Submission to the Select Committee into Stillbirth in South Australia

Joint submission from the NHMRC Centre of Research Excellence in Stillbirth, Perinatal Society of Australia and New Zealand and Stillbirth Foundation Australia

Message from the Centre of Research Excellence in Stillbirth

In Australia over 2,000 families experience stillbirth annually and over 700 experience the loss of a baby in the newborn period. Further, an estimated 150,000 face early pregnancy loss or miscarriage. These tragedies have lasting impacts on parents, families, and healthcare professionals.

Australia has an important story to tell of strong bipartisan efforts over the last five years to reduce rates of stillbirth nationally. The 2023 *Global Stillbirth Advocacy and Implementation Guide*—co-authored by leading international organizations—recognized Australia's progress, including its distinction as the only country with a national stillbirth action plan.

The National Stillbirth Action and Implementation Plan (NSAIP), released in 2020, provides a strategic framework to reduce preventable stillbirths after 28 weeks' gestation, targeting a 20% reduction by 2025. Progress will be formally reviewed in 2025 and again in 2030[1,2].

The Select Committee into Stillbirth presents a critical opportunity for South Australia to take a leading role in reducing stillbirth rates and their profound impact nationwide.

This submission, prepared by the National Health and Medical Research Council Centre of Research Excellence in Stillbirth (Stillbirth CRE), in partnership with the Stillbirth Foundation Australia and the Perinatal Society of Australia and New Zealand (PSANZ), highlights key areas for reform. Our recommendations are based on detailed knowledge and expertise in research, policy, and maternity healthcare practice in Australia and internationally. The Stillbirth Foundation Australia and PSANZ have been integral to the work of the Stillbirth CRE, and this is reflected in this submission. Contributions include insights from over 220 bereaved parents and Stillbirth CRE staff with lived experience. Additional submissions will be provided by the Bereaved Parent Advocacy Committee (led by Kirstin Tindall) and the Migrant and Refugee Research Stream, led by Stillbirth CRE Chief Investigator Miranda Davies-Tuck.

We appreciate the opportunity to contribute to this inquiry and strongly urge the prioritisation of stillbirth research and education and to seek and support synergies with initiatives to reduce other adverse pregnancy outcomes. We welcome the chance to expand on our recommendations in future public hearings.

For further information, please contact us at stillbirthcre@mater.uq.edu.au.

Yours sincerely,

Professor Vicki Flenady **Professor David Ellwood**

Co-Directors, Centre of Research Excellence in Stillbirth (Stillbirth CRE)

Message from the Stillbirth Foundation Australia

Six babies are stillborn in Australia every day. And in South Australia more than 150 babies were stillborn in 2022.

Every stillbirth is a tragedy and Stillbirth Foundation Australia acknowledges its lasting impact on parents and their families.

Stillbirth Foundation Australia submits that much more needs to be done to save the lives of these babies who do not have a voice.

The Select Committee into Stillbirth in South Australia is in a privileged position to ensure that a family's heartbreak is replaced with hope. The Foundation urges the Committee to do so and will lend all its support.

The establishment of the Committee offers a real opportunity to drive positive change in South Australia and for the state to lead the nation in reducing the incidence and impact of stillbirth.

The Foundation is recognised nationally as a leading voice on stillbirth and represents the voices of thousands of Australian families who have been touched by stillbirth.

The Foundation strongly believes that research and education are key to saving more babies' lives. This joint submission with the Centre of Research Excellence in Stillbirth (Stillbirth CRE) will expand on this thesis, highlighting the current deficiencies in data collection, research, education, communication, and clinical care and will propose potential avenues for reform.

Stillbirth Foundation Australia and the Stillbirth CRE have a close and strong relationship. The Foundation has funded many innovative research projects by the Stillbirth CRE and partnered in the development of important resources for parents and healthcare professionals.

The Foundation thanks the Parliament of South Australia and the Committee for the opportunity to provide this submission and would welcome the opportunity to elaborate further in a public hearing.

This submission has been informed by the Foundation's experience, the input of bereaved parents, and the input of experts. As the Foundation has no vested interest in the provision of a service or a single research entity, we are uniquely positioned and have complete sector visibility and support the work done across the spectrum of stillbirth, from funding research into prevention, to time of loss support, and to post-loss initiatives. As such, the Foundation is the appropriately positioned entity to partner with on new initiatives.

For more information about the Foundation, visit stillbirthfoundation.org.au or contact the Foundation on 02 80607979.

Yours sincerely,

[redacted]

A/Professor Sean Seeho

Chair, Stillbirth Foundation Australia

Message from the Perinatal Society of Australia and New Zealand

The Perinatal Society of Australia and New Zealand (PSANZ) is a multidisciplinary society dedicated to improving the health and long-term outcomes of mothers and their babies. PSANZ encompasses and strongly encourages research focused on mothers and babies during pregnancy and at birth, as well as the health of the newborn as its development continues after birth.

The Perinatal Society of Australia and New Zealand (PSANZ) welcomes the establishment of the Select Committee into Stillbirth in South Australia and appreciates the opportunity to contribute to this crucial inquiry. Stillbirth remains a deeply distressing issue, with over 150 families in South Australia affected each year. The impact is profound, leaving lasting grief for parents, loved ones, and the broader community.

PSANZ has worked extensively with both the Centre of Research Excellence in Stillbirth (Stillbirth CRE) and Stillbirth Foundation Australia to improve awareness, research, and clinical practice to reduce the incidence of stillbirth. Through this joint submission, we seek to highlight opportunities for systemic improvements to strengthen efforts in stillbirth prevention and best practice care following a loss.

There is a critical need for greater investment in stillbirth research, education, and public health initiatives. Healthcare providers must be equipped with the latest evidence-based practices, and families should have access to clear, consistent information about stillbirth prevention.

The establishment of this Committee is a significant step forward in addressing these challenges. PSANZ is committed to collaborating with policymakers, researchers, and the community to drive meaningful change.

We appreciate the Committee's attention to this important issue and look forward to further engagement. PSANZ stands ready to provide expert insights and recommendations to assist in shaping a future where fewer families experience the tragedy of stillbirth.

Yours sincerely

A/Professor Miranda Davies-Tuck

President, Perinatal Society of Australia and New Zealand (PSANZ)

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Summary of Recommendations

The Centre of Research Excellence in Stillbirth (Stillbirth CRE), Perinatal Society of Australia and New Zealand (PSANZ) and Stillbirth Foundation Australia (SFA), support this important Inquiry with the following recommendations:

Recommendations about stillbirth prevention education and awareness programs (ToR [a] and ToR [b]):

- Implement an ongoing public awareness program on stillbirth across South Australia. This program must align with nationally agreed messaging in stillbirth prevention and stigma surrounding stillbirth and targeting social and cultural groups at greatest risk of stillbirth.

- Prioritise implementation of the Safer Baby Bundle program in all South Australian maternity services.

- Implement the 'Growing a Healthy Baby' and ‘Stronger Bubba Born’ resources across South Australia. This will ensure that all women receive best practice stillbirth prevention information that is both culturally and linguistically appropriate for Aboriginal and Torres Strait Islander, and migrant and refugee communities in South Australia.

- Partner with the Stillbirth CRE to expand and enhance the Safer Baby Bundle program according to current evidence and the changing needs of women and their health care providers including resources for additional language groups and communication needs including for young parents.

Recommendations about models of care in pregnancy (ToR [c]):

- Increase access to midwifery continuity of care across all maternity services, particularly for priority populations.

- Develop and implement strategies that enhance continuity of care as part of routine maternity care across all maternity services.

- Implement strategies to enable increased time for antenatal care episodes focusing on women at increased risk.

Recommendations for follow-on care (ToR [d]):

- Increase funding for home visits for parents following a stillbirth through services such as the Red Tree Foundation.

- Promote the Living with Loss program to further support families following stillbirth and support the enhancement of this program to address the needs of families experiencing any pregnancy loss.

- Actively participate in the Stillbirth CRE’s initiative to co-design and co-implementation of a National Perinatal Loss Care Pathway.

- Expand services for care in subsequent pregnancies after stillbirth; providing a multidisciplinary continuity of care model which begins at the time of the loss and involves midwives, registrars, sonographers, counsellors, and consultant obstetricians. Partner with the Stillbirth CRE in developing a national set of core principles and establishment of an ongoing mechanism for evaluation of these services.

Recommendations about support and training for healthcare professionals (ToR [e]):

The Stillbirth CRE plays a key role in education for healthcare professionals and maternity care services across Australia. Dedicated ongoing funding is needed to ensure this program of work continues and the high standard of this work is maintained. This funding would ensure ongoing support and education activities for South Australian maternity care providers. All maternal and newborn care services should establish and foster a commitment to delivering best practice care through the following key recommendations:

- Provide adequate support to enable healthcare professionals working in maternity services across South Australia to complete training in stillbirth prevention.
    - This training includes the Stillbirth CRE's online educational programs:
        - Safer Baby Bundle
        - Healthy Yarning Guide Yarning Guide (including Stronger Bubba Born resources)
        - Partnering with Families of Refugee and Migrant Backgrounds (including Growing a Healthy Baby resources)

- Roll out and evaluate the face-to-face Healthy Yarning Guide program to enhance culturally responsive maternity care for Indigenous women in South Australia in partnership with the Stillbirth CRE.

