Research Priorities in Sudden Unexpected Infant Death: An International Consensus

Fern R. Hauck, MD, MS,^e Betty L. McEntire, PhD,^b Leanne K. Raven, MNS, BAppSc, DipNE, FAICD, MRCNA,^e Francine L. Bates, BA (Hons),^d Lucy A. Lyus, MA (Gantab),^d Alexis M. Willett, BA (Hons), MSc, PhD,^e Peter S. Blair, BSc (Hons), MSc, PhD^f

Despite the success of safe sleep campaigns and the progress in understanding risk factors, the rate of reduction in the cases of sudden infant death syndrome has now slowed and it remains a leading cause of postneonatal mortality in many developed countries. Strategic action is needed to tackle this problem and it is now vital to identify how the sudden infant death research community may best target its efforts. The Global Action and Prioritization of Sudden Infant Death Project was an international consensus process that aimed to define and direct future research by investigating the priorities of expert and lay members of the sudden unexpected infant death (SUID) community across countries. The aim was to identify which areas of research should be prioritized to reduce the number of SUID deaths globally. Scientific researchers, clinicians, counselors, educators, and SUID parents from 25 countries took part across 2 online surveys to identify potential research priorities. Workshops subsequently took place in the United Kingdom, United States, and Australia to reach consensus and 10 priority areas for research were established. Three main themes among the priorities emerged: (1) a better understanding of mechanisms underlying SUID, (2) ensuring best practice in data collection, management and sharing, and (3) a better understanding of target populations and more effective communication of risk. SUID is a global problem and this project provides the international SUID community with a list of shared research priorities to more effectively work toward explaining and reducing the number of sudden infant deaths.

Twenty-five years ago, research into sudden infant death syndrome (SIDS, also known as crib death or cot death) led to a breakthrough that has since saved thousands of lives globally. A series of case-control studies identified that, among other factors, infants who slept on their stomachs were significantly more likely to die of SIDS than infants who slept on their backs. This research led to the Back to Sleep campaign, which was launched in the 1990s in many countries around the world, reducing the number of

deaths from SIDS almost immediately by at least 50% in the United States, United Kingdom, and Australia among other countries targeted.² Subsequent findings of other risk factors in the infant sleeping environment has led to a slower but additional fall in SIDS rates.

There is now a well-established evidence base for risk factors both intrinsic and extrinsic to the infant. These have been integrated in a triple risk model, which provides a useful framework for understanding how

abstract



^aDepartment of Family Medicine, University of Virginia School of Medicine, Charlottesville, Virginia; ^bAmerican SIDS Institute, Naples, Florida; ^cFaculty of Science, Health and Engineering, University of the Sunshine Coast, Sippy Downs, Queensland, Australia; ^dThe Lullaby Trust, London, United Kingdom; ^ePunch Consulting, Cambridge, United Kingdom; and ^fSchool of Social and Community Medicine, University of Bristol, Bristol, United Kingdom

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Address correspondence to Francine L. Bates, BA (Hons), The Lullaby Trust, 11 Belgrave Rd, London SW1V 1RB, United Kingdom. E-mail: francineb@ lullabytrust.org.uk

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a critical developmental period, underlying predisposition, and environmental factors together produce an acute vulnerability.3 SIDS is a subset of the broader classification of sudden unexpected infant death (SUID, or sudden unexpected death in infancy). SUID is described as the sudden and unexpected death of an infant <1 year of age, usually during sleep. The cause of death is usually assigned after a thorough case investigation, including scene investigation, autopsy, and a review of the clinical history. Death may be explained or unexplained. When a cause can be found, the most common diagnoses are infection, cardiovascular disorders, metabolic or genetic disorders, and asphyxia,4 although this last diagnosis is often based on circumstantial evidence.⁵ The International Classification of Diseases, 10th Revision (ICD-10) code for SIDS is assigned as the cause of death when the death remains unexplained, although increasing knowledge of associated risk factors has led to a reluctance among some pathologists to use the classification code for SIDS in exchange for alternative codes such as "unascertained," "undetermined," or because of associated sleep-related unintentional injuries.^{2,6,7} This diagnostic shift is unhelpful for both monitoring and research purposes, especially as the strength of evidence of a causal relationship on a case-bycase basis is often limited. Matters are complicated further as the umbrella term SUID does not have an ICD-10 code and thus cannot be used as a proxy to resolve this debate. Despite the obvious success of the safe sleep campaigns, and progress in understanding risk factors, the rate of reduction in the numbers of SIDS cases has now slowed.2 and SIDS remains a leading cause of postneonatal mortality in many developed countries (the leading cause in some).8 In 2015, provisional estimated rates of SUID not yet

