First Evaluation Report | National Stillbirth Action and Implementation Plan

Australian Government Department of Health and Aged Care

5 May 2023

nous

Nous Group acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of country throughout Australia. We pay our respect to Elders past, present and emerging, who maintain their culture, country and spiritual connection to the land, sea and community.

This artwork was developed by Marcus Lee Design to reflect Nous Group's Reconciliation Action Plan and our aspirations for respectful and productive engagement with Aboriginal and Torres Strait Islander peoples and communities.

Contents

Acronyms

The Australian Government, state and territory governments, health peak organisations and non-government organisations are responsible for implementing tasks throughout the Action Plan. These are referred to as **implementers**.

Table 1 | Description of acronyms used

Acronym	Description
ACCHO	Aboriginal Community Controlled Health Organisation
ACM	Australian College of Midwives
ACSQHC	Australian Commission on Safety and Quality in Health Care
ACT	Australian Capital Territory
ASGS	Australian Statistical Geography Standard
AHMAC	Australian Health Ministers' Advisory Council
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIDA	Australian Indigenous Doctors' Association
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal Medical Service
ANMF	Australian Nursing and Midwifery Federation
BiOC	Birthing in Our Community
CALD	Culturally and linguistically diverse
CASAND	Care Around Stillbirth and Neonatal Death guidelines
CATSINaM	The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
CoPE	Centre of Perinatal Excellence
EMR	Electronic Medical Records
FFA	Federation Funding Agreement
GP	General Practitioner
H2H	Hospital to Home
HHS	Hospital and Health Service
HREC	Human Research Ethics Committee
ICR	International Comparator Research
IOG	National Stillbirth Implementation Oversight Group

Acronym	Description
IMPROVE	IMproving Perinatal Mortality Review and Outcomes Via Education
LHD	Local Health District
LHN	Local Health Network
MCWH	Multicultural Centre for Women's Health
MRFF	Medical Research Future Fund
NACCHO	National Aboriginal Community Controlled Health Organisation
NGO	Non-government Organisation
NHMRC	National Health and Medical Research Council
NPDC	National Perinatal Data Collection
NPMDC	National Perinatal Mortality Data Collection
NRHA	National Rural Health Alliance
NRT	Nicotine Replacement Therapy
NSW	New South Wales
NT	Northern Territory
PSANZ	Perinatal Society of Australia and New Zealand
OECD	Organisation for Economic Co-operations and Development
QLD	Queensland
RACGP	Royal Australian College of General Practitioners
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RANZCR	Royal Australian and New Zealand College of Radiologists
RCPA	Royal College of Pathologists of Australasia
SA	South Australia
SACC	Standard Australian Classification of Countries
SBB	Safer Baby Bundle
SEIFA IRSD	Socio-Economic Indexes for Areas Index of Relative Socio-Economic Disadvantage
Stillbirth CRE	Stillbirth Centre of Research Excellence
TAS	Tasmania
The Action Plan	The National Stillbirth Action and Implementation Plan
UK	United Kingdom
VIC	Victoria

Acronym	Description
WA	Western Australia
WCC	Women-Centred Care: Strategic directions for maternity services
WHA	Women's Healthcare Australasia
WHO	World Health Organization

A note on language

Nous uses the term *migrant and refugee* to describe a cohort of women who were born in specific countries and experience higher rates of stillbirth. The National Stillbirth Action and Implementation Plan (the Action Plan) calls out women born in Melanesia, Polynesia, Africa, and South and Central Asia. The main data source available to this evaluation categorises this group of women into North Africa and Middle East, Sub-Saharan Africa and Southern and Central Asia countries of birth. As we use *migrant and refugee* throughout the report, it will be referring specifically to women born in these countries. However, sometimes other terms will be used based on the nature of data used to provide insights into this cohort (that is, culturally and linguistically diverse or language other than English spoken at home).

First Nations is used in preference to *Aboriginal and Torres Strait Islander* unless the latter term is used in a title, or a different description is more appropriate based on the data source.

Nous recognises that individuals have diverse gender identities. Terms such as *pregnant person*, *childbearing people* and *parent* can be used to avoid gendering birth, and those who give birth, as feminine. However, because women are also marginalised and oppressed in most places around the world, we have continued to use the terms *woman*, *mother* or *maternity*. When we use these words, it is not meant to exclude those who give birth and do not identify as female.

Executive Summary

Stillbirth is a significant public health issue with profound and long-lasting effects for women, their families and the broader community. While Australia's stillbirth rate[1] has been generally improving since 2003, it has changed little over the past six years. It is higher than in countries that implement broadscale best practice stillbirth prevention and care.[2]

Specifically, while Australia performs well compared to other Organisation for Economic Co-operations and Development (OECD) countries,[3] rates are significantly poorer than national rates for some among the identified target cohorts – First Nations women, some migrant and refugee women, women living in disadvantaged areas or regional and remote areas, women under 20 and women who have had a previous stillbirth.

The National Stillbirth Action and Implementation Plan (the Action Plan) was released in December 2020. Its goals are:

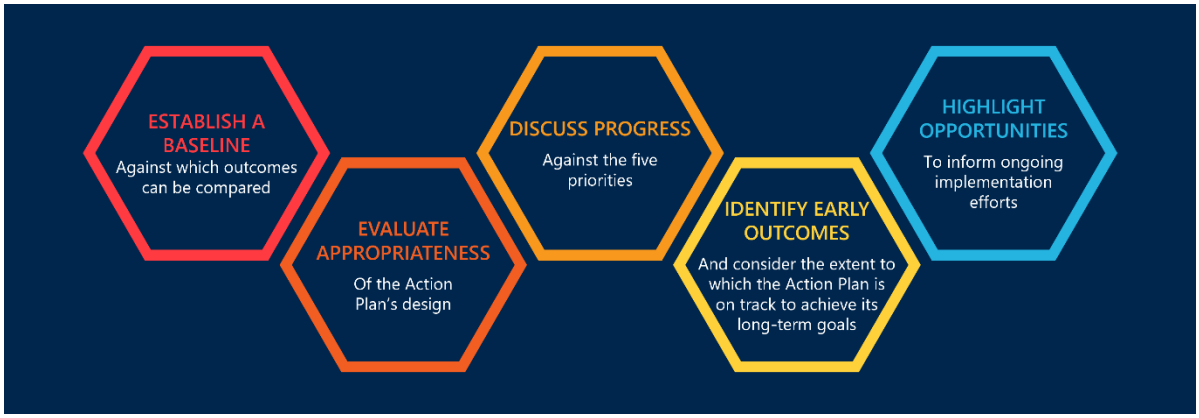
- to support a sustainable reduction in the rates of preventable stillbirth after 28 weeks; and
- to ensure that, when stillbirth occurs, families receive respectful and supportive bereavement care.

These goals are to be achieved through five priority areas:

- ensuring high quality stillbirth prevention and care
- raising awareness and strengthening education
- improving bereavement care and support following stillbirth
- improving stillbirth reporting and data collection
- prioritising stillbirth research.

Nous Group (Nous) has been commissioned to conduct the monitoring and evaluation of the Action Plan. Now two years into its implementation period, this initial evaluation report is a high-level and holistic look at the Action Plan, its design, implementation and impact. The evaluation covers the calendar years 2020 to 2022. It has five objectives, as summarised in Figure 1.

Figure 1 | Objectives of this evaluation report



[1] Australian Institute of Health and Welfare, *Stillbirths and neonatal deaths*, https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths.
[2] Flenady V, Wojcieszek AM, Middleton P et al., 'Stillbirths: recall to action in high-income countries', *Lancet*, 2016, vol 387, no. 10019, p. 691-702.
[3] UNICEF for every child, Stillbirth data - Build your own dataset [Analysis of country specific stillbirth rate data], 2023, https://data.unicef.org/resources/dataset/stillbirths/.

Note: Extensive referencing of relevant sources is not used in the executive summary as the intent of this section is to summarise key themes and insights. Details of resources consulted are cited throughout the body of the report and appendices.

Baseline

The report provides an extensive evidence base to establish a 2020 baseline for the evaluation.[4] It is structured around the five priority areas of the Action Plan.

The baseline emphasises the difference in stillbirth rates for target cohorts compared to the general population, and the need for the Action Plan to reach and support meaningful change for these women to improve the overall stillbirth rate.

The COVID-19 pandemic in Australia began in March 2020 during the baseline period for this evaluation. This had significant impacts on health services delivery and women's ability to engage with services. The effects of the pandemic have been identified and acknowledged throughout the report.

Appropriateness of the Action Plan's design

The evaluation found that the Action Plan reflects deep engagement with stakeholders across the system, as well as alignment with other policies and strategies. It was well supported at the time it was released, and it is still regarded as an important and influential document by interviewed stakeholders.

The Action Plan broadly aligns with best practice. It takes similar steps to other stillbirth and pregnancy-related strategies in other countries through its holistic focus on primary care, awareness and education, data collection and reporting, and a targeted research agenda.

Being flexible and written at a high level was an important feature of the Action Plan's design in securing support from governments and implementation partners and giving them flexibility in implementation. However, there are risks that implementers may be unclear about performance expectations and lines of accountability in the absence of a more detailed implementation plan or statement of priorities.

Implementation progress

Despite the competing priorities facing the health system, progress on early activities under the Action Plan has been relatively strong: implementation progress has been observed against all short-term and ongoing tasks, as well as some medium-term ones. There have, however, been variations, gaps or obstacles to implementation for some tasks.

Implementation was commonly **enabled** by factors including:

- close alignment between work under the Action Plan and activities being progressed as part of other pregnancy, women's health or general health strategies and initiatives
- the existence of supporting governance structures, such as communities of practice or other interest groups, that have helped troubleshoot issues, scale up pockets of excellence and make work relevant to as many people as possible
- having adequate buy-in and resources to support implementation.

On the other hand, implementation progress has been **slower** where:

- the challenges of reaching and supporting target cohorts have been underestimated

[4] 2020 calendar year

- there has been a shortage of available workforce (capability and capacity) to drive work forward
- implementers have worked in a siloed way.

When governance over the Action Plan was examined, it was found that many of the hallmarks of good practice were in place. For example, leadership and planning relating to the Action Plan are strong, but could be further enhanced - particularly to ensure that progress was being made to reach target cohorts and carry out initiatives very specific to stillbirth and bereavement care.

Many stakeholders raised the importance of funding. Stakeholders welcomed the funding that was provided by the Australian Government, the states and territories and non-government organisations during the reporting period to support implementation efforts, and they commented that this has facilitated work that would otherwise have been unlikely to proceed. They also highlighted that some implementation activities are difficult and more expensive, particularly as they relate to reaching and supporting target cohorts. This creates a risk that these activities are deprioritised in the absence of ongoing, specific funding support.

Early outcomes

Only preliminary data is available to report on the national stillbirth rate beyond 2020; with the rates showing limited change. That said, there are some promising indicators of progress on stillbirth outcomes, which can be attributed (in part) to the Action Plan.

Incremental improvements have been observed around the **provision of quality prevention and** care under Priority 1, noting that substantial changes around rates of attendance to antenatal appointments and increases in midwifery continuity of care and other maternity continuity of carer models are anticipated to take longer to materialise. There is anecdotal evidence that culturally safe maternity care is improving in some places for First Nations women, reinforced by greater participation of First Nations professionals in the health workforce. Models of care that integrate Birthing on Country principles are particularly successful in this area, although they are not yet widely available across Australia.

On the other hand, there has been limited work to increase availability of services for other target cohorts. While some progress was noted to improve services for migrant and refugee women and those in regional and remote areas, there was little reported activity from implementers around the needs of young women and those who have previously experienced stillbirth, and how these are being met.

This is a significant finding, as it is unlikely that Australia will achieve the goal of a 20% reduction in stillbirth rates from 2020 to 2025 if target cohorts are not held in focus and supported.

Awareness and education are improving under Priority 2. Stakeholders involved in maternity care report that women, their families and communities are broadly more aware of the risks of stillbirths and are more confident to manage these.

Among healthcare professionals, uptake of formal training programs has been strong, resulting in reports of higher competence and confidence to identify and act on risks and to provide improved bereavement support.

There have been some unintended consequences of raised awareness. Multiple stakeholders recounted that anxiety around stillbirth has also increased in some pregnant women, which can exacerbate some health concerns during pregnancy. It was also reported that intervention rates are rising, particularly around decisions on the timing of birth. It is likely that not every intervention is proportionate to the actual risk involved.

Improving **holistic bereavement care and community support following stillbirth** under Priority 3 has unfortunately shown limited improvement, with relatively few outcomes reported among implementers – with the exception of non-government organisations. Where bereavement support is available, the experiences of bereaved parents have shown some improvement, though access to culturally safe services is still an issue.

There are enduring challenges to define and measure bereavement care. There is still work to do to characterise the challenge and implement genuinely valuable solutions that support women from the time they find out there may be a problem with their baby, through their hospital experience, post-discharge into the community, and for the years after, including during any subsequent pregnancies.

New and existing health professionals are being trained to help **improve stillbirth reporting and data collection** under Priority 4 by bringing new capacity to the system to offer and conduct stillbirth investigations that will improve the availability and quality of stillbirth data. Evidence suggests that health care professionals are more consistently offering investigations such as autopsy when they are clinically indicated, and a majority of parents are consenting to this offer. Timeliness of reporting stillbirth data has improved with the release of preliminary data at around 12 months.

Stillbirth research activities have also increased, with sizeable investments directed into stillbirth-specific research. The work of the Stillbirth Centre for Research Excellence (Stillbirth CRE) has had a positive impact in driving greater coordination of research efforts. This will likely be magnified once national research priorities are finalised.

Opportunities

There has been considerable work by many stakeholders to implement the Action Plan, despite the context of competing demands and workforce shortages.

While progressing all elements of the Action Plan will be important to achieving goals of preventing stillbirth and improving responses to bereavement, pragmatism is required about how the limited available resources should be allocated in coming years to achieve best results.

Nous proposes there is opportunity to be more discerning around where implementation efforts are directed, so that they focus on elements of service delivery, system design research and other supports unique to stillbirth and bereavement support, or are tailored to target cohorts. This focus can be supported through better sharing of ideas and service action plans across jurisdictions to multiply successful initiatives.

Four opportunities have been provided below (Figure 2) for consideration.

Figure 2 | Summary of opportunities

OPPORTUNITY 1

Map the Action Plan's priorities to those of other women's health and maternity strategies and identify where it adds unique value

While a strength of the Action Plan is that it considers stillbirth prevention and responsiveness holistically, there are many priorities that are mirrored in other policies or strategies relating to women's health or maternity care.

There is therefore an opportunity to identify where the Action Plan is unique in its focus, providing a pathway to improve stillbirth rates and bereavement supports in a way that is unlikely to occur in the absence of a specific stillbirth plan.

OPPORTUNITY 2

Create a two-year statement of priorities to focus efforts over the short-term

A two-year statement of priorities that sits beneath the broader Action Plan may give greater clarity about what is required over the short-term, in order for the Action Plan to achieve its full impact over time.

This statement of priorities could focus on work that is very specific to stillbirth and bereavement support, and which is unlikely to be progressed under any related pregnancy or women's health strategies or initiatives as identified in Opportunity 1. It could also focus on reaching target cohorts, who are critical to support in order to meaningfully reduce Australia's stillbirth rate.

OPPORTUNITY 3

Strengthen leadership and accountability

While the ongoing collaboration by governments, Non-Government Organisations, research bodies and other implementation partners should continue to be highly valued, there is an opportunity for the Implementation Oversight Group (IOG) to operate slightly differently, to provide stronger leadership to improve accountability for action.

The IOG's role may extend to driving the development of the statement of priorities suggested in Opportunity 2, and to supporting more joined-up policy, strategy and implementation activities across the system.

OPPORTUNITY 4

Consider funding towards opportunities to support implementation of the unique priorities of the Action Plan

While significant investments into the Action Plan may be unlikely year-on-year, there may be value in reconsidering how existing funding allocations through federal or jurisdictional budget cycles support implementation of the shortlisted activities identified in the two-year statement of priorities.

Where these priorities are largely unique to stillbirth prevention and response, substantive funding allocations made into maternity and women's health may require retargeting. Identification of funding gaps may also provide impetus for seeking additional targeted funding.

1 Background and context

Stillbirth is a significant public health issue with a profound and long-lasting effect. Australia launched the National Stillbirth Action and Implementation Plan (the Action Plan) in 2020 to reduce its stillbirth rates. This section provides an overview of the Australian context leading up to the launch of the Action Plan and the purpose and scope of this evaluation report.

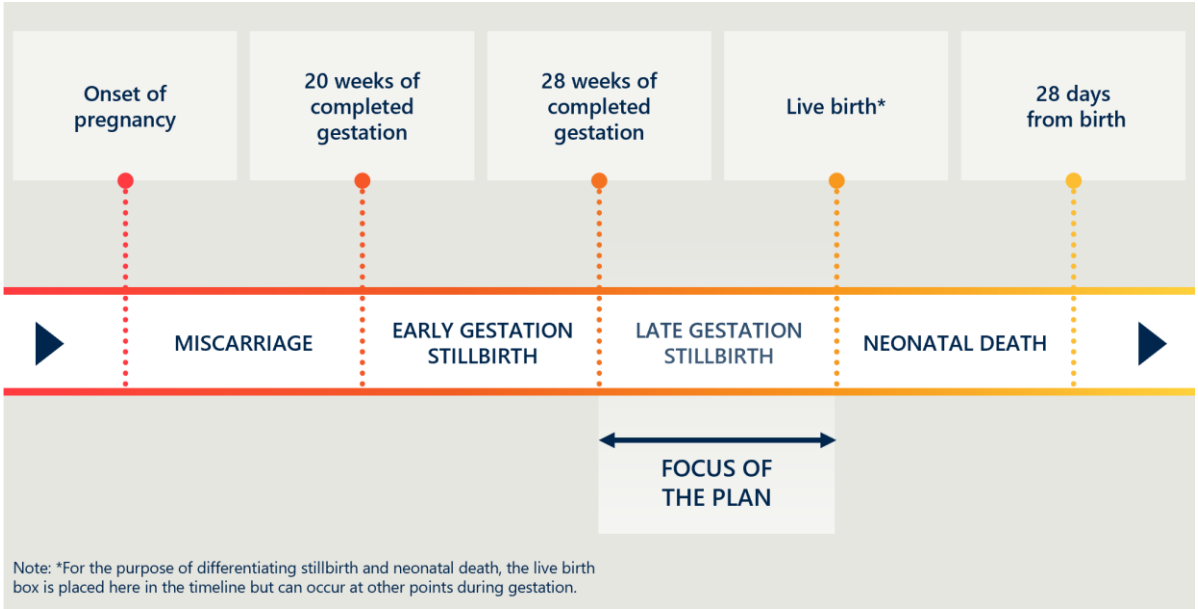
1.1 Background and purpose of the Action Plan

Stillbirth leaves a deep impact on individuals, families and communities

Experiences of stillbirth have a deep and lasting effect, with the impacts felt far beyond the parents involved. Australia has about six stillbirths a day, affecting over 2,000 families each year, causing profound grief, anxiety, fear and suffering.[5] With an aim to reduce stillbirth rates and improve bereavement care, the Australian Government launched the National Stillbirth Action and Implementation Plan (the Action Plan) in December 2020.

Some stillbirths are unavoidable. There must be strong support systems in place to help women, their families and their communities through these events. However, a proportion of stillbirths are preventable, and it is these cases that the Action Plan seeks to reduce (see Figure 3). The Action Plan's focus is on stillbirths after 28 weeks gestation,[6] but it is also anticipated that the Action Plan will contribute to a reduction in stillbirths at earlier gestations.

Figure 3 | Pregnancy loss, live births and neonatal deaths



[5] Australian Institute of Health and Welfare, *Stillbirths and neonatal deaths*, 2022, https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths.

[6] In Australia, stillbirth refers to foetal death prior to birth of baby of 20 or more weeks gestation or more than 400 grams birthweight. The Action Plan, however, focuses on stillbirth post 28 weeks gestation, which aligns with World Health Organization's definition, as most preventive interventions are specific to that period after 28 weeks.

A NOTE ABOUT THE TERM 'PREVENTABLE' STILLBIRTH:

The term 'preventable stillbirth' refers to stillbirths resulting from preventable conditions such as maternal infection, non-communicable disease, obstetric complications, preventable congenital disorders and behavioural factors (for example smoking, etc.). High-quality antenatal and intrapartum care which also support behavioural change are the key to reducing the rate of preventable stillbirths globally.

One of the Action Plan's goals is to reduce 'preventable stillbirths' at or after 28 weeks gestation. For the purpose of this report all stillbirths at or after 28 weeks gestation are considered preventable, as there is often limited information to identify whether the stillbirth resulted from a preventable cause.

In no way does Nous intend to suggest that *all* stillbirths are preventable. There are no steps that women, their care givers or others around them can take to completely eliminate the risk of stillbirth.

Australia's stillbirth rate is higher than in countries that implement broadscale best practice in stillbirth prevention and care

Australia's stillbirth rate has been decreasing,[7] yet it is still higher than in other countries that implement broadscale best practice stillbirth prevention and care.[8] Australia performs well among Organisation for Economic Co-operation and Development (OECD) countries, but stillbirth rates are inequitable, mainly with the identified target cohorts – First Nations women, migrant and refugee women, women living in socially disadvantaged areas, or regional and remote areas, women under 20 and women who have a previous experience of stillbirth.

Estimates drawn from clinical audits in Queensland suggest that around one-third of stillbirths could be avoided with improved care.[9]

This is Australia's first national plan to reduce stillbirth rates and improve bereavement care

In March 2018 the Senate Select Committee on Stillbirth Research and Education was established in response to the relatively high rate of stillbirths in Australia and substantial advocacy work by bereaved parents, advocacy groups, researchers and health professionals. Stemming from this committee, Australia's first national Action Plan to reduce stillbirth rates was launched in December 2020. The key features of the Action Plan are discussed in more detail in Section 5.

1.2 Scope and purpose of this first evaluation report

Evaluations can surface insights about the appropriateness, efficiency, effectiveness and impact of initiatives like the Action Plan. The act of evaluation can demonstrate accountability to the public and promote learning for the wider system.

The Department of Health and Aged Care engaged Nous to develop a Monitoring and Evaluation Framework 2022-2030 spanning the Action Plan's lifetime, from the start of implementation in 2020 to 2030. The purpose of the evaluation is to consider the plan as a whole, how it is being implemented and what outcomes it is achieving. It does not involve a detailed evaluation of initiatives within the Action Plan.

This first evaluation report covers the period between January 2020 and December 2022 and is targeted to the Department of Health and Aged Care and the Action Plan's implementers. The report is structured to:

- establish a baseline against which outcomes can be compared over time

[7] Stillbirth rates occurring at 28 weeks' gestation or more has decreased since 2003. Australian Institute of Health and Welfare, *Stillbirths and neonatal deaths*, 2022, https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths.
[8] Flenady V, et al., 'Stillbirths: recall to action in high-income countries', *Lancet*, 2016, vol 387, no. 10019, p. 691-702.
[9] Flenady, V, et.al., 'Making every birth count: outcomes of a perinatal mortality audit program', *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 2021, vol 6, no. 4, p. 540-547.

- evaluate the appropriateness of the Action Plan's design
- discuss implementation progress against the five priorities
- identify early outcomes and consider the extent to which the Action Plan is on track to achieve its long-term goals
- highlight opportunities to inform ongoing implementation efforts.

2 Evaluation methodology

Nous has followed a robust evaluation framework that was developed through extensive research and consultation in 2021–22. The methodology for this evaluation was developed and agreed with input from the Department of Health and Aged Care and other key implementers. This section provides an overview of the program theory that underpins the evaluation; an overview of the various data collection activities undertaken; and a summary of key limitations to data collection and interpretation.

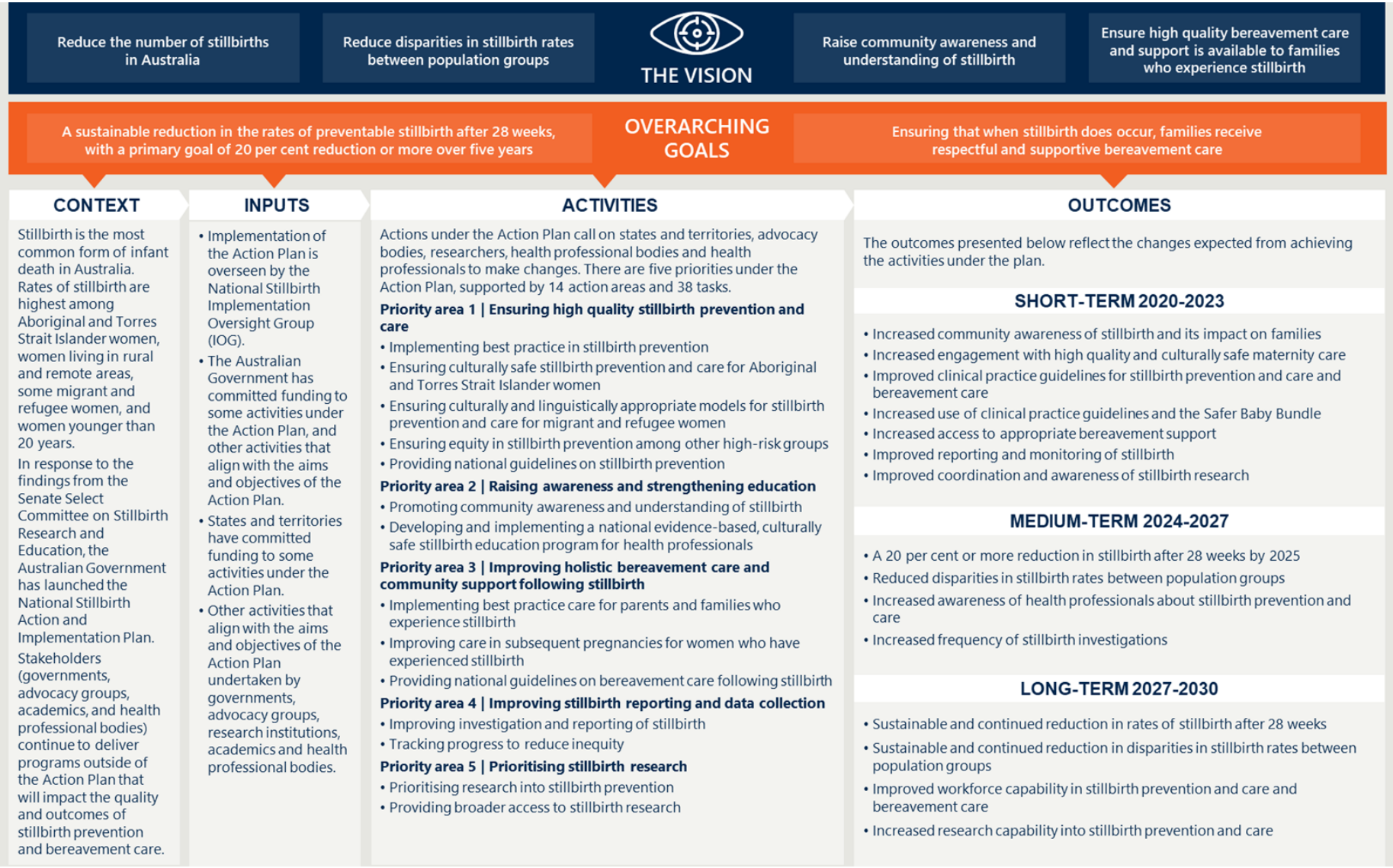
2.1 The evaluation is grounded in program theory

Nous' evaluation is underpinned by a program logic and theory of change that describe how the National Stillbirth Action and Implementation Plan (the Action Plan) intends to achieve its objectives.

- The **theory of change** (shown in Figure 4) describes the underlying mechanisms through which the Action Plan seeks to reduce preventable stillbirths and provide enhanced bereavement support.
- The **program logic** (shown in Figure 5) describes how the theory of change will be achieved by setting out clear relationships between inputs, activities, and outputs of the Action Plan, and the intended short-, medium- and long-term outcomes. Within Figure 5, the vision and goals of the Action Plan are summarised, along with the five priority areas under which the Action Plan's strategies are organised. These are discussed further in Section 4.1 as part of a broader discussion around the Action Plan's design.

Figure 4 | Theory of change

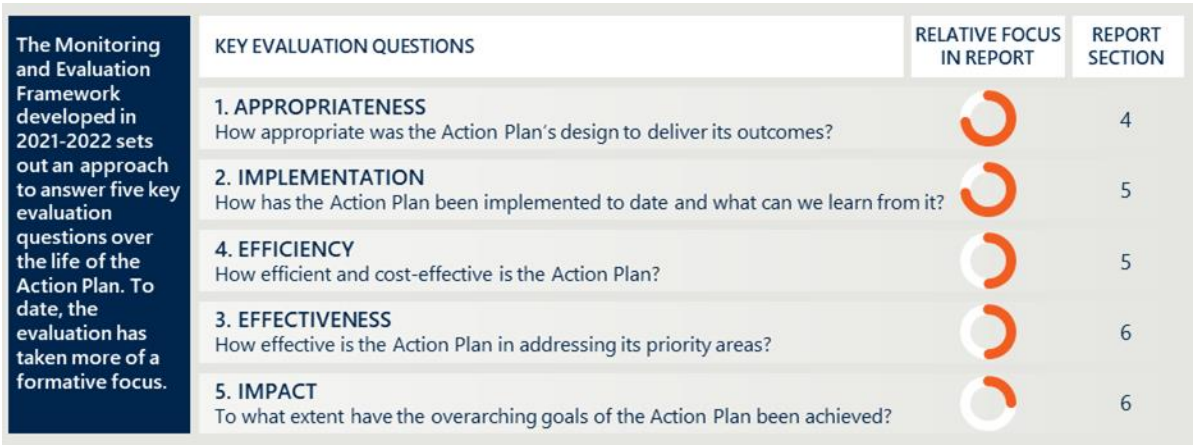
Figure 5 | Program logic for the Action Plan



2.2 Key evaluation questions

The program theory is tested through key evaluation questions, which were agreed in the Monitoring and Evaluation Framework 2022–2030. Figure 6 summarises the five questions, highlights the degree to which these can be answered two years into the implementation period, and provides information about where key information can be found in this report. Appendix A.1.3 lays out the key evaluation questions in more detail.

Figure 6 | Key evaluation questions



2.3 Data collection activities

Data collection is a critical component of the evaluation process. Nous gathered data through extensive desktop research, consultations with various stakeholders (see Appendix B and program data analysis for this report). The following evaluation methodology sub-sections elaborate on these data collection and analysis activities.

2.3.1 Desktop research

Desktop research was conducted to develop findings. This included:

- distributing and reviewing the **Annual Implementers' Progress Updates**. This is a standard data collection template that was sent out to all implementers in order to gather consistent information on delivery context, implementation activity, barriers and enablers to implementation, and any relevant jurisdictional or task-specific information (for example other evaluation reports)
- reviewing **pregnancy, stillbirth and bereavement care guidelines** to assess their alignment with national guidelines, in accordance with the methodology set out in the Monitoring and Evaluation Plan 2022-2024 (adapted as guidelines are being updated)
- reviewing **research and grant registers** to assess changes in the coordination of stillbirth related research funding, in accordance with the methodology set out in the Monitoring and Evaluation Plan 2022-2024 (adapted as research priorities are being updated)
- regular scanning of **publicly available information** to monitor implementation and developments in the stillbirth space
- reviewing relevant **academic and grey literature and state/territory and federal policies, strategies, budgets and legislation** to understand the Action Plan in context

- conducting an **international comparator review** (detail at Appendix D) of five countries to draw out the similarities, differences and learnings from these programs.

2.3.2 Consultation activities

Consultation was a central element of this evaluation. Nous identified stakeholders across the system to provide diverse perspectives on the Action Plan and its implementation. Nous conducted over 30 semi-structured interviews between October 2022 and February 2023. A full list of stakeholders consulted is in Table 17. They included the following groups:

- Australian Government and state/territory health departments
- health professional and hospital peak bodies
- not-for-profit and advocacy organisations
- research and data organisations.

Consultations were used to explore data provided, to gain a nuanced understanding of barriers and enablers of implementation and of the Action Plan itself, and to develop and confirm emerging evaluation findings. Qualitative data from consultations were triangulated with quantitative data throughout the evaluation period to verify and deepen findings.

2.3.3 Program data and analysis

Nous drew on a combination of qualitative and quantitative data to make findings in this report. Wherever possible, multiple data sources were used to infer findings, using a process called triangulation.