- Provide adequate support to enable healthcare professionals working in maternity and newborn services across South Australia to complete evidence-based training in best practice care following stillbirth. This should be undertaken through the Improving Perinatal Mortality Review and Outcomes Via Education workshops and eLearning program to complement and enhance the local South Australian Stillbirth Investigations and Bereavement Care online training program.

- All maternity and newborn services provide access to formal and peer support options for healthcare professionals who provide care around stillbirth (and all pregnancy and infant loss). Support to engage in peer networks for knowledge exchange should also be prioritised.

- South Australia actively engages in the co-design and co-implementation development and evaluation of the Stillbirth CRE's proposed National Perinatal Loss Care Pathway and centralised digital portal. This includes a major focus on optimising bereavement care for Indigenous women, those in remote areas, and some migrant and refugee communities, who bear a disproportionate burden of stillbirth. South Australia as a key partner in this project will help ensure equitable, high-quality care is provided to all families after loss, including subsequent pregnancies and beyond. High-level government support, early stakeholder engagement, and local strategies will be key to the Pathways success in standardising care across Australia

Recommendations about stillbirth investigations (ToR [f]):

- Implement the NHMRC Care Around Stillbirth and Neonatal Death Clinical Practice Guideline guidelines stillbirth investigations protocol and mechanisms for ongoing evaluation using the Stillbirth Clinical Standards.

- South Australia promotes and engages in the development and implementation of a national perinatal mortality audit program which enables timely reporting to effectively identify and mount clinical quality improvements to reduce stillbirths.

- The Improving Perinatal Mortality Review and Outcomes Via Education education program for health care professionals is made mandatory for all relevant health care professionals.

- Embed Royal Australian and New Zealand College of Radiologists training programs on imaging for stillbirths for radiologists and the Royal College of Pathologists of Australasia training programs on autopsy procedures for pathologists and adequate resources, including staffing, and appropriate referral pathways and reporting procedures.

- Stillbirth Clinical Standards key performance indicators to evaluate the quality of counselling for families on options for stillbirth investigations.

- Implement standardised protocols and referral pathways for Genomic autopsy that enable equitable access to all eligible families following stillbirth.

- Large prospective cohort studies are needed to evaluate the use and value of recommended stillbirth investigations according to clinical circumstances to enhance informed decision-making and appropriate service provision.

Recommendations about data collection, reporting and monitoring (ToR [g]):

- Implement a standardised national electronic reporting system to collect 'real-time' (and easily accessible) data on all births, including standardised definition of stillbirth and neonatal deaths.

- Ensure timely reporting on perinatal deaths nationally including Indigenous and other high-risk groups, to enable the impact of programs and policies to be monitored for effectiveness.

- Implement perinatal mortality audit programs across all maternity services where births occur following procedures outlined in the CASaND guideline, including timely reporting to jurisdictional health departments and AIHW for national reporting through an on-line reporting system.

- Ensure timely reporting on perinatal deaths nationally including Indigenous and other high-risk groups, to enable the impact of programs and policies to be monitored for effectiveness.

- Provide appropriate support and expertise to enable parents to be engaged in perinatal mortality audit thus ensuring all important information is captured and parents are counselled about the findings.

- South Australia establishes a statewide quality assurance body for maternity care.

Recommendations about allocation of research effort (ToR [h]):

- Use outcomes of the national stillbirth research priority setting to inform allocation of research funding and efforts in South Australia across the six priority areas:
    - Determine the causes of and pathways that lead to stillbirth
    - Identify and implement strategies to prevent stillbirth
    - Build the capacity of health services and systems
    - Understand and improve care for families after perinatal loss
    - Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families

- Ensure culturally safe and responsive care for migrant and refugee communities.

- Engage parents with lived experience in stillbirth research through the Stillbirth CRE's national register.

- Implement effective approaches for accessing routinely collected clinical data for the purposes of research and quality improvement.

- Contribute to national stillbirth research register to promote collaboration in the effective conduct of high quality research to reduce stillbirth and associated outcomes and improve care for families who experience perinatal loss.

Other recommendations (ToR [i]):

- To optimise outcome for families in Australia, continued efforts are needed to ensure a cohesive approach to national initiatives including those addressing stillbirth, preterm birth and early pregnancy loss.

- Further funding to continue the work of the Stillbirth CRE is critically important to effectively address the National Stillbirth Action and Implementation Plan.

Background

On Thursday 31 October 2024, The House of Assembly passed a motion to establish a Select Committee into Stillbirth in South Australia with the following Terms of Reference:

a) best practice stillbirth prevention education and awareness programs for expectant parents; including, but not exclusive to, the monitoring of babies in utero
b) public education programs/initiatives to increase community awareness of stillbirth and where people can access support in the community
c) models of care in pregnancy that may contribute to a reduction in stillbirth (including for priority populations)
d) models for follow-on care (including mental health support or care in subsequent pregnancies) for parents after stillbirth (and infant loss more generally)
e) support and training for healthcare professionals relating to stillbirth prevention and bereavement care
f) best practice regarding stillbirth investigations (including access, information for parents and case review), pathologist training and service provision
g) processes of data collection, reporting and monitoring
h) allocation of research effort
i) any other related matters.

Our submission is written in response to the Inquiry Terms of Reference.

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) – the nation's first dedicated stillbirth research centre – welcomes this Inquiry as an indication of the seriousness with which stillbirth is being treated and is grateful for the opportunity to provide a submission. Stillbirth has a profound rippling effect across communities that has lasting significant social, emotional, and economic impacts. As a National Health and Medical Research Council (NHMRC) funded initiative, the Stillbirth CRE has a priority driven national program aimed at stillbirth prevention and care after stillbirth. Importantly, parents are at the core of what we do. The Stillbirth Foundation Australia has been integral to the Stillbirth CRE, and continues to enhance engagement of families with lived experience of stillbirth to ensure relevance and quality of this national program.

Stillbirth in Australia

In Australia, over 2,000 families experience the death of a baby to stillbirth each year. In 2022, the national stillbirth rate was 7.9 per 1,000 births[2] with South Australia reporting a similar rate of more than 7 in every 1,000 babies born annually[6]. Further over 700 babies die in the newborn period and 150,000 experience early pregnancy loss in Australia. With shared causal pathways and needs of families with lived experience, efforts to address stillbirth must integrate the full spectrum of perinatal loss.

While there has been some progress in reducing late gestation stillbirths (28 weeks' gestation or more), these improvements have been slow[2]. More concerningly, no significant advances have been made in reducing stillbirths in the preterm period, where the majority of these tragedies occur[3]. Given that most stillbirths occur before 28 weeks' gestation, prioritising efforts to address the preterm period is essential to reducing Australia's overall stillbirth rate and ensuring equitable outcomes for all families.

Significantly, Australia's stillbirth rate beyond 28 weeks' gestation is 19.5% higher than that of the best-performing countries globally, highlighting that ongoing work in stillbirth prevention is still required[4]. Significant disparities in stillbirth rates persist. Stillbirth and other adverse pregnancy outcomes disproportionately affect Aboriginal and/or Torres Strait

Islander women, women living in remote settings, and women of migrant and refugee background, particularly those from countries in South Asia and Africa and young women.

In South Australia, inadequate access to antenatal care is the most significant risk factor for stillbirth[9]. Other risk factors associated with stillbirth in the state include aspects of employment and marital status; maternal age less than 19 years or more than 40 years; and smoking[9].

Stillbirths are NOT inevitable. Research led by the Stillbirth CRE collaborators, alongside national[10] and jurisdictional data[5,6 7 8 9 10 11 12 13] demonstrates that many stillbirths are preventable with improvements in routine pregnancy care, particularly beyond 28 weeks of pregnancy, where survival for babies born alive approaches 100%[14 15]. This highlights the importance of high quality perinatal mortality audit for every stillbirth in Australia for preventing further deaths.

A significant proportion of stillbirths remain unexplained. Unexplained deaths leave parents grappling with why their baby died and reduce the capacity for prevention of the population level. In 2018, 'unexplained antepartum death' was the second most common category of preterm stillbirth (14.2%) in Australia, with its prevalence increasing with gestational age[3]. Among term stillbirths (beyond 36 weeks), 28% were classified as unexplained, making it the most frequently reported cause of death category[2]. The high proportion of unexplained stillbirths is in part due to inadequate diagnostic investigations, with less than half of all stillbirths having an autopsy or acceptable alternatives.

Further, research is urgently needed to understand the causal pathways in unexplained stillbirths including those in the preterm period, and to develop strategies to reduce these deaths. Parents who have experienced the loss of a child through stillbirth want answers. Finding the cause(s) of death was the top priority in the 2023 national stillbirth research priority setting initiative conducted by the Stillbirth CRE[16]. One bereaved parent, whose daughter's death remains unexplained, expressed the heartbreaking reality:

"Babies don't just die… but for us they do".

Beyond understanding causes, bereaved parents also emphasised the need for improved monitoring and screening to predict and prevent stillbirth, greater capacity within the health system to implement preventative initiatives, and better care for families following perinatal loss.

Care for women and families after stillbirth is often inadequate[17]. Stillbirth has an enormous psychological and social impact on mothers, fathers, families and society[18]. An estimated 60–70% of women who experience a stillbirth will experience clinically significant grief-related depressive symptoms one year after their baby's death. For about half of these women, symptoms will endure for at least four years after the loss[19 20]. These impacts can extend beyond parents, and perinatal loss can also have a profound impact on other family members, including grandparents[21 22]. Many healthcare professionals report feeling unprepared to support grieving families, particularly in providing culturally appropriate care. They often lack the specific skills and training needed to navigate these sensitive situations and may also carry their own emotional and professional burden following a stillbirth[23,24].

