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RESEARCH **Open Access**

Research priorities for stillbirth in Australia: outcomes of a national priority setting partnership

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Abstract

Background Stillbirth research priorities for Australia were identified in 2015. A renewed priority setting exercise identified current research priorities to address the national burden of stillbirth.

Methods Bereaved parents, healthcare professionals, researchers, policymakers, and community-based support organisations participated in this priority setting partnership. Using a modified James Lind Alliance approach, proposed research questions were collated, refined and reviewed against existing evidence, with participants ranking their top ten research questions. Twenty-six key stakeholders at an in-person forum then determined the top research priorities.

Results Consultations were attended by 243 participants, representing over 30 community and professional organisations, 219 participated (48% with lived experience of stillbirth) in the prioritisation survey. In the final prioritisation forum 25 research questions were prioritised, and six overarching priority areas identified: (1) Determine the causes of, and pathways that lead to stillbirth; (2) Identify and implement strategies to prevent stillbirth; (3) Build the capacity of health services and systems; (4) Understand and improve care for families after perinatal loss; (5) Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families; and (6) Ensure culturally safe and responsive care for families of migrant and refugee background.

Conclusion This process identified a relevant stillbirth research agenda to improve outcomes for women and families in Australia.

Keywords Stillbirth, Research priorities, Perinatal loss, Pregnancy, Priority setting

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Background

Every day in Australia, six babies are stillborn (at 20 weeks' gestation or more) [1], with extensive and enduring impacts on families, communities, the health system and economy. The economic impact of stillbirth is estimated in the billions [2, 3], yet stillbirth research receives just 2.5% of the total funding allocated to newborn health research worldwide [4]. In Australia, the burden of stillbirth disproportionately affects Aboriginal and Torres Strait Islander families, some migrant and refugee populations, women younger than 20 years and those living in very remote and the most disadvantaged areas, with rates more than double that of the general population [1]. The National Stillbirth Action and Implementation Plan (NSAIP) [5] was established in 2020 by the Australian government, with a goal to reduce preventable stillbirths and disparities in priority populations, as well as ensuring that all families receive high quality perinatal loss care and support when stillbirth does occur. An essential outcome of the NSAIP is to 'establish agreed national priorities for stillbirth research' [5].

Robust priority setting exercises help guide national health policies and funding initiatives, promote collaboration and reduce resource wastage [6]. When research priorities are established by researchers and healthcare professionals there can be misalignment with the needs of research end-users [7]. The voices of bereaved parents are essential to ensure that research is meaningful and relevant to those most affected by stillbirth. By taking multiple perspectives into account, priority settings also provide credibility to research. As part of two Lancet Stillbirth series [8, 9] global stillbirth research priorities were identified and these helped inform Australian priority setting in 2015 [10]. Broad priorities 'care after stillbirth', 'investigation', and 'prevention', aided a multidisciplinary collaboration of researchers, healthcare professionals and bereaved parents to strategically advocate and successfully bid for funding from the Australian National Health and Medical Research Council (NHMRC) to establish The Centre of Research Excellence in Stillbirth (Stillbirth CRE) in 2017. Since then, national research initiatives include the implementation of the Safer Baby Bundle (SBB), which has five key elements aiming to reduce stillbirth rates after 28 weeks' gestation by 20% [11, 12]; co-designed adaptations of the SBB to address disparities in Indigenous communities (Stronger Bubba Born [13]) and for families of migrant and refugee background (Growing a Healthy Baby [14]); and the updated Care Around Stillbirth and Neonatal Death clinical guideline [15].

Research priorities should be revisited at least every five years to remain current and relevant [16, 17]. Therefore, the Stillbirth CRE, in partnership with Stillbirth Foundation Australia (a stillbirth research, education and advocacy organisation) and the Perinatal Society of Australia and New Zealand (PSANZ); the main society for perinatal loss researchers) conducted a renewed priority setting to determine future priorities across all areas of stillbirth research including but not limited to diagnosis, prevention, care after loss, psychosocial impacts and addressing disparities. We report the process and outcomes of this national collaboration to identify research priority areas that are most important to bereaved parents impacted by stillbirth and healthcare professionals who provide care in Australia. By bringing stakeholders together, this research priority setting makes a major contribution towards the NSAIP goals of 'improved coordination and awareness of stillbirth research' to provide 'a cohesive national approach to stillbirth research' [18].

Methods

A mixed dialogue model [19] and James Lind Alliance (JLA) [20] prioritisation approach was used. This research priority setting had three phases: consultation, refinement and prioritisation (Figure 1). The dialogue model encourages extensive and independent consultation with diverse stakeholder groups and was employed during the consultation phase to create safe spaces for stakeholders to express their views. The JLA methodology was followed for refinement and prioritisation, including an interim survey and final forum which embraced partnership in bringing stakeholders together. Various formats were used including online surveys, online workshops (via Zoom) and face-to-face forums, which were necessary as the priority setting was conducted during the COVID-19 pandemic (June 2020 to December 2023). This study is reported in accordance with the Reporting guideline for PRIority SEtting of health research (REPRISE) [21] [see Additional file 1].

