

Improving information and guidance about fetal movements: a horizon scanning project

Learning and Impact Report
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Content warning

This report covers areas that can be difficult to read about, including baby loss. Sands' support channels are for anyone who has been affected by pregnancy loss or the death of a baby before, during, or shortly after birth.

Whether your baby died long ago or recently, we are here for you. The telephone helpline is free to call from landlines and mobiles on **0808 164 3332**. You can also email the team at helpline@sands.org.uk, or use Sands support chat via our website sands.org.uk.

Our support service is also for any professionals working with pregnancy and baby loss.

Use of language and key terms

Bereaved parents and families are terms used throughout this report to describe participants, as we know they are acceptable to many of the people we support at Sands. However, we understand that not everyone who experiences pregnancy loss or the death of their baby wishes to be referred to as a parent.

Women and birthing people are terms used when discussing the whole birthing population to include individuals who do not identify as women. When discussing findings from this project or other research, we use gendered language as relevant to reflect the identity of participants and/or content of responses.

1. Introduction

This horizon scanning project, led by Sands and Dr Tomasina Stacey from King's College London, aimed to identify current challenges in discussing babies' movements in UK maternity care and achieve a professional consensus on priority actions for improvement.

Raising awareness of fetal movement is currently a key part of work to reduce avoidable stillbirth in the UK, but the effect of this approach on stillbirth rates is unclear. At Sands, bereaved parents have described feeling pressure and uncertainty as they tried to make sense of their baby's movements, based on the limited and inconsistent information they received. Research indicates that these issues are not confined to bereaved parents and that there is a wider desire among expectant parents for more detailed, accurate and accessible information about babies' movements in pregnancy.

The perspectives of bereaved parents are central to this work, providing unique insight into how certain approaches to discussing fetal movements can act as a barrier to families accessing care in time to save their baby's life. They are a critical opportunity to learn about how we can make maternity care safer and more positive for all families.

In this project, we reviewed the available evidence and used interviews, focus groups and surveys to learn more about the views and experiences of healthcare staff and bereaved and non-bereaved parents. A stakeholder event involving bereaved parents and representatives from practice, policy, research, mortality reviews and investigation, and the third sector was an opportunity to share learning and work towards a consensus on key challenges and potential solutions.

This report provides an overview of how we approached this work, our key learning, and suggestions for next steps. We hope it will inspire wider action across research, policy and practice so that discussions about babies' movements can become more accessible and informative, making it easier for parents to share their concerns and access the right care.



2

Project summary

What we already knew

Feeling their baby's movements is an important experience for pregnant women and birthing people, and they want to be informed so that they can judge what is normal and when to seek help. A reduction in fetal movements can be a sign of fetal compromise and is associated with poor pregnancy outcomes, including stillbirth. Raising awareness of fetal movement is currently a key part of work to reduce avoidable stillbirth in the UK, but the effect of this approach on stillbirth rates is unclear. Some research has linked raising awareness of fetal movement to increased anxiety in pregnancy and higher rates of monitoring and intervention, including where babies are well. Parents describe wanting more detailed information about babies' movements so that they can be more confident judging when the movements they feel are reassuring and when they should seek help.