published by the Office of National Statistics were 0.255 out of 1000 live births in England and Wales, 0.4 out of 1000 live births in Australia, and 0.926 out of 1000 live births in the United States. These statistics include SIDS cases (ICD-10 code R95), deaths that are ill-defined or of unknown cause (ICD-10 code R99) and cases of accidental strangulation and suffocation in bed (ICD-10 code W75).

Ongoing research aims to better understand both underlying and proximate causes of SUID with the ultimate aim of explaining and reducing the number of deaths across different countries. However, partly as a result of the perceived success of the risk reduction campaigns, research into SUID has become less well-funded and the international SUID research community is relatively small. There are also differences of opinion, between and within national research communities, on the implementation of certain risk reduction advice, such as bed-sharing. 11,12 Furthermore, classification and formal investigation procedures also vary widely between and within countries.5,6,13 This lack of consensus, although an inevitable part of research and data collection, impedes the prioritization and coordination of clear, culturally-appropriate public health campaigns that are needed to ultimately reduce deaths and the means to monitor such reduction.

Given limited resources internationally, it is vital to identify how the SUID research community should best direct its efforts. To better inform these efforts, we report on the Global Action and Prioritization of Sudden infant death (GAPS) project, an international consensus process that aimed to define and direct future SUID research, specifically by systematically determining the priorities of both expert and lay

members of the SUID community across countries.

The aim of the GAPS project was to identify which areas of research should be prioritized by the international research community and policy makers to reduce the number of SIDS and other SUID deaths globally. The objectives of the project were to: (1) decide where research efforts should be focused to have the greatest impact on reducing the number of SUID, and (2) establish consensus on the top research priorities across different countries, and between expert and lay members of the SUID community.

METHODS

The GAPS project was coordinated by The Lullaby Trust, a UK-based charity that provides support for bereaved families, raises awareness on sudden infant death, and provides evidence-based advice on safe infant sleep. The project was overseen by a multidisciplinary steering group from the United Kingdom, United States, and Australia, composed of Ms Bates, Dr Hauck, Dr Blair, Dr McEntire, and Adjunct Associate Prof Raven, whose expertise spans SUID research, clinical care, public health, epidemiology, health education, advocacy, and bereavement support. The steering group members are all board members of the International Society for the Prevention of Perinatal and Infant Death (ISPID), who endorsed and supported the project from its beginning. UK-based physicians with expertise in SUID provided additional support on survey content and structure. Pediatric pathologist Dr Steve Gould assisted the preliminary screening of survey 1 results and Dr Alexis Willett and Dr Jennifer Barnett, independent research and medical communications consultants, provided guidance throughout the project.

The project followed an expanded methodology of a priority-setting partnership model of the James Lind Alliance (JLA), as described in the JLA Handbook.¹⁴ As GAPS was an international project, the expansion of the model enabled the inclusion of multiple workshops and their findings, rather than 1 workshop typically undertaken in the model (Fig 1). The prioritysetting partnership model is a type of nominal group process in which the use of a facilitator to lead group discussions has been shown to be effective in enabling all participants to express their views without 1 group or perspective dominating.¹⁵ The method has been successfully applied in contentious areas of health care to identify shared research priorities, such as in sight loss, 16 palliative care,¹⁷ and stillbirth.¹⁸

Survey 1: Gathering Initial Research Priorities

Initial research suggestions were captured in an online survey. Over 100 members of ISPID (scientific researchers, clinicians, counselors, educators, and SUID family members) as well as other parents and professionals affiliated with ISPID were invited to take part during the spring of 2015. Five open-ended questions were asked to identify potential research topics (see Supplemental Table 5).