Australia's national approach to stillbirth prevention and bereavement care

The Australian government is committed to stillbirth prevention and bereavement care, with significant investment in research and national initiatives. A key milestone in this effort was the *National Stillbirth Action and Implementation Plan (NSAIP)*, developed in collaboration with healthcare professionals, bereaved parents, policy makers and health departments[1].

This plan provides a comprehensive blueprint for reducing stillbirth rates across Australia and optimising care for bereaved families experiencing the death of baby. Its scheduled revision in 2025 (and again in 2030) presents an important opportunity for South Australia to contribute jurisdictional-specific priorities to improve stillbirth research, prevention and care after loss.

The NSAIP serves as a roadmap for states and territories to guide their own stillbirth prevention strategies. Recognising the importance of research in driving change, since 2016, the Australian Government has invested $20.5M in the Stillbirth CRE to support its foundational work in critical stillbirth prevention initiatives and best practice care for those who experience a perinatal loss. This funding has enabled the development and implementation of key programs including the Improving Perinatal Mortality Review and Outcomes via Education (IMPROVE) to improve investigation of stillbirth and the Safer Baby Bundle to decrease the gap between what is *known* and what is *done* in maternity care to prevent late gestation stillbirths. Funding has also enabled the Stillbirth CRE to develop associated co-designed women-facing resources, culturally appropriate resources, and public awareness campaigns. These resources are briefly described in **Appendix 1**.

Terms of Reference response

Stillbirth prevention, education, and awareness programs

(a) Best practice stillbirth prevention education and awareness programs for expectant parents; including, but not exclusive to, the monitoring of babies in utero

(b) Public education programs/initiatives to increase community awareness of stillbirth and where people can access support in the community

CHALLENGES AND GAPS

Raising public awareness to dispel general misinformation and misconceptions about stillbirth is crucial to improving care for parents and families who have a stillborn baby. Efforts to overcome the stigma and silence associated with stillbirth can also help to mobilise action in stillbirth prevention. The 'Reduce the Risks of Cot Death' campaign resulted in a large reduction of SIDS and we work assiduously to ensure that public education and awareness campaigns will similarly reduce stillbirth rates[25]. Lack of sustained funding and resources is a barrier to ongoing education and awareness programs of stillbirth. Consumers have identified an urgent need to address evidence gaps in help-seeking during pregnancy, informed by the needs, views, and values of priority populations in Australia. As an example, driven by social and structural disadvantage, young pregnant women experience higher rates of perinatal deaths, domestic violence, smoking, and lack of social support[26]. Young parents may also experience greater barriers to help-seeking due to stigma and social isolation. Indigenous and young parents may experience significant barriers to accessing help and receiving continuity of care, despite being at higher risk of adverse pregnancy outcomes. Key concerns when help-seeking among these groups include fear/distrust in the health system, health literacy challenges, administration delays, inflexible and non-individualised care, and/or lack of provision of culturally safe and responsive care.

> *"The education and messages seem to only be heard in the echo chamber of loss, not out in the general population and this is the problem"*
>
> ***Bereaved mum (attended research priority setting workshop, 2023)***

OPPORTUNITIES AND RECOMMENDATIONS

The Australian Government has recognised that national stillbirth public awareness campaigns can be effective in promoting public awareness of stillbirth. Several campaigns promoting the Stillbirth CRE's Safer Baby Bundle messaging have shown to be highly effective in increasing knowledge and changing behaviour. This demonstrates that a national campaign using primarily digital media and earned media (e.g. media coverage) can increase awareness of three modifiable behaviours to reduce the risk of stillbirth: being aware of fetal movements, quitting smoking, and side-sleeping in late pregnancy. The national *Still Six Lives* campaign, run from February to November 2021, promoted these messages and was highly successful in increasing the community's knowledge of stillbirth prevention messaging[27].

In December 2022, Preventative Health SA (previously known as Wellbeing SA) partnered with the Stillbirth CRE to lead a 4-week digital stillbirth prevention campaign to increase awareness of these practices, targeting healthcare professionals and South Australian

women aged 18–44 years. Evaluation showed a strong level of knowledge and awareness around the three actions within the community surveyed. These findings are suggestive of the lasting impact from the original *Still Six Lives* campaign, and of the strong positive influence of the aligning Safer Baby Bundle's national implementation into routine antenatal care. Continued and consistent messaging around preventative actions to reduce the risk of stillbirth is vital to ensure the sustained high level of knowledge and awareness continues within the community.

To encourage message sustainability, SA has implemented the following initiatives:

- all Local Hospital Networks (LHNs) have been sent co-badged social media tiles for local use
- the recent Preterm Birth Prevention Project created additional resources, including posters with QR codes that directly link to Safer Baby Bundle resources
- all LHNs were asked to undertake a gap analysis against the ACSQHC Stillbirth Clinical Care Standard, which includes preventative measures for stillbirth and references the Safer Baby Bundle elements.

Additional culturally appropriate messaging is needed. The Stillbirth CRE has created culturally safe adaptations of the Safer Baby Bundle resources and messaging for Aboriginal and Torres Islander (*Stronger Bubba Born*), as well as priority migrant and refugee communities (*Growing a Healthy Baby*). This includes word-for-word translation of Safer Baby information into 30 languages, and work continues to build on this list based on feedback from the target language communities and/or healthcare services. The adapted Safer Baby Bundle provides guidance on how women and families from refugee and migrant backgrounds or Aboriginal and Torres Strait islander communities can have conversations about stillbirth prevention during pregnancy. The Stillbirth CRE has been working with the SA Health Maternal, Neonatal and Gynaecology Strategic Executive Leadership Committee to disseminate and implement culturally adapted resources in SA. In November 2023, the initial suite of the Stillbirth CRE's culturally adapted resources and implementation kit (*Healthy Yarning Guide*, eLearning for working with healthcare professionals working with migrant and refugee communities, *Stronger Bubba Born*, *Growing a Healthy Baby,* all available at https://learn.stillbirthcre.org.au/) were shared with:

- All SA Health LHNs
- SA Health Communications Team
- General Practitioners providing GP Obstetric Shared Care
- Aboriginal Health Council of SA (AHCSA), for distribution to Aboriginal Community Controlled Health Organisations
- Australian Migrant Resource Centre in SA, for distribution to their community managers.

Consultation with Aboriginal and Torres Strait Islander, as well as women from migrant and refugee backgrounds, identified the need for comprehensive, culturally relevant information on stillbirth prevention, along with miscarriage support and post-loss care. Preliminary evaluation shows overwhelmingly that women found the adapted Safer Baby Bundle resources easy to read, informative, culturally respectful and accessible.

> *"The resource is very helpful, covering a lot of important topics for pregnant women. It provided me with valuable insights, especially regarding stillbirth prevention."*
>
> ***Community member/parent 2024***

South Australia needs a cohesive, ongoing public awareness program for stillbirth that includes promotion of a national consensus on mechanisms to reduce stillbirth stigma, targeted at the communities at greatest risk of stillbirth. The Stillbirth CRE supports investment for sustained engagement with Aboriginal and Torres Strait Islander communities and services, and representatives of other priority populations, such as migrant and refugee communities. This will require identifying and facilitating community-led solutions, and tailoring public education campaigns to the specific needs of these groups.

In consultation with support organisation Brave Foundation, young parents have identified persistent and unmet needs for help-seeking during pregnancy. These include a lack of interventions aligned with young parents' lived experiences, values, and preferences. The Stillbirth CRE is currently seeking funding to address these gaps. In partnership with the Brave Foundation, the Stillbirth CRE plans to adapt stillbirth prevention resources and education programs for young parents and develop recommendations for health systems enhancements to reduce help-seeking barriers for young parents.

The above initiatives coincide with improving education for clinicians, including implementing a national best-practice, culturally appropriate education kit that equips current and future healthcare professionals to provide best practice, and support and training for healthcare professionals (refer to ToR [e]).

Recommendations about stillbirth prevention education and awareness programs:

- Implement an ongoing public awareness program on stillbirth across South Australia. This program must align with nationally agreed messaging in stillbirth prevention and stigma surrounding stillbirth and targeting social and cultural groups at greatest risk of stillbirth.

- Prioritise implementation of the Safer Baby Bundle program in all South Australian maternity services.

- Implement the 'Growing a Healthy Baby' and 'Stronger Bubba Born' resources across South Australia. This will ensure that all women receive best practice stillbirth prevention information that is both culturally and linguistically appropriate for Aboriginal and Torres Strait Islander, and migrant and refugee communities in South Australia.

- Partner with the Stillbirth CRE to expand and enhance the Safer Baby Bundle program according to current evidence and the changing needs of women and their health care providers including resources for additional language groups and communication needs including for young parents.

(c) Models of care in pregnancy that may contribute to a reduction in stillbirth (including for priority populations)

CHALLENGES AND GAPS

Maternity care provided by lots of different people with no continuity (known as fragmented care) and problems with adequate and effective communication with women (including those who speak a language other than English) are commonly reported contributors to lower quality care and poor outcomes (including stillbirth)[5]. Reducing fragmented care is particularly important for women and may reduce stillbirth and other poor outcomes[1.] Furthermore, midwifery continuity of carer – with midwives providing individualised, trauma informed and culturally responsive care – is known to be of additional benefit for women at higher risk of stillbirth, such as young mothers[28] and women from disadvantaged groups[29].