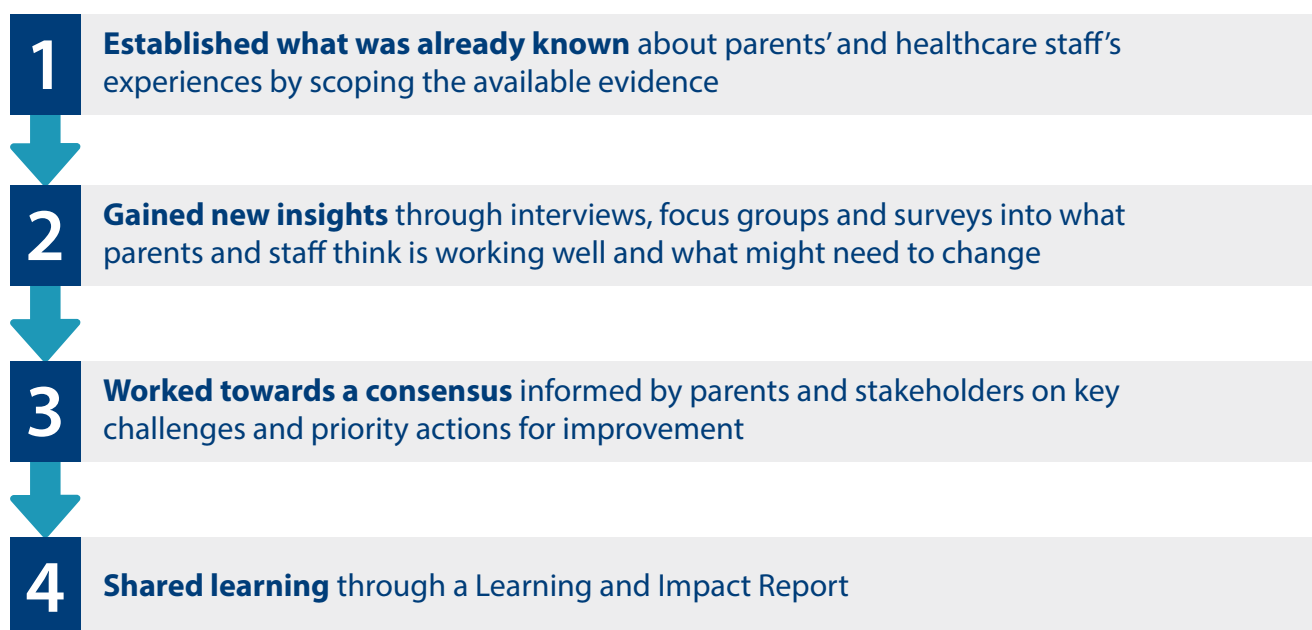
Aims

With the involvement of bereaved and non-bereaved parents, healthcare staff and key stakeholders, this project aimed to:

- ▶ identify current challenges in sharing information and guidance about fetal movements in UK maternity care
- ▶ work towards a professional, parent-informed consensus on what needs to change to help healthcare staff provide all parents with detailed, accurate and accessible information and advice about babies' movements in pregnancy

What we did

Based on a modified version of the [NHSE horizon scanning tool \(2022\)](#), we:



What we have learnt

Parents, healthcare staff and stakeholders described diverse issues and experiences relating to information, advice and care around babies' movements. From these, we have identified three key areas of challenge that relate to different stages in the wider care journey:

1 How core information is shared and received

- If this is not done well as part of routine antenatal care, women and birthing people
- may not be able to identify an important change in their baby's movement or know
- the importance of reporting it.

2 Accessibility of care

- Women and birthing people may face barriers to accessing care which can prevent them
- from sharing concerns about their baby's movements and receiving the right care.

3 Response on accessing care

If women and birthing people feel dismissed, uncertain or overly-reassured following their initial contact with staff, they may be less likely to attend for care or seek help in the future.

To be effective, solutions must lead to improvements at each of these three stages, with **accessibility, equity and trust** important considerations throughout.

Priority actions for improvement

Stakeholders identified the following priority actions:

1. Developing a national triage policy, including a fetal movement element and evidence-based recommendations for phone access
2. Distilling the available evidence base into clinical guidelines
3. Developing the evidence base further around placental factors and identifying babies most at risk
4. Developing training and guidance for healthcare professionals, including on how they approach communication
5. Developing clear, consistent, detailed information in multiple formats
6. Introducing guidance on what information and advice should be included in the fetal movement care encounter
7. Developing digital communication (including apps) to cover all aspects of fetal movement information
8. Developing wearable devices and trackers to enable remote care

Challenges and solutions are interconnected, and work is needed across a range of actions for improvements to occur. Solutions must be designed in collaboration with parents, communities, healthcare staff and wider stakeholders. This will help ensure that solutions meet the diverse needs of families and also work for the healthcare staff responsible for their implementation.

3

Setting the scene - fact finding and scoping work

3.1 Evidence review

From early on in pregnancy, a perception of the baby moving is frequently linked to a sense of excitement and reassurance. This experience of fetal movement links strongly to the baby's wellbeing. A perceived reduction in movements can be a sign of fetal compromise and is associated with poor pregnancy outcomes, including stillbirth.¹



Formal kick counting was first introduced in the 1970s after a case series of stillbirths indicated that fewer than 10 movements a day was a warning sign for fetal compromise.^{2,3} However, a large cluster randomised controlled trial conducted by Grant et al. in the following decade found no difference in the rate of stillbirth between those units that implemented formal kick counting and those that did not.⁴ The authors did not suggest that awareness of fetal movements was unimportant, but that there was no added benefit in formal, daily counting of movements.