The key indicators summarised in Table 2 are broadly quantitative in nature (proxy data were used for four out of 18 indicators where data were not available to provide a direct measure of the indicator). A broad range of statistical analysis was undertaken using data, including analysing trends over time, and well as exploring differences in outcomes between population groups.

Qualitative data also went through robust analytical approaches, including thematic analysis to surface common themes and patterns gleaned from data collected from multiple stakeholders and other qualitative resources.

Table 2 | Indicators showing data available for baseline evaluation

#	Indicator	Baseline (2020 calendar year)	New data up to end of 2022
1	Decrease in the rates of stillbirth at greater than or equal to 28 weeks gestation (disaggregated by target cohorts for greater than or equal to 20 weeks).	Yes	No
2	Increase in the proportion of women who received care via continuity of care models.	No	No
3	Increase in the proportion of women who have had continuity of carer during antenatal, delivery and postnatal care.	Proxy: proportion of models of care	Proxy: proportion of models of care
4	Increase in the proportion of women (overall and in target cohorts) attending 7 or more and 10 or more antenatal care visits.	Yes	No
5	Increase in the proportion of women (overall and in target cohorts) attending their first antenatal appointment within first 10 weeks of pregnancy.	Yes	No
6	Increase in the availability of maternity services specific to target cohorts (as defined by the Action Plan).	Yes	Yes
7	Increase in the number of Aboriginal and Torres Strait Islander maternity care professionals.	Yes	Yes
8	Increase in the availability of culturally safe maternity care.	Yes	No
9	Decrease in the proportion of women smoking tobacco during pregnancy.	Yes	No
10	Increase in the number and reach of publicly funded programs promoting awareness of stillbirth, risk factors and prevention strategies.	Proxy: webpage views	Proxy: webpage views
11	Increase in alignment of hospital, organisational and professional body guidelines with PSANZ (Perinatal Society of Australia and New Zealand) *Clinical practice guideline for care around stillbirth and neonatal death* and the national *Clinical Practice Guidelines – Pregnancy Care*.	Yes	No
12	Increase in the proportion of health professionals completing IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) training programs.	Yes	Yes
13	Increase in awareness and ability for bereaved women and families to access bereavement care (overall and in target cohorts).	Proxy: quality of bereavement care in hospital; services accessed in the community	Proxy: quality of bereavement care in hospital; services accessed in the community
14	Increase in the proportion of women and/or families who are offered stillbirth investigation(s).	No	Yes
15	Increase in the proportion of women and/or families who consented to a stillbirth investigation(s).	Proxy: number of autopsies performed	Yes
16	Decrease in the proportion of stillbirths that are unexplained.	Yes	No
17	Increase in the timeliness of published stillbirth data.	Yes	Yes
18	Increase in the number of research projects in, and amount of funding granted to, the stillbirth priority research areas.	Yes	Yes

2.3.4 Key limitations in the evaluation methodology

Limitations to evaluation scope

The scope of the evaluation is focused on the collective impact of the Action Plan. It does not include evaluation of specific tasks or activities, maternity services or models of care. Along the same lines, this evaluation does not report on the implementation progress or outcomes of individual states or territories. It only reports aggregated, national progress and outcomes. It also does not include direct consultations with bereaved women and their families, pregnant women or First Nations women. This limits the focus on insights and perspectives of the first-hand recipients of the Action Plan.

Data limitations

Several limitations arise from the data collection methods of the Action Plan:

- **Current national data reporting combines stillbirth (at 20 weeks or more gestation) and late term pregnancy termination numbers** (see call out box below). This can cloud the understanding of preventable stillbirths, as fluctuations in pregnancy terminations can impact the overall stillbirth rate.
- **As the Action Plan aims to reduce preventable stillbirths after 28 weeks gestation, and it may also impact rates of stillbirth at earlier gestations**, this evaluation intends to capture rates for stillbirths at 20 weeks or more as well as 28 weeks or more gestation. This is to ensure that broader changes in the stillbirth rate are captured and to increase the availability of data relevant to the Australian definition of stillbirth.
- **It is difficult to differentiate the experience of supports for women experiencing a first stillbirth from those experiencing a second or later one in most available data.** Evidence indicates that a previous stillbirth is a significant risk factor for later pregnancies, but the lack of specific data on this cohort limits targeted commentary.
- **A time lag has also been noted in data on key maternity services and stillbirth.** The need to finalise investigations before reporting information, as well as rigorous data governance and quality assurance processes at the state/territory and national level, leads to an average delay between event and data release of two years (with preliminary data being released at 12 months). This impacts the ability to develop contemporaneous insights grounded in this data.
- **The practice of withholding data with small counts** to protect the privacy of individuals, known as cell suppression, limits the evaluation's ability to develop insights relating to infrequently occurring combinations of individual characteristics. This is unavoidable when working with sensitive health data.

STILLBIRTH versus TERMINATION OF PREGNANCY REPORTING

Historically in Australia, some late-term pregnancy terminations (after 20 weeks) have been reported as stillbirths. In Australia, the laws governing access to pregnancy termination services are a state and territory responsibility. Pregnancy termination is legal in all jurisdictions, however the circumstances in which pregnancy termination services can legally be provided vary.

Most states/territories have gestational time limits for termination of pregnancy, ranging from 14 to 24 weeks gestation. Pregnancy terminations beyond these gestational limits are rare and tend to occur in circumstances involving complex medical circumstances, including serious or fatal foetal anomalies.

Jurisdictional changes around access to termination of pregnancy may limit the comparability of stillbirth rates over time. There is work underway with states and territories to improve data quality for reporting terminations of pregnancy separately from stillbirths.

3 Establishing the baseline

The National Stillbirth Action and Implementation Plan (the Action Plan) was launched in December 2020. This section provides headline baseline data against which progress and outcomes can be compared. Insights have been structured under the Action Plan's five priority areas and provide data against the 18 agreed outcome indicators (further described in Appendix A.1.1), where this data is available at or prior to December 2020.

Section 3 focuses on summarising key themes and trends as they relate to the five priority areas. To support brevity and readability of this section, extensive analysis and referencing of data sources has been omitted. Please note, however, that **this detail and referencing has been provided in a comprehensive manner in Appendix C.**

3.1 Implementing and evaluating the Action Plan in the context of COVID-19

The COVID-19 pandemic, which started in Australia in early 2020, has had significant direct and indirect impacts on maternity care in Australia, with implications for stillbirth rates.

Like other specialities, the maternity care system has experienced pressures on staffing (both clinical and policy staff) and supply chains. This has led to delays in treatment, longer wait times for appointments and procedures, and reduced access to necessary medical interventions. Changes to hospital policies and practices, such as visitor restrictions and reduced availability of elective procedures, have also led to disruptions in antenatal care and limited access to medical interventions. Some women have also opted to avoid potential contact with COVID-19, leading to reduced participation in antenatal services.

Indirect impacts have included heightened stress and anxiety for expectant mothers, as well as increased financial strain and social isolation, which can contribute to poor maternal and foetal outcomes, including stillbirth.

In addition, the pandemic has highlighted existing inequities in maternity care, with vulnerable populations facing even greater barriers to accessing quality care than the general population. This includes women from low-income households, First Nations communities, culturally and linguistically diverse communities, and regional and remote areas, who may face limited access to healthcare services.

The scale of the impact of the COVID-19 pandemic on maternity care is still being determined.

The figures presented at baseline cover the period up to the end of the 2020 calendar year. Where possible, longitudinal data has been included to show trends over time and offset any sudden changes occurring in 2020, directly or indirectly related to the pandemic.

3.2 Target cohorts and the effects of intersectionality

The Action Plan identifies certain cohort groups who experience disproportionately high rates of stillbirth, and it includes actions that aim to reduce these inequities. The target groups are:

- First Nations women

- migrant and refugee women (particularly from African and Southern and Central Asian areas)[10]
- women living in regional and remote areas[11]
- women living in socially disadvantaged areas[12]
- women aged under 20 years
- women who have previously experienced stillbirth.

Any discussion about target cohorts must be nuanced by understanding that they are significantly more likely to experience complex and intersectional challenges across many aspects of their lives.

Systemic barriers such as societal power imbalances, racism, discrimination, intergenerational trauma and disadvantage contribute to the inequitable health outcomes experienced by these cohorts and create additional difficulties when attempting to redress those inequities.

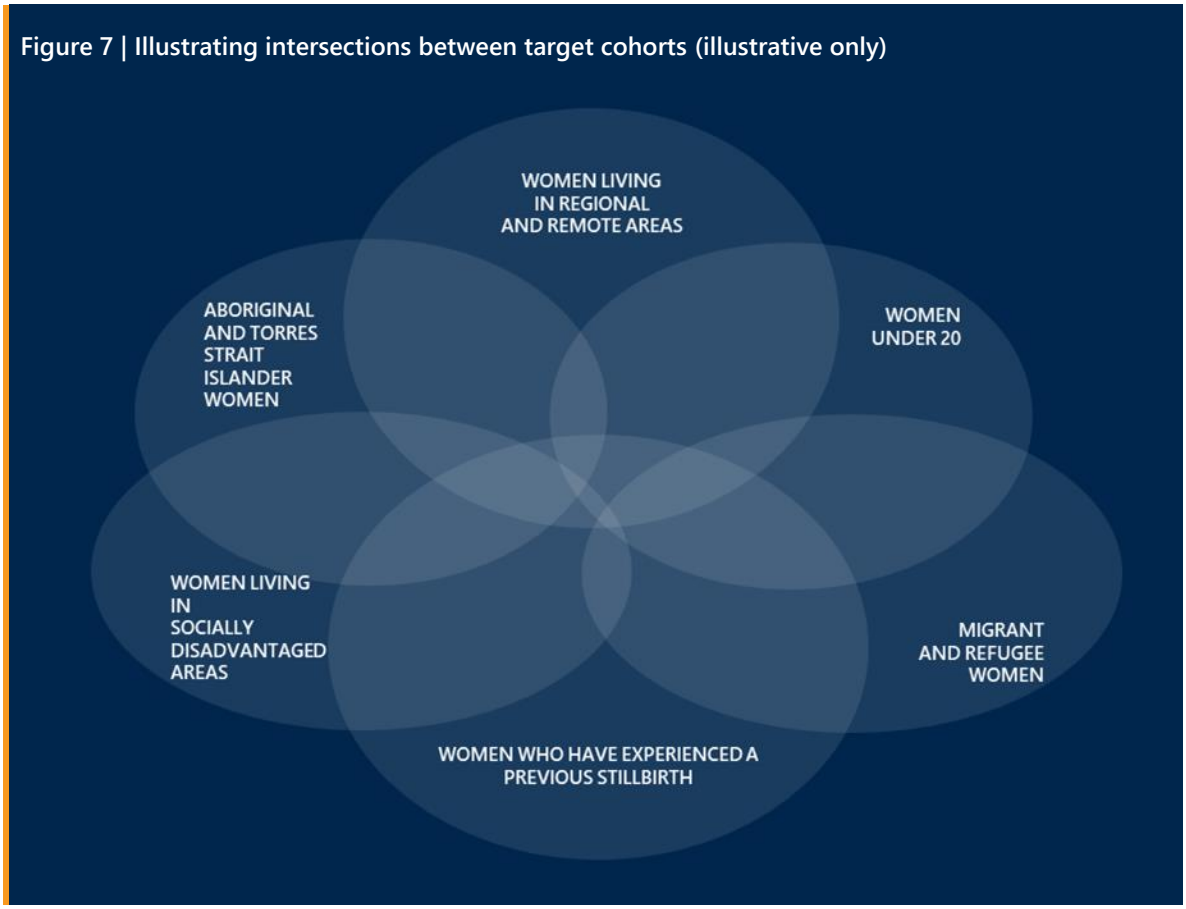
Additionally, the intersections of these identities can lead to unique experiences of disadvantage and can create significant barriers to accessing quality health care and resources. This exacerbates and compounds their risks for adverse maternal and foetal outcomes, including stillbirth (see Figure 7).

For example, a higher proportion of First Nations women who are pregnant live in regional and remote areas, and they are on average younger than non-First Nations pregnant women. Women living in regional and remote areas are also more likely to experience socioeconomic challenges. The effects of racism, poverty, discrimination, lack of social support, and distance combine to make it harder for them to access timely, high quality medical care that meets their needs.

Data is more available for some of these groups than others, depending on the topic. Challenges exist to determine the degree of intersectionality, or overlap, in target cohorts, as the sample size makes analysis that teases out the respective impact of individual factors beyond what is presented difficult. Future evaluations will consider whether more detailed analysis will be possible.

[10] Due to data availability, this evaluation reports data for migrant and refugee women born in three different country groups: North Africa and Middle East, Sub-Saharan Africa, and Southern and Central Asia.
[11] Women living in outer-regional, remote and very remote areas based on applying the Australian Bureau of Statistics 2016 Australian Statistical Geography Standard (ASGS).
[12] Women living in disadvantaged quartile one (Q1) based on the application of Australian Bureau of Statistics 2016 Socio-Economic Indexes for Areas.

Figure 7 | Illustrating intersections between target cohorts (illustrative only)



3.3 Baselining Priority 1: Ensuring high quality stillbirth prevention and care

Stillbirth prevention relies on all women and health care professionals talking about stillbirth and taking active steps to identify and manage key risks if they appear. Responses can relate to better management of behavioural risk factors or the approach taken for antenatal clinical care, or even when interventions are engaged during late pregnancy or birth. These responses work best when women have access to high quality, culturally safe care during their pregnancies. This includes continuity of care across the maternity journey.

In relation to behavioural risk factors, **smoking was declining in the lead up to 2020, however some target cohorts (particularly First Nations women) were more likely to smoke than other pregnant women.** Though no link between vaping and stillbirths has been determined, vaping was presenting as a worrying new trend, attracting new generations to inhaling potentially dangerous chemicals with the potential to compromise the health of women and their babies.

When women found out they were pregnant, most of them received at least some antenatal care. Working consistently with a trusted health care professional is generally accepted as best practice for low-risk pregnancies; however, only a minority of maternity models available across Australia were midwifery continuity of care or other maternity continuity of carer models.

Some maternity models of care were specifically designed to support target cohorts (particularly First Nations women and women from migrant or refugee backgrounds), but reliable data was not available about how many women were actually serviced through different models of care and, therefore, the extent to which their cohort-specific needs had been met.

Stillbirth rates have been largely unchanged between 2003 and 2020 for stillbirths at 20 weeks or more gestation, while stillbirth rates for stillbirths at 28 weeks or more have shown a general decline across the same period of time. However, target cohorts have higher rates of stillbirth than the general population.

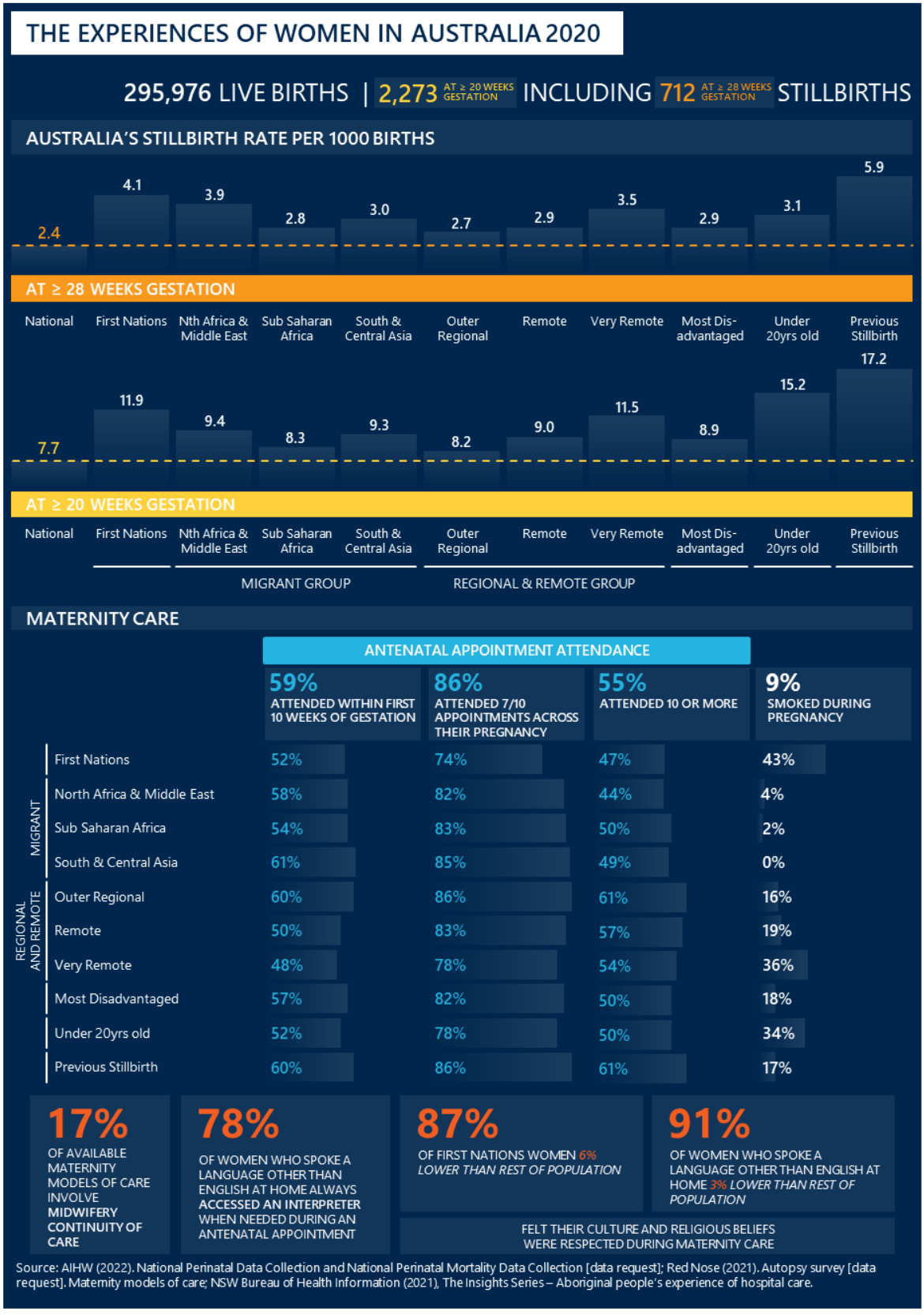
Stakeholders also reported that **awareness of stillbirth risks had been increasing** ahead of the release of the Action Plan, which was raising readiness to respond to and mitigate risks; however, this was also correlated with increasing anxiety among some women and their health care professionals.

Figure 8 summarises key statistics on Australia's stillbirth rates and experiences of care in 2020. Figure 9 summarises statistics on the maternity care landscape.

THE ROLE OF CULTURE

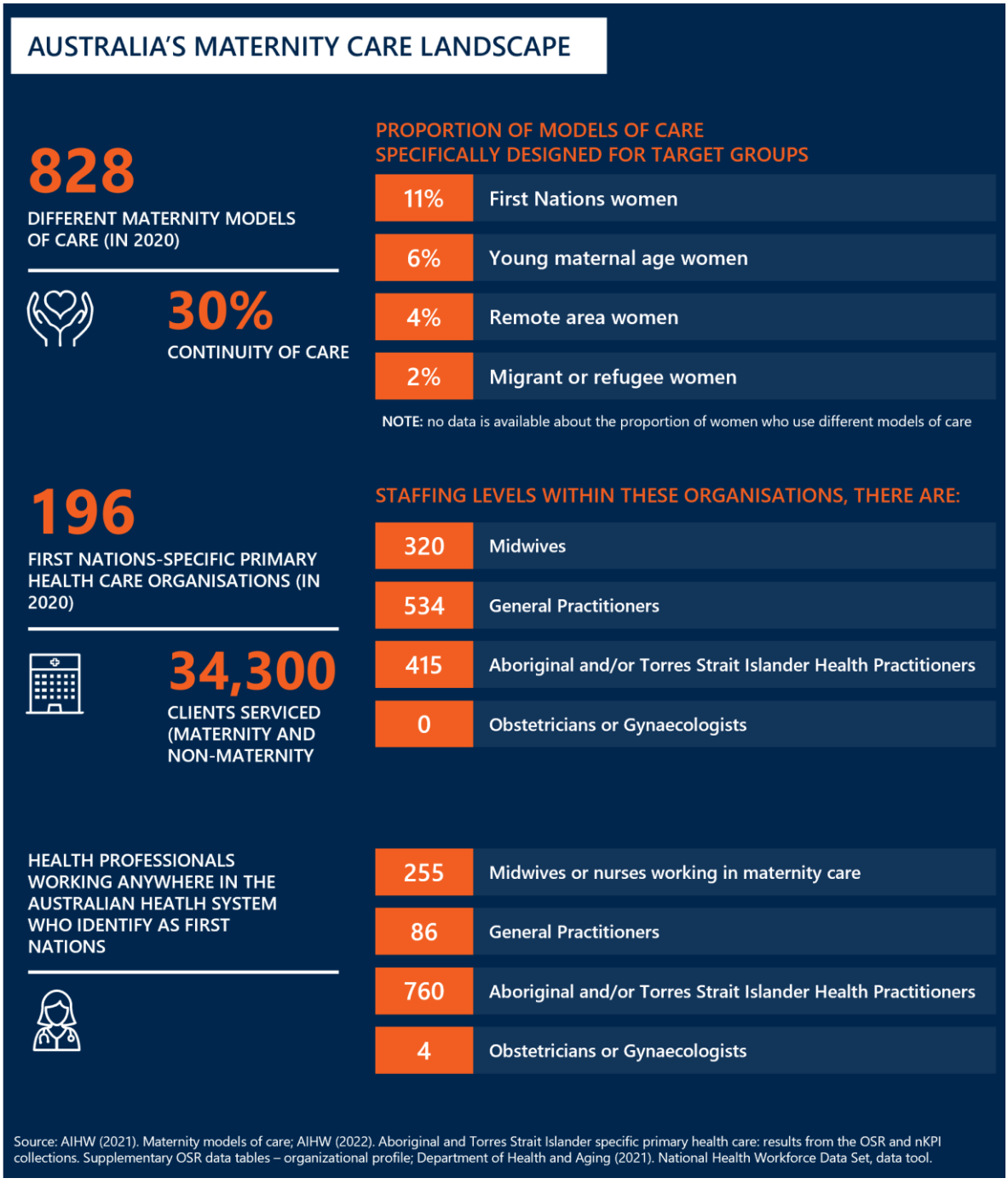
Many cultures and societies around the world stigmatise stillbirth or consider it a taboo topic. The lack of understanding of stillbirth means that many clinicians, women and families may find it difficult to discuss as a possibility during antenatal care, and that women and families cannot openly express their grief after a stillbirth, discuss their concerns or get sufficient bereavement support. These cultural practices may hinder women's engagement in stillbirth related activities in Australia. Health professionals need to be aware of cultural issues and raise the issue of stillbirth in a way that is culturally appropriate.

Figure 8 | Summary of Australia's stillbirth rates and related maternity care in 2020[13]



[13] See Appendix E for more detailed and complete presentation of statistics.

Figure 9 | Summary of key data relating to Australia's maternity care landscape in 2020



3.4 Baselining Priority 2: Raising awareness and strengthening education

Pregnant women and their health care professionals need to know about good practice so they are prepared to discuss stillbirth, manage risk factors and navigate the bereavement period if a stillbirth does occur. Raising awareness and strengthening education is therefore about how information is distributed and the degree to which individuals feel competent and confident to act.

In the lead up to the release of the Action Plan, **there were already a variety of efforts underway** to promote awareness of stillbirth, risk factors and prevention strategies. For women and their families, organisations such as Red Nose Australia, the Stillbirth Foundation of Australia and Still Aware were undertaking activities to promote awareness of stillbirth.

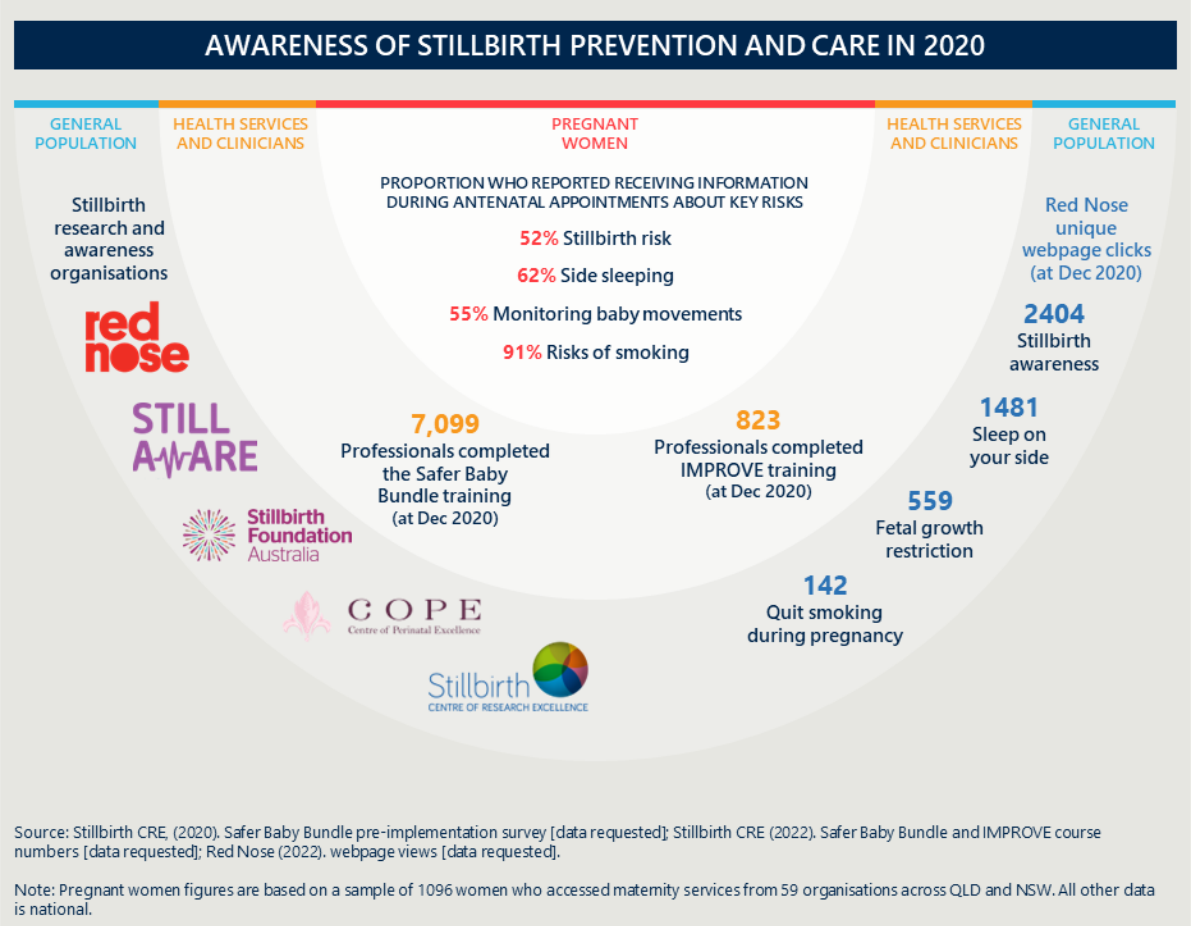
Importantly, most of these resources were written for the general population. Uptake among target cohorts was known to be low, hampered by factors such as content being available only in English, or not being presented in a culturally safe way.

Health care professionals were also being supported to learn. For example, the Safer Baby Bundle was already well underway with good uptake across its e-learning offerings. The IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) program was also known to be raising competence and confidence amount clinicians to support women and their families after a stillbirth.

Stakeholders reported that clinical care was most directly influenced by hospital guidelines. These in turn should be informed by professional body and national guidelines. However, there was evidence that **at baseline this alignment varied.**

Figure 10 provides an overview of stillbirth education and awareness activities.

Figure 10 | Summary of stillbirth awareness raising and education activities and their uptake by their target audiences in 2020



Source: Stillbirth CRE, (2020). Safer Baby Bundle pre-implementation survey [data requested]; Stillbirth CRE (2022). Safer Baby Bundle and IMPROVE course numbers [data requested]; Red Nose (2022). webpage views [data requested].

Note: Pregnant women figures are based on a sample of 1096 women who accessed maternity services from 59 organisations across QLD and NSW. All other data is national.

3.5 Baselining Priority 3: Improving holistic bereavement care and community support following stillbirth

Stillbirth can be incredibly traumatic, with the pain, distress and long-term impacts being felt not only by the mother but also by her family, community, and health care team. This trauma can also impact future pregnancies.

Supporting people through stillbirth and bereavement requires an awareness of good practice, confidence to offer support, and access to relevant support services and structures.

In 2020, it was clear that quality bereavement care was challenging to deliver, not least because it is not consistently defined and measured. Women and their families need support from the time they are first advised there may be a problem with their baby, through the hospital experience of birthing and postnatal care, to the funeral, back into the community, into subsequent pregnancies and years beyond. Good quality bereavement care looks different at each of these stages, varies depending on individual needs, and is also influenced by cultural perspectives of death, grief and healing.

Available data suggests that during their hospital stay, **women and their families received relatively good bereavement care**: they were given information in sensitive ways and supported to make decisions.

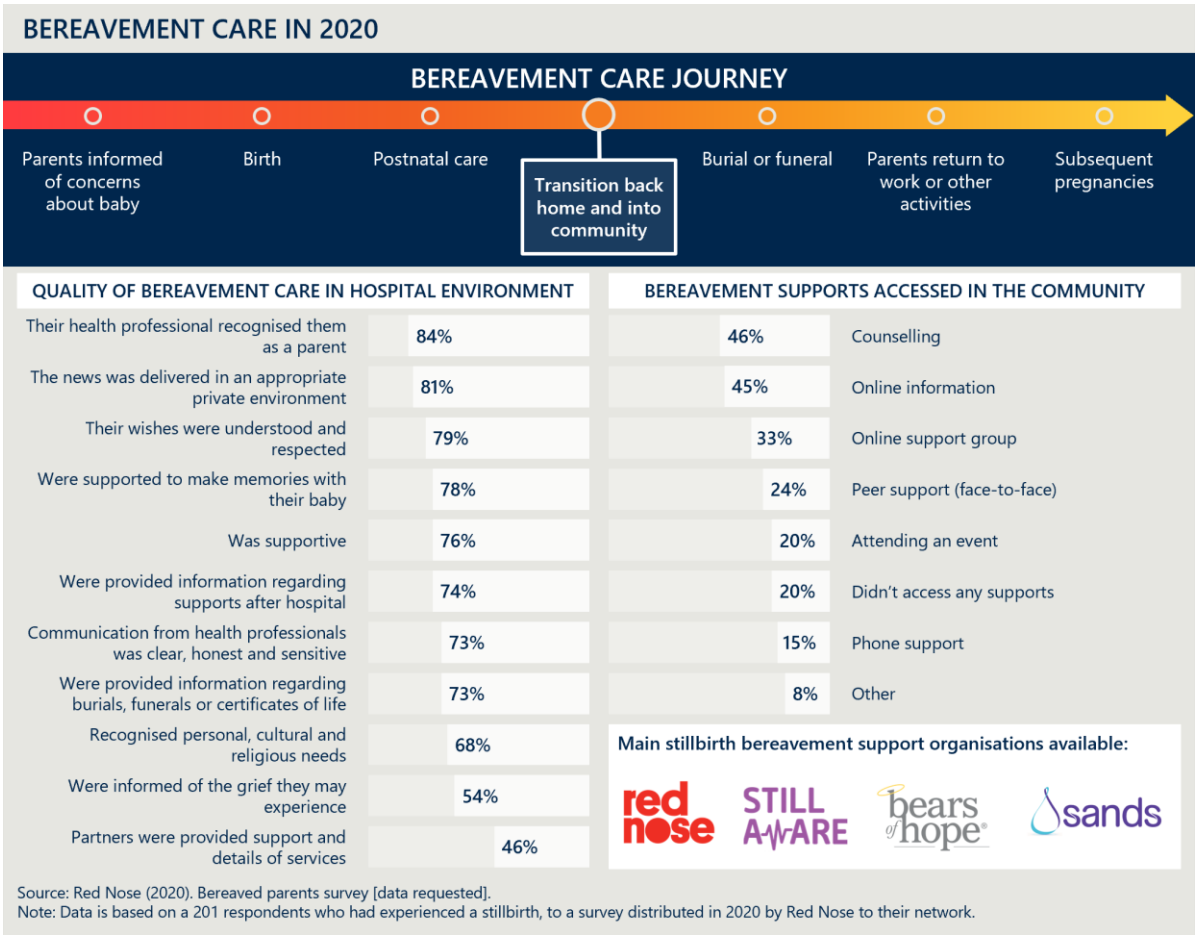
However, the transition from the hospital to the home and supports in the community was highlighted as a fracture point, where continuity of care can be disrupted and bereavement support can drop off. While only 20% of women reported that they did not access any supports after a stillbirth, data suggests

that women can struggle to connect with the most valuable supports at this time. This can be in part due to a lack of awareness around what is available, but also due to the limited availability and suitability of services, such as culturally safe bereavement supports and supports available to women living in regional and remote communities.