In South Australia, 36.8% of maternity care services provide some form of continuity of carer (care from a small group of health providers who the woman gets to know) across the entire pregnancy continuum (antenatal, intrapartum, and postnatal care). Although this is higher than the national average (29%) and on par with Queensland (38%) and the ACT (36%)[30], more work needs to be done to increase the provision of continuity of carer models[31].

Several existing models of care in South Australia address the social needs of women, as well as their health needs. For Aboriginal and Torres Strait Islander women and families, an integral component is care from Aboriginal and Torres Strait Islander health care providers, as embraced in SA's Ngangkita Ngartu (Aboriginal Family Birthing Program)[32].

Care of migrant and refugee families is another priority area. Many women accessing care in South Australia are born overseas, yet specific models of care for these women are limited, as is accessible information about how to access maternity care in Australia. Women from some migrant and refugee communities, including north, central and west Africa and central Asia, have considerably higher rates of stillbirth[33]. These groups are also less likely to engage in pregnancy care in the first trimester and less likely to attend the recommended number of antenatal appointments[34]. Migrant and refugee families experience a number of barriers to accessing and engaging in pregnancy care, including challenges with communication, social and/or geographic isolation, mistrust, lack of culturally appropriate care and resources, poor access to interpreters and experiences of racism and discrimination. Our most recent stillbirth prioritisation activity[35] that included representatives from Punjabi, Hindi, Marathi, Arabic, Syrian, Assyrian Chaldean, Dari, Farsi, Karen, Burmese and Vietnamese communities prioritised identifying care models and system changes to improve healthcare engagement, communication, access to pregnancy information and uptake of prevention strategies for migrant and refugee communities. A number of cultural models of antenatal care have improved communication and satisfaction, but their cost–effectiveness and impact on stillbirth rates have not been comprehensively shown[36]. Models of care that embed digital solutions may also support health care communication and engagement for migrant and refugee women. Given the multiple barriers to pregnancy care engagement for migrant and refugee women, multifactorial solutions to models of care are needed.

OPPORTUNITIES AND RECOMMENDATIONS

Models of maternity care that provide greater continuity of care and carer and thereby reduce the risk of fragmentation of care should be provided, and where possible prioritised for priority populations[37]. This aligns with the World Health Organisation Pregnancy Care Guidelines that recommend all women have access to midwifery continuity of care throughout the childbirth continuum[38]. As outlined in the NSAIP, effective models of care in pregnancy have a focus on the individual woman's needs and preferences, collaboration and continuity of care[1]. The Stillbirth CRE has developed a position statement on the advantages of continuity of carer as an integral part of stillbirth prevention[37].

Not all health services have capacity to provide continuity of care consistently, and there are challenges involved in redesigning services to provide continuity to all women[36]. When designing midwifery continuity of care models for women with greater complexities, it is essential to integrate access, advocacy, and time to help women establish trusting relationships and lower their anxiety levels[39]. Midwifery continuity of care models also need good consultation and referral system if complications arise so that they can seamlessly access medical and other types of care.

Other approaches that provide continuity should be supported. Such approaches include addressing the principles of continuity of care and carer, effective information-sharing and

care coordination, and ensuring a woman-centred approach to decision-making[37]. Other strategies include the provision for growth of private practice midwifery and rural and remote models of care that operate outside of major South Australian health departments.

Model of care data elements are included in the National Perinatal Data Collection (NPDC). Linking data from the NPDC with the Model of Care National Best Practice Data Set will help identify the number and characteristics of women using different models of care and outcomes for themselves and their babies — including adverse pregnancy outcomes such as stillbirth.

Lastly, increasing the time available for antenatal care events is an important strategy to help improve outcomes for women and families. Currently in South Australia, the number of screening tests and activities needed to provide a high level of care is consistently rising, but this is not reflected in the time available for appointments through the activity-based funding model.

> *"Too often, I hear stories from bereaved parents who may have had a better outcome if someone just listened to their concerns and knew their story i.e. continuity of carer. One parent I spoke with was left with zero answers and yet advocated for a new hospital policy to improve communication between care providers and ensure mother's voices are heard. The onus should not be on the parent to make change in individual services, yet by hearing their collective experiences, we could resource and implement state-wide policies to improve models of care."*
>
> ***Bereaved parent (consumer) engagement officer, Stillbirth CRE***

Recommendations about models of care in pregnancy:

- Increase access to midwifery continuity of care across all maternity services, particularly for priority populations.
- Develop and implement strategies that enhance continuity of care as part of routine maternity care across all maternity services.
- Implement strategies to enable increased time for antenatal care episodes focusing on women at increased risk.

(d) Models for follow-on care (including mental health support or care in subsequent pregnancies) for parents after stillbirth (and infant loss more generally)

CHALLENGES AND GAPS

Follow-on care after stillbirth: The impact of stillbirth extends well beyond the acute phase of grief. Parents require immediate support in the initial stage of their grief, and pathways to ongoing support in their community once they have left hospital. However, parents often report inadequate support. Lack of follow-up support is likely to compound parents' grief and contribute to ongoing feelings of isolation and loneliness.

Communication between hospital- and community-based healthcare professionals is an important part of continuity of care, which ought to be streamlined and standardised. Follow-up with bereaved parents provides healthcare professionals an opportunity to ask parents about their social and emotional wellbeing and connect them with additional support services and community resources if needed[40 41].

Care in a subsequent pregnancy begins at the time of stillbirth. Parents should be provided with information and support for future pregnancy planning and preconception at the postnatal consultation to inform plans to address modifiable risk factors (e.g. smoking), ensure further investigation into cause of death if required, and provide targeted support to parents such as genetic counselling[42]. Women who have experienced stillbirth are at risk of various adverse outcomes in a subsequent pregnancy, including up to a five-fold increased risk of stillbirth[42,43]. Parents also often face additional social and emotional challenges including heightened distress, increased risk of anxiety and depression, and delayed mother-infant attachment.

> *"I fell pregnant unexpectedly straight after loss.. I wasn't provided any mental health help through my obstetrician and had to find my own mental health help."*
>
> **Bereaved mum (attended research priority setting workshop, 2023)**

> *"Pregnancy after loss is a completely different pregnancy experience that needs specialised care and support. I think having trained staff that are very skilled at caring for bereaved parents is essential because it is such an awful experience."*
>
> ***Bereaved mum (2024)[3]***

OPPORTUNITIES AND RECOMMENDATIONS

The Stillbirth CRE works in partnership with key stakeholders to generate and synthesise evidence to improve the quality of maternity care and outcomes. Bereaved families require continuous, compassionate, and respectful perinatal bereavement care, beginning at the time they are told about the death of their baby. This support must extend through the transition from hospital to home and include accessible, ongoing services within the community. Additionally, tailored support should be available for families during subsequent pregnancies and beyond to ensure their long-term wellbeing. Support services for parents and families in rural areas are often limited or unavailable, with long wait times.

While not all bereaved parents will seek or require formal psychological support, it is essential that they have access to information about the various support options available, including professional services such as counsellors and psychologists specialising in perinatal loss. A significant gap identified by bereaved families is the transition from hospital to home and the availability of ongoing community support. Red Nose has developed, and recently expanded, a successful peer support program to help parents in the transition from hospital to home.

In 2022, Red Tree Foundation (an initiative of SIDS and Kids SA) received $800,000 from the SA Government to expand its grief counselling service over four years[44]. The Red Tree Foundation aims to reach newly bereaved families within 72 hours of referral, offering counselling and support through home visits, phone calls, telehealth, in-office, and off-site sessions. These services extend beyond parents to include grandparents, aunts, uncles, and friends. The demand for this service is evident. In 2023, Red Tree Foundation provided 2,099 counselling sessions, marking a 73% increase on sessions provided in 2020. Red Nose has developed a successful peer support program to help parents in the transition from hospital to home

Online and internet-based options can be a valuable alternative, offering easy access while ensuring anonymity and privacy for those who prefer it[41]. The Living with Loss online support program was developed and evaluated by the Stillbirth CRE to address this gap in bereavement support options. The program is online, flexible and available at any time to parents. It is currently being adapted for early pregnancy loss and subsequent pregnancies. The Living with Loss program should continue to be made available nation-wide. Further research to explore its local uptake and integration with existing support services within a stepped model of care, such as Red Tree, will contribute to efforts to increase the availability and accessibility to evidence-based support options in SA and better meet the needs of parents across the bereavement trajectory (access here https://carearoundloss.stillbirthcre.org.au/).

> *I like that it was self-paced and it was something I could do alone.*
>
> ***Bereaved father (Living with Loss evaluation, 2023)***

Internationally, the Rainbow Clinic Network across the United Kingdom provides structured care plans to meet women's clinical and counselling needs, including support for partners and extended family[45]. In 2018, a social return on investment analysis was conducted on the first Rainbow Clinic in Manchester to evaluate the effectiveness of this model of care in terms of social impact and health, wellbeing and social changes. For every pound invested in the Rainbow Clinic, £6.1 of value was derived for parents and staff. The Stillbirth CRE has established a national network of subsequent pregnancy clinics to drive improvements in care and outcomes. A social return on investment of the STAR Clinic in Melbourne, Victoria, is currently underway to determine the social value of providing care through a dedicated pregnancy after loss clinic in Australia.

Parents should be provided information and support about future pregnancy planning throughout their follow-up care. In Australia and internationally, specialist clinics dedicated to pregnancy after loss have been established. In SA, the Wattle Clinic at the Women's and Children's Hospital is led by midwives to support women in a subsequent pregnancy following a late pregnancy loss (second trimester)[46].