Moore and Piacquadio undertook further research to assess the impact of fetal movement counting for a specified time in the evening, with a trigger for review if the woman had not felt 10 movements within the 2-hour period.⁵ This resulted in a significant reduction in antenatal stillbirth (from 8.7/1000 to 2.1/1000 $p < 0.01$). However, it did not become part of regular practice, and, based on Grant et al.'s findings, daily movement counting was phased out of routine maternity care in many parts of the world.

Two decades later, there was a renewed focus on fetal movements, when a large national study in Norway suggested that the combination of raising awareness of fetal movement along with consistent clinical management significantly reduced the rate of late stillbirth.⁶

In the past few years there have been a number of initiatives aimed at reducing stillbirth through raising awareness of fetal movements. However, the research findings from these studies have not been convincing.^{7,8} The 2018 AFFIRM trial, a large stepped-wedged randomised controlled trial in the UK that tested the introduction of a fetal movement care package found no significant reduction in late stillbirths.⁷ Similarly, an Australian-based study, which explored the impact of raising awareness of decreased fetal movements through the My Baby's Movements initiative did not find a significant reduction in stillbirth rates.⁸

A further study from Sweden, which involved increasing awareness of fetal activity ('Mindfetalness'), found a reduction in some adverse outcomes (such as small for gestational age) but not low Apgar Scores at 5 minutes, and there were not enough participants to assess stillbirth rates.⁹

A recent systematic review concluded, therefore, that increasing awareness of fetal movements may be associated with reduced adverse perinatal outcomes, but the impact on stillbirth rates remains uncertain.¹⁰ These results may be due to wide variation in what is considered 'normal' movement, and to the fact that a perceived reduction in movements is not a very specific indicator of poor outcome (evidence suggests that more than a third of all women experience reduced movements at some point in later pregnancy).^{11,12}

Raising awareness of reduced fetal movements is currently a key part of work to reduce avoidable stillbirth in the UK.¹³⁻¹⁶ However, it is unclear whether any particular approach to counting or monitoring movements leads to an improvement in outcomes without increasing anxiety or obstetric intervention, and the information shared by healthcare staff can be varied and is not always evidence-based.¹⁷



An international consensus paper has proposed that a personalised, conversational approach to sharing comprehensive and gestation-appropriate information about fetal movements may help women to identify when their baby is well and when additional assessment is needed.¹⁷ Currently, there is not enough evidence to know which approaches to sharing advice and guidance about fetal movements would be the most acceptable to women and birthing people in the UK, and what their impact might be on birth experiences and outcomes.

3.2 Learning from parents and healthcare staff

Between July and September 2024, we used surveys, interviews and focus groups to get a snapshot of bereaved and non-bereaved parents’ and healthcare staff’s perspectives on how information and advice about fetal movements is currently being shared in UK maternity care.

Figure 1 – Formats used to gather the views and experiences of healthcare staff and parents

Format (online)	Who took part
Survey for healthcare staff	45 maternity professionals
Survey for bereaved parents	24 mothers; 1 father
3 focus groups for bereaved parents	8 mothers
2 interviews with bereaved parents	2 mothers
Survey for non-bereaved parents	14 mothers

All those who shared their experiences had received or provided NHS maternity care since 2016. By concentrating on more recent experiences, we aimed to learn more about what care is like in the UK today.

Bereaved parents’ views and experiences

In total, 34 bereaved mothers and 1 bereaved father took part. Of these:



31 had experienced the death of their baby during pregnancy: 5 experienced their loss before 24 weeks (miscarriage) and 26 after 24 weeks (stillbirth). For 4 participants, their baby died after the birth, within 28 days of being born (neonatal death).



4 were from an Asian or Asian British background, 2 were from a Mixed Black or Mixed Black British background, and 29 from a White British, White Irish or Other White background.



29 received their care in England, 4 in Scotland, 1 in Wales and 1 in the Crown Dependencies.

Focus groups, interviews and free-text survey responses were an opportunity to learn about the experiences and views of the participants in greater depth. The key issues described are discussed below under four themes:

1 A lack of detailed, personalised information about ‘normal’ movements, underlying physiology and related risks

Nearly all those who took part said they needed more information from healthcare staff to understand what type, frequency or ‘pattern’ of movements should be considered ‘normal’ across different gestations and pregnancies.