There was a sense that **stigma around stillbirth was a real and pressing factor,** and that this compounded the difficulties of the bereavement process.

Figure 11 provides an overview of available data around bereavement care.

Figure 11 | Summary of self-reported quality of bereavement care in hospital environment and self-reported bereavement supports accessed in community



Source: Red Nose (2020). Bereaved parents survey [data requested].
Note: Data is based on a 201 respondents who had experienced a stillbirth, to a survey distributed in 2020 by Red Nose to their network.

3.6 Baselining Priority 4: Improving stillbirth reporting and data collection

There is much about stillbirth that is currently unknown. New research findings around the prevention of stillbirth or provision of bereavement support relies on good data. Moreover, data that is useful and timely can be better incorporated into clinical guidelines, policy and practice.

At baseline, the underlying cause of stillbirth was unexplained for around 13% of stillbirths, and it is likely that investigations were not carried out as frequently as they could be to surface answers. Stillbirth investigations are medical procedures or tests aimed at determining or confirming the cause of a stillbirth. While it is important to recognise that not all women and their families *want* stillbirth investigations, some notable factors that influence the uptake of investigations can be the availability of suitable health care professionals or services, and the value that the health professional places on the investigations. Even

when an investigation is undertaken, there may not be a conclusive cause determined. However, this can make it possible to rule out other potential causes, which may help bereaved families grieve and provide reassurance for subsequent pregnancies.

In 2020, **perinatal pathologists and radiologists were in short supply.** There was also some live debate about the most appropriate investigations to carry out to give families – and the broader health community – the answers they needed.

There were also **limited decision-making resources available to support bereaved parents and families** to consider the value of investigations following a stillbirth. This meant that families' awareness of stillbirth investigation as an option was not as strong as it could have been. Figure 12 provides an overview of the factors that can impact on a family's decision to pursue or decline a stillbirth investigation.

Furthermore, **when investigations were carried out, there were challenges in collecting, reporting and sharing this data in a way that supported capability uplift across the system.** Timeframes to finalise investigations before data supply to the Australian Institute of Health and Welfare (AIHW) and, to a lesser extent, Women's Healthcare Australasia (WHA) contributed to significant delays in publishing stillbirth data, insights from post-mortem investigations or other information that could benefit clinical or policy decision-making or other research efforts.

Figure 12 | Summary of stillbirth related investigations, classification and data reporting in 2020[14]

[14] Data unavailable at baseline to report number of stillbirth investigations offered to bereaved parents. See Appendix E for more complete presentation of statistics. There are likely additional reasons for parental choice that were not captured in available data, such as to inform future family planning.

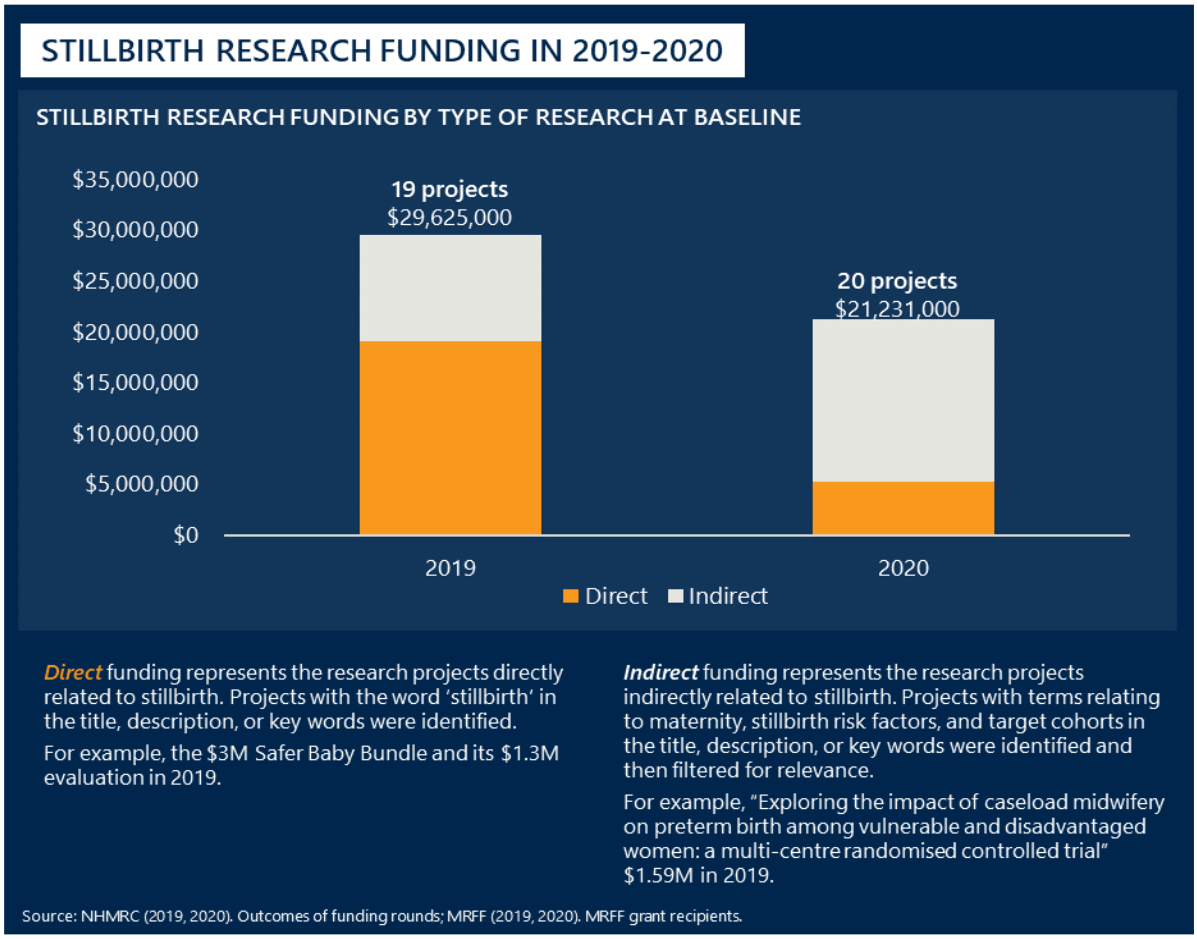
3.7 Baselining Priority 5: Prioritising stillbirth research

Expanding the stillbirth research base contributes to an understanding of stillbirth prevention, risk factors, causes, treatment, and bereavement care. There are many experienced researchers in institutions across Australia working in the field. However, their collective effort and expertise can only be optimised through good coordination of research which is anchored to agreed national priorities; adequate research funding to drive this work; and dissemination of findings.

At baseline, stakeholders reflected that breakthroughs in stillbirth research had been scarce, although there was some recent energy within the system to increase focus on this area of health. **Work had begun towards defining stillbirth research priorities,** led primarily out of Stillbirth Centre of Research Excellence.

This evaluation tracks Australian Government funding from the National Health and Medical Research Council (NHMRC) and the Medical Research Future Fund (MRFF).[15] **In 2019 and 2020, stillbirth research funding was mixed**: funding dedicated to stillbirth specific research declined from 2019 to 2020, but this was offset by increased funding to research that could indirectly improve stillbirth outcomes through a focus on behavioural interventions and broader pregnancy care. This kind of year-on-year variation is to be expected, given the cyclical and multi-year nature of most research projects. Figure 13 provides an overview of stillbirth research funding in 2019 and 2020.

Figure 13 | Summary of stillbirth research funding allocated in 2020



[15] The MRFF has verified the figures for research funding provided by the MRFF that is *directly* related to stillbirth. The figures for other direct funding and for MRFF *indirect* funding were drawn from public information and classified by Nous on the basis of independent analysis of their relationship to stillbirth risk factors, other behavioural interventions, and maternity care. See Section C.5.2 for methodology details.

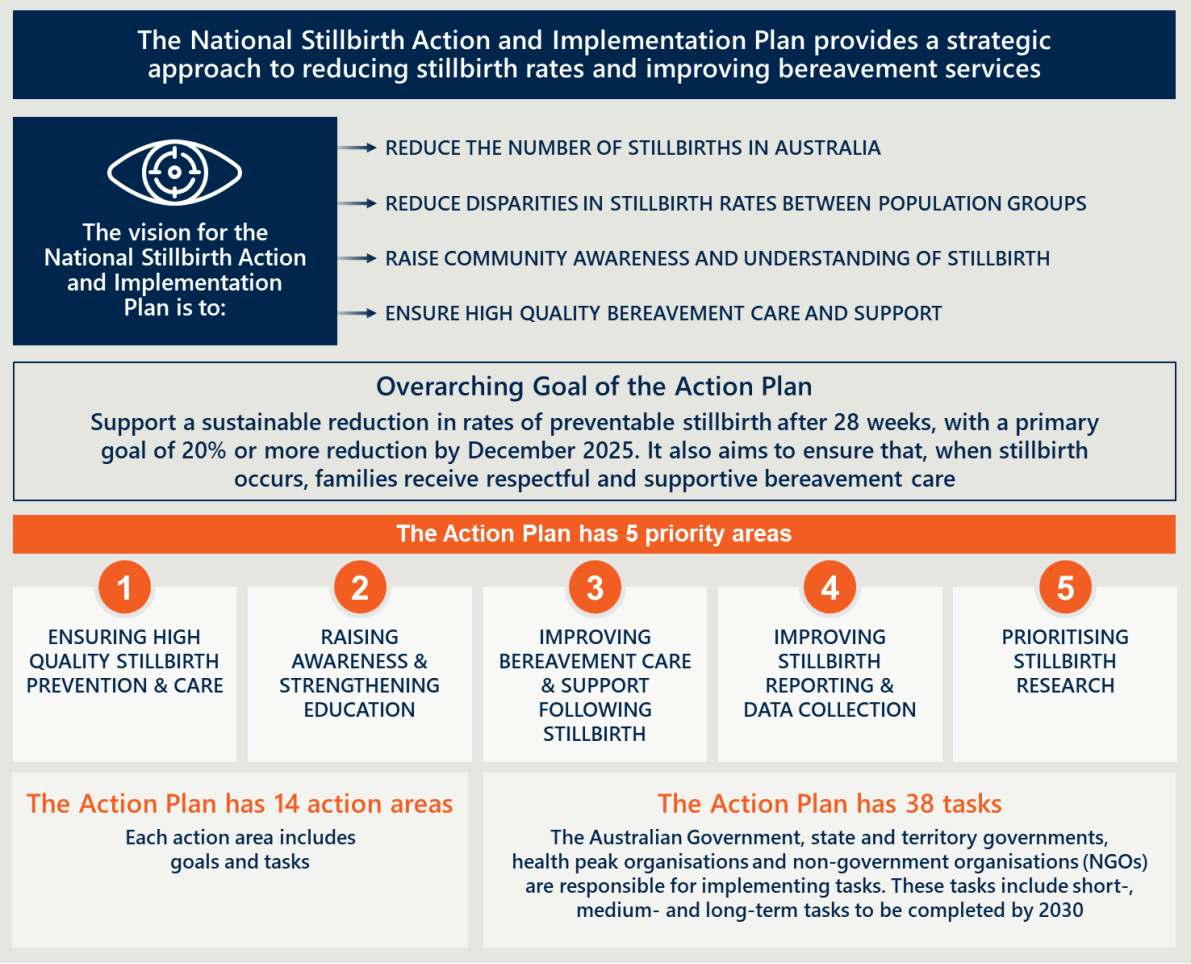
4 Strengths and limitations of the Action Plan's design

A strong design is foundational to a successful National Stillbirth Action and Implementation Plan (the Action Plan). This evaluation found that this Action Plan was appropriate for achieving its goals. This section describes key features of the Action Plan and the degree to which its design was appropriate, based on good evidence and championed into practice by engaged stakeholders.

4.1 The Action Plan sets out a comprehensive approach to reduce stillbirth rates and improve bereavement services

The Action Plan has two overarching goals and five priority areas to achieve its goals (see Figure 14). Activities under the Action Plan focus on stillbirth prevention and care, support afterwards, and the supporting pillars of education and awareness, data and research. The Action Plan further acknowledges the disparities in stillbirth rates between the target cohort groups and the general population, and it aims to reduce those disparities through specific actions to improve the availability and quality of care for those groups.

Figure 14 | Overview of the Action Plan

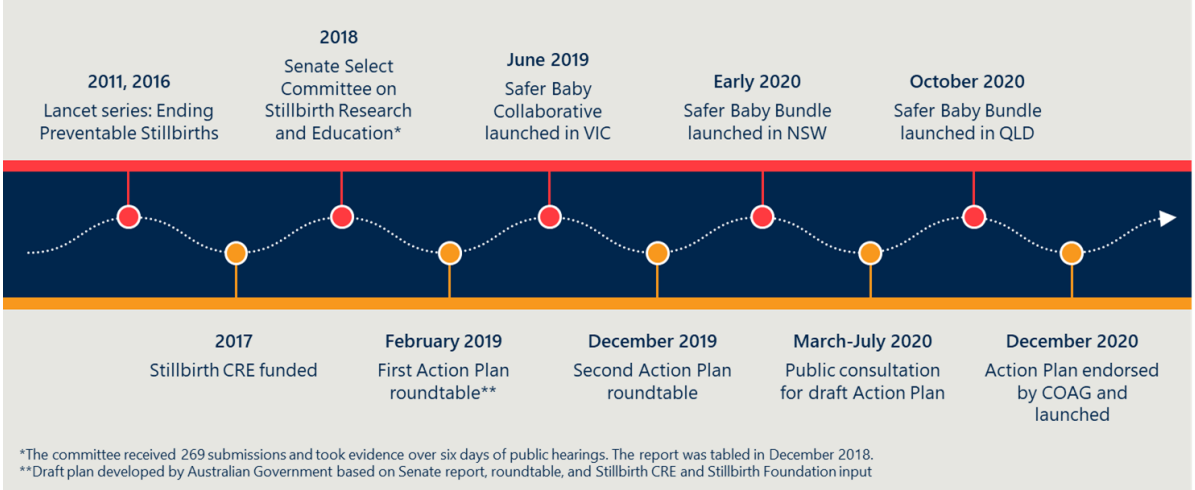


4.2 The Action Plan reflects deep engagement with stakeholders across the system and alignment with other policies and strategies

There had been significant attention and work around the importance of quality maternity and stillbirth care across Australia in the lead up to the Action Plan. There was, however, a recognised need to enact a cohesive, uniting strategy to focus these efforts.

The Action Plan was informed by extensive previous work by bereaved parents, health professionals, advocacy groups, researchers, not-for-profits and government stakeholders to raise the profile of stillbirth in the decade leading up to the Action Plan, summarised in Figure 15.

Figure 15 | Timeline of critical events leading up to the Action Plan launch



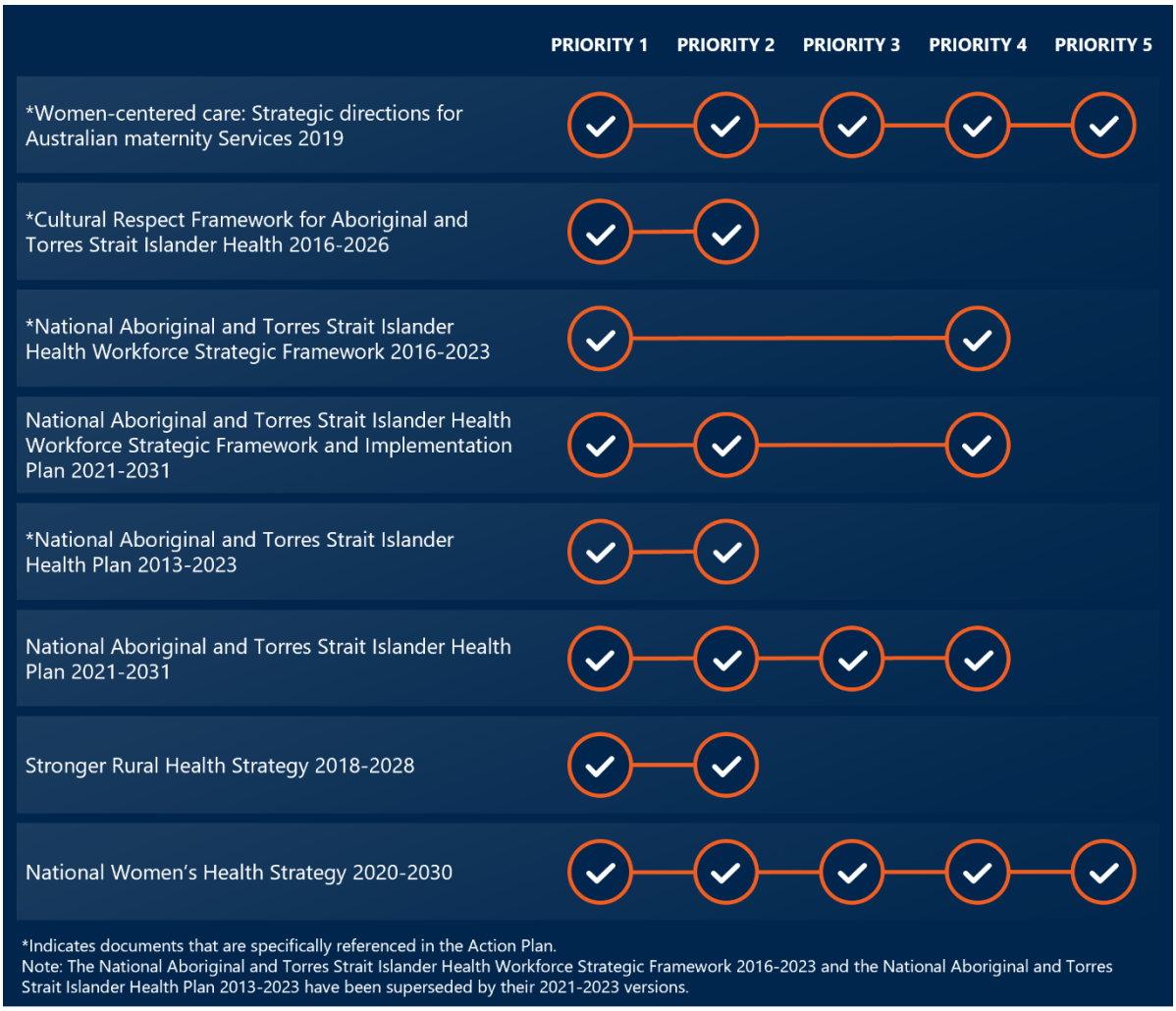
Stakeholders reflected that the quality of engagement in the design of the Action Plan was good, and expert advice and lived experience in the stillbirth space had been appropriately accessed. Stakeholders reported significant pride over the Action Plan and held it up as a *"useful document"*.

> "It's simple and achievable: it gives us small changes, with big rewards."
>
> – Implementer

Furthermore, the Action Plan's authors considered how it fits within the broader policy and strategy context, amplifying the good work already underway to progress good maternity care and women's health, while bringing particular focus to factors that are unique to stillbirth and bereavement supports.

Figure 16 maps tasks from other national plans that are related to the Action Plan's priority areas, with documents that are explicitly referenced in the Action Plan marked with an asterisk (*). This exercise provides an indicative overview of the areas that are well covered by other initiatives and those that are unique to the Action Plan.

Figure 16 | Alignment of the priorities of the Action Plan with those of other major strategies[16]



Some other relevant initiatives and documents include:

- The **Safer Baby Bundle (SBB)**, which had already begun implementation in Victoria, New South Wales, and Queensland. All other jurisdictions have since begun implementation. Many of the Action Plan's activities, particularly under Priority 1, are based on the pre-existing Safer Baby Bundle.
- **IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education),** first implemented in 2019. Along the same lines as the Safer Baby Bundle, many of the Action Plan's activities are based on this education program, particularly under Priorities 2 and 3.
- The **Pregnancy Care Guidelines and Care After Stillbirth and Neonatal Death (CASAND) Guidelines**. The Action Plan has seven explicit tasks relating to these guidelines.
- The **Australian Preterm Birth Prevention Alliance** was established in 2018 and has since been working on initiatives that are closely related to stillbirth. The Action Plan has several activities that align with their work, such as smoking cessation initiatives and timing of birth components of the Safer Baby Bundle.
- Other national and state and territory strategies that cover maternity care, women's health, perinatal mental health, continuity of care, smoking cessation, health workforce, First Nations' health and other minority group or target cohorts' health.

[16] Documents that are explicitly referenced in the Action Plan are marked with an asterisk (*)

- Relevant Australian Government and state and territory legislation, including the *Health Practitioner Regulation National Law Act 2009* and the National Employment Standards of the *Fair Work Act 2009*, both of which are explicitly named in tasks in the Action Plan. Relevant state and territory legislation includes termination of pregnancy and other health and medical-related laws.

4.3 The Action Plan's design aligns with many of the hallmarks of best available practice and evidence

4.3.1 The focus of the Action Plan reflects lessons learnt within Australia and globally

The international comparator research (further detail in Appendix D) shows that other high-income countries use similar approaches to Australia, with similar visions, focus areas and expected outcomes. There has been a common mix of activities, generally focussing on raising awareness for pregnant women and their families, monitoring foetal growth and movements, and further training midwives specifically in relation to stillbirth.

A review of international literature suggests that reaching marginalised populations remains an enduring challenge in many countries, influenced heavily by culture, geography and organisational barriers. The research highlights that many of these population groups are difficult to reach and service, and without sustained focus and accountability for making progress in this space, implementation with these cohorts can be limited. No other comparator country had fully solved these challenges yet.

4.3.2 A high-level Action Plan has many benefits, but also drawbacks

The Australian Government led the development of the Action Plan, but it is a collectively owned strategy that needs to work within Australia's federated system.

During the development of the Action Plan, it was recognised that there were many competing priorities at play in the health system and that implementers had variable resources and budgets with which to progress their initiatives. The Action Plan was therefore designed with a high degree of flexibility for implementers – while there are clear target outcomes in the Action Plan (and some detail around tasks and timeframes required) there is little prescription in the document around how implementers should approach their work.

Many stakeholders noted this 'jigsaw' approach as a strength of the Action Plan, in that it allows implementers to adapt approaches and tasks according to their existing activities and contexts, and it provides an enabling environment for them to operate innovatively. Most implementers have received Australian Government funding to implement their activities.

> "The Action Plan has given implementers the opportunity to look at what's already happening and how it fits into the Action Plan, and then make changes after that. We've only got so many resources and can only work on so many things at once."
>
> – Jurisdictional implementer

However, a disadvantage of this approach is that the lack of prescription makes it more difficult to ensure consistency and coordination as implementation is progressed. In particular, there are few formal service expectations placed upon implementers. Many activities under the Action Plan rely on other substantive maternity and health supports and are not funded directly under the Action Plan. This creates risks that more challenging tasks may be deprioritised, which could have significant effects on the overall impact of the Action Plan.

5 Implementation progress

Action matters. This section describes the progress made in the first two years (2020 to 2022) of the National Stillbirth Action and Implementation Plan (the Action Plan), highlighting common barriers and enablers and lessons learned.

5.1 The Action Plan has been implemented in the midst of a watershed moment for the Australian health system

As discussed in Section 3.1, COVID-19 was already a factor at baseline and it was having significant impacts on the way health care was delivered, as well as women's ability to engage with services. Since then, the impacts of COVID-19 accumulated and were further exacerbated by widespread workforce shortages (within and beyond the health system), disruptions to global supply chains, drastically rising costs of living and other stressors bought in by unstable geopolitics.

In this context, implementers have faced challenges in balancing priorities and progressing work under the Action Plan. There is therefore particular cause to celebrate where progress has been strong and to be pragmatic about where and why there have been delays.

Nous has focused its commentary in this section on providing a snapshot of progress under the five priority areas, and highlighting lessons learned by implementers which may have relevance to other implementation partners moving forward.

5.2 Progress has been made against all priorities

Despite the complex maternity health care system and the challenging operating environment in recent years, the implementation of short-term (2020 to 2023) and ongoing tasks has been strong: implementation progress has been observed against all short-term and ongoing tasks, as well as some medium-term ones.

Many tasks have been completed, and the implementation of most other tasks is on track. A few tasks present some minor delivery risks, mostly due to delays to timeframes. Implementation has also started for some medium-term tasks and other related activities that are not specifically named in the Action Plan.

Implementation progress throughout this section will use the following indicators:

ACHIEVED	ADVANCING	ADAPTING
An activity is considered '**achieved**' when it has been successfully finished.	An activity is considered '**advancing**' when it is progressing without any significant concerns or obstacles. This includes: • activities that are progressing towards their expected completion • activities that do not have an expected completion due to being classified as "ongoing" in the Action Plan, but that are progressing as expected	An activity is considered '**adapting**' when there is variation, gaps or obstacles to implementation, such as: • not reaching certain cohorts or areas • only implemented by some of the intended implementation partners • timeframes are delayed

A brief discussion of any considerations is provided where relevant, particularly for activities that have been assessed as 'adapting'.

Progress is further illustrated with case studies.

5.2.1 Priority 1: Ensuring high quality stillbirth prevention and care

The majority of implementation progress under Priority 1 has been around the Safer Baby Bundle, smoking cessation, cultural safety and adaptation of resources, and continuity of care.

Table 3 | Progress under Priority 1: Ensuring high quality stillbirth prevention and care

Action area	Activity	Timeframe	Status at December 2022	Note
1	• Safer Baby Bundle implementation, evaluation, translation, and cultural adaptations are underway in all jurisdictions. • Development of resources (Decision Aid, Clinicians Guide and Brochure) to support the fifth element of the Safer Baby Bundle – timing of birth – have been progressed.	Ongoing	ADAPTING	COVID caused implementation delays in some jurisdictions, leading to variation across Australia. Implementation is now progressing everywhere.
1	• Royal Australian College of General Practitioners funded to update smoking cessation guidelines. • States/territories are undertaking activities to expand cessation supports. • The Australian Government has progressed the new National Tobacco Strategy (subsequently released 2023).	Ongoing	ADVANCING	
1, 2	• Some states/territories and implementers have begun mapping and reviewing models of maternity care to increase continuity of care models, especially midwifery models. • Some are specifically targeting continuity of midwifery care models for First Nations women. • A review of maternal models of care provided by Aboriginal Community Controlled Health Organisations is being performed. • Funding for Birthing on Country models has been expanded, including to build a Birthing on Country Centre of Excellence with Waminda South Coast Women's Health and Wellbeing Aboriginal Corporation in Nowra, NSW. • The AIHW has continued work and publication of the *Model of Care National Best Endeavours* dataset.	Medium term	ADVANCING	Not all states/territories report progress regarding the implementation of continuity of care models. However, this is a medium-term task, so the states/territories that have reported progress are ahead of schedule.
2	• Some organisations and state/territory governments have been developing and	Ongoing	ADAPTING	This task has not yet been implemented consistently

Action area	Activity	Timeframe	Status at December 2022	Note
	implementing cultural safety education programs for undergraduates and health professionals involved in maternity care, with particular reference to stillbirth prevention and bereavement care.			across Australia, although there are pockets of good practice.
2	• The *Health Practitioner Regulation National Law Act 2009* has been amended to incorporate provisions for cultural safety in alignment with *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2016-2026.*[17]	Short term	ACHIEVED	
2, 3	• There has been continued activity to translate Safer Baby Bundle resources, which are currently available in 23 languages. • Cultural adaptation of the Safer Baby Bundle has also been underway for First Nations women and for four language groups for migrant and refugee women. • Other organisations and states/territories are also adapting/translating approaches and resources. Notably, one jurisdiction has developed stillbirth resources in six languages and made these publicly available online.	Medium term	ADVANCING	
5	• A tender to update the *Pregnancy Care Guidelines* has been released, with work to start in early 2023.	Medium term	ADVANCING	

CASE STUDY 1: LEVERAGING MAINSTREAM SERVICE AVAILABILITY WHILE PROVIDING ENRICHED SERVICES FOR YOUNG AND VULNERABLE MOTHERS

Challenge

A major city's Local Health Network identified that young and disadvantaged women needed extra support throughout their pregnancy and parenting journeys

A major city's main public maternity hospital provides **a wraparound model of care which helps every pregnant woman under 21 to access appropriate information and care.** Women are automatically booked for an initial appointment with a dedicated program midwife as early as possible in their pregnancy. At that appointment, they are provided with age-appropriate information and resources in a relaxed atmosphere, and their whole situation is assessed, including:

- clinical needs
- emotional and mental health
- housing
- safety
- education
- finances.

The midwife serves as a consistent primary contact for the young woman throughout her pregnancy and postnatal care, and referrals are made as appropriate, including to social services. The program is conducted in close

[17]National Justice Project, 'Health practitioners must now deliver culturally safe care', *National Justice Project*, 2023, https://justice.org.au/health-practitioners-must-now-deliver-culturally-safe-care/#:~:text=What%20is%20the%20reform%3F,and%20Torres%20Strait%20Islander%20Peoples.%E2%80%9D

Key Features

- ✓ Models of care that enhance continuity and are tailored for young and vulnerable mothers
- ✓ A program that efficiently leverages and aligns with existing services and resources
- ✓ An approach that builds in collaboration between different services and areas of the health and human services systems

collaboration with the local youth health service and other community services, and appointments can be held at the hospital or at local community clinics according to the woman's preference. The program aims to bolster the woman's existing support networks, fill any gaps and help create an ongoing sustainable situation.

This youth model has close links with a program at the same hospital aimed at vulnerable mothers. The program is also a targeted enhancement to mainstream community health services. It organises convenient home visits by maternal and child health nurses and has a similar aim of **providing wraparound support that takes the woman's whole situation into account.**

5.2.2 Priority 2: Raising awareness and strengthening education

Progress towards promoting community awareness and understanding of stillbirth has been strong.

Table 4 | Progress under Priority 2: Raising awareness and strengthening education

Action area	Activity	Timeframe	Status at December 2022	Note
6	• The implementation and adaptation of the Safer Baby Bundle continues to serve as a community awareness package that provides consistent and considered messaging about stillbirth. • Other initiatives by the Stillbirth CRE have been progressed or completed, including maternal health education for migrant and refugee women; stillbirth education webinars targeting regional and remote clinicians; the development of a Baby Buddy app (providing stillbirth education and awareness information to pregnant women); and the Living Literacy program.	Short term	ADVANCING	The delays in some jurisdictions due to COVID noted in Table 3 also apply here, meaning the degree of implementation progress varies across the country. However, education and awareness raising activities have shown more overall progress, so this activity has been assessed as advancing.
6	• Australian Government Stillbirth Education and Awareness Grants funded Red Nose's Still Six Lives and the Stillbirth Promise campaigns. • The Centre of Perinatal Excellence ran a perinatal mental health campaign that included stillbirth called "The Truth". • Red Nose's SMS 4 Dads (raising awareness of risk factors for stillbirth via SMS messages sent to expectant fathers).	Short term	ADVANCING	

Action area	Activity	Timeframe	Status at December 2022	Note
7	• The rollout and uptake of the Safer Baby Bundle eLearning training[18] has continued. • The rollout and uptake of the IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) eLearning module has continued,[19] and face-to-face workshops were launched in March 2022.[20] • Some jurisdictions have specific training programs/modules.	Ongoing	ADVANCING	
7	• The Stillbirth Clinical Care Standard was launched in November 2022.	Short term	ACHIEVED	

[18] Safer Baby Bundle: 7319 completions Oct 2019-end 2020, 2608 completions in 2021, 1417 completions in 2022 up to Nov 28th.
[19] IMPROVE: 860 completions in 2020, 602 completions in 2021, 547 completions in 2022 up to Nov 28th.
[20] IMPROVE workshops: 336 participants from then to Nov 28th.

CASE STUDY 2: ADAPTING THE DELIVERY OF HEALTH EDUCATION TO OVERCOME DIGITAL, LINGUISTIC AND ACCESS BARRIERS FOR CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) COMMUNITIES DURING COVID-19

Challenge

The Multicultural Centre for Women's Health (MCWH) has decades of experience running multilingual education sessions for migrant and refugee women, and. It has a strong reputation and is trusted by their network of community organisations.