The potential research topics generated from Survey 1 were reviewed and grouped into categories by an independent research consultant and a consultant pediatric pathologist with SUID expertise (as listed in the Acknowledgments). They excluded duplicates and reviewed the remainder by using PubMed and recent reviews^{8,19} to ascertain whether each suggestion was likely to be feasible in the next 10 years and ensuring that it had not already been adequately addressed by previous research. The steering group assessed the resulting list with

Survey 1: Gathering initial research priorities 79 respondents from 19 countries provided suggestions 516 individual suggestions submitted

Refining and validating suggestions 144 suggestions remained after grouping 41 research priorities and 15 working principles remained after feasibility screening

Survey 2: Rating research priorities 612 respondents from 18 countries rated statements 30 research priorities and 10 working principles taken forward to workshops

Prioritization workshops
3 workshops held in the United Kingdom, the United States, and Australia
10 research priorities agreed by mixed-stakeholder groups at each workshop
Working principles prioritized at each workshop

Final top 10 research priorities
Aggregate score applied to workshop priority lists to establish final 10 research priorities

FIGURE 1Outline of the GAPS study design, including the key stages and headline figures.

respect to each statement's potential to impact SUID prevention based on current evidence. Those considered to have limited potential were excluded. The remaining suggestions were refined into a list of statements for ranking by participants in a second survey. The statements were grouped into 2 main categories: (1) those relating to specific areas of research (research priorities), comprising the majority of the statements, and (2) those relating to broader research principles (working principles), considered secondary to the research priorities, although of importance for underpinning high quality research. The 2 groups of statements were subsequently evaluated separately, with the emphasis placed on the research priorities.

Survey 2: Rating Research Priorities

A second online survey (see Supplemental Table 6) was

implemented to prioritize the statements brought forward from survey 1. The target recipients of the survey were family members bereaved by the sudden and unexpected loss of an infant and professionals working in an area related to SUID. The survey link was emailed to all professionals and parents who had consented to receiving the participating charities' communications, and was also publicized on the participating charities' Web sites, social media, and newsletters. A paper copy of the survey was available to participants reporting difficulty completing the survey online. Responses were gathered over a 4-week period from October 2015 to November 2015.

The survey asked participants to state which country they were based in, their experience or expertise in relation to SUID, and to rate a series of statements on research priorities based on how important

Stage	Process	Further Detail
1	Preworkshop: Participants were sent a list of 30 research priorities to rank	Ranking statements in advance of the workshop enabled participants to quickly identify areas of agreement or difference of
	in advance.	opinion as a starting point for discussion in the first small group ranking session.
2	Workshop (small groups): Participants worked in three small groups, containing both parents and professionals, to rank the 30 statements. Two rounds of ranking in small groups took place.	An aggregate ranking of the results of all groups from the first round was calculated and used as the basis for discussion in the second round. Participant composition of small groups changed after the first round and the ranking process was then repeated.
		Aggregate ranking calculated from the second round formed the basis of discussion in the plenary session.
3	Workshop (plenary session): All participants discussed the aggregate ranking from the second round to reach consensus on a top 10 list of	Minor rewording of the statements was allowed, but only if the majority of the group agreed when put to a vote and if the rewording did not change the overall meaning of the statement.
	research priorities.	The workshop in each country started with the same original wording of the statements. Participants were not informed of other workshops' results until they had finalized their final top 10 priorities.

FIGURE 2

Summary of the workshop process, based on the JLA model, which describes the 3 main stages during which participants arrived at a consensus on research priorities in the GAPS project.

they thought they were for reducing the rate of SUID in the next 10 years. Participants were asked to rate each statement on a scale from 1 (not important) to 5 (very important), allowing for don't know (0). Participants were asked to take into account achievability, timescale, cost, and number of lives potentially saved.

