

## Sands' research support framework and process

Sands aims to save babies' lives and ensure anyone affected by the death of a baby receives the care and support they need. We believe that research has a central role to play in this and that supporting research is vital to increase knowledge, improve care and maintain the political will to reduce baby deaths. We are committed to supporting research that will make care safer, help us understand why babies die, and improve bereavement care and support (you can find out more in our Research Strategy).

#### How we support research

We offer different types of support to research projects, broadly covering: research partnership; supporting parent and family member involvement in research; helping with participant recruitment; and providing letters of support for funding applications. Research partnerships and PPI support, which includes helping find parents to undertake PPI roles on studies and providing advice and support on PPI strategy and setup, represent full collaboration on a research project with significant time and resource commitment over the course of the project. This includes support with dissemination and impact, especially from a comms and policy perspective where Sands is uniquely placed to help the findings of research studies go on to inform practice and influence policy. For support to be provided at the partnership level, the researcher will be required to sign a partnership agreement.

The likes of sharing research opportunities or providing letters of support are more flexible, involving our input only at certain times during a project. We remain open to considering other modes of support. Regardless of the level of support we provide, we will expect researchers to provide Sands with regular progress updates and to acknowledge Sands' involvement during and after the study.

As a charity, we have limited capacity, and we need to ensure that we prioritise our time and resources to support research projects that are likely to have the greatest impact on achieving our core aims. Due to the limited likelihood of such impact, we do not consider requests for support from students studying at Master's level or below.

Our research decision framework highlights the factors we consider when we review requests for research support. We consider **all** requests against our research priority areas, which are:

- The relevance of the proposed research to Sands' <u>strategic aims and objectives</u>
- The expected impact of the research and the timescale of this impact
- The approach to involving Sands, parents, families and other organisations in the research, for example the amount and frequency of involvement, at which stages of projects we are involved and whether we would be directly or indirectly involved
- Sands' capacity to support the research



# **Decision framework**

Criteria	Out of Scope	Low Priority	High Priority
Relevance to Sands' aims	Research with considerable	Research around grief not linked to	Research focussed on:
	existing evidence	directly improving support	<ul> <li>Saving Babies' Lives by preventing</li> </ul>
			pregnancy loss or neonatal death
	Clear conflicts of interest	Research around preconception care	- Understanding of the causes of pregnancy
		and support	loss and neonatal death
	Research focusing on infant		- Making health care more equitable and
	deaths after the neonatal	Very similar research	safer
	period	already being supported by Sands	- Neonatal palliative and end of life care
			- Improving bereavement care and support
	Research around birth trauma		
	separate to baby loss		Funding applications to specifically identified calls
Expected impact of	No clear impact relating to	Focus on generating evidence and	Clear or novel impact relating to Sands' aims within
research	Sands' aims within 5 years	theory without clear demonstration	5 years
		of how this will be applied to ensure	
		impact	Studies with longer-term impact trialling new
			interventions in a high-priority area (see above)
			Clear pathways to publication, dissemination, and
			impact
Research approach to	Research around parents'	Study already submitted to	Sands will be involved from the early stages
involvement	experiences that does not	ethics/funding bodies prior to Sands	
	include bereaved parents	involvement	Significant scope for PPI input at start of and
			throughout study
	Research which has non-	Little opportunity to offer meaningful	
	inclusive exclusion criteria	input into developing the study	
	without strong justification		
Research support capacity		Last-minute request	Request at the earliest stages of the project



### Guidance on the request and support processes

All research requests must be submitted via our online request form.

Given our limited capacity, it can take up to six weeks to fully review a request for support, so please ensure that requests are submitted at least six weeks before you need a decision. This time might include initial meetings to discuss a request in more detail before a decision is made (please note that organising such a meeting does not mean we are agreeing to support the study; official agreement is always confirmed by email).

We encourage researchers to submit requests for support as early as possible in the development stage of a research project or proposal, **before** any submissions to ethics committees or funders. This applies to requests for sharing recruitment opportunities on our social media channels and website.

We require research studies applying for research funding to cost Sands support into funding applications at a rate of £100 per hour. For studies where funding is already in place we can have a flexible approach to costings, and for projects without funding we will consider providing support for free if capacity allows.

When you submit a request for support, please do supply the information we ask for to avoid delays in reviewing your request. We are always happy to discuss details of support, and early submissions of requests for support helps with this. The level of involvement we can offer will also depend on our capacity and we will review this during initial discussions.

We appreciate that if you are contacting us at early stages, you might not know the extent to which you would like Sands to be involved or what that might look like. Regardless, we would prefer to hear from you early on to discuss our involvement. We are happy to discuss your request ahead of submission. Please email us at <a href="mailto:research@sands.org.uk">research@sands.org.uk</a> and we will be in touch.

### Types of support we can provide:

- Letter of support for funding/ethics application if you are seeking a letter of support without any other research involvement, we need to have a clear idea on application timescale, the expected impact of the study in line with Sands' priorities, whether there are specific letter templates to use, or contact details needed for the letterhead.
- Participant recruitment for requests to share recruitment opportunities without any further support input, we need a clear timescale for sharing, time to review any study materials before they are shared (including surveys, questionnaires, interview topic guides etc), and confirmation that any changes needed to these materials can be made before sharing. We strongly recommend requesting support before ethics review, if possible, as we may require changes to be made before materials can be shared.



- Parent and Public Involvement (PPI) support this covers both Sands' direct involvement in a PPI role, and indirect involvement such as recruiting parents into PPI roles for a study. We need a clear idea of whether PPI support would include direct involvement, such as Sands being represented on an advisory group as a PPI member, or indirect involvement in an advisory role including helping with recruitment of parents as PPI members, advising on establishing a PPI group or developing a PPI plan for the project.
- Research partnership this covers active involvement throughout a study across development, oversight and dissemination that goes beyond (but may well include) helping with parent involvement, recruitment or writing a letter of support. This also includes being a co-applicant on a study or joining a steering or oversight group. To review research partnership requests, we need to have a clear idea of what level of involvement is required throughout the project, including an outline of study oversight requirements, details of any advisory roles with an idea of group meeting frequency, information on any funding or ethics application deadlines and clear indication of budget available for our support. For support to be provided at the partnership level, the researcher will be required to sign the a partnership agreement.

To ensure that the support we provide for any research proposal or project is beneficial for all involved, we require certain criteria to be met:

- **Regular, timely updates** the researcher / research team should provide regular and timely updates throughout the support process and ensure the Sands team receive ongoing updates until the research is completed.
- Impact and publications the researcher / research team should notify the Sands team of any publications, presentations or examples of impact originating from the research project so that Sands can share these with their audiences. Our prior written approval must be obtained before using Sands name or Logo.
- Payment schedules if payment for Sands' support has been agreed, the researcher / research team will liaise with their institution's finance department and the Sands team to clarify payment processes and create a payment schedule for the research support activity. This will be done as soon as possible once the study has commenced.
- Acknowledgement of Sands' input the researcher / research team should ensure that Sands' input into the study is acknowledged in any publications or other outputs including comms and media related to the research study, with our prior written approval.
- Research governance and GDPR the researcher / research team and Sands will comply with the General Data Protection Regulation (GDPR) and any applicable national data protection laws. The researcher / research team will also comply with Sands Data Protection and Privacy policy, which can be found here.