The Stillbirth CRE is developing a national approach to optimise perinatal bereavement care to standardise and connect care across the perinatal loss continuum including into subsequent pregnancies and beyond. This initiative will provide a centralised digital portal for clinical management care pathways and a comprehensive toolkit of resources to support implementation of care pathways including evidence-based education programs such as the SA Stillbirth Investigations and Bereavement Care and IMPROVE program. The overarching goal of this initiative is to operationalise best practice care recommendations outlined in the CASaND Guideline and to meet key performance indicators in the ACSQHC Stillbirth Clinical Care Standard which are based on the CASaND Guideline.

Recommendations for follow-on care

- Increase funding for home visits for parents following a stillbirth through services such as the Red Tree Foundation.
- Promote the Living with Loss program to further support families following stillbirth and support the enhancement of this program to address the needs of families experiencing any pregnancy loss.

- Actively participate in the Stillbirth CRE's initiative to co-design and co-implementation of a National Perinatal Loss Care Pathway.

- Expand services for care in subsequent pregnancies after stillbirth; providing a multidisciplinary continuity of care model which begins at the time of the loss and involves midwives, registrars, sonographers, counsellors, and consultant obstetricians. Partner with the Stillbirth CRE in developing a national set of core principles and establishment of an ongoing mechanism for evaluation of these services.

(e) Support and training for healthcare professionals relating to stillbirth prevention and bereavement care

CHALLENGES AND GAPS

Healthcare professionals need training and continuous education in provision of best practice care relating to stillbirth prevention and care after loss. The NSAIP recognises that stillbirth education for healthcare professionals is a crucial prevention strategy. The Stillbirth CRE's **Safer Baby Bundle**, a comprehensive, evidence-based collection of steps and interventions, is aimed at reducing late-pregnancy stillbirth. Our research has shown that 70% of healthcare professionals agree that implementation of the Safer Baby Bundle has improved the quality of care they provide. However, only 60% felt they have enough time to follow the recommendations in their everyday practice[47]. Healthcare professionals need to be given the opportunity and protected time to attend evidence-based training.

> *"I think it's been good, because it's nice to have everyone on the same page, with education. But not just locally, it helps the women who are getting transferred for various reasons between hospitals during their pregnancy as well, everyone's on the same page with this information."*
>
> **Clinical Midwife (Safer Baby Bundle interview participant, 2022)**

High-quality respectful bereavement care and appropriate investigation of the causes of perinatal death can improve the experience of care and well-being of bereaved families. However, many healthcare professionals feel under-equipped to support parents and care provision is often varied and inconsistent. Evidence-based education, ongoing training and resources are critical enablers to implementation of best practice care recommendations and in services meeting national clinical care standards. Providing appropriate and high quality perinatal loss care requires healthcare professionals to understand the law, policy, practices, and clinical care standards related to reporting perinatal deaths. This is particularly pertinent for termination of pregnancy for medical reasons. Organisational support and financial commitment are both required to create the conditions and structures for implementation, evaluation and monitoring of best practice care.

Australia lacks enough Aboriginal and Torres Strait Islander midwives to care for Indigenous women and their families. In 2020, there were approximately 490 Aboriginal and Torres Strait Islander midwives, making up 1.7% of the total midwifery workforce[48]. This means many Indigenous women and their families receive most of their health and maternity care from non-Indigenous healthcare professionals. As we build the Indigenous healthcare workforce, we must simultaneously upskill non-Indigenous healthcare professionals to ensure they can provide strength-based, individualised, trauma-informed and culturally responsive care and perinatal spaces for Indigenous women and families.

> *"We don't shy away from hard yarns but if we feel unsafe by systems or people around us, then we shut down. It is a coping mechanism. We have been so hurt in the past and we protect ourselves from harm. If the health providers talk to the Aboriginal community in a way that shows cultural integrity and safety in their practice, then it gives that room for us to feel alright to open up. Aboriginal people want to receive health care. We just want that health care to be safe for us."*
>
> ***Community member/parent (2024)***

Feelings of emotional exhaustion, hopelessness, and stress are common for care providers when faced with a traumatic death such as stillbirth. Although providing bereavement care can be professionally and personally rewarding, bereavement care providers are at increased risk for work-related burnout, compassion fatigue, and secondary traumatic stress, impacting retention, absenteeism, and care quality. Despite it being a professional requirement in many national and international quality standards and guidelines, many care providers receive little to no training in self-care.

> *"It is...very difficult as the Midwife to swap between 'positive' mindframe when caring for a family excited to meet their baby/or a family that has just birthed their live baby — to going back into a room with a family during the worst time of their lives."*
>
> ***Health professional (2024)[1]***

OPPORTUNITIES AND RECOMMENDATIONS

The NSAIP proposes the development and implementation of a national evidence-based, culturally safe education programs for stillbirth prevention and bereavement care. The Stillbirth CRE working in partnership with jurisdictional health departments, colleges and parents has developed high quality educational programs to address this need. These programs have been very well-received, however ongoing centralised support is needed to ensure continued benefit for HCP and women receiving maternity care.

Stillbirth prevention:

The Stillbirth CRE's training programs for healthcare professionals include the Safer Baby Bundle and culturally appropriate adaptations, *Healthy Yarning Guide*, *Partnering with Families of Refugee and Migrant Backgrounds*, and Safer Baby Bundle interpreter professional development; and IMPROVE **(Appendix 1)**.

The SBB has already demonstrated a reduction in stillbirth rates in the communities where it has been effectively implemented. This gold-standard educational package has been designed for Australian maternity healthcare professionals and serves as a powerful tool to empower both clinicians and families. The five elements of the SBB address key gaps in best practice that, if effectively implemented, will not only reduce stillbirth but also improve a range of other adverse pregnancy outcomes through early detection and appropriate management of women at increased risk.

Implementation of the Safer Baby Bundle implementation in NSW and QLD showed that the proportion of healthcare professionals performing assessments for risk factors for both FGR

and stillbirth in early pregnancy 'all the time' was high in the post-bundle period (84% NSW and 73% Qld). However, the effectiveness of the SBB depends on its continued implementation and integration into healthcare practices. In 2024, 15,419 healthcare professionals throughout Australia will have completed the SBB eLearning program.

Between 2019 and 2022, the jurisdictional health departments of all Australian states and territories signed formal partnerships to implement the SBB. South Australia was the final state to support the rollout. Now that the SBB has been rolled out nationally, sustained and increased funding is needed to reach priority populations, to ensure that no group is left behind in efforts to prevent stillbirth. Sustaining the use of the SBB requires ongoing commitment, adequate resourcing, and a long-term strategy for embedding it into everyday clinical practice. Monitoring of unintended consequences is a critically important component of any strategies to improve pregnancy outcomes. The Safer Baby Bundle program is being monitored for increases in rates of non medically indicated induction of labour, preterm birth and early term birth. However the lack of timely clinical data is a major barrier to effective monitoring.

The Stillbirth CRE's Indigenous Advisory Group (IAG) works collaboratively with Aboriginal and Torres Strait Islander communities, Indigenous healthcare professionals, and organisations including NACCHO, Waminda, and Apunipima Cape York Health Council. The Stillbirth CRE co-designed the *Stronger Bubba Born* resources to speak to Indigenous women and their families in culturally appropriate ways about stillbirth prevention and bereavement care. Funding has been approved to translate the *Stronger Bubba Born* suite of video resources into traditional language in a community where English is a second or third language. These translated resources will then be embedded into community clinics and regional hospitals for opportunistic health literacy messages. Ongoing work is required to embed these resources into community healthcare settings and into women's handheld records.

Specific areas in stillbirth prevention to target in future versions of *Stronger Bubba Born* and aligned educational programs and resources include:

- Reinforcing early and culturally relevant and responsive perinatal care for Aboriginal and Torres Strait Islander women by supporting non-Indigenous maternity health care practitioners. The lasting, intergenerational impacts of colonisation and racism contribute directly to the health of Aboriginal and Torres Strait Islander people today, with Aboriginal and Torres Strait Islander women and babies bearing the burden of these inequities along the childbirth continuum.

- Delivering culturally safe training to create culturally safer mainstream health environments.

- Building capacity in Aboriginal and Torres Strait Islander women to support their autonomy and self-advocacy, increase their health literacy around stillbirth and stillbirth prevention and to navigate the processes of health systems.

Broader priorities include:

- Research in partnership with Aboriginal and Torres Strait Islander researchers and communities into culturally relevant strategies to support social and emotional wellbeing. To recognise that pregnancy for Aboriginal and Torres Strait Islander women is a key opportunity to acknowledge and understand the ongoing intergenerational impacts of racism, trauma and disadvantage and the way health systems can minimise the added stress of these issues on women during pregnancy and maximise their autonomy and self-efficacy[49].

- Support for national and local/State initiatives that enable Aboriginal and Torres Strait Islander participation in decision making about research such as the Lowitja Institute and the SA Aboriginal Family Health Research Partnership[50].