Key features

- ✓ Education and awareness that is tailored for migrant and refugee women's needs
- ✓ Approaches that make use of MCWH's existing trusted relationships with community organisations and align stillbirth awareness into broader women's health education
- ✓ Approaches that specifically overcome service delivery barriers caused by COVID-19

MCWH began working with Stillbirth CRE in 2020 to integrate stillbirth prevention messaging into their antenatal education resources and sessions, drawing on their team of 25 multilingual health educators.

2020 was also the year of COVID-19. MCWH identified that **restrictions on physical gatherings would severely limit their ability to deliver education in hard-to-reach communities. They also knew that they could not rely solely on digital or written methods of communication,** since a large proportion of women in their target communities have lower digital literacy and less access to technology. Some communities also have low levels of literacy more generally, even in their own languages. **A variety of education approaches, platforms and mechanisms are needed.**

MCWH rapidly adapted their service delivery mechanisms to provide health education across many languages and platforms in order to cater for women with different situations and needs. They:

- delivered **in-language Zoom sessions** as well as **radio segments** for those with limited access to technology, particularly those in regional and remote areas with less contact to their own community groups.
- created an **in-language COVID-19 information phone call program**, targeted at migrant women living in public housing estates.
- created **in-language women's health videos** and distributed them to Victorian organisations working with migrant women, again trying to reach into community groups who were likely to be missed by mainstream campaigns.
- conducted **in-language promotion and education on social media platforms** for women who were most likely to seek information online.

In 2021 and 2022, MCWH started the cultural adaptation of the Safer Baby Bundle on behalf of the Stillbirth CRE, focusing on four language groups (Arabic, Dari, Karen, Dinka). They ran community consultation with each language group and a selection of healthcare providers to gain perspectives around pregnancy, barriers and enablers to accessing care, and to find out what resources they were missing.

Their key finding was that these women want clear, comprehensive information about their pregnancies. While all acknowledged the taboos around stillbirth, there was significant interest in having better resources that include stillbirth within the reproductive health and pregnancy care continuum. Providers also indicated a desire to overcome the taboo and build their capability in the area.

Armed with this information, the MCWH have been going through the elements of the Safer Baby Bundle to ensure they are culturally relevant and appropriate for these language groups. Based on the consultations:

- They have produced **in-language booklets and multimodal resources** that cover general best practice antenatal care; stillbirth prevention and the SBB elements; and what to do in an emergency.
- They have included information about **antenatal care** more generally alongside the stillbirth information.

MCWH reports that since 2020 women have higher awareness of stillbirth and show more confidence and readiness to learn about the topic. Migrant and refugee organisations also reportedly show more willingness to include stillbirth as a topic in the work they do with their own women's groups.

5.2.3 Priority 3: Improving holistic bereavement care and community support following stillbirth

Many of the short-term activities in Priority 3 rely on updates to the national guidelines, which have not yet been completed. This means that there is minimal progress to be reported and standardised approaches are still lacking, although other in-scope activities that are not listed in the Action Plan have been underway.

Table 5 | Progress under Priority 3: Improving holistic bereavement care and community support following stillbirth

Action area	Activity	Timeframe	Status at December 2022	Note
8	• Some maternity facilities are able to provide quiet, private, appropriate spaces where bereaved parents can receive physical and emotional care **(limited data).** • Some jurisdictions have been conducting planning/mapping work around the availability of local perinatal bereavement support services. • Some jurisdictions have implemented or allocated funding to activities around perinatal mental health services, perinatal education loss coordinators, bereavement midwives and the creation or update of resources.	Ongoing	ADAPTING	There is variation between jurisdictions in implementing this activity. While some jurisdictions have made progress towards improving bereavement care, others report limited activity in the area.
8	• The *Fair Work Act 2009* (Cth) has been amended to improve leave entitlements for parents who experience stillbirth.	Short term	ACHIEVED	
8	• Building on previous rounds, a new Australian Government grant round for stillbirth and miscarriage support was released, with recipients announced early 2023.	Short term	ADVANCING	
8	• Bereavement information has been included in community awareness and education packages. • Red Nose has received federal funding to continue implementing the Hospital to Home program, and it has established two bereavement peer support workers for remote Australia through funding from the Phoebe Joan Foundation • Stillbirth CRE has been developing an online support program for parents following the death of their baby through stillbirth or neonatal death. • Non-government organisations (Red Nose, Stillbirth Foundation) have developed	Short term	ADVANCING	

Action area	Activity	Timeframe	Status at December 2022	Note
	clinician and parent resources to support decision making after the loss of a baby.			
8, 9, 10	• Updates to the Care Around Stillbirth and Neonatal Death guidelines are underway, due for completion in 2023.	Short term	ADAPTING	There have been delays to timeframes for this activity, but progress is underway.
8	• There has been some progress to increase access to continuity of care models: see section 5.2.1.	Medium term	ADVANCING	
9	• Stillbirth CRE has developed and commenced a national survey to map services that provide care in a subsequent pregnancy. • Some jurisdictions have been conducting early planning or mapping work to understand and improve care for women who have experienced a previous stillbirth.	Medium term	ADVANCING	

CASE STUDY 3: FUNDING TWO BEREAVEMENT SUPPORT WORKERS TO SERVICE REGIONAL AND REMOTE AUSTRALIA: THE PHOEBE JOAN PROJECT

Challenge

Red Nose received funding from the Phoebe Joan Foundation to address the gap in the provision of short-term bereavement peer support for families in regional and remote Australia.

Key features

- ✓ Hub-and-spoke model of bereavement care that specifically caters to regional and remote families
- ✓ Multimodal, flexible delivery mechanisms that are designed to overcome workforce and access challenges
- ✓ Additional support for bereaved families in subsequent pregnancies

The Hospital to Home (H2H) bereavement support program was first developed by Sands in 2020 through Australian Government funding. In December 2020, they merged with Red Nose, who took over the management of the pilot program. H2H provides individualised support to families for the first months after the loss of a baby. **It gives families a range of emotional, social and practical supports, including helping with memory making, practical assistance with funeral arrangements and Centrelink entitlements, helping to prepare people in the community (for example workplaces) to respond sensitively to parents' needs, and connecting families with ongoing community support.**

After realising **regional and remote areas still did not have adequate services available through the H2H and other programs,** Red Nose set about creating a program that would address the access barriers experienced by those harder-to-reach bereaved families and would carry H2H-type supports to them. The Phoebe Joan Project started in September 2021, when two bereavement support workers were recruited. They both live and work in regional Australia (in Western Australia and Victoria) and have experienced baby loss. They were each given extensive training, resources and supervision to carry out their work.

Red Nose reports excellent outcomes for the first twelve months of the program. The bereavement support workers provided H2H-style emotional, social, and practical support to almost 100 families, about 80% of whom had experienced a stillbirth. **They divided up the country between them and set up a hub-and-spoke model of bereavement care, where they each conduct outreach, build their networks and identify referral sites and pathways across their regions.**

The funding has been provided for another 12 months to:

- use a telehealth model to provide up to six support sessions through hospital referral, GP referral, or self-referral
- increase online community engagement to create activities and spaces for bereaved families to connect with one another across Australia
- facilitate local groups to form where there are clusters of bereaved families, and help organise memorial events and connection sessions.

Due to the demand for assistance in subsequent pregnancies, the bereavement support workers now also provide:

- additional monthly one-on-one support as required through the subsequent pregnancy and for the first month post-delivery
- fortnightly informal drop-in sessions on Zoom
- a suite of four psycho-educational workshops, delivered monthly on repeat to ensure all participants have access to all four sessions.

Red Nose has identified that the **keys to success** for this kind of program are to:

- account for **language and technology access barriers**
- provide adequate training, support and resources for the bereavement support workers themselves
- focus not only on supporting families directly, but also on **sustainably reinforcing local referral networks and upskilling the local workforce (for example GPs, social workers, counsellors)**: "We've had to think about who and how we're upskilling, for communities to be able to support communities."

5.2.4 Priority 4: Improving stillbirth reporting and data collection

Although most activities under this priority are medium-term, there has been significant early progress in improving investigations and reporting of stillbirth.

Table 6 | Progress under Priority 4: Improving stillbirth reporting and data collection

Action area	Activity	Timeframe	Status at December 2022	Note
11	• Updates to the Care Around Stillbirth and Neonatal Death guidelines are underway, due for completion in 2023.	Short term	ADAPTING	There have been delays to timeframes for this activity, but progress is underway.
11	• The Australian Institute of Health and Welfare are in the third stage of developing the *Perinatal Mortality National Best Endeavours Dataset*. • Most jurisdictions have been undertaking data improvement activities. • Nous have been undertaking monitoring and evaluation of the Action Plan.	Medium term	ADVANCING	
11	• The rollout and uptake of IMPROVE eLearning module has continued,[21] and face-to-face workshops were launched in March 2022.[22]	Medium term	ADVANCING	
11	• Jurisdictions have been funded through two Federation Funding Agreements to provide education, develop resources, increase workforce capacity, create new positions, and cover transport costs for stillbirth investigations. The first Federation Funding Agreement focused on capability. The second, which was still under negotiation in December 2022, focuses on capacity. • The Royal Australian and New Zealand College of Radiologists and the Royal College of Pathologists of Australasia have received Australian Government funding to increase their professions' capacity to conduct stillbirth investigations. • Still Aware was funded to build awareness about perinatal pathology services, but this project was delayed due to staff shortages. • Some jurisdictions have planned or are planning to establish centres of excellence for perinatal autopsy.	Medium term	ADVANCING	
11	• Red Nose has been developing a survey and resources to help parents in making	Medium term	ADVANCING	

[21] IMPROVE: 860 completions in 2020, 602 completions in 2021, 547 completions in 2022 up to Nov 28th.
[22] IMPROVE workshops: 336 participants from then to Nov 28th.

Action area	Activity	Timeframe	Status at December 2022	Note
	decisions about autopsies and investigations options following stillbirth. • Some jurisdictions have also developed and rolled out decision-making resources including fact sheets in different languages, videos and other resources.			
12	• Stillbirth CRE is in the process of providing a report against the Global Scorecard produced by the International Stillbirth Alliance.	Short term	ADVANCING	

CASE STUDY 4: INTEGRATING THE ACTION PLAN INTO BROADER DATA INFRASTRUCTURE AND REPORTING IMPROVEMENT ACTIVITIES IN THE WIDER HEALTH SPACE

Challenge

Many jurisdictions states/territories have embedded Action Plan requirements and initiatives into broader data development programs of work.

Key features

- ✓ Combatting siloing in the health system and facilitating higher levels of continuity of care
- ✓ Leveraging existing data work and system upgrades to embed and streamline Action Plan initiatives
- ✓ Optimising data collection and reporting to facilitate its use in making evidence-based service delivery and policy decisions

Implementers identified that the fragmented nature of documentation and data across the health care system is a barrier to several aspects of the Action Plan:

- Different care sites often use different medical record systems that do not always integrate with each other. This makes it challenging to share results, notes, discharge summaries, and other information between providers. This severely limits continuity of care.
- Data quality and availability around many stillbirth-related factors can be poor, often because it is not collected or is not recorded at the site level. Even when data is collected, standardisation is a challenge.

These sorts of challenges are not unique to the stillbirth and bereavement space. Many jurisdictions have therefore in recent years been migrating towards single standardised electronic medical records (EMRs) that can be used across all public sites in a given jurisdiction or in a given set of Local Health Districts. While different jurisdictions are at different levels of maturity of their EMR systems, stakeholders in these jurisdictions noted several ways in which it is expected to impact stillbirth and bereavement care:

- **Having a single EMR means that as a woman moves through the health care system, her care providers will have better visibility over her journey and needs, and the continuity of her care will be improved.** For example, if a stillbirth occurs, everyone involved in the woman's care can more easily be notified to ensure seamless and sensitive approaches.
- The large-scale reforms and investment have been an opportunity for implementers to **improve consistency of practice by embedding some aspects of Action Plan activities, particularly investigation initiatives and the Safer Baby Bundle, into the new customised EMRs and handheld records.** For example, in line with the Safer Baby Bundle, built-in clinical workflows can prompt clinicians to record fundal height at every appointment.
- The same principle has been applied to **embed inputs for more standardised perinatal indicators and information into EMRs to facilitate more automated and standardised data collection and reporting mechanisms.** The Perinatal Society of Australia and New Zealand's Perinatal Death Classification (which is used by the Australian Institute of Health and Welfare) was cited as an example.
- Having more standardised and consistent data collections creates efficiencies in aggregating data at a jurisdictional level and the national level. **Some jurisdictions maintain maternity dashboards to provide more timely information for service delivery decisions and to promote system learning.**

Stakeholders also noted limitations to data improvement activities, notably the fact that implementing a standard EMR across many sites does not happen all at once; it only affects the public sector; and it often does not extend to primary care providers like GPs and Aboriginal Community Controlled Health Organisations).

Fragmentation and access are ongoing issues, and the full benefits of these systems are not expected to be seen for many years. **Implementers commented that the next horizon of work is to find ways to share more timely data between sites and jurisdictions to enable more evidence-based approaches and sharing of lessons learned.**

5.2.5 Priority 5: Prioritising stillbirth research

Progress against this priority has had some delays, but activity is well underway.

Table 7 | Progress under Priority 5: Prioritising stillbirth research

Action area	Activity	Timeframe	Status at December 2022	Note
13	• Nationally agreed research priorities are under development and are expected to be finalised in late 2023.	Short term	ADAPTING	Nationally agreed research priorities were originally planned for completion by early 2022.
13	• Many stillbirth research projects are ongoing and funding for new projects has been allocated each year.	Ongoing	ADVANCING	
14	• The *Cochrane Special Collection: Stillbirth prevention and respectful bereavement care* was published on 24 August 2021.	Short term	ADVANCING	

CASE STUDY 5: BOOSTING RESEARCH INTO FIRST NATIONS MOTHERS AND BABIES THROUGH A TARGETED MEDICAL RESEARCH FUTURE FUND (MRFF) GRANT ROUND IN 2021

Challenge

The Senate Select Committee on Stillbirth Research and Education found that funding larger-scale, longer-term collaborative research partnerships and projects through federal Australian Government research funding could help improve stillbirth outcomes. One such grant opportunity in 2021 proved to be effective at boosting research activity for a priority population that will benefit from targeted attention.

Key features

- ✓ Bringing attention and resources to the needs of First Nations mothers and babies
- ✓ Using existing system mechanisms to understand stillbirth prevention and care within a holistic continuum of culturally safe maternity health

The *MRFF 2021 Improving the Health and Wellbeing of Aboriginal and Torres Strait Islander Mothers and Babies* grant opportunity significantly boosted the amount of stillbirth-related funding that was targeted towards First Nations health nationally. This evaluation identified $4.8 million of First Nations projects in 2020. This increased to $26.1 million in 2021, $19.7 million of which was from this grant opportunity. Many of the projects are targeted at investigating or implementing culturally safe models of care for First Nations families:

- "Birthing on Country: RISE SAFELY in regional, remote, and very remote Australia", which aims to "translate existing knowledge on culturally safe maternity care, that saw unprecedented success in an urban site, into three unique settings."
- This was complemented by additional funding from the National Health and Medical Research Council to establish and evaluate the 'very remote' site in Galiwin'ku, Elcho Island, NT. This is an example of **careful planning by the Birthing on Country research team to account for the additional complexity and access barriers that can be expected for the hardest to reach populations.**
- The Birthing in Our Community program (explored in a callout box in Appendix C.1.3) also received MRFF funding to extend into three settings and follow cohorts of families to assess clinical outcomes, scalability and feasibility.
- "Replanting the Birthing Trees to Support First Nations Parents and Babies" includes the development of infrastructure for culturally safe, trauma-integrated, holistic, transdisciplinary perinatal care, such as: a resource repository for parents, clinicians and decision-makers; workforce development resources; culturally and emotionally safe continuity-of-care implementation toolkit.
- "Arelhe Ante Areyele Arntarnte-Arelhetyeke Ampe Akweke Arle Atnyenetyenheke (Arrernte) – Women guiding women who are going to have babies (English)" aims to develop a national First Nations-designed maternal and child health primary care systems framework, adaptable to local cultural practices, as well as two new cultural wellbeing tools validated by Western and First Nations perspectives.
- The "Digital Infrastructure For improving First Nations Maternal & Child Health" project will develop a data linkage platform with a nationally agreed health data set for First Nations child and maternal health outcomes. It will include interoperability standards to support closing the gap in maternal and perinatal health outcomes.

This example of setting research priorities at a federal level shows promise for the broader system level priorities currently under development by Stillbirth CRE.

5.3 Implementation is proving strong where common success factors are in place

Consultations have surfaced a series of lessons to take forward around when implementation of Action Plan activities have been most successful. See Table 8 below.

Table 8 | Implementation success factors

Success factor	Success in practice
Close alignment between work under the Action Plan and activities that are being progressed as part of other pregnancy, women's health or general health strategies and initiatives. This includes: • **Assessing which Action Plan activities can be combined with existing initiatives and reforms**, and which need to be championed and progressed on their own. This helps to reduce duplication of work and avoids work stalling due to competing demands on implementers. • **Integrating Action Plan initiatives into existing systems,** which can reduce frictions. • **Using existing resources** as an efficient way to make a difference in a constrained environment.	**Careful consideration of jurisdictional priorities, strengths and weaknesses, and related initiatives enables more efficient implementation.** • A jurisdiction had limited resources to implement Action Plan initiatives. They decided to use the Action Plan as an opportunity to consider what they already did well and which areas needed extra attention: • "[Our jurisdiction] already do foetal growth restriction really well – we don't want to be interfering in things that aren't necessarily a problem for us. That means we can target areas that really need it, like smoking, where we might be able to make a difference." – Jurisdictional representative • This jurisdiction has been able to bolster their smoking cessation activities, including acquiring carbon monoxide monitors and Nicotine Replacement Therapy packs and training clinical champions across the jurisdiction. This is partly enabled by linking in with activities under the Preterm Birth Prevention Alliance work. • See also Case Studies 1, 2, 4, 6.
Making Action Plan activities relevant for as many people as possible through multidisciplinary approaches. This includes: • **Bringing relevant people from across the system together** to gain different perspectives, ensure alignment, and share lessons learnt. This makes initiatives more robust, fit-for-purpose and likely to last. Implementers often referenced the Stillbirth CRE committees and working groups as examples of this. • **Reaching outwards across the system** to strategically involve people in the aspects of implementation that are relevant to them. This embeds the Action Plan into practice across the system.	**Involving stakeholders in implementation in a strategic manner, to get them invested in relevant Action Plan initiatives without overburdening them, creates widespread buy-in and ownership.** • It can be difficult to balance the many demands on subject matter experts' and stakeholders' time with the need to have the right input and participation in initiatives. • Some implementers have convened system-wide expert working groups and communities of practice to tackle specific problems such as smoking and vaping in pregnancy and perinatal investigations work. • Jurisdictions noted that using their relationships with local health districts, ACCHO networks, primary health networks, consumer networks, clinical networks and non-government organisations has resulted in more widespread buy-in and implementation of Action Plan initiatives. • See also Case Studies 1, 2, 3, 4, 6, 7.
Having adequate buy-in and resources to support implementation. This includes: • The **dedication, passion, and innovation** of people working to implement stillbirth initiatives. This has enabled strong progress, even in extremely challenging circumstances. • Having a **dedicated point person** for stillbirth initiatives to centralise and maintain focus on the work. • Having **buy-in from senior executives** to create an enabling authorising environment within which to push initiatives forward more efficiently.	**Activities that have had dedicated funding and resources have been well progressed, even beyond what would have been expected at this stage of the Action Plan.** • For example, progress under Priority 4 is ahead of schedule, with many medium-term activities relating to stillbirth investigations well underway. • This is largely due to the first Federation Funding Agreement (focusing on capability) between the Australian Government and the states/territories, which earmarks funding for each jurisdiction to specifically progress stillbirth investigation capability, rather than having to find it within existing budgets. • Attaching funding to specific activities also attaches a level of priority, attention, accountability and motivation to get those activities done.

Success factor	Success in practice
• **Having enough funding** to provide the resources and impetus for implementation that factors in the time, distance and longer engagement timeframes required to effectively engage with target cohort groups.	• See also Case Studies 3, 5, 6, 7.

CASE STUDY 6: EXPLICITLY TYING ACTIVITIES UNDER THE ACTION PLAN TO THE BROADER HEALTH CARE AGENDA AND SYSTEM

Challenge

Faced with a significant number of different strategies and plans coming from national and jurisdictional state/territory levels, one jurisdiction overcame the challenge of trying to implement everything independently.

Key features

- ✓ Aligning implementation of the Action Plan with other related initiatives to reduce duplication and make use of existing resources
- ✓ Combatting siloing by strategically getting people involved across the health care system

Stakeholders in this jurisdiction have taken a pragmatic approach to knowing where to focus their implementation efforts:

"**We try to make the conscious effort to remove that stress factor and consolidate and align everything that we possibly can.** When we adopt both national and internal pieces of work, part of our approach is always looking at ensuring there is sustainability of the approach by building into quality and routine practice."

This jurisdiction cited several factors that characterised their implementation approach:

- **Identifying actions and tasks in the Action Plan that link into other bodies of work already underway.** For example, they noticed that several areas across government were making perinatal loss and bereavement a focus, so they all came together to map out and prioritise the work underway. This will be followed up with a workshop to make a coherent and streamlined plan for local health districts to use in implementation.
- **Writing aspects of the Action Plan into enduring documentation and practice where possible, to ensure its longevity.** For example, several jurisdictions have included relevant aspects of the Action Plan in policy directives, clinical trainings and toolkits, workforce plans and communities of practice.
- **Effective communication with partners across the health care system to ensure that tasks, roles and responsibilities are clear for everyone involved.** This helps to translate the general 'in principle' support of the Action Plan into concrete action. For example, to roll out the Safer Baby Bundle in clinical settings, they emphasised its effectiveness, simplicity and strong evidence base. They also made sure to embed its elements into hospital systems to encourage uptake.
- **Using the combined weight of the Action Plan and other strategies to make the case for more support for target cohorts.** This is most effective where Action Plan target cohorts align with those of other initiatives (for example First Nations women, migrant and refugee women, regional and remote women).
- **Being realistic about where timeframes can be shortened or need to be expanded**, to ensure that the time is taken to do things well. This also involved holding off on finalising some of their clinical guidelines, for example, to ensure alignment with the new Stillbirth Clinical Care Standard.

5.4 Implementers have faced common barriers to progress

Consultations with stakeholders have surfaced areas of implementation that have experienced substantial challenges. These challenges or barriers need to be considered as the Action Plan continues its implementation activities (see Table 9 below).

Table 9 | Barriers to implementation of the Action Plan

Barrier	Barrier in practice
The challenges in reaching and supporting target cohorts have been underestimated. • It takes **strong relationships, time, and resources** to co-design or adapt materials and messaging for all the different language and cultural groups around Australia. • Service delivery for target cohorts can be more complex, and interventions need to be designed to address **significant structural challenges**.	**Funding and delivery of activities for target cohorts bring consistent complexity and challenges.** • One jurisdictional implementer commented: "What works in a metropolitan area cannot be compared with co-designing and implementing multiple culturally acceptable roll-outs in various geographically remote communities to support (often intersectional) target cohorts." • There has been progress in adapting messaging and resources for these cohorts, particularly the Safer Baby Bundle. However, stakeholders noted the time and care needed, particularly with hard-to-access communities, to build strong relationships to co-design/adapt material, and for the material to then have any chance at being taken up. COVID-19 related restrictions exacerbated these challenges in accessing and working with these communities. • Some stakeholders also noted that the contracts for cultural adaptation were awarded to mainstream organisations who then partnered with communities, and that it would have been preferable to award the contracts directly to community organisations, to ensure that the intellectual ownership rested with them. • See also Case Studies 1, 2, 3, 5.
There has been a workforce shortage (capability and capacity) to support implementation. • The maternity workforce, including both stillbirth and bereavement, have not been exempt from the broader **health workforce constraints** currently facing Australia. This has been exacerbated by COVID-19 imperatives and workforce fatigue post COVID-19. • **COVID-19 related social distancing and travel restrictions** severely limited service delivery for a time, as well as outreach and education activities.	**Workforce has been tight at all levels of the health care system.** • Stakeholders across Australia spoke about overall workforce pressure, but particularly shortages in regional and remote areas and among pathologists and midwives. • The clinicians who are available have had many demands on their attention over recent years, so they have had less time and energy to learn new interventions and requirements for stillbirth. Service delivery has also looked different, with more care being provided over telehealth, meaning that some Action Plan initiatives had to be carried out differently then expected. • Some state/territory health departments have also had difficulties filling positions. Smaller jurisdictions also face the challenge of having smaller pools of clinicians and stakeholders to draw upon to implement the wide range of Action Plan activities, resulting in risks to timeframes and engagement fatigue. • See also Case Studies 3, 7.
Implementers have worked in a siloed way. • Outside of twice-yearly meetings of the National Stillbirth Implementation Oversight Group, the major implementers of the Action Plan do not have **formal mechanisms** to maintain coordination and communication. • Siloing within jurisdictional governments and across the health care system makes coordination of activities challenging, particularly given health departments have **limited ability to mandate changes.**	**The complexity of Australia's health care system and stillbirth as an event means that implementation requires coordination across a broad range of stakeholders.** • At the national level, some jurisdictional implementers have commented that they do not have good visibility on who their equivalents in other jurisdictions are, or how to get in contact with them. Turnover in positions is not always communicated out to the network, meaning communication and coordination can be lengthy. • At a jurisdictional level, it can be hard to know who is responsible for implementing which activities across

Barrier	Barrier in practice
	government (for example, maternity care for the Safer Baby Bundle, mental health for bereavement care, population health for smoking cessation) without strong central coordination. • At a local level, connecting with GPs and other service providers to encourage them to implement Action Plan initiatives is a consistent challenge, since they are individual operators and there are no standard communication channels for health departments or local health networks to leverage. Similarly, implementers have limited reach and visibility into the private sector. • See also Case Studies 1, 2, 3, 4, 6, 7.

CASE STUDY 7: ALLOCATING DEDICATED STAFF TO ENSURE FOCUS IN PUSHING IMPLEMENTATION FORWARD

Challenge

The Action Plan is at risk of being deprioritised if resource allocation is not carefully considered and efficiently utilised.

Key features

- ✓ Allocating clear responsibility for implementation to maintain momentum
- ✓ Combatting siloing with improved coordination by a specific person or team who have visibility across the system

Several jurisdictions have established a dedicated project officer role to push implementation of the Action Plan forward from the government level.

All those who implemented this noted that progress had been limited before the role was established. One implementer in this project officer role commented that before they started, their responsibilities had been shared across several different people who all had differing priorities that extended outside the Action Plan. This meant that no one person had visibility over the connections between aspects of the Action Plan. Along the same lines, progress stalled in cases where this project officer role became vacant due to secondments or extended leave.

Progress on initiatives accelerated and came into focus as soon as the dedicated role or team was established. In some jurisdictions funding for these roles came from within existing health department budgets. In others a portion of funds from large initiatives like the Safer Baby Bundle or the first Federation Funding Agreement (focusing on capability) was earmarked to establish the dedicated role.

Implementers commented that a versatile project officer, generally embedded within a maternity team, keeps stakeholders accountable to their goals and tasks and acts as a point of contact and coordination for everyone involved.

The same principle applies at the clinical site level. Several stakeholders cited examples in hospitals where **the existing midwife education officer or another local clinical champion was tasked to drive the messaging of Action Plan activities** like the Safer Baby Bundle or investigation and bereavement procedures, and to act as a clear point of contact for others.

Stakeholders noted that those in these roles may feel a disproportionate burden of responsibility, and they identified several important considerations in these types of roles:

- **Smaller jurisdictions had success with a single project officer, but larger jurisdictions are more likely to need a team, to ensure that the workload remains proportionate.** Having a single person responsible for supporting the implementation of the Action Plan, often alongside Preterm Birth Prevention Alliance work and other related maternity strategies, may be too ambitious. Reporting requirements also multiply in these circumstances.
- **The project officer or team will have the most success if they have the support of leaders and stakeholders across the system,** to ensure their work gets the appropriate level of attention. They are there to improve coordination and accountability, but they still need other stakeholders to lean in and play their part in implementation.

5.5 Current governance arrangements meet some hallmarks of best practice, but there is room to be even better

Where governance around national strategies like the Action Plan is effective, it generally aligns with several principles:

- **Leadership and planning:** There is clear leadership, strategic direction, and forward-planning to effectively deliver a plan or strategy.
- **Performance and accountability:** There are clear performance expectations for each implementer, and there are mechanisms to hold stakeholders accountable for meeting these expectations.
- **Funding:** Funding arrangements enable the successful delivery of initiatives and drive improved performance aligned with system-wide priorities.
- **Engagement:** There is appropriate engagement to receive and share information about relevant activities across the system, to maximise synergies and to maximise the positive impact on insights or lessons learned.

The following sections consider the degree to which governance of the Action Plan aligns with these principles.

5.5.1 Leadership and planning are strong, but could be further enhanced

The Action Plan was developed through extensive stakeholder consultation and was endorsed by governments. As part of the endorsement process, a decision was made to establish an Implementation Oversight Group (IOG) to provide governance over the Action Plan.

While the Chair of the IOG is a representative from the Australian Department of Health and Aged Care, some effort has been taken to brand the Action Plan as a national, collectively owned strategy, which recognises the important contributions of the states/territories, non-government organisations and other stakeholders in driving progress.

The IOG has had regular productive meetings focusing on issues such as:

- stakeholder representation required to deliver effective governance over the Action Plan
- progress on activities under the Action Plan, including insights and lessons learned
- options to reduce the data collection burden on implementers
- emerging risks and mitigation strategies.

The IOG is an advisory body only. However, in the context of constantly changing policy and operational demands, many stakeholders noted that there would be value if the IOG had a clear decision-making authority to endorse changes or agree short-term priorities, to ensure that progress under the Action Plan continues.

> *"A barrier has been the lack of making sure that people are committed to the Action Plan and are keeping things going. Everyone is aware that there is an Action Plan, and that it's a thing that's happening, but there isn't a consistent point of care at the moment. It would be good to get leaders pushing this through as well."*
>
> – state/territory government IOG member

5.5.2 Greater visibility around contemporary priorities under the Action Plan may clarify performance expectations

Implementers currently complete regular progress reports to the IOG and to the evaluator (Nous) to detail their activities under the Action Plan.

The Action Plan assigns implementation leads against key activities; however, stakeholders have highlighted that the high-level language in the Action Plan creates some ambiguity around what is expected to be done and by which stakeholders.

Some implementers also highlighted that in the absence of clear incentives and consequences around implementation progress, there is a risk that some initiatives are being deprioritised, especially when they are particularly challenging to implement. As highlighted in section 5.4, this can include work directed at target cohorts, who are the most important to reach to reduce the overall stillbirth rate.

> *"I would appreciate knowing 'this is what our goals are for next few months, this is what we're reporting on'."*
>
> – Implementer

Governance arrangements for some similar plans (e.g., the National Alcohol Strategy 2019-2028) rely more heavily on accountability mechanisms to ensure things are getting done. The Action Plan does not take that approach; however, it benefits from strong buy-in from leaders across the system and a reported genuine motivation to achieve positive change.

There may, however, be significant value in drawing greater attention to certain activities to ensure that work is progressing and that there is shared language around what success looks like. This would be particularly beneficial where it involves target cohorts, or where it relates to initiatives specific to stillbirth and bereavement support which are unlikely to be progressed as part of other maternity and other health care initiatives.

5.5.3 Targeted funding is an important enabler of progress

Stakeholders have lauded the value of the Action Plan as a vehicle for corralling efforts and supporting sustainable activities to prevent stillbirth and deliver good bereavement care. In the absence of the Action Plan, it is unlikely that many of the activities underway would have occurred.

The attachment of funding to the Action Plan has been critical to its success, as it has created the enabling conditions for governments and other implementers to sign up and commit to action. While most implementers have received funding in some form to support their activities, there are some areas of known duplication or inefficiencies. For example, multiple jurisdictions and non-government organisations have been funded for some activities, resulting in similar outputs where a single national approach may have been more efficient.

Stakeholders report that some initiatives, notably the first Federation Funding Agreement (focusing on capability), have used population-based funding arrangements or similar. This disadvantages jurisdictions that have smaller populations but wider geographical distributions and higher representation of target cohorts, which makes implementation more challenging and costly for them.