If they had just given more information like what to look out for [...] what the differences are between the types of movement, not just using this word, ‘kicking’. [...] Because how can we as first-time mums know what to expect, how these different movements are, what time of the day, or how much gap there should be between the movements

Mother to a baby who died at 37 weeks

”

Some mothers described also wanting more information about the relationship between fetal movements, placental function and important risks, including stillbirth.

It just says that [Reduced Fetal Movement] is a sign that the baby is ‘unwell’. My baby wasn’t ‘unwell’, she was growth restricted at the end of pregnancy as the placenta wasn’t working so well. ‘Unwell’ isn’t the same as having a reduced blood/oxygen supply.

Mother to a baby who died at 41 weeks

”

While acknowledging that their views on discussing risks were shaped by their personal experiences of loss, several mothers felt there was a minimum amount of information required for parents to be able to make informed choices and help keep their babies safe.

2 Fetal movement concerns are often ‘explained away’

We heard many examples of explanations that had been given by midwives or doctors as to why a mother may have felt less movement, for example: ‘you’re getting quite far along now’; ‘it’s getting cramped in there’; ‘you’re a night owl, your baby’s probably a night owl as well’; ‘they might be a bit lazy’; and ‘some babies aren’t as active as others’. Mothers were also told that anterior placentas or a high Body Mass Index could stop them feeling their baby’s movements accurately, as well as them being distracted by other responsibilities or feeling anxious. To some mothers, these kinds of comments felt like a dismissal of their concerns, and could make them reluctant to seek help in the future.

3 Closed questions from healthcare staff can be a barrier to raising concerns

Many mothers felt that the limited questions asked by healthcare staff did not encourage them to reflect on the details of their experience of feeling movements or help them to understand what features were important. Closed 'yes-no' questions were highlighted as a particular problem, which could lead to healthcare staff having to work with incomplete or inaccurate information about movements, with potential effects on the quality or timing of care.

My doctor only ask: do you feel movements. I say: yes. That's it. [...] Just asking if I can feel movements is not enough. Same like just asking a friend: are you ok? [...] It is a yes or no answer but it doesn't give you specific details to make a good decision.

Mother to a baby who died at 40 weeks

”

4 'Worry' is too subjective to be a useful benchmark

Several mothers who had called maternity services because they were concerned about their baby's movement felt it was unhelpful when healthcare staff offered advice along the lines of, 'If you are worried, come in'. Some felt that it should already be clear to healthcare staff that they were worried, otherwise they would not have called. Others explained that, because they did not know what 'normal' movements should feel like, they didn't know how worried they should be. Their accounts indicated that 'worry' – how it is felt and understood – is highly subjective and personal. Therefore, a mother's level of concern may not be a useful measure of whether or not she should attend for care after she has reported a perceived or possible change in movements.

What the healthcare system struggles with is being able to deal with people who are optimists and people who are worriers in the same bracket. So if you're an optimist you don't think anything's wrong and you're positive. Even if there might be some little signs, you sort of shrug it off. But if some words had been slightly different, then maybe I'd have done something different, which would mean that she would still be here.

Mother to a baby who died at 39 weeks

”



Effects of these approaches to care

Based on mothers' accounts, the effects of these practices were wide ranging, including: making them feel dismissed or foolish, or causing them to doubt their experience or instinct and sometimes not share concerns.

They made me feel like I was just overly worried and a typical anxious first-time mum. The constant dismissal made me feel stupid to the point where I didn't feel I could say anything.

Mother to a baby who died at 27 weeks

”

Some parents linked the advice and guidance they had received to increased pressure and anxiety, or to trauma, self-blame or guilt after a loss. According to several parents, it was not simply an awareness of risk that made them feel anxious, but the way in which this was coupled with 'vague' information, uncertainty about how to keep their baby safe, and a lack of action by healthcare staff. One mother described as 'gaslighting' the experience of following advice to report her baby's reduced movements and staff apparently 'not being bothered by it':

The only thing you can really do is look after yourself, follow the guidance, and look out for these things that they say are red flags. And so it's really confusing when you then have these red flags and they're not really bothered by it. And I think in a weird way that probably makes you more anxious.

