would only schedule a maternal request caesarean for after 40 weeks (NICE guidelines suggest a planned caesarean should be scheduled for after 39 weeks).

A number of Trusts such as City Hospitals Sunderland, Hywel Da, Imperial and University Hospitals of Bristol approach this request as being driven by a mental health issue. It is not clear what happens when the request is made for another reason. Ipswich's policy suggests a maternal request caesarean will only be granted after the woman has been seen by an appropriate healthcare professional such as a psychologist or psychiatrist.

Other amber Trusts such as Brighton and Sussex and Shrewsbury and Telford had very sketchy policies and were close to being categorised as unknown or red. CCGs Did you tell Trusts how they were going to be categorised before publication?

Yes, we notified all Trusts of our intention to publish their results and their individual category, and gave all Trusts the opportunity to respond. A number of Trusts were recategorised as a result.

Are all Trusts now happy with their result?

We have applied our criteria consistently across all Trusts but this does mean that there are some edge cases that could be regarded as anomalous.

For example, the Royal Free in London has been categorised as red because they have a policy that states, "The RFL promotes a philosophy of no unnecessary intervention. It is not the policy of the RFL maternity services to perform caesarean sections at maternal request". Furthermore their policy also stated that women must be seen by the Birth Options clinic before a caesarean can be booked. However the Royal Free clearly does have a pathway for making exceptions to this "policy" in some cases which is not the case for all "red" Trusts. The Royal Free London has disputed their "red" categorisation on the basis that they have carried out 209 in the year for which figures were requested. However as already stated, we do not feel the figures provided by Trusts are consistent enough to be relied upon, and we believe our categorisation of the Royal Free is defensible based on its own stated policy.

The University Hospitals of Leicester NHS Trust has also challenged its "red" categorisation and has said that it does offer this option and defended its figure of zero maternal request caesareans as being reflective of a genuinely zero number of requests. As the Trust has over 11,000 births a year we have kept this Trust as a red due to the lack of clarity over its policy and the zero figure provided. However we recognise

that this may reflect a genuine difference between how Trusts record a maternal request caesarean, or genuine local differences in numbers of requests.

Medway NHS Trust asked us to change their categorisation from green to amber on the grounds that they sometimes refuse requests for caesarean section, which we have done.

Did you take into account intelligence from your advice service in your analysis?

No. We did not feel this would be fair as we do not get a representative sample of advice service enquiries across all Trusts or enough to be representative of an individual Trust. Therefore, we have only judged Trusts on the information they provided and not taken into account other intelligence we may have about a Trust. However we are aware of incidences from our advice service where women receiving care from Trusts, including "green" Trusts have not had treated in accordance with the policy we have been sent. For example, we have recently written to Mid-Essex, to ask them to explain a case in which their "green" policy was clearly not followed and have yet to receive a response.

Annex 2: Oxford

The position at Oxford University NHS Foundation Trust and Oxfordshire CCG

On 27th July 2018 lawyers acting for Birthrights wrote to Oxford University Hospitals NHS Trust and Oxfordshire Clinical Commissioning Group asking for further information about the policy in place at the John Radcliffe hospital not to offer maternal request caesareans. A similar policy is also adopted by a number of surrounding Trusts which leaves women around Oxford with very little choice over their mode of birth.

As stated in this report Birthrights is concerned that any statement or policy from a Trust, that caesarean would only be granted on medical grounds may be incompatible with Trusts' obligations to have an open, supportive, two-way discussion that explores all reasonable options. And if such a policy is then applied in a blanket way, we are further concerned that such a policy could be incompatible with human rights law. Following significant numbers of advice service enquiries concerning MRCS in the Oxford area, and a chain of correspondence with the Trust and CCG (all published letters are available on the Birthrights website) we have taken legal advice which indicates that our concerns may be well founded.

Local MP Anneliese Dodds has also written to both the Trust and the CCG expressing concern about this policy and the impact it is having on women.