Some stakeholders also spoke of the ongoing challenges around funding insecurity associated with a relatively short-term investment period for some funded activities. While this is arguably a necessity to support innovation and diversification, there may be opportunities to streamline funding and commissioning processes to minimise the burden placed on entities seeking funding.

Lessons so far have emphasised the difficulties in reaching target cohorts and the need for targeted investment in them. Many stakeholders have reflected that more is needed to achieve deep and lasting outcomes for these groups, which includes potentially better earmarking existing funding to be directed into targeted activities. To better recognise the additional activity that may be needed to support the target cohorts, consideration could be given to both providing additional dedicated funding and redirecting existing funding towards target cohorts, with clear linkage to performance expectations.

5.5.4 Engagement has been fostered by passionate individuals rather than formal governance structures

The Action Plan works within a web of other policies and strategies (see Section 4.2). It is also the coordinating mechanism for its own initiatives, from the Safer Baby Bundle to national awareness campaigns to the creation of a new Stillbirth Clinical Care Standard and national research priorities. These activities work best when they are well linked.

> *"I feel like it's a bit siloed still. I think everyone's trying – there are a heap of meetings and working groups. […] It can be hard to remember what part of which Plan this is for, and which part of what project."*
>
> – Implementer

Currently, these linkages are largely driven by the passionate and dedicated individuals who are involved across the system and participate on multiple committees and working groups. They act as the connectors, ensuring flows of information and trying to line up complementary initiatives where they exist.

To ensure these interpersonal relationships are reinforced by appropriate structures, there may be value in ensuring the IOG routinely considers linkages with other strategies and plans as well as its existing consideration of the linkages between its own activities.

6 Early outcomes

This section explores the early achievement of outcomes, that is tangible changes, after the first two years of the National Stillbirth Action and Implementation Plan (the Action Plan). While progress towards short-term activities has been strong, it often takes time for the intended outcomes from these activities to be realised. However, some early positive outcomes have been noted in all five priority areas.

The limited availability of data has limited reporting changes against some indicators. Qualitative reports from stakeholders have been used to provide anecdotal evidence in circumstances where data is limited or incomplete. Qualitative reports have also been used to provide additional context across all outcome measures.

The level of improvement in outcomes that is expected based on the sequencing of activities under the Action Plan, in comparison with the level of improvement observed to date, will be presented under each priority area using the following system:

IMPROVEMENT	EARLY SIGNS OF IMPROVEMENT	DECLINE	NONE

6.1 Priority 1: Ensuring high quality stillbirth prevention and care

The evaluation considered changes from calendar year 2020 to late 2022 around women and their health care professionals taking the recommended steps towards identifying and managing key stillbirth risk factors. This is closely linked to the general provision of high quality and culturally safe maternity care, so outcomes around behavioural factors, models of care, appropriateness of care and appointment attendance are relevant, as well as stillbirth rates themselves. Available data on key outcome indicators are summarised in Figure 17 below.

Figure 17 | Snapshot of observed changes relating to quality stillbirth prevention and care [23]

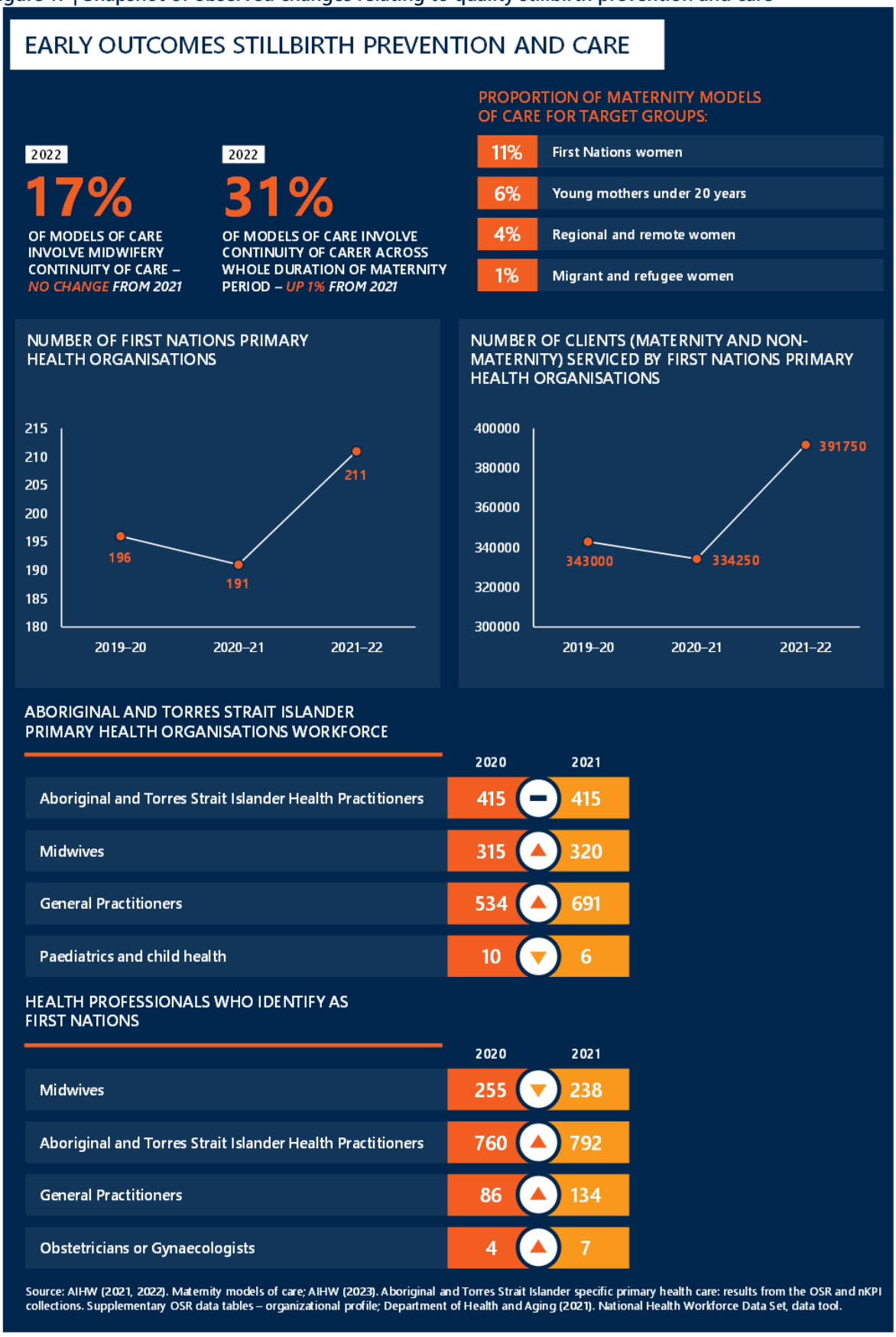


Table 10 indicates where improvements are expected and where they were observed. Further comment on the outcomes is below.

Table 10 | Early outcomes for Priority 1: Ensuring high quality stillbirth prevention and care

Outcome	Improvement expected	Improvement observed
Smoking cessation	Early signs of improvement	Early signs of improvement
Continuity of care or carer	None	None
Maternity services designed for First Nations women	Improvement	Early signs of improvement
Maternity services designed for other target cohorts	Early signs of improvement	None
First Nations maternity care professionals	Early signs of improvement	Early signs of improvement
Culturally safe maternity care	Early signs of improvement	Early signs of improvement
Antenatal appointment attendance	None	Decline
Stillbirth rates	None	None

The risks of smoking during pregnancy are being communicated to women more routinely than at the 2020 baseline. This should contribute to reductions in smoking rates in coming years. While smoking rates during pregnancy are not yet available beyond 2020, a reduction in smoking during pregnancy is likely occurring, as more jurisdictions have been making smoking cessation a priority. There is evidence that the risks of smoking during pregnancy are also being communicated more routinely to pregnant women as part of Safer Baby Bundle messaging. However, many of the systemic barriers that were present at baseline (outlined in Appendix C) still exist and require tailored interventions to overcome.

Midwifery continuity of care and other maternity continuity of carer models remain available only to a minority of women. However, more work in this space is planned as a 'medium term' focus of the Action Plan. Early progress to date has revolved around discovery and planning activities by states/territories, with work to improve continuity of care yet to come. Accordingly, data similarly shows limited change in the proportion of models of care that involve continuity of carer. [24]

Maternity services for First Nations women have shown some improvements. Improvements in availability of models of care designed for and with First Nations women were expected, complemented by better representation of First Nations people across the health workforce.

Encouragingly, Birthing on Country models of care are increasing in recognition and funding. Using this funding to increase availability of these models will take time. Availability of Aboriginal primary health organisations shows improvement.[25] Changes in the First Nations health workforce were noted: there has been a drop in the proportion of First Nations people in some professional groups such as nurses compared to the 2020 baseline, but an increase in other groups, such as Aboriginal and Torres Strait Islander Health Practitioners, First Nations GPs, and midwives.[26]

[23] Data is not yet available for other indicators under this priority, such as proportion of women who received continuity of care or carer, antenatal appointment attendance, smoking during pregnancy, availability of culturally appropriate care and stillbirth rates to measure outcomes.
[24] AIHW, 'Maternity models of care, 2022 - Continuity of carer', *AIHW* 2022, https://www.aihw.gov.au/reports/mothers-babies/maternity-models-of-care-2021/contents/what-do-maternity-models-of-care-look-like/continuity-of-carer.
[25] AIHW, 'Aboriginal and Torres Strait Islander specific primary health care: Results from the OSR and nKPI collections (supplementary OSR data tables – organizational profile), 2023.
[26] Department of Health and Aged Care, 'National Health Dataset – data tool', 2023, https://hwd.health.gov.au/datatool/.

Stakeholders reflected that the cultural safety for First Nations people was also likely to be increasing due to a number of factors, notably the reported improved access to training and awareness among clinicians. The requirement for clinicians to provide culturally safe care has also been legislated through the Australian Health Practitioner Regulation Agency.[27] The continued work on the cultural adaptation of the Safer Baby Bundle and other maternity resources for First Nations communities is also encouraging.

There is no evidence of improvements around availability of services developed specifically for target cohorts other than First Nations women.[28] While available data does not provide a picture of how many women are being cared for under different models, there are enduring risks that the needs of these other target cohorts are not being adequately identified and met, perpetuating stillbirth risks.

While resources in different languages have been developed for migrant and refugee women and interpreters are being provided, there was little data available to this evaluation to provide insights into availability of culturally safe care for this cohort.

Anecdotal evidence suggests that women's attendance at antenatal appointments temporarily declined from 2020 to 2022. Stakeholders report that COVID-19 related restrictions, anxiety and workforce pressures continued to impact availability and uptake of antenatal care into 2021 and 2022. Some stakeholders report that antenatal appointment attendance rates have returned to pre-COVID-19 levels in 2022, while others report ongoing lower levels.

Many challenges related to pandemic conditions likely impacted target cohorts more than the general population, further deepening their disadvantages in receiving quality maternity care. For example, stakeholders reported that increasing cost-of-living pressures may also be limiting target cohorts' attendance at appointments in particular, because of the cost of transport, childcare, the need to take time off work, and similar factors.

Stillbirth rates have likely remained relatively unchanged since baseline, although national stillbirth rates for the years following the baseline are not yet available.

It will take time for the changes expected from the Action Plan's combined activities to take effect. Because of this, a marked reduction in the rates of stillbirth is unlikely during the first years of the Action Plan. This conclusion was reached as with the continued roll-out of the Safer Baby Bundle, some localised reductions in stillbirth rates have been reported.[29] Some stakeholders speculated that there was likely an increase in stillbirth rates due to the challenges present during the COVID-19 pandemic.

6.2 Priority 2: Raising awareness and strengthening education

The evaluation considered the degree to which women and their health care professionals saw improvements in their awareness of leading stillbirth prevention practices and their confidence to take appropriate action. Available data on key outcome indicators are summarised in Figure 18.

[27] National Justice Project, 'Health practitioners must now deliver culturally safe care', *National Justice Project*, 2023, https://justice.org.au/health-practitioners-must-now-deliver-culturally-safe-care/#:~:text=What%20is%20the%20reform%3F,and%20Torres%20Strait%20Islander%20Peoples.%E2%80%9D.

[28] AIHW, 'Maternity models of care, 2022 - Target groups', *AIHW*, 2022, https://www.aihw.gov.au/reports/mothers-babies/maternity-models-of-care-2021/contents/what-do-maternity-models-of-care-look-like/target-groups

[29] Safer Care Victoria, 'Safer baby collaborative', *Safer Care Victoria*, 2022, https://www.safercare.vic.gov.au/improvement/projects/mbc/safer-baby

Figure 18 | Summary of uptake of awareness raising activities, grouped by target audience[30]

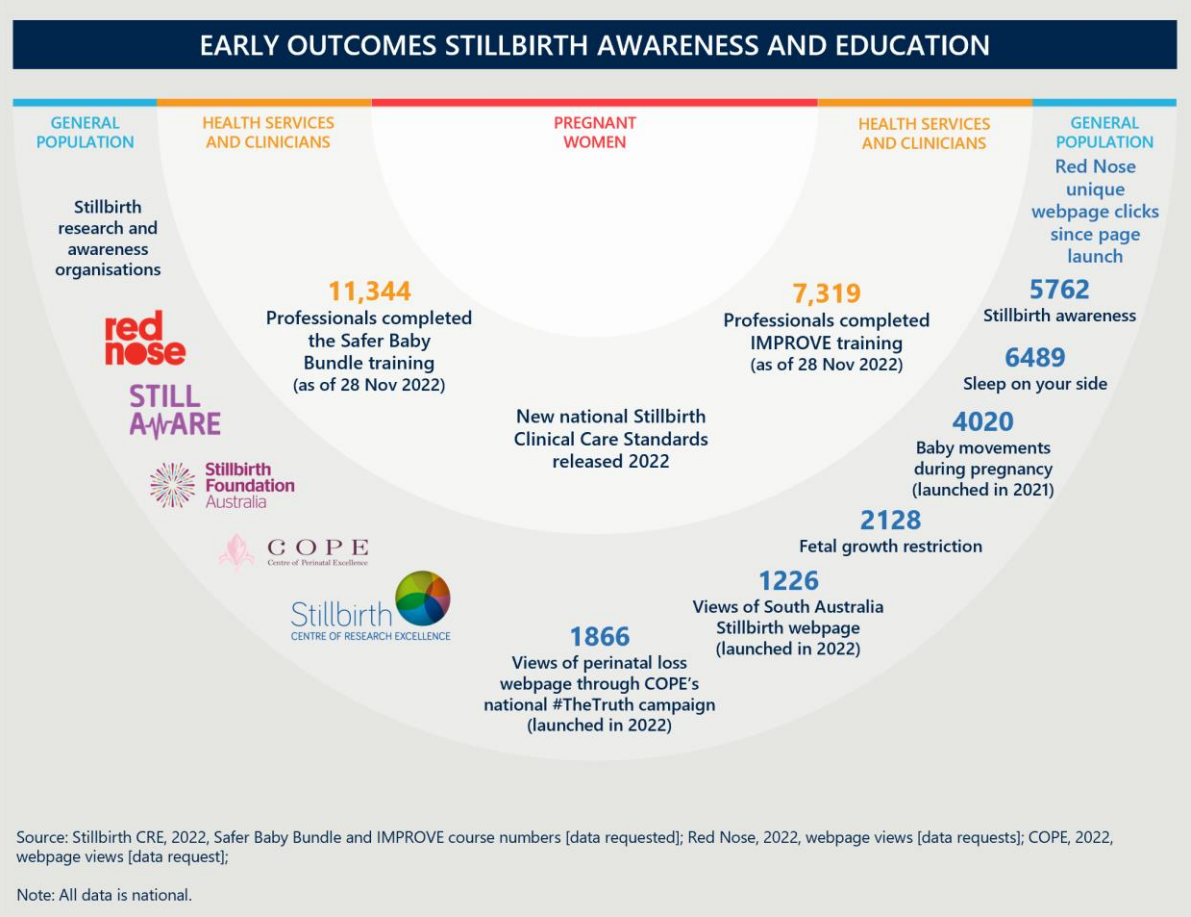


Table 11 indicates where improvements are expected and where they were observed. Further comment on the outcomes is below.

Table 11 | Early outcomes for Priority 2: Raising awareness and strengthening education

Outcome	Level of improvement expected	Level of improvement observed
Stillbirth risk and prevention awareness	Improvement	Improvement
Safer Baby Bundle and IMPROVE training uptake	Improvement	Improvement
National guideline alignment	None	None

Some awareness-raising campaigns targeted to women are gaining traction, in line with expectations. Ongoing stillbirth awareness activities by Red Nose and other non-government organisations, such as the Centre of Perinatal Excellence's newer national The Truth campaign,[31] show that women are accessing

[30] No data is available since baseline about the proportion of pregnant women advised of stillbirth risks during their antenatal appointments.
[31] The Truth [online videos], *Centre of Perinatal Excellence*, https://www.cope.org.au/thetruth/?playVideo

stillbirth related information. Resources and messaging appropriate for First Nations women and women from culturally and linguistically diverse (CALD) backgrounds are becoming more available, although reaching these communities during the COVID-19 pandemic has been challenging. Stakeholders consistently report that awareness-raising activities are having a positive impact – more women are coming to appointments better informed and confident to make decisions and follow advice regarding stillbirth prevention. However, some stakeholders have also reported increasing anxiety in women and clinicians about stillbirth as awareness has improved, resulting in increased interest in interventions.

Uptake of clinical training is on track and is delivering early results. As the number of completions for the Safer Baby Bundle and IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) eLearning modules increases, there are more and more clinicians with the awareness, confidence and capability to provide high quality stillbirth prevention and bereavement care. Stakeholders have noticed a shift since 2020 in the consistency of care around the elements of the Safer Baby Bundle, as well as an increase in the confidence and capability of clinicians to engage in appropriate conversations with women around stillbirth prevention and bereavement care.

Updates to national guidelines are still in progress, but the Stillbirth Clinical Care Standard has been released and has been received with strong support from stakeholders. National clinical guidelines are still being updated, so the alignment of state/territory guidelines to the national ones could not be assessed in accordance with the evaluation framework and plan. One jurisdiction has reported choosing to delay updates to some of their own plans and strategies until after the release of the Stillbirth Clinical Care Standard to ensure optimal alignment. This suggests that uptake in some jurisdictions will be effective once updates to the national guidelines are released.

6.3 Priority 3: Improving holistic bereavement care and community support following stillbirth

Supporting people bereaved by stillbirth requires an awareness of good practice, confidence to offer support, and access to appropriate support services.

The evaluation looked for changes in awareness of good bereavement care, the quality of care provided, and accessibility to key services. Available data regarding bereavement care are summarised in Figure 19 below.

Figure 19 | Summary of early outcomes for stillbirth bereavement care [32]

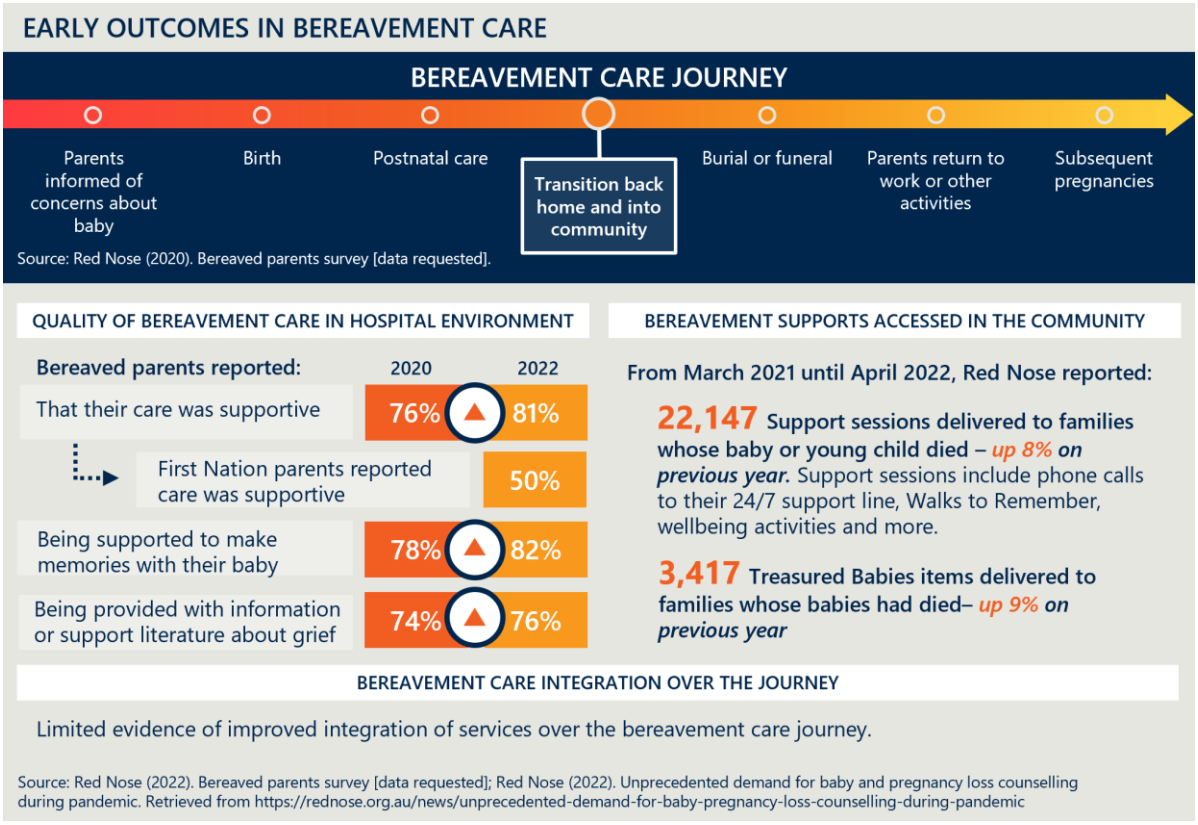


Table 12 indicates where improvements are expected and where they were observed.

Table 12 | Early outcomes for Priority 3: Improving holistic bereavement care and community support following stillbirth

Outcome	Improvement expected	Improvement observed
Availability of bereavement care	Early signs of improvement	None

Improvements around access to and quality of bereavement care appear to be limited, and the challenges in defining and measuring bereavement care have persisted. There was limited mention of bereavement-related activities in this evaluation's data collection, outside of non-government organisations. This suggests that there are risks that the Action Plan is not on track to achieving improvements in this domain.

Where data was available it suggested that there have been pockets of improvements in availability, mainly through the delivery and expansion of programs run by non-government organisations through Australian Government funding (see Section 5.2.3). Some jurisdictions are also scoping, planning or implementing improvements, but most jurisdictions had limited visibility over this area due to challenges in linking across bereavement journey transitions. This means that improved outcomes are not expected and cannot be observed due to limited data.

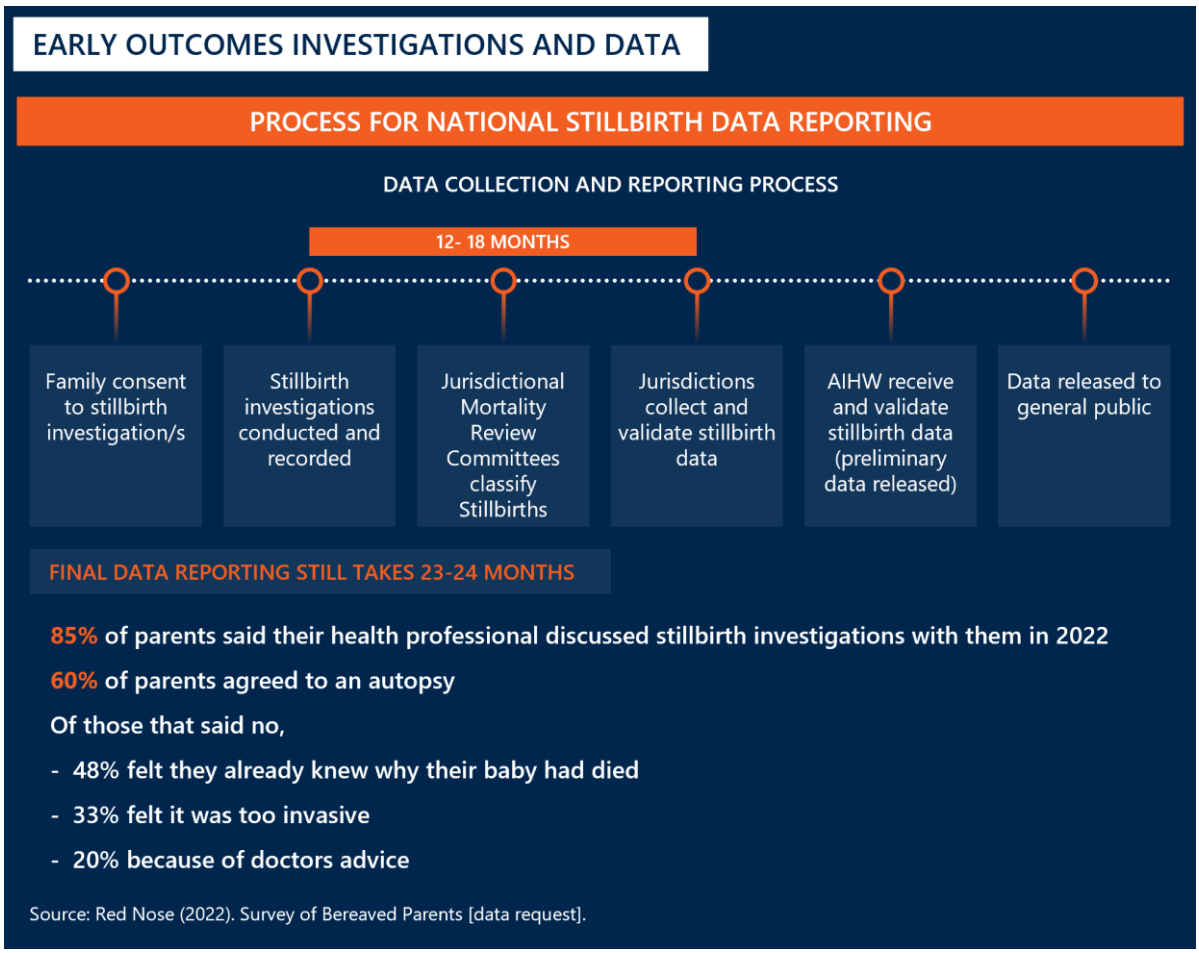
[32] Data is limited regarding early outcomes in bereavement care. Red Nose service provision data is provided as a proxy for supports accessed.

Where bereavement support is being offered, the experiences of bereaved parents have shown some improvements,[33] but newly available data indicates that the experiences of First Nations parents are substantially less positive.[34] This reflects reports from stakeholders that bereavement care is too often provided from a Western perspective and is less appropriate for people from different cultures.

6.4 Priority 4: Improving stillbirth reporting and data collection

The evaluation examined changes around stillbirth investigations, including availability of suitable health professionals to carry out such tests. It also explored any changes around how data is collected, reported and used to inform clinical and policy decision-making. Available data on key outcome indicators are summarised in Figure 20.

Figure 20 | Summary of early outcomes for stillbirth investigations and data[35]



[33] Red Nose, 'Survey of bereaved parents', *data request Red Nose*,2022
[34] Red Nose, 'Survey of bereaved parents', *data request Red Nose*, 2022
[35] Data is not available beyond baseline for number of stillbirth investigations performed and proportion of unexplained stillbirths.

Table 13 indicates where improvements are expected and where they were observed. Further comment on the outcomes is below.

Table 13 | Early outcomes for Priority 4: Improving stillbirth reporting and data collection

Outcome	Improvement expected	Improvement observed
Stillbirth investigations offered	Early signs of improvement	Early signs of improvement
Stillbirth investigations consented to	Early signs of improvement	Improvement
Proportion of stillbirths that are unexplained	None	None
Timeliness of published stillbirth data	None	Improvement

Efforts to increase the availability of investigations are showing promising early outcomes. Data on the number of perinatal pathologists and radiologists are not available to measure any increases. However, there has been good engagement by pathologists and radiologists in perinatal investigation education, resources and webinars. The training was reported to be of good quality and relevant to their roles.

Autopsy is being increasingly discussed as an investigation option after stillbirth. The rates of stillbirth investigations performed or cause of death data are not available post baseline. However, in 2022 new data has found that most bereaved parents were offered investigations, including autopsy, and many consented.[36] As more health professionals complete the IMPROVE training and other similar training programs, the quality and occurrence of stillbirth investigation conversations are likely to have increased. Common reasons for parents declining autopsy were already knowing the cause of death, worry that it would be too invasive, and advice from doctors.

Data quality improvement activities are underway for perinatal mortality data, and preliminary stillbirth data have been released at around 12 months starting from December 2021. Interviews with stakeholders did not identify any changes around the way that data is reported, shared or used in decision-making at this time. Stakeholders noted that differing indicators and reporting requirements between sites, jurisdictions and organisations was an ongoing challenge.

6.5 Priority 5: Prioritising stillbirth research

The evaluation explored changes in the research ecosystem, including the degree to which research efforts have been coordinated and focused on areas specific to stillbirth and bereavement care. Available data on key outcome indicators are summarised in Figure 21.

[36] Survey of bereaved parents [data requested] *Red Nose,* 2022

Figure 21 | Summary of outcomes for stillbirth research funding

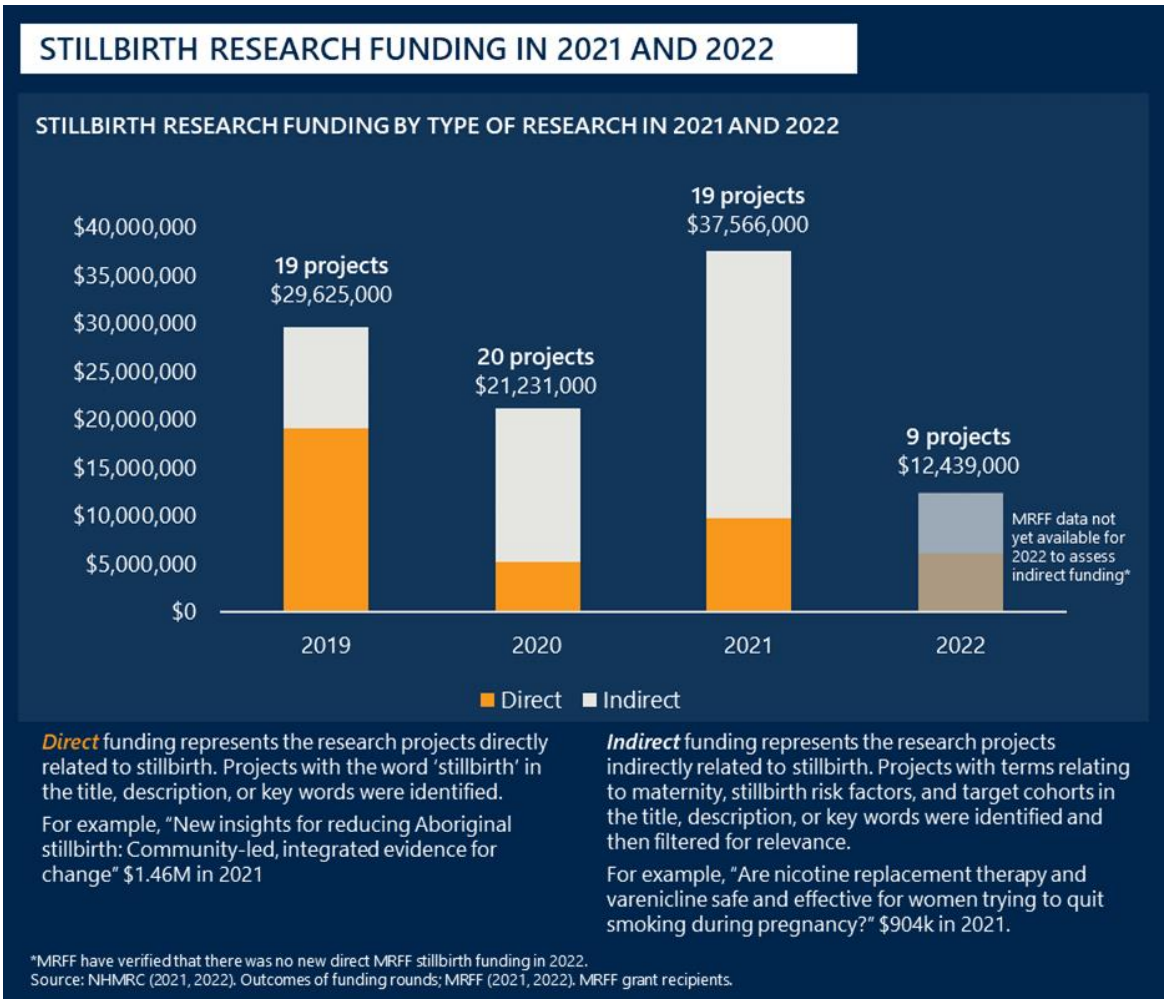


Table 14 indicates where improvements are expected and where they were observed.