Governance

This research priority setting was a partnership between the Stillbirth CRE, Stillbirth Foundation Australia and PSANZ. Members of the project team had prior experience with stillbirth research priority setting. A steering committee was formed with representation from each of the partner organisations and other peak national healthcare professional and perinatal bereavement support organisations including Red Nose, Royal Australian and New Zealand College of Obstetricians and Gynaecologists. Royal Australian College of General Practitioners, and Australian Preterm Birth Prevention Alliance. An advisory group of bereaved parents with research experience, approached through known networks, was established to guide the process and support bereaved parent involvement. Facilitators with a research background and previous experience conducting research priority settings moderated all consultations.

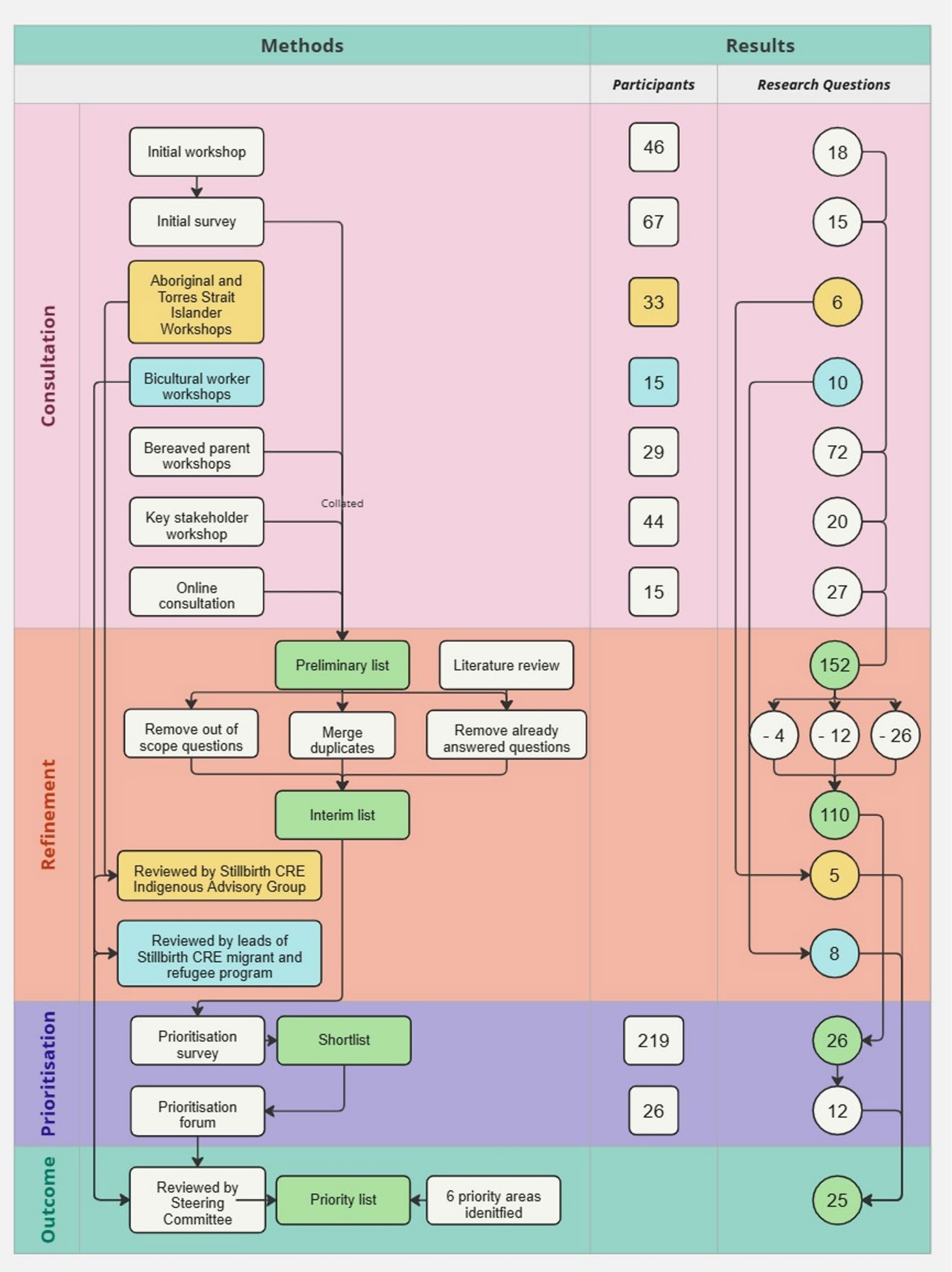


Fig. 1 Process overview of stillbirth research priority setting. Methods including comprehensive consultations, refinement and prioritisation are listed on the left. Number of participants and research questions at each stage are listed on the right. Aboriginal and Torres Strait Islander and migrant and refugee priorities, shaded in yellow and blue respectively, were deliberated separately by the appropriate groups

Participants and recruitment

Participants were eligible if they were aged 18 years or older, currently residing in Australia and had a lived experience of stillbirth, or a professional interest or expertise in stillbirth research. This included bereaved parents and family members (identified through Stillbirth Foundation and Stillbirth CRE's research involvement registry [22]), maternity consumer advocates, maternal and newborn health researchers (identified through known networks of the steering committee, and via a literature search of relevant researchers in the field), maternity healthcare professionals, policy makers, Aboriginal and Torres Strait Islander maternal infant care workers, program managers of Aboriginal health services, the Stillbirth CRE Indigenous Advisory Group, bicultural workers (spoke English as well as Punjabi, Hindi, Marathi, Arabic, Syrian, Assyrian Chaldean, Dari, Farsi, Karen, Burmese, or Vietnamese), and members of community-based stillbirth support and awareness organisations (Red Nose, Still Aware, Bears of Hope). Participants were recruited directly via email, through social media or mailing lists of partner organisations and provided with the relevant participant information and consent form.

