Agreed: Dec 2015 Addendum: July 2017

Date of next full review: Dec 2017



Sands Research Strategy 2016-18

1. Introduction

The Sands Research Strategy is designed to help us achieve two of our three aims, to:

- promote and support research to reduce the number of babies dying before, during or shortly after birth
- work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible care.

We are committed to supporting, where possible, research that will further these aims. To help us achieve this we have a dedicated Research & Prevention team and a Research Subcommittee and we work closely with the Stillbirth Clinical Studies Group (see 3.2.1).

2. How we support research

Over 2016-2018, we will support research in the following ways.

- We will build Sands Research Fund and Research Grants Programme to fund research directly.
- We will communicate the impact of the research we fund to our supporters.
- We will incorporate the views of bereaved families in recommending research priorities by taking account of the priorities identified by the Stillbirth Priority Setting Partnership (PSP), and by regularly surveying our supporters.
- We will consider funding in partnership with other research funding bodies where this moves work forward.
- We will support the work of the Stillbirth Clinical Studies Group.
- We will support researchers who are seeking study participants or patient input.
- We will use expert advice to assess and confirm the quality of studies we support.

3. Sands' Research Fund and Grants Programme

Sands directly funds scientific research that has potential to make a significant impact on reducing the numbers of babies who are stillborn or die neonatally, or to improve care for families when a baby dies.

3.1 To help us meet our aims, we fund research focusing on:

- understanding the causes of stillbirth and neonatal death
- identifying pregnancies at risk of perinatal deaths and improving interventions to manage those pregnancies
- defining good bereavement care.

3.2 Research grant selection process

We have a process in place to ensure applications for research funds are assessed fairly and consistently. We select the highest-quality research for Sands to fund through a transparent process of peer review by an independent expert group – the Stillbirth CSG (see below).

- Proposals must demonstrate that they align with at least one of the three areas in 3.1.
- Priority is given to proposals that demonstrate clear potential to generate robust evidence that can lead to changes in clinical practice.

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• For studies aligning with either of the first two criteria above (understanding the causes, and identifying pregnancies at risk), we prioritise proposals according to the number of babies who may potentially benefit from the research.

The application process has clear guidance for those applying, including funding limits, the maximum grant duration, geographical restrictions, co-funding sought and items covered. Although recommendations are made by the Research Subcommittee following review by the Stillbirth Clinical Studies Group, the Board makes the final decision to award funding.

3.2.1. Stillbirth Clinical Studies Group

The Sands-sponsored Stillbirth Clinical Studies Group acts as Sands' research advisory group. The aim of the Group, which comprises academics, health professionals and Sands R&P team, and meets twice yearly, is to share expertise and knowledge and to encourage high-quality work relevant to stillbirth and early infant deaths, advising on research design and funding proposals. The minutes of the Group's meetings are published on the Sands website and that of the British Maternal Fetal Medicine Society.

3.3. Research Fund monitoring and evaluation

Sands' Research & Prevention team are responsible for monitoring each research study approved for funding by the Sands Board, and report on a regular basis to the Research Subcommittee. Each research grant has a signed grant agreement in place, which includes reporting and evaluation mechanisms appropriate to the project.

3.4. Dissemination

Sands is committed to disseminating information about the projects we fund as widely as possible. We publish information about the projects Sands funds on our website and through other communication channels. We aim to hold an annual grant holders meeting/research conference to share information about research with our supporters and donors. We will publicly thank all those who donate to our Research Fund as well as those who help with the peer review process. Our annual impact report will feature the projects we have funded.

4. Standards

By 2017 we aim to:

- have a clear policy for conflict of interest for members and peer reviewers (priority)
- follow good practice in the awarding of research funding, as described by the Association of Medical Research Charities (AMRC)
- achieve National Institute for Health Research (NIHR) portfolio status
- endorse the AMRC's position statements on supporting research in universities and the use of animals in research.

5. Review and access

We will review our Research Strategy in April 2017, and annually thereafter. The Research Strategy and details of our peer review process will be published on our website.

Addendum July 2017

With reference to (3.2.1), Sands established the Perinatal Expert Panel (PEP) in Jan 2017 to advise on research funding applications, with clear terms of reference. Membership has largely been drawn from the Stillbirth Clinical Studies Group. Names and affiliations of members of the CSG and PEP are published on the Sands website.