Upskilling non-Indigenous maternity care professionals to ensure they can provide strength-based, individualised, trauma-informed and culturally responsive care and perinatal spaces for Indigenous women and families is essential. This will be facilitated by non-Indigenous maternity care providers receiving education on the impact of Australia's historical laws and policies on Indigenous women and their reproductive rights, pregnancy, birthing and mothering. The *Healthy Yarning Guide* was developed to provide an understanding of Indigenous ways of knowing, being and doing around pregnancy and birthing practices pre- and post-colonisation, and gives context to the stressors Indigenous women experience when birthing in mainstream systems. Co-designed with Indigenous communities, the guide aims to support non-Indigenous health care practitioners to build trust and practice in a holistic, woman and family centred way when introducing the sensitive topics of stillbirth, stillbirth prevention, and respectful bereavement care with Indigenous women. The *Healthy Yarning Guide* learning package was launched in 2024 and is delivered by face-to-face yarning circles or as eLearning. No other guide combines this level of cultural sensitivity with practical application for busy clinical settings[51].

> *"Great training and beautiful resources. Easy to navigate and very interactive which is awesome. Applicable to anyone working with Aboriginal and/or Torres Strait Islander women, in the hospital or community setting!"*
>
> ***Midwife (Healthy Yarning Guide eLearning evaluation, 2024)***

In addition to the co-designing and translation of woman-facing resources, recognising the important role that interpreters play in facilitating the provision of pregnancy care in the Australian maternity services, Stillbirth CRE partnered with Stronger Futures CRE at the Murdoch Children's Research Institute to develop an educational program for interpreters. This training package is designed to support interpreters working in diverse pregnancy care settings across Australia. Modules include information about the design and delivery of maternity care in Australia, common tests and investigations offered during pregnancy, approaches to stillbirth prevention, and interpreter wellbeing and self-care. Funded by the Commonwealth Government, this educational program was launched online on 23 December 2024 and is available at https://learn.stillbirthcre.org.au/. This program, alongside a similar educational program targeted at healthcare professionals (also developed by Stillbirth CRE in partnership with Murdoch Children's Research Institute), is expected to address the current gap in knowledge and practice around meaningful engagement of healthcare providers and interpreters in the provision of culturally responsive pregnancy care for women from migrant and refugee backgrounds.

> *"The information is in my language, which is great. I feel much more comfortable reading and understanding it without needing to translate."*
>
> ***Pregnant woman (Growing a Healthy Baby evaluation, 2024)***

Feedback from women on the *Growing a Healthy Baby* resources indicated women appreciated having the resources in their own language. Women found the resources informative and engaging, particularly the information on actions women can take to prevent stillbirth and the use of analogies to convey information.

> *"The resource is very helpful, covering a lot of important topics for pregnant women. It provided me with valuable insights, especially regarding stillbirth prevention."*
>
> ***Pregnant woman (Growing a Healthy Baby evaluation, 2024)***

Perinatal bereavement care:

The *Care Around Stillbirth and Neonatal Death* (CASaND) clinical practice guideline is a foundational document that underpins all resources and training development for best practice care after stillbirth Recently, in partnership with the Perinatal Society of Australia and New Zealand (PSANZ), the Stillbirth CRE comprehensively updated the guideline as part of the national plan to provide individual healthcare professionals and maternal and newborn services with best practice recommendations to enable optimal care for parents who experience perinatal loss. This update has a greater focus on culturally responsive care as well as perinatal palliative care and care in subsequent pregnancies. The latest update was approved by the NHMRC in December 2023.

The IMPROVE education program[52,53] coordinated by the Stillbirth CRE is a key mechanism for implementation of best practice care recommendations from the CASaND guideline. This program addresses key areas of care including respectful and supportive care, diagnostic investigations, and communicating with parents about autopsy and other investigations. The IMPROVE program is currently being enhanced and expanded to align with the updated CASaND guideline.

The online education program *Stillbirth Investigations and Bereavement Care* is also based on the CASaND Guideline and is freely available to clinicians in South Australia. As of Q3 of 2024, 3,133 healthcare professionals have completed IMPROVE training. This training has been consistently well-received; however, further funding is needed to support its implementation in South Australia[54], and the training could be further strengthened if supplemented with face-to-face education, as proven successful by the national IMPROVE program.

To ensure bereaved parents and families receive compassionate and respectful care around stillbirth, we must prioritise caring for the carer. The Stillbirth CRE's *Caring for the Carer* online program aims to increase the availability and accessibility of support options for healthcare professionals caring for families who have experienced stillbirth and perinatal loss. The program provides evidenced-based psychological strategies to support healthcare professionals in managing their health and wellbeing, and aims to help prevent burnout and compassion fatigue in the long-term. Making this support option available, as well as formal and peer support options, to all healthcare professionals in SA is an opportunity to better support healthcare professionals and optimise care for bereaved families.

Sustained funding and support at the government policy level is needed to see meaningful and ongoing change. The future of the Stillbirth CRE is uncertain, with current funding of the Centre to cease in October 2026. A sustainability plan is needed to ensure gains in program development and delivery such as through IMPROVE, the Safer Baby Bundle, the *National Perinatal Loss Care Pathway,* and the *Healthy Yarning Guide* (Appendix 1) continue.

Recommendations about support and training for healthcare professionals:

The Stillbirth CRE plays a key role in education for healthcare professionals and maternity care services across Australia. Dedicated ongoing funding is needed to ensure this program of work continues and the high standard of this work is maintained. This funding would ensure ongoing support and education activities for South Australian maternity care providers. All maternal and newborn care services should establish and foster a commitment to delivering best practice care through the following key recommendations:

- Provide adequate support to enable healthcare professionals working in maternity services across South Australia to complete training in **stillbirth prevention**.
    - This training includes the Stillbirth CRE's online educational programs:
        - Safer Baby Bundle
        - Healthy Yarning Guide (including *Stronger Bubba Born* resources)
        - Partnering with Families of Refugee and Migrant Backgrounds (including Growing a Healthy Baby resources)

- Roll out and evaluate the face-to-face Healthy Yarning Guide program to enhance culturally responsive maternity care for Indigenous women in SA in partnership with the Stillbirth CRE.

- Provide adequate support to enable healthcare professionals working in maternity and newborn services across South Australia to complete evidence-based training in best practice care following stillbirth. This should be undertaken through the IMPROVE workshops and eLearning program to complement and enhance the local SA Stillbirth Investigations and Bereavement Care online training program.

- All maternity and newborn services provide access to formal and peer support options for healthcare professionals who provide care around stillbirth (and all pregnancy and infant loss). Support to engage in peer networks for knowledge exchange should also be prioritised.

- South Australia actively engages in the co-design and co-implementation development and evaluation of the Stillbirth CRE's proposed National Perinatal Loss Care Pathway and centralised digital portal. This includes a major focus on optimising bereavement care for Indigenous women, those in remote areas, and some migrant and refugee communities, who bear a disproportionate burden of stillbirth. South Australia as a key partner in this project will help ensure equitable, high-quality care is provided to all families after loss, including subsequent pregnancies and beyond. High-level government support, early stakeholder engagement, and local strategies will be key to the Pathways success in standardising care across Australia.

"Currently we only have a handful of staff who routinely and comfortably care for families who have lost a baby or are requiring bereavement support. I would like to expand this by passing knowledge and skills on to a greater number of staff."

Health professional, Australia (2024)

Stillbirth investigations

(f) Best practice regarding stillbirth investigations (including access, information for parents and case review), pathologist training and service provision

CHALLENGES AND GAPS

Access to timely, high-quality information on causes and factors contributing to a stillbirth are critically important for parents struggling to understand 'what went wrong', for future pregnancy planning, and to inform effective prevention strategies at the population level. Our research indicates significant room for improvement in investigation into causes of stillbirth with low compliance with recommended investigations and 50% of affected parents reporting that they felt more could have been done to find out why their baby died. Our research has found the most useful investigations in stillbirths are placental pathology, a comprehensive maternal history, genetic analysis, maternal blood investigations for infection, fetal-maternal haemorrhage and fetal autopsy[55]. Magnetic Resonance Imaging and Genome Wide Sequencing are increasingly playing an important role in understanding the causes of stillbirth. Further research is required to develop more individualised approaches to stillbirth investigations which give parents evidence-based options. Counselling families about their options should follow an individualised approach based on a multidisciplinary team discussion, taking into account the cultural and religious needs of the family.

Investigation into causes of stillbirth needs to consider factors relating to care which may have contributed to the death. High quality perinatal mortality audit to identify areas for practice improvement to reduce these deaths. International programs have highlighted the need for in-depth review of all perinatal deaths as part of clinical quality improvement to reduce further deaths including a comprehensive global guideline from WHO *Making every baby count* (https://www.who.int/publications/i/item/9789241511223). However, many services in Australia do not have effective programs in place and reporting nationally is suboptimal.

OPPORTUNITIES AND RECOMMENDATIONS

To support initiatives to increase stillbirth investigations in Australia, the Stillbirth CRE established a Stillbirth Investigations Collaborative with the Royal Australian and New Zealand College of Radiologists (RANZCR), Royal College of Pathologists Australasia (RCPA), Stillbirth Foundation Australia and Red Nose Australia to improve stillbirth investigations in Australia. In 2024, Red Nose partnered with this collaborative to assemble a national toolkit of parent resources including stillbirth investigation resources. Resources were sent to 26 maternity services, 10 ACCHOs, and 5 PHNs in South Australia.

The Stillbirth CRE's recent updates to the CASaND guideline provide healthcare professionals with contemporary evidence-based information and recommendations about stillbirth investigations, communicating with parents, and perinatal mortality audits. Chapter 6 and 7 of the guideline contains recommendations and appendices to assist maternity services with ensuring informed decision-making for families on options for stillbirth investigations and establishing and maintaining a high quality, effective perinatal mortality audit programs.