Table 14 | Early outcomes for Priority 5: Prioritising stillbirth research

Outcome	Level of improvement expected	Level of improvement observed
Funding towards stillbirth priority research areas	None	Early signs of improvement

While national stillbirth research priorities have yet to be set, Australian Government funding from the National Health and Medical Research Council (NHMRC) and the Medical Research Future Fund (MRFF) injected into stillbirth research has continued.[37] In 2021, almost $10 million was allocated to seven projects that are directly related to stillbirth ($30 million to projects indirectly related). This was a significant increase from 2020, although this kind of variation is to be expected due to the cyclical and multi-year nature of research funding. The MRFF has verified that it did not fund any projects directly related to stillbirth in 2022, and public MRFF grant data for 2022 was not available at the time of writing to assess indirect funding. Data for 2022 is therefore limited to only NHMRC grants, which funded $6 million

[37] The MRFF has verified the figures for research funding provided by the MRFF that is *directly* related to stillbirth. The figures for other direct funding and for MRFF *indirect* funding were drawn from public information and classified by an independent Nous analysis of their relationship to stillbirth risk factors, other behavioural interventions and maternity care. See Section C.5.2 for methodology details.

to projects directly related, and close to $6.5 million indirectly related. This continued funding reflects the importance of stillbirth research and increased visibility among maternity care academics resulting from the Action Plan.

The overall proportion of research funding allocated to projects related to target cohorts has increased since 2020. Funding specifically for First Nations women increased substantially in 2021 following the MRFF releasing a grant opportunity for projects targeting First Nations maternal and child health (See Case Study 5 in section 5.2.5).

Stakeholders report that the existing research priorities of the Stillbirth Centre of Research Excellence (Stillbirth CRE) aid in coordinating stillbirth research, and that this is likely to improve further once national research priorities have been finalised under the Action Plan. Further, the *Cochrane Special Collection: Stillbirth prevention and respectful bereavement care,*[38] published in 2021, improved the accessibility of stillbirth research.

6.6 The impacts of the Action Plan are emerging

6.6.1 The Action Plan has contributed to a shared focus, language and goals for stillbirth and bereavement care

Stakeholders reported that the Action Plan is an important step in improving stillbirth prevention and bereavement care. While there were already many maternity care and women's health policies and strategies underway, the Action Plan adds value by raising the profile of stillbirth and bereavement care as a public health issue. It has shone a light onto stillbirth and highlighted the factors that are most instrumental to preventing it.

Stakeholders have lauded the value of the Action Plan as a vehicle for corralling efforts and supporting sustainable activities to prevent stillbirth and deliver good bereavement care. In the absence of the Action Plan, it is unlikely that many of the activities underway would have occurred.

> *"Articulating a plan like this is fantastic for getting different parts of the sector to work together – this was co-created and these sorts of things work really well. I don't know if it's because of this, or the Senate enquiry, or people being more open, but I've definitely noticed a change. Having more communication and collaboration in this area has made a difference."*
>
> – System stakeholder

6.6.2 There are tangible changes being observed relating to stillbirth prevention and bereavement support – but this is not reaching target cohorts to the extent required

The evaluation suggests that the Action Plan is having a positive impact. There is clearly momentum in the system and strong progress on many dimensions of the Action Plan.

That said, care must be taken to look beyond the 'headline figures' and consider the extent to which change is being observed among target cohorts. Women in these cohorts experience stillbirth at much higher rates than the general population. The overall stillbirth rate will only change if significant improvements are seen at a cohort level. There is evidence that reaching these women has been a challenge to date and may require greater attention moving forward.

[38] Cochrane, 'Special collection: Stillbirth prevention and respectful bereavement care', *Cochrane*, 2021, https://www.cochrane.org/news/special-collection-stillbirth-prevention-and-respectful-bereavement-care

7 Opportunities to enhance delivery and effectiveness of the Action Plan

The evaluation has highlighted opportunities to enhance the performance of the National Stillbirth Action and Implementation Plan (the Action Plan) in the coming years.

In the course of the evaluation, opportunities were identified to strengthen the strategic management of the Action Plan so that the great work that has already taken place will continue, and to position the Action Plan to achieve its maximum possible impact over the remaining years of implementation.

These opportunities are described below.

7.1 Opportunity 1: Map the Action Plan's unique purpose and value in a changed maternity landscape

The evaluation has highlighted the important linkages between the Action Plan and other policies and strategies focused on woman and/or maternity that are underway across the country. It has also highlighted the resource constrained environment in which the health care system is currently operating and the need to allocate resources strategically.

A strength of the Action Plan is that it considers stillbirth prevention and responsiveness holistically. However, it should be noted that many of its priorities are mirrored in other policies or strategies where relevant work may already be underway and is supported by substantive funding arrangements. There is therefore an opportunity to identify areas where the Action Plan is unique in its focus or where there are not substantive resources despite being included in multiple strategies, and to consider where the Action Plan provides a pathway to improving stillbirth rates and experiences in a way that would not happen without it.

> "There's a need to go back to the 'why we're doing things', so that the work becomes a bit more meaningful. We need to reflect on where there are still gaps."
>
> – state/territory government stakeholder

Mapping out the policy and strategy landscape in more detail may be a practical first step to this work. Importantly, **this suggestion is not intended to diminish the importance of the broader Action Plan** or minimise the outcomes observed which are attributable to the Action Plan. Rather, it may provide a shortlist of priorities and actions that implementers and the National Stillbirth Implementation Oversight Group (IOG) can focus on in the coming years.

This work is foundational to progressing Opportunity 2.

7.2 Opportunity 2: Develop a statement of priorities to focus effort over the next two years

This evaluation has highlighted that while good progress has been made over the last two years, it is proving challenging to consistently reach the target cohorts. It is also difficult to carry out work that is very specific to stillbirth prevention and bereavement support (as opposed to more general quality maternity care). Further, stakeholders have reported that while the high-level language within the Action Plan allows

flexibility in implementation, it also creates ambiguity around who is responsible for doing what and what is actually expected. This creates ambiguity about the degree to which implementation is on track.

A two-year statement of priorities that sits beneath the broader Action Plan may give greater clarity about what is required as the Action Plan transitions towards medium-term activities, in order to achieve its full impact over time.

> "We need more coordination and detail on what to do when it comes to implementation responsibilities."
>
> – state/territory government stakeholder

Work over the next two years could, for example, prioritise:

- reaching target cohorts
- understanding the maternity care needs of young mothers and women who have previously experienced stillbirth, given there has been relatively little focus on these cohorts to date
- achieving common language and practice around bereavement care and what is required to deliver quality care, as well as the concrete steps to embed this into practice
- continuing the momentum of work around stillbirth investigations
- exploring how data collected by implementers can be better made available and used to inform timely clinical and policy decision-making.

7.3 Opportunity 3: Strengthen leadership and accountability

There are strong foundations in place around the Action Plan's governance, which are further supported by the passion and commitment of stakeholders to achieve the Action Plan's goals. If opportunities 1 and 2 are pursued, changes to governance such as the ones outlined below would help to ensure there is unambiguous leadership in place to drive change.

Specifically, while the highly valued ongoing collaboration among governments, non-government organisations, research bodies, peak bodies and other implementation partners should continue, there is an opportunity for stronger leadership to improve accountability. This may extend to driving the development of the statement of priorities suggested in Opportunity 2 and supporting more joined-up policy, strategy and implementation activities across the system.

The Implementation Oversight Group (IOG) is an important forum to provide governance over implementation efforts. For it to be most effective, it should continue to review and provide advice around strategic issues such as addressing key risks and opportunities, as surfaced through evaluation findings.

However, there may also be value in reviewing the current scope of responsibility of the IOG. It is currently an advisory body. Given its membership, it could be converted to a decision-making body providing a focal point for the Action Plan. This may create the necessary authorising environment to a statement of priorities and to hold implementation partners accountable for action, noting the ongoing need to be pragmatic about available resources and competing priorities across the health system.

7.4 Opportunity 4: Seek targeted funding to support the next phase of implementation efforts

The funding allocation made to date to support implementation of the Action Plan has been instrumental in creating momentum and stimulating activity. However, Nous note that a common experience across the health care system is for plans or strategies to lose momentum over time when the adequacy of funding is not regularly re-examined.

Currently, there is significant substantive funding that is directed into the maternity and women's health space. This presents an opportunity to consider how this can be better leveraged to support

implementation of the Action Plan, particularly where there are synergies between the Action Plan and other maternity or women's health strategies or initiatives.

Where activities are quite specific to stillbirth and bereavement care (for example, those that are likely to be called to attention in the statement of priorities suggested in Opportunity 2), there may be value in seeking additional funding, either through federal or jurisdictional budget processes.

> *"When you know what needs to be done [for target cohorts], when you have something that works, with the high-level evidence – it should be scaled out across the country, intensified, we should pour money into it. It could be done, but there's no money for it."*
>
> – Researcher

Business cases for additional funding can be informed by lessons from this evaluation, including:

- Reaching target cohorts is more challenging and costly and requires longer timeframes compared to the general population.
- Costs of service delivery are higher in regional and remote areas.
- Some programs benefit from longer funding and commissioning periods. This allows for greater stability and certainty across the sector. It improves collaborative arrangements, workforce retention and skills, and certainty for consumers.
- Activities that are not likely to be covered by other plans but that have received Action Plan funding, notably the stillbirth investigations initiatives, have benefitted significantly from that additional attention and are progressing ahead of schedule.

Appendix A Evaluation framework

This evaluation of the National Stillbirth Action and Implementation Plan (the Action Plan) is focused on assessing the impact, effectiveness and outcome of the Action Plan as a whole, rather than assessing the outcome or appropriateness of specific tasks.

The evaluation is guided by outcomes, indicators and key evaluation questions described in the Action Plan's approved Monitoring and Evaluation Framework 2022–2030 to develop relevant and robust findings and opportunities.

A.1.1 National evaluation indicators

National evaluation indicators provide a consistent basis to measure the progress and impact of the Action Plan

The national evaluation indicators sit alongside the key monitoring and evaluation questions and are taken from the approved Action Plan's Monitoring and Evaluation Framework 2022–2030. They are intended to track the extent to which the Action Plan's priorities and outcomes are achieved between 2022 and 2030.

Table 15 lists the 18 national evaluation indicators, mapped against the Action Plan's priority areas. These indicators can be tracked annually to identify year-on-year changes. The current indicator design balances the objective of evaluating elements of the Action Plan with limitations on data availability and what can be practically measured.

Table 15 | National evaluation indicators

#	Indicator
Priority 1: Ensuring high quality stillbirth prevention and care	
1	Decrease in the rates of stillbirth at greater than or equal to 28 weeks (disaggregated by target cohorts, data also reported for greater than or equal to 20 weeks).
2	Increase in the proportion of women who receive care via continuity of care models.
3	Increase in the proportion of women who have had continuity of carer[39] during antenatal, delivery and postnatal care.
4	Increase in the proportion of women (overall and in target cohorts) attending 7 or more and 10 or more[40] antenatal care visits.
5	Increase in the proportion of women (overall and in target cohorts) attending their first antenatal visit within the first 10 weeks of pregnancy.
6	Increase in available maternity services specific to target cohorts[41] (as defined by the Action Plan).

[39] Both continuity of care and continuity of carer are included as per the Women-centered care: Strategic Directions for Australian Maternity Services. Continuity of care involves shared understanding of care pathways by all health professionals involved in a woman's care, with the aim of reducing fragmented care and conflicting advice. Continuity of carer means care provided, over the full length of the episode of care, by the same named carer.

[40] National Institute for Health and Care Excellence (United Kingdom) guidelines and the Department of Health's 2020 Australian Pregnancy Care Guidelines recommend first-time mothers with uncomplicated pregnancy have 10 antenatal visits and 7 visits for subsequent uncomplicated pregnancies.

[41] A targeted cohort service is defined as a health or maternity service that is specifically designed to provide care to specific cohorts. Examples include Aboriginal Medical Services, including Aboriginal Community Controlled Health Organisations, and antenatal care programs specifically designed for adolescents or women who have previously experienced loss. An example would be Aboriginal Medical Services, including Aboriginal Community Controlled Health Organisations, that receive funding from the Indigenous Australians' Health Programme. Other examples may include antenatal care programs specifically designed for adolescents or women who have previously experienced loss.

#	Indicator
7	Increase in the number of First Nations maternity care professionals.
8	Increase in the availability of culturally safe maternity care.
9	Decrease in the proportion of women smoking tobacco during pregnancy.
Priority 2: Raising awareness and strengthening education	
10	Increase in the number and reach[42] of publicly funded programs promoting awareness of stillbirth, risk factors and prevention strategies.
11	Increase in alignment of hospital, organisation and professional body guidelines with PSANZ (Perinatal Society of Australia and New Zealand) Clinical Practice Guideline for care around stillbirth and neonatal death and the national Clinical Practice Guidelines – Pregnancy Care.
12	Increase in the proportion of health professionals completing the IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) training program.
Priority 3: Improving holistic bereavement care and community support following stillbirth	
13	Increase in awareness and ability for bereaved women and families to access bereavement care (overall and in target cohorts).
Priority 4: Improving stillbirth reporting and data collection	
14	Increase in the proportion of women and/or families who are offered stillbirth investigation(s).[43]
15	Increase in the proportion of women and/or families who consent to a stillbirth investigation.[44]
16	Decrease in the proportion of stillbirths that are unexplained.[45]
17	Increase in the timeliness of published stillbirth data.[46]
Priority 5: Prioritising stillbirth research	
18	Increase in the number of research projects in, and amount of funding granted to, the stillbirth priority research areas.

[42] Reach considers the intended collective geographic distribution of publicly funded awareness programs and intended audiences. It is out of scope for the national evaluation to measure the reach of individual programs, so we will rely on implementers providing program-specific evaluations or monitoring information about the intended and achieved reach of their awareness programs to develop a collective view for the national evaluation.

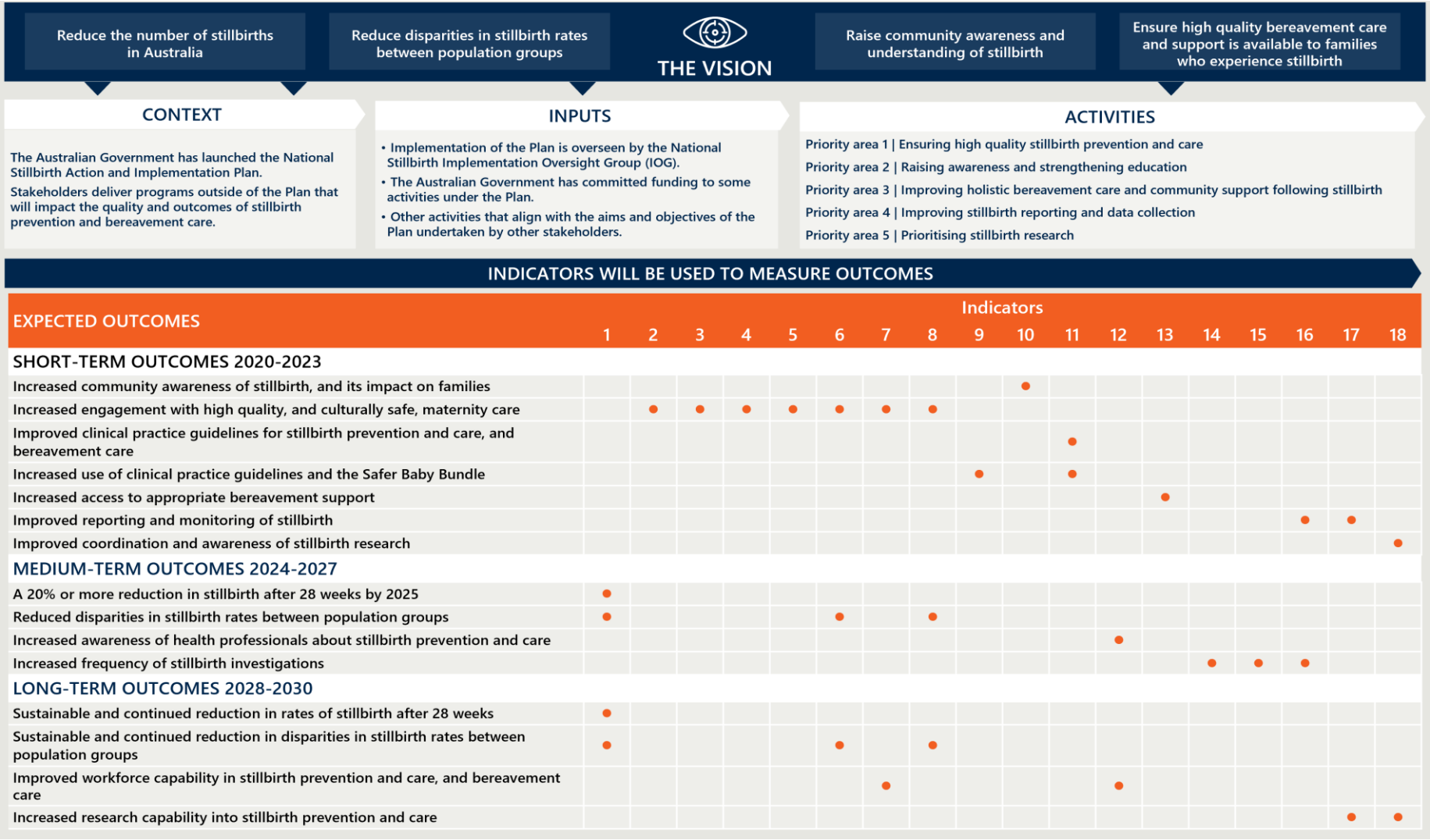
[43] Investigation here includes maternal and pregnancy history, test for foetal to maternal haemorrhage, diagnostic imaging and external examination of the baby including clinical photographs of the baby, full and limited autopsy, macroscopic examination of the placenta and cord, placental histopathology, and cytogenetics.

[44] See the previous footnote.

[45] It is important to note that the rate of unexplained stillbirths will never drop to zero as there are instances where no contributory factor was sufficient to be considered cause of death.

[46] Timely access to data on stillbirth is essential to reduce Australia's stillbirth rate. This indicator will consider the time between a stillbirth and logging the cause of death; the time between logged cause of death and when the data is sent to AIHW; and the time between when data is received by the AIHW and publication.

A.1.2 Outcomes mapped to indicators



EXPECTED OUTCOMES	Indicators 1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
SHORT-TERM OUTCOMES 2020-2023																		
Increased community awareness of stillbirth, and its impact on families										●								
Increased engagement with high quality, and culturally safe, maternity care		●	●	●	●	●	●	●										
Improved clinical practice guidelines for stillbirth prevention and care, and bereavement care											●							
Increased use of clinical practice guidelines and the Safer Baby Bundle									●		●							
Increased access to appropriate bereavement support													●					
Improved reporting and monitoring of stillbirth																●	●	
Improved coordination and awareness of stillbirth research																		●
MEDIUM-TERM OUTCOMES 2024-2027																		
A 20% or more reduction in stillbirth after 28 weeks by 2025	●																	
Reduced disparities in stillbirth rates between population groups	●					●		●										
Increased awareness of health professionals about stillbirth prevention and care												●						
Increased frequency of stillbirth investigations														●	●	●		
LONG-TERM OUTCOMES 2028-2030																		
Sustainable and continued reduction in rates of stillbirth after 28 weeks	●																	
Sustainable and continued reduction in disparities in stillbirth rates between population groups	●					●		●										
Improved workforce capability in stillbirth prevention and care, and bereavement care							●					●						
Increased research capability into stillbirth prevention and care																	●	●

A.1.3 Key evaluation questions

Key evaluation questions (taken from the Action Plan's Monitoring and Evaluation Framework 2022–2030) have guided data collection, analysis and reporting to develop the baseline evaluation. The questions are presented below in Table 16.

Table 16 | Key monitoring and evaluation questions

Key question	Research questions	Intent
IMPACT **1. To what extent has the overarching goal of the Action Plan been achieved?**	1.1 What progress has been made against the goal of reducing the rates of preventable[47] stillbirths after 28 weeks by 20%?	This question focuses on understanding the extent to which the two overarching goals of the Action Plan are being or have been achieved. It will rely on quantitative data captured in the national indicators and some qualitative data sources, particularly for bereavement care.
	1.2 What progress has been made in improving the quality and availability of respectful and supportive bereavement care, including for target cohorts?	
APPROPRIATENESS **2. How appropriate was the Action Plan's design to deliver the Action Plan's outcomes?**	2.1 What goals and outcomes does the Action Plan aim to achieve?	This question seeks to understand the appropriateness of the Action Plan's design and delivery approaches (including in different jurisdictions) to deliver the desired outcomes. Insights against this question may inform changes to the Action Plan's focus as it is implemented and newer evidence or feedback on its appropriateness emerges. These questions will largely be answered through desktop review and consultations.
	2.2 What are the key features of the Action Plan's design?	
	2.3 To what extent do the objectives of the Action Plan contribute to the women-centred care: strategic directions for Australian maternity services?	
	2.4 To what extent is the Action Plan's design supported by stakeholders?	
	2.5 To what extent does the Action Plan's design align to the best available practice/evidence, including best practice relevant to target cohorts?	
	2.6 To what extent does the Action Plan align to national and jurisdictional priorities?	
IMPLEMENTATION **3. How has the Action Plan been implemented to date and what can we learn from it?**	3.1 What is critical to understand about the policy and operating context in which the Action Plan is being implemented?	This question largely relates to the monitoring objectives. It will support monitoring of implementation of the individual tasks under the Action Plan. The Annual Monitoring Report Card provides the structure to report on implementation of individual tasks. Insights against this question are intended to support ongoing adjustments in delivery as stakeholders learn about what works well or less well. These questions will largely be answered through the information provided by and consultations with key implementers.
	3.2 What progress has been made in implementing the Action Plan?	
	3.3 What are the lessons learned from implementation to date?	

[47] Note that this research question includes the term 'preventable' to align with the overarching goal of the Action Plan.

Key question	Research questions	Intent
EFFECTIVENESS **4. How effective is the Action Plan in addressing its priority areas?**	4.1 To what extent have the Action Plan's priorities been achieved?	This question focuses on understanding how effective the Action Plan is as a tool to achieved desired outcomes. Many of the national evaluation indicators will help to understand effectiveness. Attribution of observed changes to the Action Plan will be challenging. A range of qualitative and quantitative data sources will be used to report against these questions.
	4.2 To what extent did the Action Plan contribute to observed changes in desired outcomes?	
	4.3 What unintended consequences, if any, have resulted from the Action Plan?	
EFFICIENCY **5. How efficient and cost-effective is the Action Plan?**	5.1 How have the Action Plan's resources been allocated across its priority areas, target cohorts and activities?	This question will consider whether investments in the Action Plan were cost-effective in achieving the Action Plan's desired outcomes. Monitoring and evaluation to 2024 will record funding and resources allocated based on information provided by implementers or funded. Detailed cost effectiveness analysis is intended to take place during the final evaluation reporting period in 2029. Cost data and consultations will be used to report against these questions.
	5.2 To what extent has the allocation of resources supported the delivery of the best possible outcomes?	

Appendix B Stakeholder consultation

The baseline evaluation was supported by the generous contribution of insights and reflections from a wide range of stakeholders, listed in Table 17. The objectives of engagement are to:

- understand how the National Stillbirth Action and Implementation Plan (the Action Plan) is implemented in practice, from a range of perspectives
- contextualise and validate insights from other qualitative and quantitative data sources
- inform the key monitoring and evaluation questions and identify areas for improvement.

Consultations were mainly conducted between October 2022 and December 2022, with some conducted between January and February 2023. Stakeholders contributed through a combination of the Annual Implementers Progress Update, other forms of written submissions, and semi-structured interviews.

Table 17 | Stakeholders consulted for the baseline evaluation

Government	• Australian Government Department of Health and Aged Care • NSW Ministry of Health • ACT Health • NT Department of Health • WA Department of Health • SA Department of Health • QLD Department of Health • TAS Department of Health • VIC Department of Health (Safer Care Victoria) • Australian Institute of Health and Welfare • National Health and Medical Research Council • Australian Commission on Safety and Quality in Health Care
Governance groups	• National Stillbirth Implementation Oversight Group
Health professional and peak bodies	• Australian College of Midwives • Australian Nursing and Midwifery Federation • Australian Private Hospitals Association • The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives • National Aboriginal Community Controlled Health Organisation • National Rural Health Alliance • Royal Australian and New Zealand College of Obstetricians and Gynaecologists • Royal Australian College of General Practitioners • Royal College of Pathologists of Australasia • Perinatal Society of Australia and New Zealand • Royal Australian and New Zealand College of Radiologists • Women's Healthcare Australasia
Not-for-profits and advocacy groups	• Multicultural Centre for Women's Health • Centre of Perinatal Excellence • Red Nose • Still Aware • Stillbirth Foundation of Australia
Research organisations	• Stillbirth Centre of Research Excellence • Birthing on Country

Appendix C Detailed evaluation baseline

Establishing a detailed baseline is an important enabler to tracking changes on key indicators over time and ultimately estimating the impact of the National Stillbirth Action and Implementation Plan (the Action Plan). This appendix expands on the summary in Section 30 of the report and provides a wealth of data, structured under the five priority areas.

C.1 Priority 1 | Ensuring high quality stillbirth prevention and care

C.1.1 Smoking during pregnancy is a significant risk factor for stillbirth

Smoking during pregnancy is the most common preventable risk factor for pregnancy complications.[48] For example, in 2020 the stillbirth rate at 28 weeks or more gestation was 77% higher for women who reported smoking during their pregnancy than for those who did not smoke.[49]

Australia's national smoking rates were decreasing in the lead up to 2020 (24% in 1991, 12% in 2016, and 11% in 2019), mainly driven by younger people not taking up smoking.[50] People who experienced socioeconomic disadvantage and First Nations people were respectively 18% and 25% more likely to smoke than the general population in 2020.

Smoking rates among pregnant women showed similar trends and breakdowns to smoking rates among the whole population. The proportion of pregnant women who reported smoking at any time during their pregnancy decreased from 14% in 2010 to 9% in 2020.[51] Higher smoking rates were observed among First Nations mothers (43%), mothers living in remote areas (19%), very remote areas (36%), and disadvantaged areas (18%) in 2020.[52]

While the overall smoking rate in young women was low (8% for 15 to 24 year olds in 2019), smoking during pregnancy was more common for young mothers. In 2020, 34% of pregnant women aged under 20 and 21% of pregnant women aged 20 to 24 of age smoked.[53] That is, young pregnant women are more likely to be smokers than young women who are not pregnant. Young pregnant women are also more likely to be smokers than older pregnant women. Smoking rates during pregnancy were also higher among women who lived in very remote areas (36%) than among the whole population.[54] These high smoking rates in First Nations women, women under 20 years of age and women living in very remote areas suggest a high overlap between these cohort groups.

[48] AIHW, 'Australia's mothers and babies: Smoking during pregnancy', *AIHW*, 2020, https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/antenatal-period/smoking-during-pregnancy
[49] AIHW, 'National Perinatal Data Collection,2020', *Data request AIHW*, 2023
[50] AIHW, 'National drug strategy household survey 2019', *AIHW*, 2019, https://www.aihw.gov.au/reports/illicit-use-of-drugs/national-drug-strategy-household-survey-2019/contents/summary
[51] AIHW, 'Australia's mothers and babies: Smoking during pregnancy', *AIHW*, 2019, https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/antenatal-period/smoking-during-pregnancy
[52] AIHW, 'National Perinatal Data Collection, 2020', *Data request AIHW*, 2023
[53] AIHW, 'Australia's mothers and babies: Smoking during pregnancy', *AIHW*, 2020, https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/antenatal-period/smoking-during-pregnancy
[54] AIHW, 'National Perinatal Data Collection, 2020', *Data request AIHW*, 2023

Smoking cessation supports were available at baseline, but they had limited effectiveness for some target cohorts

Most pregnant women (about 91%) were given information about the risks of smoking during pregnancy,[55] and about half of smoking women quit once they found out they were pregnant.[56]

While education on the risks of smoking during pregnancy is important, smoking cessation is most successful when paired with appropriate quitting supports such as tailored referral pathways and clinical and psychosocial interventions.[57]

Stakeholders report that smoking cessation interventions and education designed for the general population are less effective among pregnant women, and those that are effective for pregnant women generally may not be as effective for pregnant First Nations women in particular.

Further, these types of tailored supports for pregnant women and for target cohort groups were not consistently available across Australia, particularly in certain regions. These factors likely contributed to the variations in smoking rates among cohorts of pregnant women at baseline.

There were promising targeted interventions being developed in 2020. For example, $1.03 million was awarded to the University of Sydney for the "Midwives and Obstetricians Helping Mothers to Quit" trial (MOHMQuit). Researchers identified that the quality and delivery of quitting supports were often barriers to quitting. They developed a program that uses a wraparound, whole-of-system approach to improve the consistency and quality of supports provided to pregnant smokers.

Stigma around smoking during pregnancy has wide-ranging effects on a woman's behaviour and experience.

- Smoking is an addiction and the decision or ability to quit can come with complex and multi-layered challenges. A lack of nuance in community understandings of smoking during pregnancy can create stigma which further perpetuates the problem.
- Fear of shaming conversations with health care providers can deter women from attending antenatal appointments, resulting in a further lack of access to other vital aspects of pregnancy care. Women who smoke are 11% less likely to attend seven or more antenatal visits throughout their pregnancy.[58]
- Communication with pregnant women about smoking should be respectful, supportive and free of shame or blame. It should not assume that the woman has a lack of motivation or concern for her baby. It should acknowledge the barriers she may be facing and try to provide education and support.

Vaping was on the rise in younger women

While overall fewer people were smoking, increased e-cigarette use (more commonly known as vaping) was a concerning trend that emerged in the years leading up to the baseline period. The adverse impacts of nicotine on the general population,[59] and on maternal and foetal health,[60] are well documented. Further research is required to determine whether vaping specifically contributes to stillbirth.

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[55] Stillbirth CRE, 'The Safer Baby Bundle Initiative: Survey of women, pre-implementation Queensland & New South Wales [requested data]', Stillbirth CRE, 2021.
[56] AIHW, 'Australia's mothers and babies: Smoking during pregnancy', AIHW, 2020, https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/antenatal-period/smoking-during-pregnancy; Stillbirth CRE, 'The Safer Baby Bundle Initiative: Survey of women, pre-implementation Queensland & New South Wales [requested data]', Stillbirth CRE, 2021.
[57] Calder R, et.al., 'Vaping in Pregnancy: A Systematic Review', *Nicotine Tob Res.,* vol 23, no. 9, p. 1451-1458. doi: 10.1093/ntr/ntab017. PMID: 33538828; PMCID: PMC8372638.
[58] AIHW, 'National perinatal data collection, 2020', *data request AIHW*, 2023
[59] Winnall, W, Greenhalgh, EM & Scollo, MM, '18.6 The health effects of e-cigarette use', *Tobacco in Australia: Facts and issues*, 2023, https://www.tobaccoinaustralia.org.au/chapter-18-e-cigarettes/18-6-the-health-effects-of-e-cigarette-use
[60] Winnall, W, Greenhalgh, EM & Scollo, MM, '18.6.1 Health effects of e-cigarette use during pregnancy', *Tobacco in Australia: Facts and issues*, 2023, https://www.tobaccoinaustralia.org.au/chapter-18-e-cigarettes/18-6-the-health-effects-of-e-cigarette-use/18-6-1-health-effects-of-e-cigarette-use-during-pregnancy

The proportion of people who had ever used vapes rose from 9% to 11% from 2016 to 2019. This increase was reported across all age groups, but it was particularly marked among young people: nearly two thirds (64%) of smokers and one fifth (20%) of non-smokers aged 18 to 24 reported having tried vaping in 2019. Among those who tried vaping, the frequency of use also increased, with more young people using them at least monthly (from 10% in 2016 to 18% in 2019).[61]

Clear data regarding vaping rates among pregnant women is not available.[62] However, given the popularity of vaping among young people, particularly young people who smoke, and the high rates of smoking among young pregnant women, it is likely that vaping among young pregnant women was also rising in 2020.