Data analysis

All data collected during consultations were collated and analysed in Microsoft Excel (Microsoft Corp., Redmond, Washington, USA). Descriptive statistics were used to summarise demographic and survey data.

Consultation

Consultations were iterative and involved 12 workshops, a survey and online consultation form. All participants had the opportunity to provide feedback via email following their respective workshops as a member checking process.

Initial workshop and survey

An initial workshop was held online on 31 July 2020, to review the research priorities established in 2015 [10]. Participants, representing the views of multiple stakeholder groups, also engaged in group discussions to identify novel research questions. A stakeholder list consulted during the priority setting is provided in Additional file 2. Research questions proposed in this workshop were compiled into a Qualtrics (Qualtrics, Provo, UT) survey and participants ranked the research questions on a modified 9-point rating scale (1–3: limited importance; 4–6: important but not urgent; 7–9: important and urgent) [23]. Free-text opportunities were available to propose additional questions.

Aboriginal and Torres Strait Islander, and bicultural worker workshops

Culturally safe consultations are essential for priority populations. Two Indigenous-led (online, 30 September 2020 and in-person 18 February 2021) and two bicultural (both online, 24 June and 8 July 2020) 1.5-hour workshops were held to identify priorities for Aboriginal and Torres Strait Islander communities and families of migrant and refugee background. Key themes identified during the first workshops were collated and refined by the facilitators to develop a list of research questions that were reviewed at the subsequent workshops. Concurrently with this project, consultations took place with Indigenous communities and women of migrant and refugee background (who spoke Arabic, Dari, Karen, and Dinka), as part of the Stillbirth CRE programs to co-design culturally responsive resources, 'Stronger Bubba Born' [13, 24] and 'Growing a Healthy Baby' [14]. During these consultations, priorities were also identified by communities which strongly aligned with the priorities proposed during these workshops.

Bereaved parent workshops

Bereaved parent attendees of the initial workshop indicated that there was limited time for small-group discussions which introduced a considerable power imbalance. To create more opportunities for parent voices to be heard, the bereaved parent advisory group was established in 2022, and a bereaved parent researcher (KT) was appointed to coordinate the remainder of this priority setting. Five, small group, 2-hour online workshops were held in August 2023 to consult bereaved parents, with one exclusively attended by bereaved fathers. Participants were supported with a hard copy of the co-designed resource 'Getting Involved in Stillbirth Research; A guide for bereaved parents' [25, 26]. Members of the bereaved parent advisory group co-facilitated each workshop. Participants were reimbursed in line with Health Consumers Queensland rates [27].

Key stakeholder workshop and online consultation form

Professional organisations, colleges and societies involved in maternity and bereavement care were invited to nominate a representative [Additional file 2] to attend a final key stakeholder workshop on 27 September 2023. The aim of this workshop was to review the priorities identified in all previous consultations and propose any vital missing research questions. The list was also distributed in an online consultation form for those who were unable to attend.

Consolidation and refinement

Questions proposed during consultations were collated into a preliminary list. Detail on which stakeholder group each question originated from (i.e. bereaved parent, researcher, or healthcare professionals) was included. Members of the project team iteratively reviewed the preliminary list. Common themes were identified, and obvious duplicates were either merged (to ensure the wording encompassed the intent of both/all questions) or removed. Questions with a policy or implementation context (action priorities) were reviewed on a case-by-case basis to determine whether they were within scope. A literature review using PubMed and Google Scholar was performed to check whether research questions had already been answered and were removed. The project team compared refinements and reached consensus on an interim list of questions which was presented to the steering committee and advisory groups for endorsement before progressing to prioritisation.

It was agreed that the research priorities identified in the Aboriginal and Torres Strait Islander, and bicultural worker workshops were of vital importance to addressing disparities regarding stillbirth in these communities. These priorities were reviewed and refined by the relevant advisory groups, rather than being ranked in the prioritisation phase detailed below.

Prioritisation

Prioritisation involved a survey and final in-person prioritisation forum.