A full autopsy is the most comprehensive investigation for identifying the causes of stillbirth. While national data are incomplete, it is estimated that only 40% of stillbirths have full or limited autopsy[56] Autopsy rates are higher in some jurisdictions, such as WA (rate of 60%) and SA (rate of 56%)[11]. Barriers to autopsy include the lack of qualified pathologists and poor counselling of parents by health professionals about the option of having the procedure performed. Parents and their clinicians need more support and guidance to

facilitate decision-making that incorporates parents' values and minimises the likelihood of later regret. Often, parents accessing private maternity care are charged for the autopsy, adding to existing inequities. Coordinated public services, such as those in SA and WA, may be associated with higher autopsy rates and lower rates of unexplained stillbirths. Such a comprehensive autopsy service includes the provision of perinatal pathologists as well as clinical geneticists with interest in paediatric and reproductive genetics.

South Australian researchers are leading a national team of collaborators studying the usefulness of genomic analysis in stillbirth and perinatal death investigations. In 2020, Professor Hamish Scott and Professor Chris Barnett were awarded $3.4 million funding to establish a Genomic Autopsy Study to undertake genomic research into causes of stillbirth and perinatal death. To date, at least 50% of the 200 families enrolled in the study have received an 'answer' to the cause of their stillbirth or perinatal death[64]. Genomic testing is (autopsy) not currently standard care. In SA, the cost for whole genome sequencing is $3,000. This cost may be covered for families who meet certain requirements.

Magnetic resonance imaging (MRI) is a less invasive option to a full autopsy. The 2024 edition of the CASaND guideline recommends offering parents a postmortem MRI as an adjunct to autopsy or, in some clinical circumstances or upon parent request, in place of an autopsy[41]. However, counselling parents about the option of an MRI is suboptimal and services and referral pathways often inadequate.

The Royal Australian and New Zealand College of Radiologists (RANZCR), with funding from the Department of Health and Aged Care (DoHAC), developed a Perinatal Post-mortem Investigation Training Package targeting radiology services to address these gaps. In 2024, the Stillbirth CRE led evaluation of the package and found it to be well-received with early signs of an increased uptake of postmortem imaging and increased discussions with parents about this procedure. Similarly, the Royal College of Pathologists of Australasia (RCPA) was funded to develop programs to improve the quality of autopsy and ancillary investigations targeting pathologists.

Recommendations about stillbirth investigations:

- Implement NHMRC CASaND guidelines stillbirth investigations protocol and mechanisms for ongoing evaluation using the Stillbirth Clinical Standards.
- South Australia promotes and engages in the development and implementation of a national perinatal mortality audit program which enables timely reporting to effectively identify and mount clinical quality improvements to reduce stillbirths.
- The IMPROVE education program for HCP is made mandatory for all relevant HCP
- Embed RANZCR training programs on imaging for stillbirths for radiologists and the RCPA training programs on autopsy procedures for pathologists and adequate resources, including staffing, and appropriate referral pathways and reporting procedures.
- Stillbirth Clinical Standards KPI's to evaluate the quality of counselling for families on options for stillbirth investigations.
- Implement standardised protocols and referral pathways for Genomic autopsy that enable equitable access to all eligible families following stillbirth.

- Large prospective cohort studies are needed to evaluate the use and value of recommended stillbirth investigations according to clinical circumstances to enhance informed decision-making and appropriate service provision.

Data collection, reporting and monitoring

(g) Processes of data collection, reporting and monitoring

CHALLENGES AND GAPS

Current national practice in data collection of births is suboptimal, and better data are needed to improve care and outcomes. Access to timely clinical data on stillbirths and live births is essential for researchers and policy makers, and current arrangements need to be improved.

Major impediments include significant duplication of effort and disparate approaches across and within states and territories and the time lag in national reporting due to laborious processes in collating jurisdictional data.

Stillbirth data in Australia are collected and reported in different ways. National rates and causes of stillbirths are reported by two government agencies that use different sources of information and report findings in different ways:

- The Australian Bureau of Statistics (ABS) report data on stillbirths that are collected as part of Vital Registrations based on death certificate data.

- In parallel, the Australian Institute of Health and Welfare (AIHW) reports stillbirth data from data collections on all births within the states and territories.

When the same definition of stillbirth is used, the stillbirth rate reported by the ABS is 5.5/1,000 births[57] compared with the AIHW reported rate of 7.1/1,000[58]. This equates to around 500 fewer stillbirths being reported annually by the ABS. This under-reporting is thought to be due to parents not notifying their local registrar of the stillbirth (required in addition to notification by the attending clinician) and the limited capacity of registrars to follow-up on partially registered stillbirths[59]. Importantly, the onus to make this notification should not be left on the parents.

AIHW has improved reporting of stillbirths by publishing a comprehensive *Stillbirths in Australia*[59] report and biennial reports on perinatal mortality[58], However, the value of these reports is restricted by the limitations in consistency and comprehensiveness of existing data collections and timeliness of reporting.

States and territories have developed different approaches to collecting data on all births within their jurisdictions and different mechanisms for clinician review of perinatal deaths (stillbirths and neonatal deaths)[59].

Variations in definitions between jurisdictions for perinatal deaths and important perinatal indicators impact the accuracy of comparisons and capacity to benchmark. With several different definitions of stillbirths and perinatal deaths in use[60] there is wide variation in reported rates across jurisdictions. For example, stillbirth rates can vary if terminations of pregnancy (TOP) are included or excluded. Many countries exclude TOP from their stillbirth rates. The South Australian Abortion Reporting Committee published its 2023 annual report in April 2024[61] yet the latest perinatal mortality report published by South Australia was in 2020. The abortion report contains figures for termination of pregnancy due to congenital abnormalities; however, the figures provided in 2020 are not aligned with

the 2020 SA perinatal mortality report. Further, recent reports from the South Australian Abortion Reporting Committee only include a reason for termination of pregnancy from 22 weeks, whereas previously this was reported from 20 weeks. This change creates additional misalignment between reports. Finally, although 35% of stillbirths in SA were termination of pregnancy in 2020, the ABS reports do not include these in SA data.

Variation in reported causes of stillbirth is also evident across jurisdictions in the AIHW reports indicating further training and support in classification of perinatal deaths. Further, ABS reports triple the proportion of unexplained stillbirths than AIHW — with ABS reporting 64%[57] versus AIHW reporting 20%[58]. This is because ABS uses information on the death certificate issued at the time of the stillbirth, which is prior to the results of investigations into the causes of stillbirth being conducted. Data from AIHW are based on classification of causes following review of all available postmortem investigations. A further issue is the use of the International Classification of Diseases (ICD) by ABS, which limits the value of data on causes of stillbirth reported due to deficiencies in this system for perinatal deaths.

Commonly, there is a lag of two to three years between data collection and publication in state/territory and national perinatal mortality reports. For SA, the lag is even longer: the most recent SA perinatal mortality report contains 2020 data and was published in 2023[11]. By comparison, Queensland published its 2022 data in September 2024. The timeliness of data availability could be improved significantly by streamlining the processes for accessing de-identified data at the local, state and national level, including agreement on definitions and the processes used.

Deficiencies in the quality of care in pregnancy and labour are implicated in 20–30% of stillbirths[62] National perinatal mortality audit programs to identify substandard care contributing to stillbirths can reduce these deaths through an ongoing cycle of practice improvement[63]. Without a national perinatal mortality audit program, opportunities for prevention are often lost and the consequence for future families is high. While AIHW now includes contributing factors (substandard care) associated with stillbirths in routine reports, inadequate data collection and reporting across jurisdictions limits the value of these data. Appropriate engagement of parents is important to ensure high quality audit and to improve parents' experience of care. However, this engagement is often lacking or non-existent.

A key limitation in the use of routinely collected jurisdictional and national data to undertake analyses to drive change are the lengthy and costly processes to access data that often extend beyond the time available to researchers often dependent upon three-year research funding cycles. According to the National Perinatal Epidemiology and Statistics Unit, the cost of accessing data ranges from $12,000 to $25,000 depending on the nature of the data requested. It can take three to five years just to obtain the necessary jurisdictional, national and ethical approvals required by AIHW to access national perinatal data.

> *"We talk about the road toll every year, but stillbirth doesn't get the same kind of mention"*
>
> ***Bereaved dad (attended research priority setting workshop, 2023)***

OPPORTUNITIES AND RECOMMENDATIONS

To improve timely data sharing, the Stillbirth CRE has worked in partnership with Women's Healthcare Australasia (WHA) to integrate the nine performance indicators of the Safer Baby Bundle as a standalone feature within their digital clinical dashboard. The dashboard is accessible to all clinicians within WHA's existing national membership benchmarking portal and inclusion of a stillbirth prevention specific page will further support maternity services efforts to reduce rates of stillbirth across Australia. This work has been a catalyst for the implementation of clinical dashboards in many jurisdictions. HCP and policy makers need access to timely data to ensure optimal pregnancy outcomes and efforts to address this critical gap must be urgently escalated.

Quality in maternity care and reporting in some Australian states is overseen by formal quality assurance bodies: Centre of Clinical Excellence (NSW); Clinical Excellence Queensland; Safer Care Victoria. These bodies work with health services, clinicians, and consumers to conduct quality improvement initiatives, support professional development of healthcare professionals, measure care through performance data and patient experience, and improve access to care. A state-specific quality assurance organisation and statewide plan for maternity care in SA would increase accountability for LHNs.

