

# Research Strategy: **Saving Lives**

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Achieving a world where  
fewer babies die

**#sandsresearch**

# Introduction



**babies are stillborn or die within the first 4 weeks of life**



**In 2018 in the UK around 5,000 babies were stillborn or died within the first 4 weeks of their lives. This made up 75% of the deaths of children under 16 years old.**

We still do not fully understand why many babies die, or what more can be done to prevent deaths. For as many as **one in four babies the cause of death is still not known.** We also know the care and support for families when a baby does die is inconsistent and there are unanswered questions about what is most helpful.

We believe research can save babies' lives and improve care and support for bereaved families. Investment in research is vital to increase knowledge, to improve care and to maintain the political will to reduce perinatal mortality.

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# Our goals

We are committed to supporting and funding research so that means we can:



Save babies' lives by  
improving maternity  
and neonatal care



Understand  
why babies die



Provide better  
bereavement care  
and support



# Our approach

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We will focus  
on five areas  
of success

1. Support bereaved parents to inform and shape research
2. Work with others to create collaborations of research excellence
3. Support research projects that will make the biggest difference to care and saving babies' lives
4. Use research to improve care
5. Increase the profile and funding of all perinatal mortality research

*Research is one of  
the only ways we  
will get answers to  
why our baby died*

Priya,  
bereaved parent

## 1. Support bereaved parents to inform and shape research

We will bring bereaved parents' views and experiences into the heart of research to improve the quality and usefulness of research.

### 1.1 Parents are supported to get involved in research

#### **We will:**

- share opportunities to get involved in shaping research with bereaved parents
- create resources which enable parents to get involved and contribute to research
- make sure that parents who do get involved in research are supported through the process.



## 1.2 Researchers are skilled and enthusiastic at involving bereaved parents in their work

### We will:

- provide learning opportunities, guidance and resources on how to involve parents
- support researchers to carry out meaningful and high quality involvement.



## 2. Work with others to create collaborations of research excellence

The quality of stillbirth and neonatal death research is inconsistent. For research to save babies' lives and improve care we need a stronger community of well supported, trained and talented researchers. To encourage the best research we need to bring people together from different scientific areas, with different experiences and expertise.

By bringing people to work together we can speed up progress and find new and creative ways of tackling issues.

We will grow our existing partnerships and build new relationships to create a perinatal research network.





*For us the association with Sands is a strong symbol of our belief that parents are central to finding answers about stillbirth and our commitment to growing the role of parents in our future work.*

Professor Gordon Smith, Cambridge University

**2.1 Create Sands research collaborations which will work to reduce the numbers of stillbirth and neonatal deaths, as well as improving care and support for anyone affected by the death of a baby**

**We will:**

- develop a network of Sands supported research centres
- build the capacity of key research staff within these centres to act as spokespeople to raise the profile of stillbirth and neonatal death research.



## 2.2 Build relationships with key research institutions and create a network of organisations working in stillbirth and neonatal death research across the UK and from different research backgrounds

### We will:

- develop relationships with key organisations across the UK and share information, discuss future plans, identify gaps in research
- put together proposals for research projects for other research funders.



*It's important to identify pregnancies at risk of stillbirth so we can monitor them more closely, perhaps deliver them early, and also reassure mothers who are at low risk of stillbirth and avoid unnecessary medical intervention.*

Professor Asma Khalil,  
St George's, University of London

## 2.3 Bring people together and build expertise

### We will:

- bring our network of research organisations together to share learning
- develop an online community and host networking events and conferences
- support and expand perinatal Clinical Studies Groups (CSGs) that will:
  - bring together leaders in the area to identify key research gaps and emerging issues
  - support good quality proposals to maximise external funding for research in the field
  - offer skills development opportunities.

### 3. Support research projects that will make the biggest difference to care and saving babies' lives

By supporting new research we can reduce the numbers of babies dying and ensure the care and support that is offered is the best quality.

We will make sure that the research we support answers the most important questions that parents, healthcare professionals and researchers ask, so we can make the biggest difference.

We will also help researchers with their studies to secure funding, demonstrate impact, and involve parents.



# Sands Research Fund

## What we have funded

### Side-sleeping

New advice that the risk of stillbirth is reduced if women in the last third of pregnancy go to sleep on their side.

### Economic costs

Estimating the economic and social cost of stillbirth to families and society as a whole.

### Third trimester ultrasound

Ultrasound scan measurements at the end of high risk pregnancies that predict if a woman is at risk of stillbirth.

### Mortality reviews

How to support parents in communicating with and involving parents in a review of the baby's death.

### Bereavement care

Evidence for what good bereavement care looks like.

### Intrahepatic cholestasis (ICP)

Getting the best management possible for women with a liver condition during pregnancy.

### Fetal movements

Testing a package of care for pregnant women who report changes in their baby's movements.

### Post-mortem data

A new system for collecting information on post-mortem that could improve our understanding of why babies are stillborn.



## 3.1 Fund studies that address the priority research questions we have identified that can make the biggest difference to babies and families

### We will:

- produce a set of priority questions with parents, researchers and clinicians which will help us focus on areas that will make the biggest difference
- fund research based on those questions
- increase the amount of funding available in Sands' research fund.