Mother to a baby who died at 18 weeks

”



Non-bereaved mothers' views and experiences

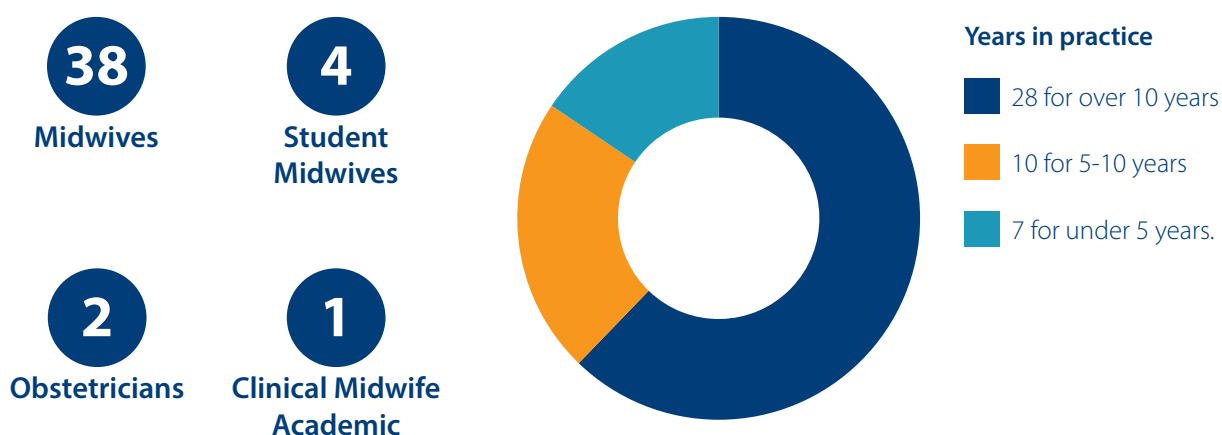
A survey on fetal movements was distributed through Maternity and Neonatal Voices Partnership groups in Yorkshire and London. It was completed by 14 non-bereaved parents, all of whom had given birth to at least one baby in the UK since 2016.

Of the mothers who shared their views, 7 had been to the hospital because of concerns about their baby's movements and 1 had been worried about her baby's movements but did not share her concerns with healthcare staff. The key theme was that they wanted more detailed information about fetal movements, as 'it was hard to know when to be concerned'. Of those who responded, 3 did not remember receiving information about patterns of fetal movement from their midwife, and only 1 described receiving too much information.

Although this was a small sample, the findings are reflective of earlier work using a similar survey which had 955 respondents and found that, in general, respondents found receiving information on fetal movements reassuring, with anxiety being reported in association with receiving insufficient information.¹⁸

Healthcare staff views and experiences

Among the 45 healthcare staff who responded to the online survey, there were



Staff were asked to select all the areas they had worked in since 2016. The results indicate a broad range of experience across clinical settings, including community and hospital-based roles providing antenatal, intrapartum and postnatal care; antenatal education; bereavement care; midwifery education; Governance; and Perinatal Mortality Review Tool (PMRT) implementation.

In their survey responses, staff described a range of challenges and potential solutions, many of which echoed those cited by parents, including:

1 Vague and inconsistent information

According to staff, the information currently shared lacks detail and varies depending on the healthcare worker providing it. Information shared online or from family and friends can confuse or directly contradict the core messages shared by healthcare staff. National guidance could support standardised information-sharing across pregnancy, with key messages linked clearly to a strong evidence base.

2 Barriers to understanding

Staff reported that many parents struggle to understand the information they are given about fetal movements in pregnancy, including – but not only – those who speak limited or no English. Staff would like to see evidence-based information in a range of accessible and culturally sensitive formats, with improved access to interpreters when sharing information and advice about fetal movements.

3 Barriers to accessing care

Staff responses indicated that families may face a wide range of barriers when accessing care for reduced movements, including busy phone lines, limited language options, hostile attitudes from staff, travel costs, and a lack of community-based services and continuity of carer. Suggested solutions included more varied lines of communication (e.g. texts, online chat, free call-backs, and multi-language services), community-based hubs, financial support for travel, and improved staff attitudes.

4 Insufficient time and staff

Insufficient time and staff were described as significant barriers to staff having detailed, personalised conversations about babies' movements, particularly when working with families with more complex needs or limited English. Some suggested that longer appointments for those who need them and improved continuity of care were ways to address this.

5 High levels of anxiety among mothers

Increased anxiety was mentioned by several respondents as something that could make it harder for mothers to monitor their baby's movement and identify changes in activity. While suggestions for improvements did not focus specifically on addressing maternal anxiety, staff indicated that 'generalised advice', the responsibility of monitoring movements, and fear of intervention were exacerbating factors.

