

GAPS project update – February 2016

The GAPS project is a global research collaboration led by the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID), The Lullaby Trust (UK), SIDS and Kids (Australia) and the American SIDS Institute. Its aim is to identify which gaps in research, if filled, have the most potential to reduce further the number of sudden unexpected infant deaths (SUID, also known as SUDI) around the world in the next 10 years.

The findings will help to set a research agenda, both in the different countries involved but also internationally. Funders and donors are increasingly expecting research communities to develop consensus on key priorities before committing funds to new research, so GAPS will help us to secure funding for projects that could make the most difference in reducing SUID.

Current progress

Stage 1: Gathering initial research priorities (May–September 2015)

- **80** physicians, researchers, bereaved family members and charity representatives responded to an **open-ended survey** with what they felt were the key research priorities in SUID
- **19 different countries** were represented, with the majority from the USA
- **Over 500** suggestions were made, which was gradually reduced to **41 individual research priorities** after removing duplicates, grouping similar suggestions and conducting a literature review to confirm potential and feasibility

Stage 2: Rating research priorities (September–November 2015)

- A second **closed-ended survey** asking participants to rate how important they thought each of the 41 research priorities was received almost **700 responses**
- **Bereaved family members** and **healthcare professionals** were represented almost **equally** (40% each)
- **18 different countries** were represented, with the majority from the UK
- The top-scoring **30 research priorities** were taken forward to be discussed at the workshops

Stage 3: Prioritisation workshops (November–December 2015)

- **Three** one-day workshops took place in the **UK, USA and Australia** to build consensus on which of the 30 priorities should make it into a final Top 10
- **56 people** took part in the workshops: 23 in the UK, 17 in the US and 17 in Australia
- Participants across all three workshops included physicians, researchers, bereaved family members, public health professionals and charity representatives
- Each workshop agreed on a list of **final Top 10 priorities**, with slight wording changes between them

- Broad themes were shared among the countries, such as the need to understand **physiological mechanisms leading to death** and how they **interact** with behavioural risk factors. There was also a shared recognition of the need to find **more effective ways of educating** about modifiable risk factors, and a common concern that pathologists/medical examiners needed **better tools to classify** sudden infant deaths
- Outside of prioritising the research statements, participants also raised issues such as the importance of **supporting the mental health of bereaved families** and improving the **evidence base** to support this area through research



Participants in the US workshop



Two of the UK workshop facilitators, Lucy and Francine of The Lullaby Trust



Participants in the Australia workshop

Stage 4: Communicating the top research priorities (January–September 2016)

- The **workshop findings** are currently being analysed and will be reported in a paper that is aiming to be published by **late summer 2016**
- The paper will aim to inform where future funding in SUID research should be directed, and the findings will be disseminated widely by the participating organisations
- An abstract will also be submitted to the **International Conference on Stillbirth, SIDS and Baby Survival**, to be held in Uruguay in September 2016

For questions about any aspect of the GAPS project please contact the Project Manager Lucy Lyus at: lucyl@lullabytrust.org.uk