Although vapes can be used as nicotine replacement therapies to aid in smoking cessation, further research is required to investigate the potential use of vaping for smoking cessation in pregnancy.[63]

C.1.2 A large proportion of the models of care available did not involve continuity of care or carer

Maternity models of care that include either continuity of care or continuity of carer, especially midwifery led continuity models, create better outcomes for women.[64] Efforts to increase midwifery continuity of care predate the Action Plan.

Continuity of care and Continuity of carer

It is important to note there is not a consistent definition of 'continuity of care / carer'. For example, some models are based on a relationship with a single health professional like a midwife or private obstetrician, while others may involve a small number of known providers like a midwifery group practice model. For patients with more complex needs, continuity of care often refers to coordinated and integrated care across multiple health professionals from different services.

The Cochrane Institute states that while most women should be offered midwife-led continuity of care due to the benefits to women and babies, models of care should be responsive to escalating levels of clinical risk.[65] Best-practice care for higher risk pregnancies may need multiple specialists and providers across different services to be involved. In these cases, continuity of carer may not be optimal, but coordinated and integrated care remains the goal.

Data was not available at baseline to quantify the proportion of women who receive continuity of care or carer during their pregnancies. In 2021, there were 828 different maternity models of care being provided across Australia, with 90% provided in the public sector. Services with continuity of carer made up 30.3% of all models and midwifery continuity of care models made up 18% of all models. A survey administered by Stillbirth CRE found that about 17% of women received midwifery group or team practice in 2020.[66]

[61] AIHW, 'National drug strategy household survey 2019' *AIHW*, 2019, https://www.aihw.gov.au/reports/illicit-use-of-drugs/national-drug-strategy-household-survey-2019/contents/summary

[62] Pregnancy smoking rates reported by AIHW do not explicitly include vaping and e-cigarette use, unless those who vape self-report it as smoking.

[63] Calder R, et.al., 'Vaping in Pregnancy: A Systematic Review', *Nicotine Tob Res.,* vol 23, no. 9, p. 1451-1458. doi: 10.1093/ntr/ntab017. PMID: 33538828; PMCID: PMC8372638

[64] Sandall J, et.al., 'Midwife-led continuity models of care compared with other models of care for women during pregnancy, birth and early, parenting', *Cochrane,*2916, https://www.cochrane.org/CD004667/PREG_midwife-led-continuity-models-care-compared-other-models-care-women-during-pregnancy-birth-and-early

[65] Sandall J, et.al., 'Midwife-led continuity models of care compared with other models of care for women during pregnancy, birth and early, parenting', *Cochrane,*2916, https://www.cochrane.org/CD004667/PREG_midwife-led-continuity-models-care-compared-other-models-care-women-during-pregnancy-birth-and-early

[66] Stillbirth CRE, 'The Safer Baby Bundle Initiative: Survey of women, pre-implementation Queensland & New South Wales [requested data]', Stillbirth CRE, 2021

Midwifery continuity of care models are logistically more complex to resource and administer than mainstream models, and are not being routinely offered to most pregnant women.

Case study 8: Developing a model that aims to provide the correct level of care and create more continuity across the system without the need to reorganise the workforce, based on an early assessment of risk factors.

A local health district used COVID-19 lockdowns as an opportunity to optimise their care pathways. They developed and implemented an initiative to book a first trimester screening appointment alongside every woman's 12-week scan. Women are assessed and given a tailored care pathway, including appropriate referrals, according to several factors including their risk of preeclampsia, preterm birth and stillbirth.

This approach sets the building blocks in place for early identification, planning, and management of risk factors. If women do need more than one care provider, they can begin developing relationships and trust with them earlier in their pregnancy care. This model is a pragmatic yet impactful solution that aims to provide as much continuity for women as possible without requiring a complete reorganisation of services and the workforce.

C.1.3 Maternity services designed for target cohorts were available

In addition to mainstream maternity services, there were some services available at baseline designed for three of the target cohorts:

- First Nations women
- women in regional and remote areas
- migrant and refugee women.

Services for First Nations women were available, but cultural safety in mainstream services was lacking

Many maternity models of care designed for First Nation women incorporated elements of Birthing on Country, which is generally considered as the 'gold standard' of maternity care for First Nations families. The Molly Wardaguga Research Centre, which was established in 2019 and is Australia's leading proponent of Birthing on Country, describes it as *"a metaphor for the best start in life for First Nations babies and their families, an appropriate transition to motherhood and parenting for women and an integrated, holistic and culturally appropriate model of care for all."*[67]

Case study 9: Redesigning a First Nations maternity clinic to better meet the needs of the community through the Birthing in Our Community (BiOC) model

The BiOC model in Brisbane was established in 2013 in response to a need for better continuity of carer and better health outcomes for First Nations women and babies. It is an enhanced midwifery group practice-based model under First Nations governance that is specifically tailored to the needs of the community. BiOC provides holistic wraparound social and cultural support for women and families including transport, childcare, allied and mental health care, and smoking cessation throughout the whole pregnancy and postpartum journey.

It was established through a partnership between the mainstream maternity hospital and two key Aboriginal Community Controlled Health Organisations that service the region. It supports the next generation of the First Nations maternity workforce through cadetships and placements, as well as improving the cultural capability of the non-First Nations workforce.

[67] Charles Darwin University, 'Birthing on Country', *Charles Darwin University*, 2022, https://www.birthingoncountry.com/

This mature Birthing on Country model of care had positive outcomes. Women engaged with antenatal care earlier in their pregnancies, were more likely to attend five or more antenatal appointments, had lower intervention rates, were more likely to breastfeed, and were significantly less likely to have a preterm birth. These results have remained sustainable over time, and the service is still operating.[68] [69]

The strength and maturity of Birthing on Country approaches, which draw on 60,000 years of traditional knowledge to decolonise Western maternity experiences, shows that best practice in maternity care for First Nations women was already well understood at baseline. Stakeholders confirm that these models were of extremely high quality but that they were not widely available. Most First Nations women received care through other models that cater to a broader range of patients, reinforcing the need for all services, including those in the mainstream, to be culturally safe.

First Nations maternity care and the health care system

Aboriginal primary health services (which cater to more than just pregnant women) were available at baseline, but the number of organisations decreased from 210 in 2018–2019 to 196 in 2019–2020.[70] The numbers of clients serviced was also decreasing, from about 363,000 in 2018–19 to 343,000 in 2019–20.[71] Data was not available to indicate how many pregnant First Nations women received care through First Nations primary health services.

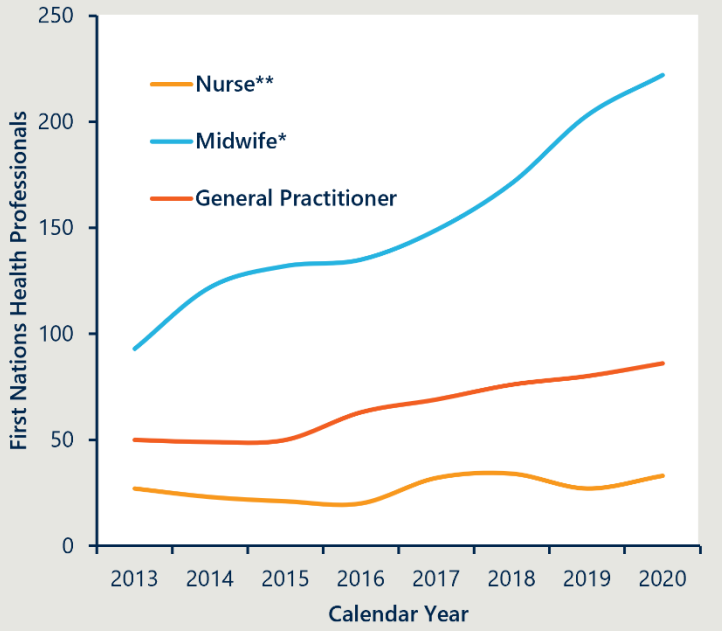
While the number of organisations decreased, the number of maternity-related health professionals within these organisations show a more encouraging trend, with a steady increase from 2013 to 2020 in health practitioners and general practitioners. Discouragingly, midwives had decreased by around a sixth (from 385 in 2013 to 320 in 2020), and there were virtually no obstetricians or gynaecologists.[72] Filling roles in these organisations was an enduring challenge, with consistent vacancy rates.[73]

As the majority of First Nations women receive their care through the mainstream maternity care system, health professionals who identify as First Nations are an important contributor to cultural safety. This is regardless of whether or not they work in services specifically designed for First Nations women.

The overall numbers of First Nations health professionals across the whole health care system were increasing in the years leading up to baseline (from 310 in 2013 to 792 in 2020),[74] especially for midwives (see Figure 22). The number of obstetricians or gynaecologists who identified as First Nations[75] remained very low.[76]

[68] Sue K, et.al., 'Effect of a Birthing on Country service redesign on maternal and neonatal health outcomes for First Nations Australians: a prospective, non-randomized, interventional trial', *The Lancet Global Health*, vol 9, no. 5, 2021. P. 651-659. https://doi.org/10.1016/S2214-109X(21)00061-9.
[69] Charles Darwin University, 'Birthing on Country', *Charles Darwin University*, 2022, https://www.birthingoncountry.com/
[70] AIHW, 'Aboriginal and Torres Strait Islander specific primary health care: Results from the OSR and nKPI collections (supplementary OSR data tables – organizational profile), 2023.
[71] Calculated based on multiplying number of organisations by client number grouping (median number). Data sourced from: AIHW, 'Aboriginal and Torres Strait Islander specific primary health care: Results from the OSR and nKPI collections (supplementary OSR data tables – organisational profile), 2023.
[72] Department of Health and Aged Care, 'National Health Dataset -Data Tool', *Department of Health and Aged Care*, 2023, https://hwd.health.gov.au/datatool/
[73] AIHW, 'Aboriginal and Torres Strait Islander specific primary health care: Results from the OSR and nKPI collections (supplementary OSR data tables – organisational profile), 2023.
[74] Department of Health and Aged Care, 'National Health Dataset -Data Tool', Department of Health and Aged Care, 2023, https://hwd.health.gov.au/datatool/
[75] Department of Health and Aged Care, 'National Health Dataset -Data Tool', Department of Health and Aged Care, 2023, https://hwd.health.gov.au/datatool/
[76] Department of Health and Aged Care, 'National Health Dataset -Data Tool', Department of Health and Aged Care, 2023, https://hwd.health.gov.au/datatool/

Figure 22 I Maternity related health professionals who identify as First Nations from 2013 to 2020



First Nations midwives have increased from 93 in 2013 to 222 in 2020

Source: Department of Health and Aged Care (2023). National Health Dataset, Data Tool. Available from https://hwd.health.gov.au/datatool/

* Midwife includes anyone trained as either a midwife only or as a nurse and midwife.
** Only reporting number of nurses that are practicing in maternity care.

Though the increasing numbers of First Nations health practitioners was encouraging, there was evidence that cultural safety was not a universal experience for all pregnant women.

A 2019 New South Wales survey of women's maternity care experiences in the public health system found that 87% of First Nations women reported that their cultural or religious beliefs were respected – 6% less than non-First Nation women.[77] The survey showed outcomes across many maternity care experience measures were significantly less positive for First Nations women.

Stakeholders report that there was a lack of cultural awareness in mainstream services, citing common circumstances such as male staff being inappropriately present for care that is part of Women's Business, or ACCHOs not receiving a discharge or handover from the mainstream hospital, breaking the continuity of care – this is particularly harmful when a woman experiences stillbirth or other traumatic circumstances.

The survey also found that the maternity care experiences of First Nations women who were supported by a First Nation health worker were significantly more positive than those who were not.[78]

A lack of locally available workforce and other linkages between services were barriers to delivering quality care to rural and remote women

Four per cent of models of maternity care available in 2021 were designed for women living in remote areas. Stakeholders report significant barriers around care for these women, particularly due to remote area staffing, which was already a national challenge in 2020. Care pathways in regional and remote areas are limited, impacting women living in these areas. Care is largely provided by local primary care health professionals such as midwives, nurses, Aboriginal and Torres Strait Islander Health Workers and general practitioners. Access to specialist advice for these professionals is important for them to provide quality care.

[77] NSW Bureau of Health Information, 'The Insights Series – Aboriginal people's experience of hospital care: Dataset NSW maternity care survey 2019', *Bureau of Health Information NSW*, 2021, p.26
[78] NSW Bureau of Health Information, 'The Insights Series – Aboriginal people's experience of hospital care: Dataset NSW maternity care survey 2019', *Bureau of Health Information NSW*, 2021, p.17, 25, 33, 41

A significant proportion of women living in these areas are First Nations women.[79] A substantial proportion of Aboriginal primary health organisations (37%) are in very remote areas, although staffing challenges increase with remoteness.[80]

Many pregnant women had to travel long distances to access a midwife or other maternity specialist. Between 2016 and 2018, Queensland Health found that 41% of women living in remote areas giving birth to First Nations babies needed to travel outside of their Hospital and Health Service (HHS) area to give birth.[81] Stakeholders report that women from some very remote areas need to leave their communities to stay in the closest tertiary centre from 24 weeks gestation in case of pregnancy complications, sometimes crossing state/territory borders. This is significantly disruptive and can have negative impacts on their mental health, financial situation and continuity of care. For First Nations women, it may also disrupt the cultural safety of their care.

Innovative models of care in this environment provide specialist outreach and midwifery group care; leverage digital communication where appropriate; and integrate with community networks and existing community programs. [82]

Tailored services for migrant and refugee women were not consistently available

While 2% of maternity models of care in 2021 were designed for migrant and refugee women,[83] it is likely that most women in this cohort group are serviced by mainstream services.

A survey of New South Wales pregnant women who went through the public system found that 91% of women who spoke a language other than English[84] felt their cultural and religious beliefs were respected, which is 3% less than the general population.

Access to professional interpreters to support these patients has been a priority across the health system, although this is not always adequate to deliver a culturally safe experience; the survey found only 78% of women were always provided with an interpreter when needed during their maternity care. These figures reflect stakeholders' comments that tailored services and cultural safety for migrant and refugee women were not consistently available at baseline.

Services were rare for women under 20, women experiencing socioeconomic disadvantage, and women with a previous experience of stillbirth

Only 6% of maternity models of care were designed for young women, though the proportion of young pregnant women who are supported by these models are unknown. No data was available about maternity care designed for disadvantaged women or women with a previous experience of stillbirth. As with other target cohorts, these groups can access services through mainstream models but are likely to need tailored support to receive quality maternity care (See Case Study 1).

[79] AIHW, 'Rural Remote and rural health', *AIHW*, 2022, https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health

[80] AIHW, 'Aboriginal and Torres Strait Islander specific primary health care: Results from the OSR and nKPI collections (supplementary OSR data tables – organizational profile), 2023.

[81] Queensland Government, 'Growing deadly families: – Aboriginal and Torres Strait Islander maternity services strategy 2019 – 2025' *Queensland Government*, 2019, https://www.health.qld.gov.au/__data/assets/pdf_file/0030/932880/Growing-Deadly-Families-Strategy.pdf

[82] Department of Health and Aged Care, 'Other population groups with specific care needs', *Department of Health and Aged Care, 2019,* https://www.health.gov.au/resources/pregnancy-care-guidelines/part-a-optimising-pregnancy-care/other-population-groups-with-specific-care-needs.

[83]Department of Health and Aged Care, 'Pregnancy guidelines – Other population groups with specific needs', *Department of Health and Aged Care*, 2019, https://www.health.gov.au/resources/pregnancy-care-guidelines/part-a-optimising-pregnancy-care/other-population-groups-with-specific-care-needs

[84] This evaluation notes that the Action Plan specifically names migrant and refugee women, whereas this survey uses the broader categorisation of 'women who speak a language other than English', which includes women from higher income non-English speaking countries who are likely to have their needs more easily met in mainstream Australian services.

The World Health Organization has identified that young people need services that are tailored to their unique biological, cognitive and psychosocial needs as they transition into adulthood, and this is particularly vital for women under 20 who are preparing for parenthood.[85]

Services appropriately designed for disadvantaged women's needs similarly provide low-cost or no-cost care, flexibility in service design, additional tailored resources and education, and wraparound care and referrals. While some services were able to provide this at baseline, for example community health clinics and bulk billing primary care services, stakeholders report that limited workforce availability had a significant impact on the capacity of these services.

There has been limited research into services designed for women with a previous experience of stillbirth, and no data was available for this evaluation. Design of services for this cohort of women should take their particular risk factors into account and incorporate any knowledge gained from their previous pregnancy and experience of stillbirth. Care must also be trauma-informed and sensitively designed to acknowledge and proactively support the emotional experience of going through a pregnancy after the trauma of a stillbirth.

C.1.4 Women's attendance at antenatal appointments varied between population groups

The national Pregnancy Care Guidelines recommend that a woman's first antenatal visit should occur during the first ten weeks of pregnancy. Early attendance is important, particularly in a first pregnancy, due to the high volume of relevant information that needs to be communicated and the need to conduct certain tests that are most effective in early pregnancy.[86]

Attendance at antenatal appointments allows for education and monitoring by health professionals. The guidelines also recommend that for pregnancies without complications a woman should have ten antenatal visits during her first pregnancy and seven for any subsequent pregnancies.

Overall, in 2020, most women (59%) attended their first antenatal appointment in the first ten weeks.[87] 86% of women attended at least seven antenatal appointments, and 55% attended at least ten.

Some target cohorts[88] were less likely to attend their first appointment before ten weeks, notably First Nations women and women living in very remote areas (only 48% of both cohorts). Some groups[89] were much less likely to attend seven or more appointments, notably only 74% of First Nations women, as shown in Figure 9 in Section 3.3.

Appointment attendance is impacted by structural barriers and individual drivers that are complex and intersectional

Women's attendance at antenatal appointments relies on:

- women having the health literacy to know that it is recommended and perceiving value in attending appointments.
- the availability of high quality care, especially care that is convenient, affordable and culturally safe.

Stakeholders report that the latter can be major barriers, particularly for target cohorts. For example, finding transport to appointments, the cost of arranging childcare, and waiting times at appointments severely impact ability to attend appointments, particularly for lower income women. COVID-19 was

[85] Department of Health and Aged Care, 'Pregnancy guidelines – Other population groups with specific needs', *Department of Health and Aged Care*, 2019, https://www.health.gov.au/resources/pregnancy-care-guidelines/part-a-optimising-pregnancy-care/other-population-groups-with-specific-care-needs
[86] Department of Health and Aged Care, 'Pregnancy guidelines – Other population groups with specific needs', *Department of Health and Aged Care*, 2019, https://www.health.gov.au/resources/pregnancy-care-guidelines/part-a-optimising-pregnancy-care/other-population-groups-with-specific-care-needs
[87] AIHW, 'National Perinatal Data Collection, 2020', *data request*, *AIHW*, 2023
[88] First Nations women, women under 20, women from Sub-Saharan Africa, and women living in remote and very remote areas
[89] First Nations women, women under 20, women living in very remote areas

already a confounding factor for this at baseline in 2020. The pandemic exacerbated an already stretched health workforce, affected appointment delivery and availability of services, and impacted on women's ability and willingness to leave home, especially to attend appointments in high-risk health care settings.

The cost of care is another major barrier to attendance at antenatal care. Bulk billing services are not available everywhere, especially in rural and remote settings where the only health service is often a private practice. Stakeholders pointed out that additional scans and appointments are not always covered under Medicare, even if they are medically indicated. Additionally, some women in target cohorts, particularly migrant and refugee women and First Nations women, may not have a Medicare card and so must pay everything out of pocket.

The quality, appropriateness and safety of services, particularly around language barriers and culture, present additional barriers to appointment attendance, as discussed in Section C.1.3.

First Nations women and migrant and refugee women may be reluctant to attend if they have negative or unsafe experiences with services and practitioners who were unable to provide culturally and linguistically appropriate care.

Women may also feel that appointments are simply not useful to them if services do not enable them to communicate with their provider, or if they feel the advice and interventions available do not apply to their circumstance or are not useful for their needs.

C.1.5 Stillbirth rates were significantly higher for target cohorts compared to the general population

There were persistent inequities in Australia's stillbirth rates leading up to and at baseline

Data shows a variance in the stillbirth rate at 20 weeks or more gestation from 2019 to 2020; however, this is similar to year-on-year fluctuations reported since 2003 (Figure 23).[90]

The stillbirth rate at 28 weeks or more gestation does not show this same increase.[91] This rate has declined from 3.3 per 1,000 births in 2003 to 2.6 in 2020 (Figure 24).

While small fluctuations between years are to be expected, observed fluctuations around 2020 may have been heightened by the impacts on the health system of COVID-19,[92] as described in Section 3.1.

Australia's overall stillbirth rates were similar to comparable high-income countries.[93]

[90] Australian Institute of Health and Welfare, *Stillbirths and neonatal deaths*, 2022, https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths.

[91] Australian Institute of Health and Welfare, *Stillbirths and neonatal deaths*, 2022, https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths.

[92] Lisa Het. Al., 'Increase in preterm stillbirths and reduction in iatrogenic preterm births for fetal compromise: a multi-centre cohort study of COVID-19 lockdown effects in Melbourne, Australia', American Journal of Obstetrics and Gynecology, 2021, https://www.medrxiv.org/content/10.1101/2021.10.04.21264500v1

Hui L, et.al., 'Increase in preterm stillbirths and reduction in iatrogenic preterm births for fetal compromise: a multi-centre cohort study of COVID-19 lockdown effects in Melbourne, *Australia', American Journal of Obstetrics and Gynecology*, 2021, https://www.medrxiv.org/content/10.1101/2021.10.04.21264500v1

[93] UNICEF for every child, 'Stillbirth', *UNICEF*, 2023, https://data.unicef.org/topic/child-survival/stillbirths/

Figure 23 I Stillbirths per 1,000 births at 20 weeks or more gestation from 2003 to 2020

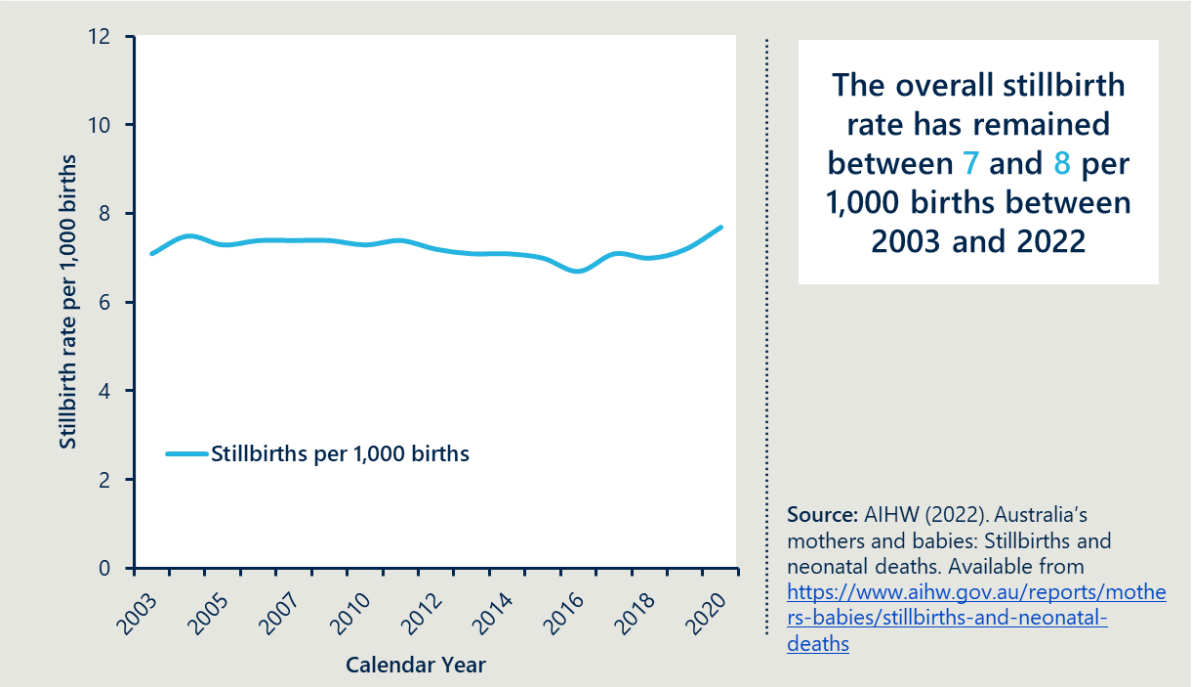
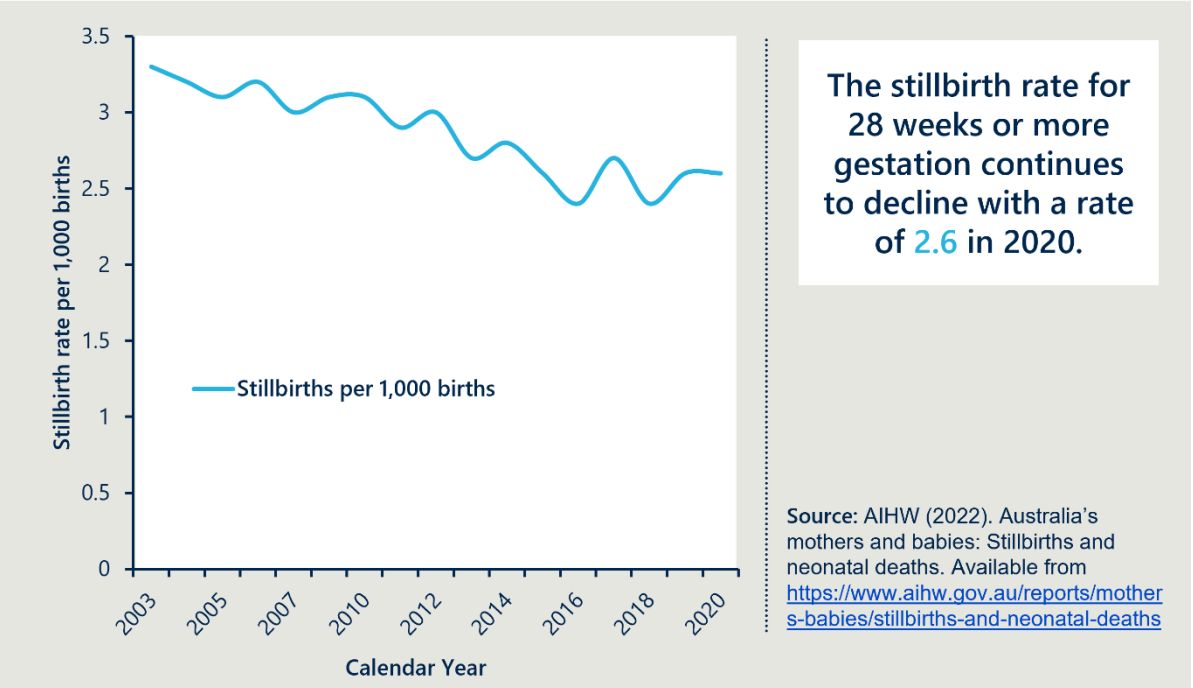


Figure 24 | Stillbirths per 1,000 births at 28 weeks or more gestation from 2003 to 2020



In 2020, there were 712 stillbirths at 28 weeks or more gestation, a rate of 2.4 stillbirths per 1,000 births.[94] There were 2,273 stillbirths at 20 weeks or more gestation, a rate of 7.7 stillbirths per 1,000 births.[95]

[94] AIHW, 'National Perinatal Data Collection, 2020' and 'National Perinatal Mortality Data Collection, 2020', *Data request, AIHW*, 2022
[95] AIHW, 'National Perinatal Data Collection, 2020' and 'National Perinatal Mortality Data Collection, 2020' *Data request, AIHW*, 2022

As shown in Figure 8 in Section 3.3, the rate of stillbirths among the target cohorts is higher than that of the general population for both 28 weeks or more gestation and 20 weeks or more gestation.

C.1.6 Intervention rates had been increasing, however neonatal death rates had been decreasing

Stakeholders highlighted that in the years leading up to the Action Plan clinicians and women were becoming more aware of stillbirth and this was having some impact on anxiety levels. Specifically, women were reporting increasing stillbirth-related fears and anxieties during their pregnancies, while clinicians were becoming increasingly reactive to stillbirth risk factors.

There are important potential consequences of these trends. For example, from 2010 to 2020 pregnancy interventions focused on timing of birth increased by about 20% (from 31.6 to 37.3 per 1,000 births for induced labour and 25.2 to 34.7 per 1,000 births for caesarean section).[96] While this trend is correlated with decreasing rates of neonatal mortality (from 2.9 per 1,000 births in 2010 to 2.3 per 1,000 births in 2020),[97] it is not without possible negative consequences, such as chronic health conditions associated with prematurity. There are many factors that influence the rates of pregnancy and timing of birth interventions, and stakeholders were careful to note that that any changes should not be wholly attributed to increased awareness or anxiety around stillbirth.

Stakeholders who mentioned these potential unintended consequences of greater stillbirth awareness highlighted that the most important mitigation tool for all of them is to ensure nuanced and personalised messaging that enables parents and their care providers to make informed decisions that are right for them.

C.2 Priority 2: Raising awareness and strengthening education

C.2.1 At baseline there were efforts underway to promote awareness of stillbirth, risk factors and prevention strategies among consumers

In 2020, public awareness of stillbirth was relatively low, and the topic remained taboo for many families, communities and clinicians.[98] Stakeholders reported that before baseline there were education and awareness-raising activities around stillbirth, but there had been no national public health awareness campaigns to date on the subject in Australia.

Non-government organisations such as Still Aware, the Stillbirth Foundation of Australia and Red Nose/Sands ran awareness raising activities including:

- organising events and awareness days
- sharing stories from families
- disseminating information about pregnancy, prevention and loss on their websites and social media platforms.

Red Nose's website page views in 2020 revealed that pages relating to stillbirth awareness and prevention strategies had varying reach. The pages relating to awareness and side sleeping had substantially more

[96] AIHW, 'National Perinatal Data Collection annual update 2020 (data tables)', *AIHW*, 2022
[97] AIHW, 'National Perinatal Data Collection annual update 2020 (data tables)', *AIHW,* 2022
[98] Adrienne G, et.al., 'Stillbirth in Australia 4: Breaking the Silence: Amplifying Public Awareness of Stillbirth in Australia', *Women and Birth*, 2020, vol 33(, no 6), p., 2020, p. 526-530, https://doi.org/10.1016/j.wombi.2020.09.010

views than the 'quit smoking' and 'foetal growth restriction' pages. All stillbirth-related pages had low views compared to the general pregnancy pages.

One major stillbirth-related awareness campaign was the Victorian "Movements Matter" campaign, run in partnership between Stillbirth CRE and Safer Care Victoria in late 2018.

This short, targeted, low-cost campaign in late 2018 predominantly used social media, posters and flyers in hospitals, combined with clinician education. Evaluation of over 1,500 women across five sites showed that pregnant women's knowledge of foetal movements as pregnancy progresses and recognising the importance of contacting their health care provider immediately if baby was moving less was 50% more likely following the campaign. After the campaign women were two and a half times more likely to report having received both written and verbal information about the importance of baby's movements, compared to before the campaign. [99]

The Safer Baby Bundle, developed by Stillbirth CRE, was the other major source of awareness and education for women and clinicians in the lead up to the baseline period. The Safer Baby Bundle is "a collection of change ideas or interventions for Australian maternity health care professionals designed to reduce late pregnancy stillbirth. The interventions are based on evidence summaries developed in partnership with the Perinatal Society of Australia and New Zealand. Development of the Safer Baby Bundle has drawn from the expertise and experience of international advisors from the UK Saving Babies Lives Bundle of care".[100] It had already been implemented in Victoria, New South Wales, and Queensland by the time the Action Plan was launched in December 2020. It is targeted at health professionals, through training and resources, and at women through flyers, brochures, posters, videos, a website and social media.

A survey run before implementing the Safer Baby Bundle in Queensland and New South Wales in 2020 found that about half of pregnant women were given Safer Baby Bundle related education (see Figure 10 for more details).[101] Survey results corroborate anecdotal comments by stakeholders that by 2020 the Safer Baby Bundle and other activities had already helped create a positive shift in women's awareness of stillbirth and their willingness to ask questions and incorporate stillbirth prevention advice such as side sleeping. However, the relatively ad hoc and uncoordinated nature of awareness activities was a limitation, and most women and communities were not sufficiently aware of stillbirth prevention and risk.