Prioritisation survey

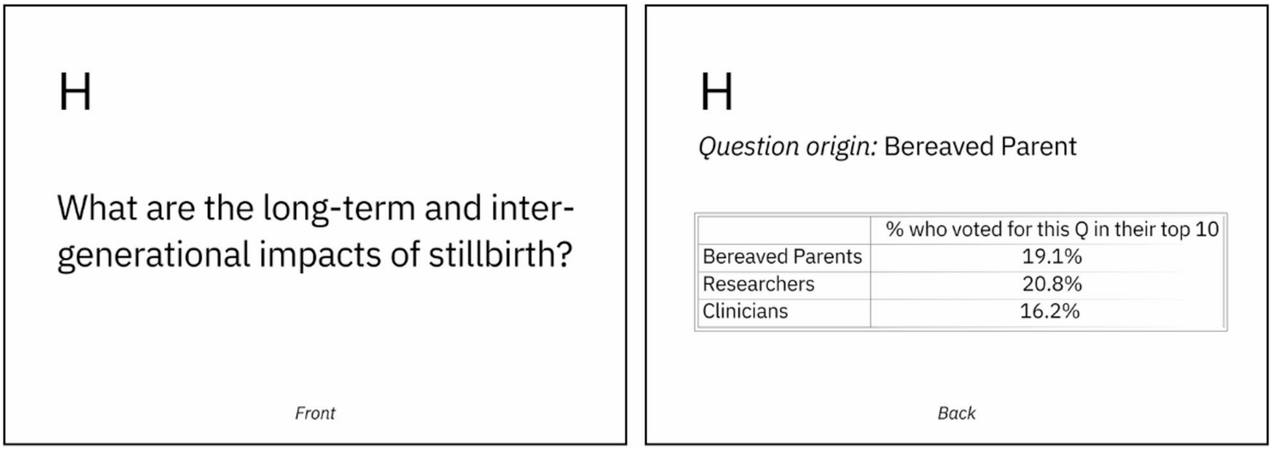
The interim list of research questions was disseminated in a Qualtrics survey between 24 October and 15 November 2023. The survey involved branching logic to facilitate list reduction, including three steps: 1). Select all questions (minimum ten) that were considered as a high priority 2). Select the top ten questions from step 1 3). Rank the final list of questions from 1 (highest priority) to 10 (lowest). The order of questions was randomised to account for selection bias. Anyone who met the inclusion criteria was eligible to complete the prioritisation survey, regardless of previous involvement during consultations. Rankings were transposed i.e. 1 = 10 and 10 = 1, to determine an aggregate score for each question. The number of total votes, average ranking and % of votes received per stakeholder group was also tabulated. These data were interpreted by the project team and cross-checked by members of the steering committee to determine a shortlist of maximum 30 priority questions [20] that were considered representative of all stakeholder views.

Prioritisation forum

On 4 December 2023, representatives [see Additional file 2] convened for an in-person forum over 6 h to determine the final research priorities. All stakeholder groups were represented, and representatives were nominated by their affiliated organisation. The forum involved two rounds of small group discussions and concluded with whole group review. In the first round, shortlisted questions were ordered from highest to lowest priority and data from the three groups were sorted by median ranking and shared with the group immediately. During subsequent reviews, participants considered the research questions in the context of this new order. To facilitate discussions, research questions with supporting information (question origin and proportion of respondents per stakeholder group who ranked the question in their top 10) were displayed on A4 cards for interactivity (Fig. 2).

Results

The outcomes of all stages (numbers of participants and research questions) are presented in Fig. 1.



H

What are the long-term and inter-generational impacts of stillbirth?

Front

H

Question origin: Bereaved Parent

	% who voted for this Q in their top 10
Bereaved Parents	19.1%
Researchers	20.8%
Clinicians	16.2%

Back

Fig. 2 Example of question cards used at the prioritisation forum. The front of the card contained the question, and the back had supporting information including which stakeholder group (bereaved parents, researchers, healthcare professionals) the question originated from during consultations and the proportion of representatives from each group that voted for that question as a priority in the prioritisation survey. Each question was assigned a letter for easy reference. A set of cards were provided to each breakout group to visually rearrange on the table and annotate

Consultation

Forty-six attendees participated in the initial workshop, with many participants representing the views of more than one group; 60% of bereaved parents (*n* = 10) also attended in a researcher or healthcare professional capacity [see Additional file 2]. Eighteen potential research questions were proposed, building on the previous 2015 research questions. There were 67 responses to the initial survey (Table 1), with 27% identifying as bereaved parents or members of parent support organisations (*n* = 18), 48% as healthcare professionals (*n* = 32) and 40% as researchers (*n* = 27). Respondents were mostly female (87%; *n* = 58), and from Eastern Australian jurisdictions (79%; *n* = 53). Most proposed research questions were ranked highly out of 9 (median 6.97; IQR 6.10–7.47). There was some dichotomy of responses between different stakeholder groups. Bereaved parents ranked questions as 'important and urgent' more frequently and scored 'novel intervention' questions very highly. Healthcare professionals and researchers attributed higher value to 'implementation' and 'investigation' based questions. Participant feedback at these initial stages stated that a broader diversity of people should be consulted.

Table 1 Demographics of survey respondents

	2020 initial survey (*n* = 67)	**2023 prioritisation survey (*n* = 219)**
Background *(select all that apply*)*	***n* (%)**	
Bereaved Parent	18 (27)	105 (48)
Researcher	27 (40)	48 (22)
Healthcare Professional	32 (48)	99 (45)
Policy Maker	2 (3)	11 (5)
Gender		
Female	58 (87)	196 (89)
Male	9 (13)	21 (10)
Prefer not to say	-	2 (1)
Jurisdiction		
ACT	2 (3)	7 (3)
NSW	9 (13)	60 (27)
NT	2 (3)	5 (2)
QLD	26 (39)	61 (28)
SA	6 (9)	20 (9)
TAS	0	1 (0.5)
VIC	16 (24)	47 (22)
WA	6 (9)	18 (8)
Aboriginal and Torres Strait Islander		
Yes	7 (10)	5 (2)
No	60 (90)	214 (98)
Research experience	*not collected*	
This is the first time	-	94 (43)
Less than a year	-	27 (12)
1–5 years	-	57 (26)
5–10 years	-	20 (9)
10 + years	-	21 (10)