A mean score was calculated for each statement and they were ranked in order from highest to lowest score. The 30 top-ranking research priorities were taken forward for discussion at the prioritization workshops, the maximum number advised by the JLA for manageability.

Survey 2: Rating Working Principles

In addition to rating research priorities in survey 2, participants also rated the extent to which they agreed with each of the working principles (1 = do not agree, 5 = strongly agree, 0 = don't know). The working principles were also

ranked based on their scores and the steering group agreed to take the top 10 forward to the workshops for additional ranking.

Workshops: Research Priorities

Three workshops were held, one each in the United Kingdom, United States, and Australia, to bring together invited SUID family members and professionals to decide which of the 30 research priorities should comprise the final top 10 research priorities. Participants were invited by the charities involved in the GAPS project, based on their high level of expertise in their field, or capacity to share their personal experience of SUID. For each workshop, the participants included a balanced representation of stakeholders including SUID family members and professionals working in wide-ranging areas related to SUID. The workshops, as outlined in Fig 2, were led by facilitators trained in the JLA process.

To produce a final list of 10 research priorities from the outcomes of all 3 workshops, an aggregate score was applied. The score for each research priority was based on the sum of its final rank at each workshop. For example, if a statement ranked first, second and fourth across the 3 workshops, the aggregate score was 7. The aggregate scores were subsequently ordered from lowest to highest, with the lowest score indicating the highest priority.

Workshops: Working Principles

The 10 working principles were not included in the discussion process but participants at the workshops were asked to indicate those that they felt were most important by marking sheets with the principles printed on them. The 5 principles with the most votes at each workshop were considered the priorities.

RESULTS

Survey 1

Survey 1 generated 79 complete responses. This equated to 48% of the original target list. However, people who received the survey also shared the link with others and, therefore, the exact number of people who received the survey, and the corresponding response rate, is unknown. People from 19 different countries participated (Table 1). Twenty-eight percent of responses came from the United States, with significant numbers also from the United Kingdom (15%) and the Netherlands (14%). SUID family members accounted for 11% of respondents and the remainder were professionals with expertise in SUID. There were 516 proposed suggestions, of which 144 remained after grouping. After the literature review, 41 research priorities and 15 working principles were taken forward to the second survey to

TABLE 1 Geographical Spread of Respondents in the 2 Surveys in the GAPS Project, Including the Number from Each Country Who Responded and Their Corresponding Percentage of the Total for Each Survey

Country	Surv	Survey 1		Survey 2		
	N	%	N	%		
United States	22	28	103	17		
United Kingdom	12	15	300	49		
The Netherlands	11	14	3	<1		
Australia	8	10	166	27		
Columbia	6	7	1	<1		
New Zealand	4	5	5	1		
Argentina	2	3	_	_		
Germany	2	3	2	<1		
Ireland	2	3	7	1		
Canada	1	1	13	2		
France	1	1	2	<1		
Italy	1	1	1	<1		
Norway	1	1	1	<1		
Denmark	1	1	_	_		
Finland	1	1	_	_		
Israel	1	1	_	_		
Japan	1	1	_	_		
Panama	1	1	_	_		
Uruguay	1	1	_	_		
Belgium	_	_	2	<1		
South Africa	_	_	2	<1		
Austria	_	_	1	<1		
Pakistan	_	_	1	<1		
Spain	_	_	1	<1		
Uganda	_	_	1	<1		
Total	79	_	612	_		

^{---,} Indicates that no response was received from that country

confirm feasibility and potential for future impact on SUID.

Survey 2

Survey 2 received 612 completed responses. As this survey was also advertised via Web sites and social media, it was not possible to calculate the response rate. People from 18 different countries took part (Table 1). Almost half of the responses came from the United Kingdom (49%), with a strong representation from Australia (27%) and the United States (17%). Responses were split almost equally between researchers and health care professionals (40% in total) and SUID family members (38%), with non-health care professionals (people working in social work, education, child care, bereavement support, lactation support, and the charity sector) and other interested members of the public providing the remainder. Health care professionals who were also SUID family members were counted as professional if their specialty was related to SUID (eg, pediatrics, SUID surveillance). There was some variation among the stakeholder groups in their ranking of the research priorities (see Supplemental Information). In many cases, non-health care professionals ranked priorities differently than other stakeholder groups. Despite some variation in thinking, all of the top 10 highest ranked research priorities of both the health care professionals and the SUID family members ended up in the final top 20. The workshop process provided the opportunity to talk through differences and achieve consensus.