Summary of learning from parents and healthcare staff

Participants across all groups described diverse issues that can be grouped under three key areas of challenge, described below. Each of these inter-connected areas relates to a different stage in the wider care journey, with the potential to impact on care-seeking behaviours and outcomes.

Figure 2 – Three key areas of challenge identified by parents and healthcare staff



1 How core information is shared and received

A lack of accessible, detailed, gestation-specific information about fetal movements means that some women and birthing people do not feel confident identifying and sharing a significant change. They may not understand the importance of promptly sharing their concerns because of a lack of information about why babies' movements may reduce and related risks, including stillbirth. A focus on raising awareness of fetal movements coupled with 'vague' information may contribute to feelings of anxiety, which, in turn, can make it harder for them to know when to seek help.

2 Accessibility of care

Women and birthing people may face a range of barriers to accessing care, which can prevent them from sharing concerns about their baby's movements or cause them to wait until their next routine appointment, particularly if they receive reassuring information from elsewhere (e.g. online or from family and friends).

3 Response on accessing care

If women and birthing people do report a change in their baby's movements, the initial conversations they have with healthcare staff (often with an unknown midwife over the phone) may put them off attending for care. Those who attend maternity services may be discharged home with a sense of false reassurance and still no clear understanding of what they should be looking out for. This can make them less likely to seek care for reduced fetal movements in the future.

Equity and accessibility were cross-cutting themes, with staff describing how language barriers in particular could be an additional challenge to providing women and birthing people with high quality information and the right care.

4

Working with stakeholders – towards a professional consensus

In November 2024, we held an event attended by 33 stakeholders, including bereaved parents and representatives from practice, policy, research, reviews and investigation, and the third sector.

4.1 Stakeholder event

Aims of the day

Through structured, focused discussions involving all stakeholders, the event aimed to:

- ▶ review learning so far and reach a professional, parent-informed consensus on key challenges relating to sharing information and guidance about fetal movements in UK maternity care;
- ▶ agree priority actions for improvement to address the challenges identified and initiate first steps in a ‘route map’ to improvement.

Before the event

To support productive discussion on the day, we asked all attendees to complete a pre-event survey to share their views on key challenges and potential solutions in this area of practice. Their responses broadly mirrored the survey responses we had already gathered from healthcare staff, with a focus on the lack of evidence-based information to benchmark ‘normal’ and acceptable variation; a lack of clarity and consistency in messaging about fetal movement; language and communication barriers; and high levels of anxiety about fetal movement among mothers who are struggling to make sense of the advice they receive. A more detailed summary of stakeholder responses can be found under [Appendix A](#).

Agreed challenges

In the first part of the day, stakeholders highlighted a range of challenges, some of which related to wider, highly complex issues such as social inequity, institutional bias or racism, and structural, organisational, and resourcing issues within maternity care. Following discussion, participants agreed on the following six challenges as being key in this area of care and ranked them according to their perceived level of importance:

Figure 3 – Key challenges identified and ranked by stakeholders



The six issues agreed to be a priority by stakeholders relate clearly to the three key areas of challenge previously discussed, i.e.: 1. How core information is shared and received; 2. Accessibility of care; and 3. Response on accessing care.

The varying accuracy and accessibility of resources and services was discussed in depth, with a strong case made for the need for more personalised and inclusive approaches to the communication of core messages, and the way in which care is structured and delivered.

There was particular interest in how helpline and triage services are organised depending on where families are receiving their care. Research by the Sands and Tommy's Joint Policy Unit (2024) has indicated significant variation within maternity triage across England, showing that 'guidance on how and when to contact triage is not clear and consistent between services'.¹⁹ The Care Quality Commission's 2024 review of maternity services in England supports this view, reporting on variation in practice that is contributing in some cases to delays in safe and timely assessment.²⁰

Stakeholders highlighted that any developments to maternity resources or services should be undertaken with consideration and the direct involvement of diverse communities, including those who are known to be at increased risk of poor outcomes, such as families from Black and Asian backgrounds and those living in the most deprived areas.

An important linked theme was the need to provide all families with a service they can trust, so that they have confidence in the information they receive and feel safe seeking care. Black, Asian and mixed ethnicity women and birthing people have reported systemic issues and discrimination when navigating maternity and neonatal care in the UK.²¹⁻²⁵ In the Sands (2023) Listening Project, some Black and Asian bereaved parents described feeling mistrust towards healthcare staff and services, linked to their own poor experiences and not being listened to, as well as wider abuses and injustices within healthcare.²⁵ Stakeholders suggested that a 'whole community' or 'whole family' approach and greater 'cultural curiosity' could help: build trust across different groups; ensure key messages are more widely understood; and address misunderstanding around fetal movements.