*% do not add up to 100 as this was a select all that apply option, with many participants representing multiple stakeholder groups

Thirty-three participants attended the Aboriginal and Torres Strait Islander priority workshops, and six key research questions were identified as priorities. The bicultural workshops had a total of 15 participants, and 10 relevant research questions were identified. Twenty-nine bereaved parents (24 mothers and 5 fathers) attended bereaved parent workshops. A total of 72 research questions were proposed at these workshops, ranging from discovery science topics to bereavement care, extending into subsequent pregnancies and the long-term impacts of stillbirth. Participants commented that the bereaved parent workshops were comprehensive, their perspectives felt truly heard, and they were honoured to contribute to this research priority setting. Forty-four participants attended the key stakeholder workshop and a further 15 provided feedback on the preliminary list via the online consultation form, to propose a further 47 research questions.

Following all consultations, the preliminary list comprised 152 research questions [see Additional file 3 for a list of all priority research questions proposed] and another 16 research questions specific to Aboriginal and Torres Strait Islander families and families of migrant and refugee background, which were deliberated independently.

Refinement

Four definitively answered questions and 12 considered out of scope (mostly policy-based questions i.e. not research) were removed. Twenty-six duplicate questions were merged or removed, resulting in an interim list of 110 research questions which progressed to prioritisation [see Additional file 3 for further detail].

Following review and endorsement by the appropriate advisory groups, questions specific to Aboriginal and Torres Strait Islander and migrant and refugee communities were refined to five and eight priority questions, respectively. Questions regarding optimal co-design approaches for prevention messaging were removed, given the extensive recent research and co-designed 'Stronger Bubba Born' [13] and 'Growing a Healthy Baby' [14] resources with communities. Another question regarding barriers to the uptake of stillbirth prevention messages amongst migrant and refugee communities was removed as many of the challenges encountered by these groups were thoroughly explored during their specific consultations. The listed questions were not ordered by priority, but the Stillbirth CRE Indigenous Advisory Group highlighted that questions regarding optimal models of care and Birthing on Country were of the utmost importance and should be addressed as matters of highest priority.

Prioritisation

The prioritisation survey was completed by 219 participants (Table 1). Incomplete (*n* = 181) and ineligible responses (*n* = 18; did not reside in Australia) were excluded. Nearly half of participants (48%) identified as bereaved family members (*n* = 105), 45% as healthcare professionals (*n* = 99) and 22% as researchers (*n* = 48), with substantial overlap across groups. All health jurisdictions across Australia were represented, with most respondents identifying as female (89%; *n* = 196). Most had limited prior involvement with research (55% <1 year) and 10% had more than 10 years' experience. Respondents selected an average 35 out of the 110 questions in the first step of list reduction. Sixteen of the highest scored questions overall were shortlisted. Despite substantial overlap in the top 10 priorities selected by different stakeholder groups, there were still differences between the groups. Any questions present in a particular group's top 10 were also shortlisted. Finally, four questions that received high average rankings but weren't scored in these 'top 10s' were also shortlisted. Twenty-six interim questions were shortlisted [see Additional file 3]. Twenty-six stakeholders attended the final prioritisation forum to review this shortlist [see Additional file 2 for stakeholder details]. Consensus and ranking of 12 priority research questions was achieved. Half of the questions [6] that were ultimately prioritised were ranked in the top 10 of the prioritisation survey.

Six overarching priority areas were identified by the project team to group the priority questions (Table 2) including (in no specific order) 1). Determine the causes of, and pathways that lead to stillbirth, 2). Identify and implement strategies to prevent stillbirth, 3). Build the capacity of health services and systems to safely reduce stillbirth rates, 4). Understand and improve care for families after perinatal loss, 5). Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families to safely reduce stillbirth rates and improve care after perinatal loss and 6). Ensure culturally safe and responsive care for families of migrant and refugee background to safely reduce stillbirth rates and improve care after perinatal loss.

Discussion

The six priority areas and specific research questions identified during this priority setting (Table 2) represent the combined perspectives of bereaved parents, researchers, healthcare professionals and relevant stakeholders involved in decision-making regarding stillbirth research and implementation. These priorities were considered the areas of highest national urgency to reduce the stillbirth burden across Australia. The research questions underpinning these topics remain unanswered by existing research and reflect critical gaps in our current knowledge of stillbirth and highlight the need to invest further resources into promptly and effectively answer these questions.

When comparing the outcomes with previous research priority settings in both Australia and the United Kingdom [10, 28], we found that many of the gaps identified in stillbirth research nearly a decade ago remain pertinent today. These include understanding the root causes of stillbirth; the effective monitoring of fetal growth to reduce stillbirth; the discovery and implementation of relevant biomarkers; optimal approaches to fetal movement assessment; placental investigations and mortality audits; accessing equitable antenatal care; delivering appropriate bereavement care and supporting families through subsequent pregnancies; and delivering effective training and development to healthcare professionals. Some novel questions were established such as addressing the long-term and inter-generational impacts, and the social determinants of stillbirth. Additionally, research questions specific to priority populations are presented as independent categories here for the first time.