Workshops

The number and proportion of SUID family members to professionals varied between each workshop. SUID family members comprised between 16% and 24% of each

workshop, with the remainder mainly health care professionals (Table 2). Distinct themes emerged during discussions for the 2 main stakeholder groups: SUID family members tended to prioritize identifying physiologic mechanisms involved in SUID, although health care professionals also had a focus on improving education around safe sleep. Consensus within each workshop was achieved for the top 10 research priorities. There was also considerable consensus across the 3 workshops. Taking into account minor wording alterations requested at the workshops, the research priorities (Table 3) included 3 broad themes.

Better Understanding of Mechanisms Underlying SUID

Over half of the research priorities emphasize the need to better understand what biological mechanisms are in play in SUID,

TABLE 2 The Range of Expertise of the Participants at Each of the 3 Workshops in the GAPS Project

Category	United Kingdom	United States	Australia
Clinician	5	1	2
Researcher	5	4	5
Clinician and researcher	4	5	5
SUID family member	4	4	4
Medical examiner	1	1	_
Nonprofit organization representative	2	2	1
Other	3	0	_
Total	24	17	17

^{—,} Indicates that there was no representative from a category.

TABLE 3 The Top 10 Research Priorities Agreed on in the GAPS Project (Final Rank), as Determined by Their Aggregate Scores, and How They Were Ranked in the 3 Workshops

Final Rank	Research Priority	UK Rank	US Rank	Australia Rank	Aggregate Score
1	Studying mechanisms leading to death and how they interact with environmental risk factors.	2	1	4	7
2	Enabling best practice processes and systematic data collection for accurate classification of SUID deaths to inform research and prevention.	3	5	1	9
3	Developing and evaluating new ways to make safe sleep campaigns more effective.	1	8	2	11
1	Understanding to what extent social and cultural factors affect parental choice in sleep practices and responses to risk reduction campaigns.	5	3	7	15
ō	ldentifying specific biomarkers to assist pathologists in determining the cause of death.	4	9	3	16
3	Understanding the role of genetic factors in SUID risk.	7	2	8	17
,	Understanding what mechanisms underlie SUID risk at different ages.	11	7	6	24
3	Conducting additional research on the role of abnormal or immature brain anatomy and physiology.	15	4	9	28
)	Better understanding of the practice of sharing any sleep surface with an infant, notably how it interacts with other factors to make it more or less risky.	9	10	12	31
10	Identifying what factors are associated with SUID in which all aspects of recommended risk reduction have been followed.	8	14	11	33

how environmental factors interact with such mechanisms, and the subsequent need to identify associated biomarkers to assist pathologists in determining the cause of death. Understanding how mechanisms that underlie SUID may differ at different ages and levels of maturation is also seen as important. Some of the other mechanistic research priorities from the original list of 30 were determined to easily be subsumed within these priority areas. A few of the priorities within this theme are as follows:

 Priority 1: Studying mechanisms leading to death and how they interact with environmental risk factors:

- Priority 5: Identifying specific biomarkers to assist pathologists in determining the cause of death;
- Priority 6: Understanding the role of genetic factors in SUID risk;
- Priority 7: Understanding what mechanisms underlie SUID risk at different ages;
- Priority 8: Conducting additional research on the role of abnormal or immature brain anatomy and physiology; and
- Priority 10: Identifying what factors are associated with SUID in which all aspects of recommended risk reduction have been followed.