*Research is vital to finding new ways to reduce baby deaths. Sands' commitment to strengthening UK perinatal research will directly lead to new discoveries and better care for women and their families.*



Dr Sarah Stock, University of Edinburgh, Sands Trustee

### 3.2 Provide non-financial support to key research projects

#### We will:

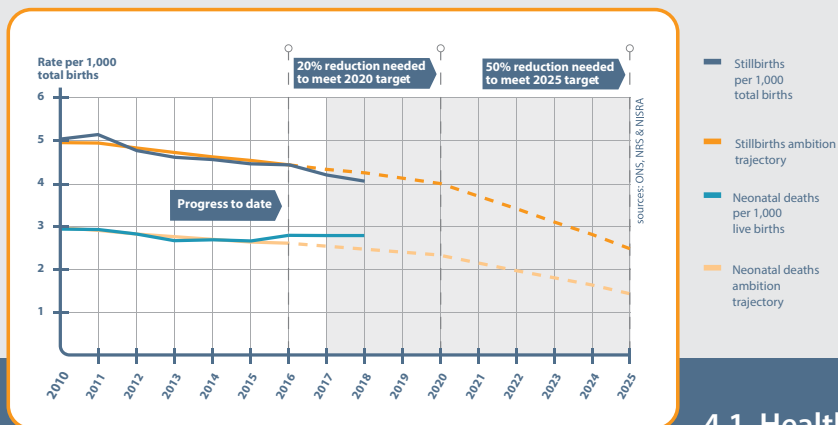
- prioritise research projects that puts the parents' voice at the centre of research
- help researchers make their case in securing funding by showing the impact we think the work will have
- clearly define our role as a key research partner when supporting studies.



#### 4. Use research to improve care

For research to make a tangible difference it needs to be communicated, understood and put into practice.

We will ensure that the findings of research we have supported are shared with experts to deliver change.



## 4.1 Healthcare professionals use latest research findings

### We will:

- make sure all Sands supported and funded research projects set out how they will share any findings
- use research to inform the production of resources and learning materials
- survey parents to find out if research is being put into practice.



Listening to bereaved parents' experiences is vital in understanding why babies die.

We're glad to see that learning from every baby's death is a key part of the new Saving Babies' Lives Care Bundle.



#SandsSavingBabies

## 4.2 Policy makers and NHS leadership use latest research findings

### We will:

- share key findings with decision makers to drive policy changes and update guidelines and frameworks
- share findings from research studies to support projects which improve the quality of care
- bring together people who are able to change care and practice
- create resources that share key research findings in easy-to-understand ways.



## 5. Increase the profile and funding of all perinatal mortality research

We want to see an increase in resources in perinatal mortality research.

We will do this by increasing the visibility of perinatal mortality research, showing the difference it can make, and ensuring that researchers have the tools they need to carry out high quality research.

We will also help a new generation of researchers committed to building a career in this field.

*We partnered with Sands on our research into women's use of digital resources in seeking help in the perinatal period. This helped us to integrate digital resources into escalation of care strategies. It also provided important insights for digital health education to reduce stillbirth and neonatal death.*

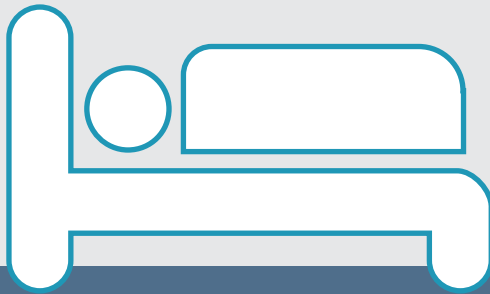
Dr Nicola Mackintosh, University of Leicester



## 5.1 Provide tools, resources and people needed to improve the quality of research

### We will:

- support students and studentships to develop their skills and careers to become future stillbirth and neonatal death experts.
- work to ensure that researchers can make use of and access data they need.



### Did you know?

**Women who go to sleep on their side in the last third of pregnancy are at a lower risk of stillbirth**

**4** stillbirths in every  
**100** are linked with going to sleep lying on the back in the last third of pregnancy\*

## 5.2 Show the difference research can make

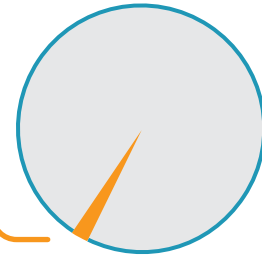
### We will:

- report on impact annually
- develop an engagement plan to reach out to key groups
- develop ways in which to recognise outstanding contributions to research.

\*MiNESS – The Midlands and North of England Stillbirth Study: [www.sands.org.uk/MiNESS](http://www.sands.org.uk/MiNESS)

### Did you know?

Only **2.1%**  
of all health research  
in the UK is spent on  
reproductive health  
and childbirth.\*



## 5.3 Increase the resources for perinatal research

### We will:

- make the case to large funders of research to support stillbirth and neonatal death research
- work in partnership with other organisations to secure funding for key projects
- analyse how much funding is available for stillbirth and neonatal death research, the number of researchers working in the area in comparison to other areas and use this evidence to campaign for change.



**#sandsresearch**

**Get involved:** [sands.org.uk/research](https://sands.org.uk/research)

**Donate today:** [sands.org.uk/donate](https://sands.org.uk/donate)

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