As of 17th August we await the Trust's reply having received a holding reply on 14th August alerting us that the Trust will respond "in the immediate future" having missed their reply deadline of 10th August. In a letter dated 8th August 2018, lawyers acting for the Oxfordshire Clinical Commissioning Group confirmed that their client "has no policy or recommendation not to fund women requesting a Caesarean Section on non-clinical grounds." Birthrights legal team is scrutinising the CCG's response.

We have made the Trust and CCG aware that we hope to resolve this issue without litigation and we hope that Oxford University Hospitals NHS Trust and its commissioners will work with us constructively to change their policy. Otherwise we will look to explore all options, including judicial review, to ensure that women living in Oxford get the respectful care they deserve and that the law obliges their caregivers to provide.

Annex 3: List of Trusts

Trusts offering MRCS

- Ashford And St Peter's Hospitals NHS Foundation Trust
- Birmingham Women's NHS Foundation Trust
- Bolton NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- Manchester University Hospitals NHS Foundation Trust
- Chelsea And Westminster Hospital NHS Foundation Trust
- Colchester Hospital University NHS Foundation Trust
- Countess Of Chester Hospital NHS Foundation Trust
- County Durham And Darlington NHS Foundation Trust
- Dumfries and Galloway
- East Cheshire NHS Trust
- East Sussex Healthcare NHS Trust
- Epsom And St Helier University Hospitals NHS Trust
- Gloucestershire Hospitals NHS Foundation Trust
- Heart of England NHS Foundation Trust
- Homerton University Hospital NHS Foundation Trust
- Lothian (Scotland)
- Maidstone and Tunbridge Wells NHS Trust
- Mid Cheshire Hospitals NHS Foundation Trust
- Mid Essex Hospital Services NHS Trust
- Mid Yorkshire Hospitals NHS Trust
- North Bristol NHS Trust
- Northern Devon Healthcare NHS Trust
- Northern Lincolnshire And Goole Hospitals NHS Foundation Trust
- Nottingham University Hospitals NHS Trust

- Pennine Acute Hospitals NHS Trust
- Royal Surrey County Hospital NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- South Eastern Health and Social Care Trust
- South Tyneside NHS Foundation Trust
- St George's Healthcare NHS Trust
- St Helens and Knowsley Hospitals NHS
 Trust
- Tameside Hospital NHS Foundation
 Trust
- The Dudley Group NHS Foundation Trust
- The Rotherham NHS Foundation Trust
- University Hospitals Coventry And Warwickshire NHS Trust
- Walsall Healthcare NHS Trust
- Wrightington Wigan And Leigh NHS Foundation Trust
- Wye Valley NHS Trust

Trusts that partially offer or offer MRCS with concerns

- Airedale NHS Foundation Trust
- Ayrshire and Arran (Scotland)
- Barnsley Hospital NHS Foundation Trust
- Barts Health NHS Trust
- Basildon And Thurrock University Hospitals NHS Foundation Trust
- Bedford Hospital NHS Trust
- Belfast Health and Social Care Trust
- Blackpool Teaching Hospitals NHS Foundation Trust
- Borders (Scotland)
- Bradford Teaching Hospitals NHS Foundation Trust
- Brighton And Sussex University Hospitals NHS Trust
- Calderdale And Huddersfield NHS Foundation Trust
- Cardiff & Vale University Local Health Board
- City Hospitals Sunderland NHS Foundation Trust
- Cwm Taf Local Health Board