Ensuring Best Practice Data Collection, Management, and Sharing

Differences in the classification of SUID across the world, as well as varying quality in the practice of data collection and sharing, was considered to be a significant hindrance to our understanding of SUID and to research progress. Addressing these issues was agreed to be a matter of great importance. The priority within this theme is as follows:

 Priority 2: Enabling best practice processes and systematic data collection for accurate classification of SUID deaths to inform research and prevention.

TABLE 4 List of Working Principles Presented to Workshops in the GAPS Project, Grouped by the Number of Workshops That Scored Each in its Top 5

No. of Workshops That Scored The Principle in its Top 5	Working Principle
3	There should be a standardized and common approach to postmortems in all SUID cases.
2	We need to move from single factor prevention approaches to addressing multidimensional risks such as smoking, poverty, and unsafe sleeping acting together.
	All SUID should be studied, not just SIDS or unexplained deaths.
	We need up-to-date data. We should carry out large-scale studies equivalent to those conducted before risk reduction campaigns to discover how vulnerability factors have changed. This may require an international collaborative study.
	We should embed SUID research in larger programs of infant safety or wellbeing research to attract more funding.
	We should improve the evidence base for the interpretation of post mortem findings.
1	We should prioritize evaluation of health service delivery programs for vulnerable families.
	SUID awareness and prevention should be mandatory in the training of all health care and early-years professionals.
0	We should lobby government to fund SUID awareness/prevention strategies.
	Developed countries should collaborate with lower-resourced countries so that they can learn from each other about successful prevention strategies.

Better Understanding of Target Populations and More Effective Communication of Risk

To further decrease SUID rates, participants stressed that more research is required to better understand the behavior and needs of target populations. As we learn more about potential causes of SUID and how to reduce risk and the requirements of target populations, it was stressed that a priority should be to communicate these effectively and develop impactful, evidence-based behavior change campaigns. Priorities within this theme are as follows:

- Priority 3: Developing and evaluating new ways to make safe sleep campaigns more effective;
- Priority 4: Understanding to what extent social and cultural factors affect parental choice in sleep practices and responses to risk reduction campaigns; and
- Priority 9: Better understanding of the practice of sharing any sleep surface with an infant, notably how it interacts with other factors to make it more or less risky.

Working Principles

There was significant variation in the ranking of the top 5 working principles among the workshops. The working principles are therefore summarized by indicating the number of workshops that scored each in its top 5, and therefore were considered a priority (Table 4). Only 1 principle was prioritized by all 3 workshops: "There should be a standardized and common approach to postmortems in all SUID cases." Five other principles were ranked as important by 2 out of 3 workshops.

DISCUSSION

The rate of decline in sudden infant death has slowed in the last decade in many developed countries and strategic action needs to be taken if SUID rates are to be significantly reduced further. The GAPS project achieved international consensus from the SUID community on the top 10 priorities for research to inform researchers, funders, and policy makers in the shared aim of reducing SUID rates. Three main themes among the priorities emerged: (1) a better understanding of mechanisms underlying SUID, (2) ensuring best practice data collection, management and sharing, and (3) a better understanding of target populations and more effective communication of risk. These themes reflect the future goal of the entire SUID community to prevent SUID deaths: (a) by identifying underlying mechanisms that can be prevented, (b) by sharing high-quality data to inform best practice and accurate classification of SUID deaths, and (c) by effectively partnering with communities most

vulnerable to SUID through culturally sensitive methods. Collaboration among countries is imperative to share best practice, monitor progress, and achieve statistical power for future investigations.

The top 10 research priorities (Table 3) represent areas that are considered by our participating international community of informed stakeholders to have the most potential to reduce the rate of SUID. Rather than form narrow research questions, they allow researchers room to interpret and refine them into a particular focus, thus enabling investigators with different expertise to add knowledge to the same topic from different perspectives. Although every priority topic originally proposed was felt to have potential at an earlier stage in the consensus process, the GAPS project has identified research priorities with the most support from the SUID community.

Although the working principles were not a primary focus of this project, they revealed the need to also improve processes to enable better SUID research. No clear order of priority in the working principles was achieved among countries. Although the discussion process in the workshops enabled participants to reach consensus on the research priorities, the working principles were not discussed as a group, which

may account for the variability in their ranking. Regardless, the final list of working principles, prioritized by stakeholders through the survey process, provides fundamental guidance as to the key approaches required to achieve meaningful progress in SUID research.