Priority actions for improvement

The second half of the day focused on identifying priority actions for improvement with small group discussions centered on four themes: technology and innovation; research and policy; resources for parents; and clinical practice (these themes were developed based on learning from parents and staff earlier in this work).

The table below shows the eight priority actions identified by stakeholders. When writing this report, we have mapped these against the three key areas of challenge to show where we think each action may have the greatest and most direct impact.

Figure 4 – Priority actions for improvement mapped against three key areas of challenge

	1. How core information is shared and received	2. Accessing care	3. Response on accessing care
Developing a national triage policy, including a fetal movement element and evidence-based recommendations for phone access		✓	✓
Distilling the available evidence base into clinical guidelines	✓		✓
Developing the evidence base further around placental factors and identifying babies most at risk			✓
Developing training and guidance for healthcare professionals, including on how they approach communication	✓		✓
Developing clear, consistent, detailed information in multiple formats	✓	✓	
Introducing guidance on what information and advice should be included in the fetal movement care encounter		✓	✓
Developing digital communication (including apps) to cover all aspects of fetal movement information	✓	✓	
Developing wearable devices and trackers to enable remote care		✓	✓

Figure 4 illustrates that no single solution will achieve improvements across all three areas of challenge – both challenges and solutions are interconnected. For example, the introduction of national triage policy may have limited impact if women and birthing people are not getting the information they need to identify a reduction in movement in the first instance. To improve outcomes and experiences where there is reduced fetal movement, cohesive work is needed across the range of priority actions for improvement.

Solutions must be designed in collaboration with parents, communities, healthcare staff and wider stakeholders. This will help ensure that solutions meet the diverse needs of families and also work for the healthcare staff responsible for their implementation.

5

Conclusion – next steps

In this report, consistent with this project's aims, we have outlined the key challenges relating to how information and guidance about babies' movements are shared in UK maternity care, as well as identifying priority actions for improvement. We hope that this content will inform wider work to improve information and guidance about fetal movements.

Current initiatives

Based on stakeholder feedback, there are several existing or planned initiatives with clear potential to address some of the challenges identified. We hope that the results of this horizon scanning project will feed into the work listed below, which Sands is committed to supporting.



In 2025, there are updates planned for the NHS England *Saving Babies' Lives Care Bundle* and the RCOG *Green Top Guideline for Reduced Fetal Movements*.



Existing resources produced by the charity Tommy's share key, evidence-based messages around fetal movements and are accessed by many UK mothers and healthcare staff. The downloadable [Tommy's leaflet about baby movements](#) has been translated into 43 languages. Information from this project will inform future reviews of these resources to ensure they are as useful and informative for families as possible.



Innovations arising from the \$50 million Wellcome Leap In Utero program are anticipated to add to the evidence base around placental factors and could lead to improved methods of identifying babies most at risk – the program's goal is to halve stillbirth rates by creating scalable methods to measure, model and predict gestational development in utero. An example of a breakthrough technology is a wearable fetal activity tracker that allows expectant parents to track baby's movements in the womb, in development by a team led by Prof Niamh Nowlan at University College Dublin. The tracker will support parents to get to know their baby's rhythms throughout the day and night and over the third trimester of pregnancy and, in the future, may allow the detection of babies at potential risk.



Dr Tomasina Stacey at Kings' College London has secured seed funding to explore the demographic characteristics of those who present to maternity services with reduced fetal movements. This will inform a larger bid to understand variations in presentation, management and outcome, and examine nuances in what causes women and birthing people to present with concerns about fetal movements. The Sands research team looks forward to collaborating on this work, which will feed into improved triage prioritisation and the development of more detailed, clear and consistent information for women and birthing people.

Work still to be done



For many stakeholders, a clear priority was improving training and guidance for healthcare professionals, including on approaches to communication and what information and advice should be included in the fetal movement care encounter. There is a need for the NHS and professional bodies to provide better training and guidance, which should build on this horizon scanning project.