- Doncaster And Bassetlaw Hospitals NHS Foundation Trust
- Dorset County Hospital NHS Foundation
 Trust
- East And North Hertfordshire NHS Trust
- East Kent Hospitals University NHS Foundation Trust
- East Lancashire Hospitals NHS Trust
- Fife (Scotland)
- Forth Valley (Scotland)
- Frimley Park Hospital NHS Foundation Trust, (includes Wexham Park)
- Gateshead Health NHS Foundation Trust
- Grampian (Scotland)
- Greater Glasgow and Clyde (Scotland)
- Hampshire Hospitals NHS Foundation Trust
- Highland (Scotland)
- North West Anglia NHS Foundation Trust
- Hywel Dda Local Health Board
- Imperial College Healthcare NHS Trust
- Ipswich Hospital NHS Trust
- Isle of Wight NHS Trust
- Kettering General Hospital NHS Foundation Trust
- King's College Hospital NHS Foundation Trust
- Kingston Hospital NHS Trust
- Lanarkshire
- Lancashire Teaching Hospitals NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- Liverpool Women's NHS Foundation Trust
- Luton And Dunstable Hospital NHS Foundation Trust
- Medway NHS Foundation Trust
- Milton Keynes Hospital NHS Foundation
 Trust
- North Cumbria University Hospitals NHS Trust
- Northampton General Hospital NHS Trust
- Northumbria Healthcare NHS Foundation Trust
- Royal Cornwall Hospitals NHS Trust

- Sherwood Forest Hospitals NHS Foundation Trust
- Shrewsbury And Telford Hospital NHS
 Trust
- Torbay and South Devon NHS Foundation Trust
- South Tees Hospitals NHS Foundation
 Trust
- Southport And Ormskirk Hospital NHS Trust
- Stockport NHS Foundation Trust
- Tayside (Scotland)
- The Hillingdon Hospitals NHS Foundation Trust
- The Newcastle Upon Tyne Hospitals NHS Foundation Trust
- The Princess Alexandra Hospital NHS
 Trust
- The Royal Wolverhampton NHS Trust
- The Whittington Hospital NHS Trust
- University College London Hospitals NHS Foundation Trust
- University Hospitals of North Midlands NHS Trust
- University Hospital Southampton NHS Foundation Trust
- University Hospitals Bristol NHS Foundation Trust
- Warrington And Halton Hospitals NHS Foundation Trust
- Western Health and Social Care Trust
- Western Sussex Hospitals NHS Trust
- Wirral University Teaching Hospital NHS Foundation Trust
- Worcestershire Acute Hospitals NHS
 Trust
- Yeovil District Hospital NHS Foundation Trust
- Royal United Hospitals Bath NHS Foundation Trust

Trusts that do not offer MRCS

- Barking Havering and Redbridge University Hospitals NHS Trust
- Royal Free London NHS Foundation Trust
- Buckinghamshire Healthcare NHS Trust
- Burton Hospitals NHS Foundation

- Trust
- Derby Hospitals NHS Foundation Trust
- George Eliot Hospital NHS Trust
- Great Western Hospitals NHS Foundation Trust
- Guy's And St Thomas' NHS Foundation Trust
- Harrogate And District NHS Foundation Trust
- Hull And East Yorkshire Hospitals NHS Trust
- Lewisham and Greenwich NHS Trust
- North West London Hospitals NHS Trust
- Oxford University Hospitals NHS Trust
- Poole Hospital NHS Foundation Trust
- Portsmouth Hospitals NHS Trust
- Royal Berkshire NHS Foundation Trust
- Salisbury NHS Foundation Trust
- Sandwell And West Birmingham Hospitals NHS Trust
- Southend University Hospital NHS Foundation Trust
- University Hospitals Of Leicester NHS Trust
- West Hertfordshire Hospitals NHS Trust
- York Teaching Hospital NHS Foundation Trust

Trusts with an unknown policy on MRCS

- Abertawe Bro Morgannwg University Local Health Board
- Aneurin Beven Local Health Board
- Betsi Cadwaladr University Local Health Board
- Chesterfield Royal Hospital NHS Foundation Trust
- James Paget University Hospitals NHS Foundation Trust
- North Tees And Hartlepool NHS Foundation Trust
- Northern Health and Social Care Trust
- Orkney Health Board

Trusts which did not provide a response

- Crovdon Health Services NHS Trust
- Dartford and Gravesham NHS Trust

- Norfolk and Norwich University Hospitals NHS Foundation Trust
- North Middlesex University Hospital NHS Trust
- United Lincolnshire Hospitals NHS Trust