Recommendations about data collection, reporting and monitoring:

- Implement a standardised national electronic reporting system to collect 'real-time' (and easily accessible) data on all births, including standardised definition of stillbirth and neonatal deaths.
- Ensure timely reporting on perinatal deaths nationally including Indigenous and other high-risk groups, to enable the impact of programs and policies to be monitored for effectiveness.
- Implement perinatal mortality audit programs across all maternity services where births occur following procedures outlined in the CASaND guideline, including timely reporting to jurisdictional health departments and AIHW for national reporting through an on-line reporting system.
- Ensure timely reporting on perinatal deaths nationally including Indigenous and other high-risk groups, to enable the impact of programs and policies to be monitored for effectiveness.
- Provide appropriate support and expertise to enable parents to be engaged in perinatal mortality audit thus ensuring all important information is captured and parents are counselled about the findings.
- South Australia establishes a statewide quality assurance body for maternity care.

Allocation of research effort

(h) Allocation of research effort

CHALLENGES AND GAPS

To have impact, all stakeholders need consensus about where and how best to allocate research funding and efforts. Australia needs national agreement on research priorities, so that funding bodies (government, philanthropic and corporate) can work together to produce

the best possible and most relevant outcomes. Research priorities should be, in part, informed by parents with lived experience of stillbirth. Women and their families, including those from Aboriginal and Torres Strait Islander peoples, migrant and refugee peoples and other priority populations, must be involved in establishing priorities for research and identifying interventions that meet their needs.

Translation of evidence into clinical practice and implementation of effective interventions in a timely manner needs priority. As well as the funding of discovery projects, there must be increased support for implementation. Major gains can be made by simply implementing what is already known to be best practice, and although implementation projects may not be as attractive to funding bodies, it is vitally important that there is a rigorous approach to translating new ideas into practice.

The NSAIP[1] identified a lack of a central repository of past, current and planned research. This impedes the collaboration required to ensure effective conduct of high quality research.

South Australia has specific research areas and populations to target[64]. The stillbirth risk factor of inadequate antenatal care access is a particularly pertinent one for South Australians living in remote areas. Research is needed to understand the optimal minimum number of antenatal care visits to reduce stillbirth risk and how to best meet this need.

Thank you for the experience, opportunity and process of this research group. It was incredibly heartbreaking hearing the stories of loss, but such a fulfilling and rewarding time knowing we are trying to help change the future so families either ultimately don't experience loss, or at a minimum have an overall improved experience due to knowledge we have provided to make things better. The women involved were absolutely incredible for sharing their stories…knowing we are collectively trying to make things better – it was very uplifting.

Bereaved parent (attended research priority setting workshop, 2023)

OPPORTUNITIES AND RECOMMENDATIONS

We continue to support a unified national priority driven approach to research and quality improvement programs to address stillbirth. The CRE's program is based on research priorities developed through consultation with bereaved parents, parent-based support and advocacy organisations, the world's foremost expert researchers and clinicians, and the community in Australia. Research activities at the Stillbirth CRE are informed and guided by the national stillbirth research priority setting led by the Centre in partnership with PSANZ and Stillbirth Foundation Australia. The research priority setting process was guided by a steering committee, advisory groups, and skilled facilitators. Over 160 research priorities were proposed by over 300 participants across Australia, of which nearly 10% were from South Australia. This included representation from bereaved family members, maternity consumers and members of community-based support organisations, healthcare professionals, researchers, and policy makers. Their breadth of experiences and knowledge informed these six overarching priority areas[65]:

- Determine the causes of and pathways that lead to stillbirth
- Identify and implement strategies to prevent stillbirth
- Build the capacity of health services and systems
- Understand and improve care for families after perinatal loss

- Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families
- Ensure culturally safe and responsive care for migrant and refugee communities

The outcomes of the research priority setting were used by the Medical Research Future Fund to guide its funding priorities at a national level. Government and policy makers in SA can similarly use research priority setting outcomes as a guide to where and how to allocate research funding and efforts in the State.

The Stillbirth CRE is collaborating with 12 academic organisations nationally and internationally and maintains up-to-date records of all research undertaken as part of these collaborations. Currently 80 studies are included in the Stillbirth CRE research register. However, further work is required to make this register comprehensive and accessible to the general community.

Recommendations about allocation of research effort:

- Use outcomes of the national stillbirth research priority setting to inform allocation of research funding and efforts in South Australia across the six priority areas:
    - Determine the causes of and pathways that lead to stillbirth
    - Identify and implement strategies to prevent stillbirth
    - Build the capacity of health services and systems
    - Understand and improve care for families after perinatal loss
    - Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families
    - Ensure culturally safe and responsive care for migrant and refugee communities

- Engage parents with lived experience in stillbirth research through the Stillbirth CRE's national register.

- Implement effective approaches for accessing routinely collected clinical data for the purposes of research and quality improvement.

- Contribute to national stillbirth research register to promote collaboration in the effective conduct of high quality research to reduce stillbirth and associated outcomes and improve care for families who experience perinatal loss.

Other

(i) Other recommendations

- To optimise outcome for families in Australia, continued efforts are needed to ensure a cohesive approach to national initiatives including those addressing stillbirth, preterm birth and early pregnancy loss.

- Further funding to continue the work of the Stillbirth CRE is critically important to effectively address the NSAIP.

Appendix 1

Summary of Stillbirth CRE resources

The Stillbirth CRE has developed a number of educational resources for healthcare professionals and for parents, to promote prevention of stillbirths and to support parents who experienced a loss.

Resources for healthcare professionals

- ***Safer Baby Bundle (eLearning/Master Class).*** Provides evidence based information for maternity health care providers on the 5 elements of the bundle: Smoking Cessation, Fetal Growth Restriction (FGR), Decreased Fetal Movements (DFM), Side Sleeping and Timing of Birth. The Safer Baby Bundle eLearning module is free to access and has accredited CPD points. The interactive learning includes videos, quiz style questions and case studies.
- ***Healthy Yarning Guide.*** This is a program to upskill non-Indigenous healthcare professionals to reduce stillbirth rates and provide culturally safe and respectful care to Aboriginal and Torres Strait Islander women and their families, including through truth-telling.
- ***Safer Baby Bundle eLearning for working with healthcare professionals working with migrant and refugee communities.*** This course builds upon the established Safer Baby Bundle eLearning course to provide additional support to health professionals working with women and families of refugee and migrant backgrounds during pregnancy. Modules include practical guidance on how families would like to have conversations about stillbirth prevention, skills for working well with interpreters, and opportunities to strengthen culturally safe and trauma responsive approaches to pregnancy care.
- ***Safer Baby Bundle eLearning for interpreters.*** This training package is designed to support interpreters working in diverse pregnancy care settings across Australia. Modules include information about the design and delivery of maternity care in Australia, common tests and investigations offered during pregnancy, approaches to stillbirth prevention, and interpreter wellbeing and self-care.
- ***Caring for the Carer.*** This online program aims to increase the availability and accessibility of support options to healthcare professionals. The program provides evidenced-based support options and interventions to help promote a holistic-approach to health and wellbeing and prevent burnout and compassion-fatigue in the long-term.

Resources for healthcare professionals: Care around loss

- ***IMPROVE (face-to-face workshops and eLearning).*** IMPROVE face-to-face workshops and eLearning modules are designed to address the educational needs of health professionals involved in maternity and newborn care in managing perinatal death based on the Care Around Stillbirth and Neonatal Death (CASaND) clinical practice guideline.
- ***Care Around Stillbirth and Neonatal Death (CASaND) clinical practice guideline.*** The aim of the guideline is to improve service provision and promote best practice care around perinatal death in Australia and Aotearoa New Zealand. Care begins at diagnosis, continues through pregnancy to birth, postnatal care and longer-term support including next pregnancies.

Resources for parents:

- ***Safer Baby*.** The Safer Baby initiative aims to help women understand the things they can do to reduce their risk of stillbirth.
- ***Stronger Bubba Born.*** These resources introduce five evidence-based elements that address key areas that can reduce the number of Sorry Business Babies (stillbirths). The resources are intended to help Aboriginal and Torres Strait Islander women and families and their healthcare providers understand what they can do to reduce the risk of Sorry Business Babies (stillbirth).
- ***Growing a Healthy Baby.*** These Safer Baby Bundle in-language resources are for women, their families and healthcare teams to reduce the chance of stillbirth. Resources have been co-designed with communities and healthcare professionals with funding from the Australian Government Department of Health and Aged Care. The resources for Arabic, Dari, Dinka and Karen speaking communities (with English translations so healthcare professionals know what they are sharing). For each of the four community groups there are three resources: summary animation video; digital audio booklet; detailed PDF booklet.

Resources for parents: Care around loss

- ***Guiding Conversations (parent version of the guideline).*** This booklet is a companion resource to the CASaND Guideline and specifically developed for parents. It is designed to support parents and assist healthcare professionals as they navigate difficult conversations and decisions around the time of a baby's death.
- ***Jiba Pepeny (Star Baby) (parent version of the CASaND guideline).*** This booklet is a companion resource to the CASaND Guideline and developed by Aboriginal people for Aboriginal people. This resource is to help Aboriginal people through the Sorry Business of losing their bub
- ***Living with Loss*.** This free online program is to support anyone who has experienced pregnancy or baby loss. The program's intent is to share practical strategies to support grief and loss through six modules: Understanding grief; Coping with grief; Thinking about grief; Facing hard situations; Strengthening relationships; The future.

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