Previous stillbirth research priority settings have traditionally been determined by researchers and healthcare professionals in the field [8, 9]. In the first global exercise [8], research gaps were identified in the literature and graded against five criteria, using the Child Health and Nutrition Research Initiative method [29]. Bereaved parents were not explicitly included in this process. The second global exercise determined priorities via two open-ended questions at the end of a survey of bereaved parents, care providers and community members [9]. Findings from this survey were then collated with the previously identified priorities [8] without further consultation or iteration [9]. The 2015 Australian priority setting exercise [10] involved qualitative analysis of this global survey [9] and synthesising research questions for deliberation at an interdisciplinary priority setting symposium but no broader consultation was undertaken. This renewed priority setting is the most rigorous prioritisation exercise undertaken in Australia to identify stillbirth research priorities with all relevant stakeholders.

Stillbirth research priorities

Determine the causes of, and pathways that lead to stillbirth

This priority area includes three questions regarding unexplained stillbirth, shared pathways with preterm birth and the social determinants of stillbirth. In Australia, 15% of all stillbirths are unexplained and 4/5 stillbirths occur prior to 37 weeks' gestation [1]. Stillbirth disproportionately affects families living in the most disadvantaged areas of Australia, mothers aged under 20 or

Table 2 The six stillbirth research priority areas with specific research questions beneath

Determine the causes of, and pathways that lead to stillbirth
How can we better understand and prevent unexplained stillbirth?
What are the shared pathways leading to preterm birth and stillbirth?
What are the impacts of social determinants of health on the prevalence of stillbirth and neonatal death and how do we address them?
Identify and implement strategies to prevent stillbirth
How do we improve monitoring of fetal growth and wellbeing to reduce stillbirth without causing unnecessary interventions or undue harm?
What is the utility of screening, including the role of biomarkers, to predict and diagnose adverse pregnancy outcomes, including stillbirth?
What approaches to fetal movement assessment will improve the detection and care of women and gender-diverse people at increased risk of stillbirth?
Build the capacity of health services and systems to safely reduce stillbirth rates
How can we best implement a national standardised perinatal mortality audit program that informs policy and practice improvement or reduce perinatal loss?
Which elements of a continuity of pregnancy care model reduce the risk of stillbirth and other related adverse pregnancy outcomes?
Understand and improve care for families after perinatal loss
How do we embed processes, training, resources and healthcare capacity to ensure that optimal bereavement care is available to families when a baby dies and in subsequent pregnancies?
What are the long-term and inter-generational impacts of stillbirth?
What approaches to stillbirth investigation are most valuable and how is this information best communicated to families?
How do we address the psychosocial and mental health impacts of perinatal loss on all subsequent pregnancies?
Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families to safely reduce stillbirth rates and improve care after perinatal loss
Which elements of models of care (or models of care themselves) improve access to antenatal care and referral pathways to services and support after loss for Aboriginal and Torres Strait Islander mothers and families?
How can birthing on Country and other culturally appropriate models of care, including care after loss, be scaled up to support Aboriginal and Torres Strait Islander mothers and families?
What are the optimal approaches to reviewing stillbirths that reflect the diversity of Aboriginal and Torres Strait Islander cultures?
What are the educational or professional development needs of maternity healthcare providers to support conversations about stillbirth prevention with Aboriginal and Torres Strait Islander mothers and families?
What are the educational or professional development needs of maternity healthcare providers to support respectful conversations about autopsy with Aboriginal and Torres Strait Islander mothers and families?
Ensure culturally safe and responsive care for families of migrant and refugee background to safely reduce stillbirth rates and improve care after perinatal loss
How can we improve access to information to ensure women from migrant and refugee backgrounds and their babies remain healthy during pregnancy?
Are we providing understandable information about risk factors for migrant and refugee background women?
What are migrant and refugee background women's perceptions of stillbirth prevention strategies and what are the barriers to uptake of prevention messaging?
What systems changes are needed to enable health professionals to have effective conversations about stillbirth and stillbirth prevention with migrant and refugee women?
What models of care reduce the risk of stillbirth in migrant and refugee communities?
What models of care improve engagement with antenatal care among migrant and refugee women at higher risk of stillbirth due to psychosocial risk factors?
How can health professionals build greater understanding of cultural differences in grief response after stillbirth into approaches to the care of migrant and refugee families?
What is culturally safe best practice for bereavement care for migrant and refugee families, including extended family members and considering cultural practices regarding grief and loss?

born overseas and Aboriginal and Torres Strait Islander families [1]. Enhanced investigations and discovery science are required to prevent stillbirth and preterm birth. Addressing the impacts of social determinants of health will also have a significant effect on improving many adverse pregnancy outcomes.

Identify and implement strategies to prevent stillbirth

It became evident that further technological advances and clinical tools to improve pregnancy outcomes are urgently required. Fetal growth restriction and decreased fetal movements are strongly associated with stillbirth [30, 31], and often attributed to placental dysfunction. Current approaches to monitor, detect and predict placental dysfunction remain poor and early detection can inform care and identify pregnancies at risk. Potential biomarkers such as placental growth factor [32] and screening techniques such as estimated placental volume [33] have been identified although clinical significance needs to be determined. The three research questions specific to this priority area emphasise improving interventions without causing undue harm and informing best care and shared decision-making.