The GAPS project was the first of its kind to bring together the expertise of both professionals and the lay community to identify which areas of research should be prioritized to reduce the number of sudden unexpected deaths in infancy. The importance of lay participation in setting the research agenda in health care is becoming well-established and offers the benefit of ensuring that future research is grounded in day-to-day reality²⁰ as well as a way of democratically legitimizing decision-making.21 The involvement of SUID family members has always been important in the history of SUID, indeed parent groups have been a driving force behind the Back to Sleep campaign and subsequent initiatives. However, little has been known about what kind of research they would like to see. Many of our advances in research would not have been possible without the efforts of families and so it is important that they have been included in this project. In addition, although the GAPS project followed a nominal groups approach based on the JLA model, it was unique in that it gathered opinions from around the world. No project has conducted priority setting workshops in multiple countries to achieve international consensus on a topic, utilizing a global opinion survey as a base. This approach aimed to secure greater buy-in to the results from the multistakeholder global SUID community and lends additional weight to the results.

Within the workshops, it was informative to observe the pattern of differing priorities between SUID family members and health care professionals, which was also supported by survey 2 data. Perhaps this is reflective of the need for SUID family members to obtain specific answers for why their infant died, whereas for professionals the experience of dealing with cases in which infants died in unsafe sleep surroundings may inform their priorities. Despite these influences, it is encouraging that there was much overlap in viewpoints and all participants were able to share their perspectives and mutually agree on the final research priorities.

There were a number of limitations to this project. Language (both scientific language as well as the English language) might have proven a barrier for some people in taking part in the surveys, regardless of category of expertise. The wording of each research statement attempted to be as accessible as possible, but it may have prevented some people from taking part. The findings of this project can only be representative of the people who took part. Although people from 25 different countries participated, reflecting the widespread nature of the SUID research community and the global importance of SUID, the workshops only took place in 3 countries where the final priorities were established. Furthermore, although a number of individuals from developing countries participated in the surveys, the large majority of the project participants were from developed countries. As such, the findings may not reflect the priorities of those in developing countries. In addition, it is not known how representative the survey was of different racial or socioeconomic groups, which are affected differently by SUID. SUID family members were significantly better represented in survey 2 than survey 1, so a different range of priorities might have been identified if more families had been included at an earlier stage. Furthermore, this exercise only included research

that could potentially reduce the rate of SUID and did not look at how to best to help families who have experienced SUID. This is an important area currently limited by a dearth of evidence, and one that might benefit from a future prioritization effort.

SUID RESEARCH PRIORITIES AND NEXT STEPS

SUID is a global problem and the international SUID community now has a list of shared research priorities to make targeted progress in ultimately preventing more SUID cases. These priorities offer a unique opportunity for global action and for pooling limited resources and capitalizing on the expertise of colleagues in many countries. All researchers, funders, and policy makers working in the field of infant mortality are urged to implement the research priorities, supported by the working principles, at both the individual country and international organizational levels to maximize impact globally.

Beyond the areas of international agreement, 3 countries also achieved consensus on their own research priorities. The United Kingdom, United States, and Australia are now equipped with their own top 10 research priorities reflective of their own particular interests and needs. These countries have an important opportunity to use these resources to strategically guide policies and processes that will most effectively address SUID in their own populations and circumstances.

To aid the international SUID community in maintaining a shared vision over the long-term, progress on the identified research priorities should be reviewed in 5 years. The review should reflect upon lessons learned over the 5 years and use the new evidence base to inform whether future priorities need to be revised or expanded.

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ABBREVIATIONS

GAPS: Global Action and
Prioritization of Sudden
infant death

ICD-10: International
Classification of Diseases,
10th Revision

ISPID: International Society for the Prevention of Perinatal and Infant Death

JLA: James Lind Alliance SIDS: sudden infant death syndrome

SUID: sudden unexpected infant death

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