Many of the bereaved parents who took part in this project described the harmful effects of negative interactions with triage or helpline staff, often linked to inconsistent advice or a failure to take fetal movement concerns seriously. Among stakeholders, there was wide agreement that developing a national triage policy, including a fetal movement element and evidence-based recommendations for phone access should be a priority action for improvement. The Birmingham Symptom-specific Obstetric Triage System (BSOTS)²⁶ and Royal College of Obstetricians (RCOG) good practice recommendations for the operational structure and pathways within maternity triage²⁷ provide valuable guidance, underpinning care in some Trusts, but their recommendations are not implemented consistently across the UK. At Sands, in line with recommendations from the Care Quality Commission and Royal College of Obstetricians and Gynaecologists,^{20,27} we would like to see the NHS lead work towards an agreed national standard and reporting tool for maternity triage, to be implemented across the UK.



In this project, most parents expressed a strong wish to receive more detailed, gestation-specific information about fetal movements endorsed by the NHS and in a wider range of formats, including digital communication and apps. Stakeholders echoed this call for evidence-based, accessible information tailored to families' specific needs. The NHS should work with researchers, health providers and third sector groups to initiate research or wider consultation to explore which information content and formats would be most useful for diverse families, along with processes for evaluating the effectiveness of any new resources in this area.

Sands will support these changes by sharing what we have learnt from this project. We will continue to put parents' voices at the heart of our work, with a particular focus on groups that are more likely to be affected by pregnancy loss and the death of their baby, but whose stories are often not included in research and service development. We are committed to monitoring developments across the eight priority actions for improvement and will share a summary of progress to encourage continued awareness and drive further improvements in how we share information and guidance about fetal movements for safe and positive pregnancies.

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Appendix A

Summary of findings from pre-event stakeholder survey

Key challenges

- ▶ **High anxiety** about fetal movements among mothers who are struggling to make sense of the advice they receive and worry their concerns will be dismissed or that they are 'wasting time' in a stretched maternity system.
- ▶ **Lack of evidence-based information** to benchmark what constitutes a 'normal' pattern or amount of movements and/or acceptable variation.
- ▶ **Lack of clarity and consistency in messaging** about fetal movement, including what constitutes 'normal', reduced, or recurrent reduced movements. This is further complicated by differences in information provided by local healthcare services and conflicting advice online and from friends and family.
- ▶ **Language and communication barriers**, including lack of translated materials, which make it challenging for those with no or limited English to understand the guidance.
- ▶ **Tension between standardisation and need for a personalised approach:** perceptions of risk vary based on individual experiences and personal factors - 'one size does not fit all' when communicating about fetal movements.
- ▶ **Systemic limitations:** disjointed, under-resourced systems prevent the delivery of evidence-based, personalised care. High demand in maternity triage services contributes to long waiting times and a lack of timely and consistent support, which reduces the effectiveness of care following reports of reduced fetal movements.
- ▶ **Staff training and attitudes:** healthcare professionals may lack up-to-date knowledge, not be aware of the high-quality resources that already exist, or dismiss concerns – this can lead to a lack of trust and reluctance to seek help on the part of women and birthing people.

Potential solutions

- ▶ **Clearer guidelines on what constitutes normal fetal movement patterns**
- ▶ **Better data and research**, including on the duration of reduced fetal movements to refine monitoring recommendations and trials with co-developed tools to enhance understanding.
- ▶ **Invest in models that support continuity of care**, enabling long-term, trusting relationships between healthcare staff and women and birthing people, and supporting personalised care that accounts for their unique situations and preferences.
- ▶ **Better co-produced materials** with clear, simple messages in diverse and accessible formats (e.g. translated, easy read, digital etc)

► **Education for healthcare staff**

- Training to equip staff to provide detailed, evidence-based information about fetal movements and address individual concerns (scripts may be used to provide consistent guidance across pregnancy stages).
- Training on the evidence-base relating to fetal movement experiences, care, and pregnancy risks and outcomes.
- Training to raise awareness of how their approach and language can affect help-seeking behaviours.

► **Develop tailored, culturally sensitive approaches** for different communities, addressing language barriers and accessibility to information for marginalised groups.

► **Establish consistent national standards and guidance** on fetal movement monitoring and maternity triage (where discussion about fetal movements may take place) to reduce conflicting messages and improve patient care. Consider removing routine auscultation as it may send mixed messages about fetal health. Promote more effective monitoring strategies aligned with movement awareness.

► **Explore sensor technology** that can help objectively monitor fetal movements, reducing the burden on individuals to self-monitor complex patterns over time.

► **Apply behavioural science** to understand and address the psychological aspects of anxiety around fetal movements, separating these from physical risks like placental insufficiency.



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