Build the capacity of health services and systems to safely reduce stillbirth rates

Substandard care contributes to up to 1/3 of perinatal deaths in Australia [34], with care fragmented across providers. Continuity of care and carer are recognised as important strategies with demonstrated reductions in stillbirth [35]. While there are existing guidelines for optimal audit and care in the event of stillbirth [15, 36], implementation and uptake of high-quality perinatal mortality audits and models of continuity of care are suboptimal. Given that evidence supports the effectiveness of these strategies, building the capacity of health services and systems to aid implementation and evaluation was determined a priority.

Understand and improve care for families after perinatal loss

Care following a stillbirth to improve immediate and ongoing wellbeing for the direct family and the wider community was consistently raised as a priority. There were many accounts, however, of substandard care, both historical and recent, shared in consultations with parents, providers and researchers. The highest priority questions included understanding the long-term and inter-generational impacts of stillbirth, addressing psychosocial and mental health impacts on subsequent pregnancies, optimal approaches to conducting and communicating stillbirth investigations, and ensuring that optimal bereavement care is accessible to all. During this exercise, comprehensive Care Around Stillbirth and Neonatal Death guidelines [15] were updated and endorsed by the NHMRC and are currently being implemented in maternity settings nationwide. New sections focused on perinatal palliative care, care in subsequent pregnancies and culturally responsive and safe care practices have been incorporated.

Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families to safely reduce stillbirth rates and improve care after perinatal loss

The stillbirth rate in Aboriginal and Torres Strait Islander families remains approximately double the non-Indigenous rate [1]. Providing culturally safe and responsive care to Aboriginal and Torres Strait Islander families during pregnancy and after 'Sorry Business Babies' is vital to improve outcomes. Priority setting workshops were conducted in parallel with comprehensive and Indigenous researcher-led consultations to understand experiences and perceptions of stillbirth [24]. Thematic analysis revealed priority areas including: "(a) Stillbirth or Sorry Business Baby care needs to be family-centred, (b) Using Indigenous "ways of knowing, being and doing" to ensure cultural safety, (c) Application of Birthing on Country principles to perinatal care, (d) Yarning approaches to improve communication, and (e) Learning and education through stories" [24]. The Stillbirth CRE Indigenous Advisory Group sense-checked that the developed research questions from this research priority setting aligned with these themes (Table 2). In conjunction, the themes identified in consultations with communities offer valuable insights into the way these priority questions can and should be addressed [24].

Ensure culturally safe and responsive care for families of migrant and refugee background to safely reduce stillbirth rates and improve care after perinatal loss

Families of migrant and refugee background in Australia are more likely to have poorer pregnancy outcomes and to be more often dissatisfied with their pregnancy care, compared to the general population [37–39]. Research priorities identified specific to families of migrant and refugee background highlight lack of access to comprehensible information about stillbirth prevention and awareness, as well as gaps in clinical care. Research on perinatal loss care to understand cultural differences in grief response [40] and how to equip healthcare professionals to provide best practice care when considering cultural practices is crucial. This priority setting and recent consultations with migrant and refugee communities spanned 12 language groups, including countries with the highest migration rates to Australia [41]. Given the breadth and diversity represented by migrant and refugee groups, it was not possible to capture all views, and these may differ depending on the country-of-origin, language, religion, and cultural practices. Further consultation is required to appropriately co-design future research and address inequities to make meaningful changes to experiences of perinatal loss in Australia.

Strengths

Modifying the methodology to a dialogue approach [19], which emphasises the importance of consulting stakeholder groups separately, fostered a safer space for stakeholders to contribute, feel heard and supported. Workshops for bereaved parents, Aboriginal and Torres Strait Islander, and bicultural workers were conducted to enable open discussions and iterative refinement of research priorities specific to these groups. There are large disparities in stillbirth rates and experiences of care amongst Aboriginal and Torres Strait Islander families, and families of migrant and refugee background in

Australia. We consulted appropriate advisory groups, so that the priorities for these respective communities would not be diluted amongst the larger list of research priorities. We also implemented strategies to enhance meaningful bereaved parent involvement [19, 25]. Bereaved parent workshops were co-designed and co-facilitated by members of the bereaved parent advisory group. A separate workshop was also conducted for bereaved fathers, who are traditionally underrepresented in stillbirth research [25]. The feedback provided from bereaved parents was highly positive, stating that independent consultations created a safe space for them to feel heard and validated. All stakeholder groups then came together in a shared decision-making process, ensuring that the views of any particular group were not diminished.

Due to the pandemic, we shifted to online workshops, which then enabled participation by stakeholders from rural and remote areas, who face considerable access issues and are known to experience higher rates of stillbirth [1]. However, there were advantages in bringing representatives together in person for the final prioritisation forum, with interactive, collaborative and thoughtful discussions key. We also consulted stakeholders who traditionally may not participate in stillbirth research, ranging from genetic counsellors to funeral directors, and representatives from other community-based groups such as those who have experienced birth trauma or early pregnancy loss.

Another lesson learnt from the initial approach in 2020 helped to inform adaptions in 2023. Results from the initial survey indicated that most research questions were considered 'important', although the data were not robust enough to draw conclusive inferences on which were the top priorities. The subsequent prioritisation survey provided greater understanding of the priorities of each stakeholder group.

