

# The Stillbirth

## Priority Setting Partnership



## Introduction

The Stillbirth Priority Setting Partnership (PSP) saw doctors, midwives, parents, third sector organisations, funders and pathologists come together to agree by consensus the ten most important priorities for stillbirth research in the UK.

The UK has around 3,600 stillbirths each year and despite a repeated fall in occurrence over the past three years, it maintains one of the highest stillbirth rates in the developed world.

Whilst the government has pledged to prioritise stillbirth prevention and there have been encouraging research developments around understanding how the placenta functions, a major breakthrough remains distant. The taboo that continues to surround baby loss has proved another stumbling block to progress being made.

## Who carried out the research and why?

In collaboration with the James Lind Alliance, which is co-ordinated by the National Institute of Health Research (NIHR), the purpose of the Stillbirth Priority Setting Partnership was to establish the key priorities in this area following extensive consultations with numerous stakeholders and individuals.

This will act as a blueprint for funders, like the NIHR, who are tasked with giving the green light to new research projects. Going forward, researchers know that they'll be in a better position of having their funding application approved if they address one of the chosen priorities.

With stillbirth research in its early days, it's vital to build up a strong body of evidence. Roughly 3,000 papers have currently been published on the subject and no comprehensive review of active research studies has yet been undertaken. Small pockets of research have been taking place which can't be translated on a national scale. For example, no standard guidance on what clinicians should do when women report reduced fetal movements exists yet because there's a lack of evidence on what works best.

No less important was the chance to give bereaved parents a voice and bring them into the conversation and decision-making process. The PSP was the ideal platform to do this.

The Stillbirth PSP is a vital stepping stone on the way, not only to furthering our understanding of what causes stillbirth and how we can best prevent it, but to ensuring we can establish best care practices more efficiently.

## What was the process?

The process was an exhaustive one, taking 18 months to complete. An initial callout asking those invested in stillbirth research, either in a professional or personal capacity, to share their views resulted in 1,272 suggested questions from 574 respondents.

This list was then filtered down to remove duplicates, leaving 361 unique research questions to be cross-checked against published research. After a further sixty-one questions were removed because they had already been answered, the remaining unanswered questions were sorted and ranked in order of priority depending on:

- If suggested by both practitioners and parents
- Had a high number of responses
- Suggested by an expert group

The highest-ranked 48 questions were then included in a final prioritisation questionnaire which went out to the public and was completed by 1,118 respondents. From this, 25 final questions were shortlisted which were then put to a steering group, tasked with making a final decision on what the top-ten research priorities should be.



## What was discussed and agreed?

The input of parents was reflected in the final list of priorities with an emphasis on good bereavement care and supportive antenatal care in subsequent pregnancies.

Understanding the causes of 'unexplained' stillbirth and what tests and care packages have maximum impact for women at risk also sat high on the agenda.

11 priorities were eventually chosen:

- How can the structure and function of the placenta be assessed during pregnancy to detect potential problems and reduce the risk of stillbirth?
- Does ultrasound assessment of fetal growth in the third trimester reduce stillbirth?
- Do modifiable 'lifestyle' factors (e.g. diet, vitamin deficiency, obesity, sleep position, sleep apnoea, lifting and bending) cause or contribute to stillbirth?
- Which investigations identify a fetus which is at risk of stillbirth after a mother believes she has experienced reduced fetal movements?
- Can the wider use of existing tests and monitoring procedures, especially in later pregnancy, and the development and implementation of novel tests (biomarkers) in the mother or in early pregnancy, help prevent stillbirth?
- What causes stillbirth in normally grown babies?
- What is the most appropriate bereavement and post natal care for both parents following a stillbirth?
- Which antenatal care interventions are associated with a reduction in the number of stillbirths?
- Would empowering women to know about relevant evidence-based signs and symptoms and raise them with healthcare professionals reduce stillbirth?
- How can staff support women and their partners in subsequent pregnancies, using a holistic approach, to reduce anxiety, stress and any associated increased visits to healthcare settings?
- Why is the incidence of stillbirth in the UK higher than in other similar high-income countries and what lessons can we learn from them?

## What parents had to say

*"I've worn the hat of a bereaved parent for a very long time. People don't realise that you take it to your grave. You can still touch and feel the pain. I naively thought that all I had to do was raise awareness and everyone would jump on board. It didn't happen. When we merge science with the voices of parents we can make a difference - we've got something. I am grateful to have been able to contribute and I think there is hope for the future."* Jenny Chambers