Limitations

Given this priority-setting operated over a three-year period, we acknowledge that priorities may have changed over time. This was mitigated by conducting renewed consultations in 2023 independent of prior knowledge of the questions suggested in 2020. We also acknowledge that those disproportionately affected by stillbirth, such as mothers under the age of 20 and from diverse cultural and ethnic backgrounds were still underrepresented, so specific issues unique to these groups may not yet have been identified. This exercise was overrepresented by the east coast of Australia and considerations to reach other states and territories better in future should be made.

Implications and recommendations from this research priority setting

An important finding is to ensure that all stakeholders are included in the decision-making process from the outset of prioritisation, through to implementation. Having bereaved parents in an advisory capacity was extremely valuable and validated that prioritisation should be led by bereaved parents in future. This requires addressing power dynamics and embedding bereaved parents into planning and steering committees. Priority setting helped strengthen relationships for ongoing collaboration to address the identified priorities. Reinforcing these partnerships and dedicating efforts to increase engagement will maximise the quality and impact of research arising from this priority setting. By ensuring these priorities are reflective of the affected communities and the results are shared with the participants and made publicly available, representatives will be empowered to use these research priorities to advocate for change in future. The outcomes of this research priority setting will be made freely accessible to the public with a plain language summary, shared on social media, distributed via stakeholder mailing lists and published on relevant partner organisations websites.

It also became evident during refinement that several research questions proposed could be considered 'already answered' by preliminary data but are yet to be implemented into clinical practice. Similarly, other questions were considered policy- or advocacy-based issues and not necessarily 'researchable'. It was contentious whether these types of questions should progress throughout the prioritisation process, given that without implementation, these interventions cannot reduce stillbirth or improve care. The wording of such questions is reflected in the stage of research, for example, 'how can we best implement' or 'how can we embed' as opposed to questions at the discovery stage such as 'how can we better understand' to aid interpretation of the priorities.

Stillbirth prevention and care remain intractable challenges that require sustained effort. To ensure these research priorities can be adequately addressed and implemented effectively, we make the following recommendations. They reflect a collective perspective, informed by the authors in consultation with the steering committee and parent advisory group, and incorporating feedback and discussions from the prioritisation exercises.

Recommendations

1. *Resources and funding are allocated to implement these research priority areas,*
2. *A stillbirth research registry is established to reduce research wastage/duplication.*

3. *Bereaved family members and maternity consumer advocates are actively involved and supported in co-designed research,*
4. *Collaborations with community-based organisations are strengthened to enhance engagement with priority populations, and.*
5. *The impact of these priorities is evaluated over the next five years, to be renewed in 2028.*

Conclusion

The voices, knowledge and perspectives of bereaved parents, healthcare professionals, dedicated researchers, and relevant stakeholders were integral to informing these stillbirth research priorities. Given similarities with previous prioritisation exercises in the past decade, addressing these questions with the utmost priority is needed to make impactful differences in reducing the devastating burden of stillbirth in Australia. The impact of these priorities will be evaluated by achieving an 'increase in the number of research projects in, and amount of funding granted to the stillbirth priority research areas' [18]. These stillbirth research priorities can now be used by organisations to build research capacity and guide the allocation of national research funding and have already informed a funding call from Stillbirth Foundation Australia in 2024. A priority-driven national agenda with adequate resourcing has the potential to save many families and communities the heartbreak of stillbirth, reduce disparities in stillbirth rates, and ensure that optimal bereavement care is offered to every family.

Abbreviations

NSAIP	National Stillbirth and Implementation Plan
NHMRC	National Health and Medical Research Council
CRE	Centre of Research Excellence
SBB	Safer Baby Bundle
PSANZ	Perinatal Society of Australia and New Zealand
JLA	James Lind Alliance
REPRISE	Reporting guideline for PRIority Setting

Supplementary Information

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Additional file 1. REPRISE checklist.

Additional file 2. Stakeholder list consulted during priority-setting.

Additional file 3. List of all priority research questions proposed.

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Author contributions

VF conceived the study and oversaw its development and execution with KT, FB, CA1, CA2 and DE. All authors (KT, FB, CA1, CA2, JY, SM, BJ, SS, MDT, DSB, PM, DE, AG, VF) critically reviewed and advised on the study design and interpretations. FB, CA1, MDT, DSB, PM, DE, AG and VF organised and oversaw 2020 priority setting activities. KT organised priority setting activities described in 2023. KT and FB facilitated bereaved parent advisory group meetings. JY, SM, BJ and DSB facilitated the workshops. KT and CA2 performed the literature reviews. KT, FB, CA1, CA2 and VF analysed all data. KT drafted the initial manuscript and created all tables and figures, with critical input from VF. KT and CA1 completed the REPRISE checklist. All authors contributed to reviewing and revising the final priorities report and this manuscript and agreed on the final version.

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Data availability

All data generated or analysed during this study are included in this published article [and its supplementary information files].

Declarations

Ethics approval and consent to participate

Ethical approval for this study was obtained from the Mater Misericordiae Ltd Human Research Ethics Committee on the 3rd of June 2020 (HREC/MML/64164). The study meets the requirements of the Australian National Statement on Ethical Conduct in Human Research (2007) updated 2018 and adhered to the Declaration of Helsinki. All participants provided informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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