There are enduring challenges to deliver education and awareness raising to target cohorts

The delivery methods of the above activities limited their reach and effectiveness among some target cohort groups, particularly with regard to linguistic and cultural appropriateness for First Nations and migrant and refugee women. Most education and awareness activities were in English and were designed for the general population. Adequate resources had not been made widely available to comprehensively adapt or translate education for the great linguistic and cultural diversity that exists across target cohort groups.

Many of the above activities also relied on digital methods of delivery. This limited their effectiveness among some target cohorts who were less likely to have ready access to technology and the digital literacy to engage, particularly First Nations women, migrant and refugee women, women who are disadvantaged, and those living in rural and remote areas.

COVID-19 created an additional reliance on digital communication, further disadvantaging these women and creating an increased need for multi-platform, tailored information campaigns (see Case Study 2).

[99] Adrienne G, et.al., 'Stillbirth in Australia 4: Breaking the Silence: Amplifying Public Awareness of Stillbirth in Australia', *Women and Birth*, 2020, vol 33(, no 6), p., 2020, p. 526-530, https://doi.org/10.1016/j.wombi.2020.09.010
[100] Stillbirth CRE, 'The Safer Baby Bundle', *Stillbirth Centre of Research Excellence*, 2023, https://stillbirthcre.org.au/about-us/our-work/the-safer-baby-bundle/
[101] Stillbirth CRE, 'The Safer Baby Bundle Initiative: Survey of women, pre-implementation Queensland & New South Wales', *data request Stillbirth CRE,* 2021

C.2.2 Key education programs for health professionals had recently been launched

Education for health professionals enables them to feel confident in providing consistent, high quality stillbirth prevention and bereavement care, even if stillbirth is rare in their practice or they have never encountered it before.

The Safer Baby Bundle was already one of the main mechanisms for clinician education at baseline, although this was mainly in the states where it had already begun implementation. There were 8,320 registrations and 7,099 completions of the Safer Baby Bundle e-Learning training between its launch in October 2019 and the Action Plan's launch in December 2020. Stakeholders agreed that at baseline the Safer Baby Bundle had already created a positive shift in stillbirth-related care such as standardised surveillance practices and growth monitoring by clinicians.

The IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) program, also developed by Stillbirth CRE, was the other major source of education and awareness for clinicians at baseline. Where the Safer Baby Bundle focuses on stillbirth prevention messages for women and their doctors, IMPROVE aims to educate clinicians on what happens after a stillbirth. The 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 … This includes supporting health care professionals respond to women and families who have experienced stillbirth, conduct perinatal autopsy and mortality reviews, and communicate with bereaved parents."[102]

The IMPROVE eLearning training had 1,841 registrations and 823 completions between its launch in December 2019 and December 2020. The uptake of training is also expected to impact on outcomes under the Action Plan's third and fourth priorities regarding bereavement care and stillbirth investigations (see Sections C.3 and C.4).

C.2.3 Alignment of hospital, organisation and professional body guidelines with national guidelines was somewhat patchy[103]

Another way to drive consistency and quality of practice and ensure clinicians have enough awareness and education to confidently care for women is by including up-to-date stillbirth information in clinical guidelines.

At the time of the Action Plan's launch, there were two national-level guidelines that impacted on stillbirth and bereavement care: the *Clinical Practice Guidelines: Pregnancy Care*, also known as the *Pregnancy Care Guidelines* (maintained by the Australian Government Department of Health and Aged Care); and the *Clinical Practice Guidelines for Care Around Stillbirth and Neonatal Death*, often shortened to the CASAND (Care Around Stillbirth and Neonatal Death guidelines) (maintained by Stillbirth CRE).

National guidelines are expected to influence state/territory-level guidelines, which in turn influence hospital and practitioner-level ones. In order to explore this system uplift, this evaluation has taken a selection of relevant health and state/territory-level guidelines as proxies to assess the 'trickle down' process of updates to national guidelines over the life of the Action Plan (this approach was adapted from the Monitoring and Evaluation Plan 2022–2024, as national guidelines are still being updated).

State/territory-level guidelines were assessed against the national guidelines to ensure coverage in state/territory guidelines of stillbirth and bereavement care topics covered in the national guidelines (see Table 18). Where alignment was *High,* all or almost all of the relevant topics were covered; *Moderate,*

[102] Stillbirth CRE, 'IMPROVE: Improving perinatal mortality review and outcomes via education', *Stillbirth Centre of Research Excellence*, 2021, https://stillbirthcre.org.au/about-us/our-work/improve/

[103] Note that in the Action Plan, actions for updating guidelines are spread across most priority areas. For clarity and consistency, this evaluation will discuss guidelines under Priority 2.

about half of the relevant topics were covered; and *Limited,* few or none of the relevant topics were covered.

Table 18 | Assessment of state/territory guidelines against national guidelines

Action area	Easily accessible online	Alignment with national guidelines
South Australia Health – Perinatal clinical practice guidelines	Yes	High
Queensland Clinical Guidelines – Maternity and neonatal clinical guidelines	Yes	Moderate
Victorian Department of Health and Safer Care Victoria – Maternity and newborn services user guide	Yes	Moderate
King Edward Memorial Hospital (adopted by Western Australia Health) – Obstetrics and gynaecology guidelines	Yes	Limited
New South Wales Government – Guidance for maternity and newborn care	Yes	Limited
RANZCOG (Royal Australian and New Zealand College of Obstetricians and Gynaecologists) – Obstetrics and Gynaecology	Yes	High

At baseline, there was mixed alignment of state/territory guidelines with national guidelines. Stakeholders noted that there were inconsistencies in practice between sites and jurisdictions, resulting in differences in care and outcomes, indicating a lack of alignment and consistency of guidelines.

C.3 Priority 3: Improving holistic bereavement care and community support following stillbirth

C.3.1 Good quality bereavement care is different at each stage of the journey, making it challenging to establish and measure

Quality bereavement care is complex and multifaceted, making it challenging to define and measure. As an indicative example, the current CASAND guidelines lay out 49 recommendations across 11 care factors around the provision of respectful and supportive perinatal bereavement care.

As outlined in Figure 11 in Section 3.5, bereavement care starts at the point of the parent/s being informed that there might be something wrong with their baby or that their baby has died. It continues throughout the hospital experience of birthing and postnatal care, to the funeral, back into the community, into subsequent pregnancies, and years beyond. Good quality bereavement care looks different at each of these stages, varies depending on individual needs, and is also influenced by cultural perspectives of death, grief and healing.

While many health services do provide quality bereavement support, many are still centred in Western understandings of grief and are not equipped to adequately support women with different cultural needs around bereavement. For example, some stakeholders commented on the common practice of providing

parents with a quiet space and time alone to grieve in hospital before returning home. They noted that this can be very valuable to many parents, but that for some First Nations women and families being left alone in a hospital room to grieve can be very painful, as their priority would be to be with their community and potentially to return to their Country as they grieve.

Continuity of carer throughout the whole journey is a critical component for good bereavement care. A known and trusted care professional is in a better position to communicate important information to the parents, give them support, counselling and advice, and advocate for their particular needs.

Measuring the quality and availability of bereavement care would require measurement at each stage listed above, according to different qualitative measures that vary between stages and individual needs. Data regarding bereavement care is minimal at baseline, but this evaluation has access to some survey data regarding the hospital period. No data is available regarding specialised care for subsequent pregnancies for women with an experience of stillbirth.

C.3.2 Bereavement care in hospital settings was mostly reported to be good, with some room for improvement

Clinicians strive to provide high quality, compassionate bereavement care. At baseline, there were national guidelines (CASAND and Sands), and the main nationwide training program, IMPROVE, had recently been made available (see Section C.2.2). However, the reach and content of these resources was still limited. Stakeholders reported that care could be inconsistent and experiences varied. This was likely influenced by the broader taboo around stillbirth and the challenging nature of the conversations on the subject, for clinicians as well as for parents.

In a survey of bereaved parents,[104] the majority of respondents (76%) reported that their care was supportive. 81% said the news was delivered in appropriate private environment and 78% said they were supported to make memories with their baby. Only 68% said their care recognised personal, cultural and religious needs. This survey did not measure differences by target cohort.

Only 54% reported that they were informed of the grief they may experience. This reflects stakeholder comments that the resources available at the time covered the clinical and administrative aspects of bereavement care, with less guidance around some of the emotional and psychological elements that women and their families may experience.

Stakeholders commented that quality and availability of immediate bereavement care depended strongly on the preparedness and the personality of the staff on duty, as well as the preparedness of services and the maturity of referral pathways, which varied strongly across different sites. This was a particular issue in rural and remote hospitals, which see fewer births and therefore fewer stillbirths, meaning staff and systems had less experience of what to do in the event of a stillbirth. Stakeholders cited instances where bereaved parents were inappropriately placed in beds in postnatal recovery wards, among newborn babies and families; or instances where the birth hospital did not have the capacity to do follow-up bereavement care, so it was pushed onto child and family health nursing units instead, resulting in a loss of continuity as well as care that may not feel appropriate for bereaved parents.

C.3.3 Most women were connected to supports in the community

The transition from the hospital to the home and supports in the community is a fracture point where continuity of care can be disrupted and bereavement support can drop off (see Case Study 3).

In the survey of bereaved parents, 74% of respondents reported that they were given information regarding supports available to them after hospital discharge, meaning that the other 26% of parents were not supported in their journey back to the community. Supports available to the partner or family

[104] The voluntary nature of the survey, while critical, limits the generalisability of these findings in particular to target cohorts. Red Nose, 'Survey of bereaved parents', *Data request Red Nose*, 2020

members were only discussed in the minority of cases (46% and 32%, respectively). About 20% of respondents reported that they did not access any formal support; however, some reported receiving adequate support through informal relationships in their lives such as family members, friends or religious communities.

Best practice suggests that transitioning bereavement care back into the community should always involve notification of the woman's regular health practitioner (for example general practitioner or ACCHO) and seamless transfer of notes and care. Continuity of care/carer during this period is vital to ensure that the supports provided are as personalised as possible, and to minimise the difficulty of having to bring new people up to speed. On top of continuous health care support, the transition can also involve a combination of informal (family and friends) and formal supports (peer support groups, online information specialist bereavement services, etc.) Figure 11 | Summary of self-reported quality of bereavement care in hospital environment and self-reported bereavement supports accessed in community in Section 3.5 lists a range of supports that bereaved parents accessed in 2020.

Stakeholders noted that social media was making it easier to connect bereaved women and families with each other for peer support, advice, sharing stories and forming communities. This was often through the social media accounts of advocacy organisations, or informally. This access to free, informal supports can be invaluable. However, it depends on people having digital literacy and access to technology, and being able to find a community they identify with.

Stakeholders commented that there was not enough recognition or systems in place to enable cultural safety and wellbeing in bereavement care in 2020. For example, ACCHOs are well placed to provide critical ongoing psychological counselling & holistic wellbeing support for First Nations women, but they are limited by barriers such as not being notified that a stillbirth has occurred, and inadequate staffing or funding arrangements.

Stakeholders also highlighted the critical need for ongoing support for the non-clinical workforce in the provision of community supports, including social and emotional wellbeing workers, peer support workers, Aboriginal liaison officers, cultural workers and translators, traditional healers, community elders and spiritual leaders.

Stigma surrounding stillbirth can exacerbate the pain of bereavement

A lack of community awareness and understanding around stillbirth causes, risk factors, and effects can result in bereaved women and families encountering harmful stigmatising views and behaviours. This stigma may be:

- **structural,** for example workplaces or institutions not having adequate structures in place such as leave policies.
- **social,** for example insensitive depictions and misinformation in popular media and opinion; harmful comments, blame, judgement or avoidance from friends, family, colleagues, clinicians.
- **self-stigma,** for example women internalising the structural and social stigma and worrying that they are somehow to blame for their stillbirth.

Data is not available to measure how these factors impact on experiences of bereavement, but stakeholders report that these layers of stigma and blame can further complicate and exacerbate the painful bereavement process.

To combat the culture of shame and stigma around stillbirth, it is vital that conversations around stillbirth prevention and care are carefully nuanced to avoid placing the blame on the mother, even if she has struggled to adopt recommended preventative behaviours, for example. Making stillbirth less of a taboo topic will also help to ensure a woman's support system (including clinicians, friends and family) feel better equipped to talk to her and support her through her bereavement. Having answers to what happened can also help the bereavement process.

C.4 Priority 4: Improving stillbirth reporting and data collection

C.4.1 The underlying cause of stillbirth was often unexplained

At baseline there were still significant gaps in understanding the causes of stillbirth. In 2020, 18% of stillbirths at 28 weeks or more gestation were unexplained (see Figure 12 in Section 3.6). 53% of unexplained stillbirths at 20 weeks or more gestation involved an incomplete investigation.[105] An equivalent figure for stillbirths at 28 weeks or more gestation cannot be reported due to lack of reliability of small numbers.

Reducing unexplained stillbirths and improving research in this space requires increasing the number of stillbirth investigations. An investigation is not always medically indicated, as the cause of death can sometimes be determined without one, although some parents will still choose to have an investigation to confirm the diagnosis.

Investigation can take various forms:

- external examination
- imaging
- blood tests
- DNA tests
- abdomen drainage
- placental histopathology
- autopsy

Autopsy is the most complete or thorough form of investigation, as it surfaces the largest volume of information. It has also received the most attention in stillbirth implementation activity and reporting. This is partly due to data availability, as only autopsies and placental histopathology are currently included in mandatory data reporting.

C.4.2 Only half of all stillbirths in 2020 had an autopsy performed

Increasing the number of appropriate investigations relies on:

- clinicians **offering** such investigations
- families **consenting** to them
- **availability** of investigation services and suitable health professionals.

At baseline there is no data on the extent to which clinicians offer investigations or the proportion of families who, when offered an investigation, consent. The availability of investigation services and professionals able to undertake investigations varied across the country. Centres that were able to perform stillbirth investigations were reported to experience high demand and long waiting times.

The number of investigations performed has been used as a proxy for a minimum number of parents who consented to investigations, although some investigations that were consented to may not have been able to occur due to limited availability of pathologists. In 2020, 48% of stillbirths at 28 weeks or more

[105] AIHW, 'National Perinatal Mortality Data Collection, 2020' *Data request AIHW*, 2023

gestation had an autopsy performed, and 89% had a placental histopathology performed.[106] First Nations parents were 6% less likely to have an autopsy performed for stillbirths at 20 weeks or more gestation. Equivalent data for 28 weeks or more gestation is not reportable due to unreliability of small numbers.

C.4.3 There were rigorous data governance processes in place, which impacts how quickly data is available to others

At baseline, the Australian Institute of Health and Welfare (AIHW) was the central source for reliable, national, cleaned data on stillbirth and related factors. Due to rigorous data governance and quality assurance measures, it takes up to two years to release final national public stillbirth data (in the last two years, preliminary data have been released within 12 months for most states/territories). Figure 12 in Section 3.6 summarises the steps involved.

Stakeholders noted that delays in publication of data were mainly caused by the multiple stages of reporting and review processes. Many described challenges in coordinating and collecting data due to differences in indicators and reporting requirements for different sites, jurisdictions and organisations.

Women's Healthcare Australasia (WHA) was another key player for timely stillbirth data at a national level. They run a data collection and benchmarking program across their member network of over 150 women's hospitals and maternity units throughout Australia. The aim is to enable "meaningful comparisons among peer services that help each service to appreciate both their key strengths as well as opportunities for improving care and outcomes."[107] This data was less robust than AIHW data, as it did not provide fully national coverage and was only available to WHA member sites, but it was much timelier than AIHW data.

While rigorously verified data provides assurance of data accuracy and is important from an evaluation perspective, the time required for this process may be detrimental from a governance perspective. Access to more timely data at a national level, even with less verification, is underway with the release of preliminary data after 12 months, allowing clearer oversight over what is happening with stillbirths, and the Action Plan governance to be more responsive.

C.5 Priority 5: Prioritising stillbirth research

C.5.1 Important stillbirth research was already occurring in the lead up to the Action Plan, but there were still gaps in knowledge

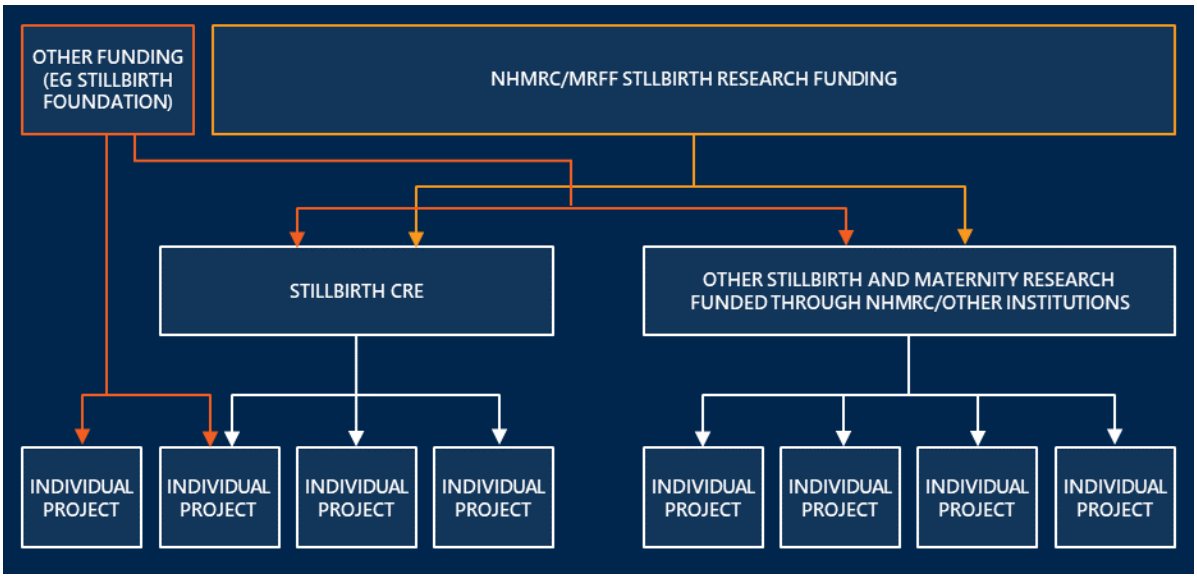
Strategically expanding the stillbirth research base will improve our understanding of stillbirth prevention, risk factors, causes, treatment and bereavement care.

Some stakeholders noted that at baseline there had not been any major breakthroughs in stillbirth prevention or care for some time and there were still significant knowledge gaps in our understanding of stillbirth.

The stillbirth research funding landscape involved limited coordination across a variety of players. At baseline, there were already a variety of research funders and organisations in the space, as mapped in Figure 25.

[106] AIHW, 'National Perinatal Mortality Data Collection, 2020', *Data request AIHW*, 2023
[107] Women's Healthcare Australasia, 'Benchmark', *Women's Healthcare Australasia*, 2022, https://women.wcha.asn.au/benchmark/

Figure 25 | Indicative map of stillbirth research funding



This evaluation tracks stillbirth research funding allocated by the Australian Government through the National Health and Medical Research Council (NHMRC) and the Medical Research Future Fund (MRFF),[108] in line with the methodology outlined in the Monitoring and Evaluation Framework 2022-2030.[109]

It is not the role of these federal agencies to prioritise research funding to the level of a particular topic like stillbirth. However, when the NHMRC provided funding to the Stillbirth Centre for Research Excellence (Stillbirth CRE) in 2016, following a peer review and scoring process, stillbirth was recognised as an area of importance, and Stillbirth CRE was able to start enabling some research coordination in the space.[110]

To that end, any degree of coordination in stillbirth research at baseline stemmed from the Stillbirth CRE's work. They were already organising their research according to research priorities that had been workshopped in 2015–2016, but these priorities were not nationally endorsed and were due for a refresh by the time the Action Plan was launched in 2020.

Only the NHMRC funding provided to the Stillbirth CRE can be considered directly influenced by their priorities. However, the existence of the Stillbirth CRE automatically provides a degree of coordination to the space, as it supports a networked approach and good sharing of information across the system, which magnifies the impact that investment in research can have.

There was also research work happening outside the Stillbirth CRE. This was not necessarily formally linked to or funded by Stillbirth CRE networks, but it affords innovation and diversification of the research field. Stakeholders reflected that researchers and other non-government organisations can and do informally or formally align with Stillbirth CRE's priorities, regardless of their funding relationships.

[108] The MRFF has verified the figures for research funding provided by the MRFF that is *directly* related to stillbirth. The figures for other direct funding and for MRFF *indirect* funding were drawn from public information and classified by Nous on the basis of independent analysis of their relationship to stillbirth risk factors, other behavioural interventions and maternity care.
[109] This methodology was adapted slightly - it was written with the intent to compare the alignment of stillbirth research funding to the Stillbirth CRE research priorities, with the expectation that research priorities would be set by the time the first evaluation was conducted. As this has not yet occurred, the comparison is not possible. Stillbirth research funding data has simply been collected and analysed to describe the amount allocated and how closely related it is to stillbirth.
[110] Stillbirth CRE, 'Centre of Research Excellence in Stillbirth 2016-2021 - Final report', *Stillbirth CRE*, 2021, p.8

C.5.2 New funding for stillbirth research declined from 2019 to 2020, while new funding for research indirectly related to stillbirth increased

As stillbirth is so intrinsically linked to the broader spectrum of good pregnancy care, there is great diversity in the research projects that are likely to impact on stillbirth outcomes. This evaluation has broken the distribution of research projects down to research that is directly related to stillbirth and indirectly related.

- **directly** related to stillbirth: there is specific reference to stillbirth in the project description, title or key words.
- **indirectly** related to stillbirth: there is reference to key words and concepts relating to stillbirth risk factors, maternity care and/or target cohorts in the project description.[111] These projects related to physiological, behavioural and systemic interventions that are relevant to stillbirth.

Most research funding is for multi-year projects, so this analysis tracks how much new research funding is put into circulation each year. Year-on-year variation is to be expected due to the cyclical and irregular nature of research work and funding availability.

Figure 13 shows there was a drop of $8.39 million of funding from 2019 to 2020. The drop in overall funding may have been due to COVID-19 and bushfire-related research being prioritised in 2020. There was notably a large drop in research directly related to stillbirth. This is potentially due to the large investment in the previous year, including projects like the Safer Baby Bundle that were planned to be rolled out across multiple years.

[111] Search terms used to determine stillbirth related research include: stillbirth, placenta, midwife, perinatal, birth, maternal, maternity, pregnant, pregnancy, gynaecology, obstetrics, fetal, foetal, reproduction, reproductive, and paediatrics

Appendix D Insights from the design of comparable plans

This section compares the Action Plan with similar stillbirth prevention programs in comparable economies. This international comparator research explored stillbirth program implementation and evaluation from five health care systems: the United Kingdom (UK), Scotland, Denmark, New Zealand and Canada. The comparative research provides information on evidence-based best practices, similarities, and barriers to implementation.

D.1 Overview of findings

Nous conducted desktop research of stillbirth prevention programs similar to the National Stillbirth Action and Implementation Plan (the Action Plan), in the comparable economies. These programs and evaluations (where available) were reviewed thoroughly and the learnings were collated. Nous also conducted a literature review to back up some of the findings and learnings.

There are several common elements in these programs, including the focus areas, implementers and intended impact. The UK and Scotland have well-structured programs that have formed the basis for stillbirth programs in many other comparable countries.

A common finding across comparator countries is the lack of targeted approach for target cohorts similar to the ones in the Action Plan. While these countries target pregnant women, it is unclear how their programs impact specific groups of women from diverse backgrounds and contexts. All reviews indicate the need for more research into care for vulnerable women such as women from ethnic minorities, homeless women and women in the criminal justice system. A differentiating factor for the Australian Action Plan is that there are clearly defined target cohorts.

Another key difference between the Australian Action Plan and the comparator countries relates to the focussed approach for bereavement support provided to the families with stillborn babies. While most comparator programs recognise the value of psychological and emotional support, this area lacks rigour in most programs. The UK National Institute of Health and Care Research[112] strongly recommends that hospital policies should incorporate bereavement counselling or psychological services for women experiencing stillbirth.

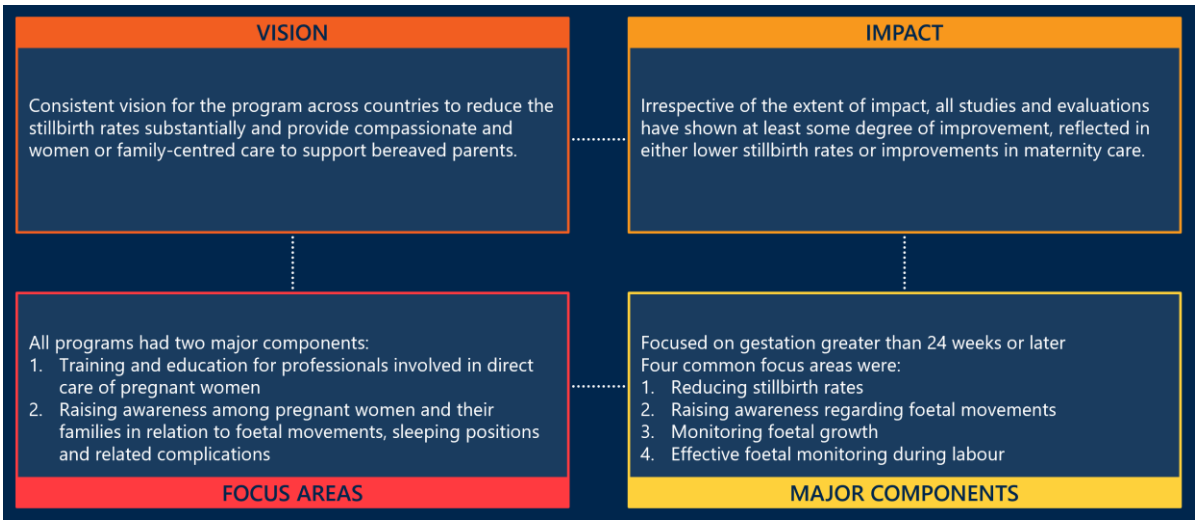
Key findings are synthesised from the analysis of available information of the comparator countries' practices and are summarised below.

There are key similarities and barriers in the stillbirth reduction programs across the comparator countries.

There are several common themes among the comparator countries which reflect alignment in vision for stillbirth prevention, desired impact, focus areas and the major components of the program. Figure 26 describes the key themes shared by comparator countries.

[112] National Institute for Health and Care Research, 'Healthcare workers can help parents mourn their stillborn baby', *NIHR*, 2022. https://evidence.nihr.ac.uk/alert/healthcare-workers-can-help-parents-mourn-their-stillborn-baby/

Figure 26 | Similarities between stillbirth programs in comparator countries



The major barriers reported in the Action Plan are very similar to those reported in the comparator countries. Cultural and socioeconomic barriers associated with specific target cohorts such as First Nations and migrant and refugee women have posed a tremendous challenge. All the reviewed programs indicate difficulty in addressing this challenge.

Organisational barriers are the second major challenge associated with embedding the stillbirth program into the day-to-day operations of health professionals.

Some of the common barriers experienced by comparator systems are summarised in Figure 27.

Figure 27 I Barriers to implementation of stillbirth programs in comparator countries[113]

D.2 Learnings from previous programs

Generally, the common learnings from the comparator programs are around workforce planning, provision of services across varying geographical landscapes and use of technology in providing maternal and neonatal services. It is important to note that of the comparators, only Canada has similar challenges to Australia around geographical size, spread and remoteness of the population. Learnings have therefore been interpreted as needed to suit the Australian context.

[113] Flenady V, et al., 'Stillbirths: recall to action in high-income countries', Lancet, 2016, vol 387, no. 10019, p. 691-702.

A critical feature of Australia's Action Plan, the emphasis given to defined target cohorts, is largely absent from the comparator countries. This means that lessons from these systems about improving cultural safety and engaging generally with target cohorts are limited. Most of the comparator countries recognise the need to engage with culturally diverse populations and the difficulties around this; however, there is a lack of rigorous approach towards specific target cohorts. There is also a lack of specificity around engagement with younger mothers.

Learnings and recommendations from the reviewed comparator programs are summarised in Table 19 below.

Table 19 I Summary of learnings from other programs in comparator countries

Key lesson	Description
The cultural needs of pregnant women must be kept front of mind	Culture has a huge influence on the outcomes of stillbirth interventions and investigations. Studies have indicated important steps to be taken to cater for varying needs of women from diverse ethnic backgrounds. • Sensitive interaction with culturally and linguistically diverse women is vital. Research indicates that these women especially value cultural sensitivity of healthcare workers, including empathy, concern and willingness to support.[114] Health care professionals need to be culturally competent to provide services to different ethnic communities. Needs may vary with geographical locations. • Long-term follow-ups with culturally and linguistically diverse women may help in ensuring proper implementation of activities. Ideally, follow-up by staff from similar cultures helps to create a sense of cultural safety and more responsiveness to the interventions. Acculturation can have significant impact on stillbirth rates.[115] Acculturation refers to the cultural adaptation of individuals to the new country. Research indicates that migrant and refugee women who are less acculturated – those who have overseas-born partners, who have lived in Australia for less than five years and who do not use interpreters regularly – are at higher risk of stillbirth. Of these risk factors, not using professional interpreters was a particularly strong risk factor. This suggests that interpreters should be used more frequently in antenatal care to ensure better understanding and creating a sense of cultural safety.
Remote and rural care requires special planning	To better service women in regional and remote areas, comparator countries have found: • **Investing in staff training is vital.** Reviewing key competencies and skills required for staff in remote and rural areas and structuring training around their capabilities is important. Structured rotations to larger units or secondment placements should be considered to develop, maintain and update appropriate skills. • **It is important to invest in clinical models of care, support staff from larger hospitals providing regular outreach, and maintain a small physical presence in regional and remote areas.** This can also assist with transfer of knowledge and training the existing staff in remote areas. • **Telemedicine has been cited as a highly valuable means of delivering maternity and neonatal service.** Where distance is a barrier, especially in the Australian context where major health care facilities can be quite inaccessible from remote and rural areas, telemedicine may help mitigate the risk associated with women in this cohort.
There are benefits from investing in	To improve available evidence and data, comparator countries have found value in: • **Establishing a unified system for collecting and verifying neonatal and maternity data.** This can **simplify data collection and sharing**, reduce **duplication**, and improve access to data from all settings.

[114] National Institute for Health and Care Research, 'Healthcare workers can help parents mourn their stillborn baby', *NIHR*, 2022, https://evidence.nihr.ac.uk/alert/healthcare-workers-can-help-parents-mourn-their-stillborn-baby/

[115] Mozooni, M, Preen, DB & Pennell, CE, 'The influence of acculturation on the risk of stillbirth in migrant women residing in Western Australia', *PLoS One*, 2020, vol 15, no. 14, https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0231106

Key lesson	Description
technology to support collection, quality assurance and reporting of data	• **Developing a single maternity care system across the country.** This can help with accessing information from all health settings, and it can potentially improve communication between health professionals involved in care of pregnant women. • **Conducting regular maternal and perinatal audits.** This can help to identify and focus on key issues present in any specific target cohorts and develop a strategy to address them.

Appendix E Data tables

This evaluation used data collected and analysed by the Australian Institute of Health and Welfare (AIHW) through a data request. The data provided baseline measures for several indicators presented in Section 0 of this report. This data draws upon the National Perinatal Data and National Perinatal Mortality Data Collection. The following data tables provide complete reporting for selected statistics presented in Section 3.

Table 20 | Stillbirth rates by maternal risk factors and demographic information, 2020[(a)(b)]

Disaggregation	Description	Stillbirths (at or from 20 weeks gestation) *Rate/1000 births*	Stillbirths (at or from 28 weeks gestation) *Rate/1000 births*
Australia	Total	7.7	2.4
Mother's First Nations status	First Nations	11.9	4.1
	Non-First Nations	7.4	2.3
	Not stated	13.6	2.8
Mother's country of birth[(c)]	Australia	7.6	2.3
	Other Oceania and Antarctica	8.0	2.7
	North-West Europe	5.7	2.2
	Southern and Eastern Europe	6.9	2.0
	North Africa and the Middle East	9.4	3.9
	South-East Asia	5.8	2.3
	North-East Asia	6.6	2.1
	Southern and Central Asia	9.3	3.0
	Americas	6.3	1.5
	Sub-Saharan Africa	8.3	2.8
	Not stated	32.9	4.2
Maternal age at birth	Under 20	15.2	3.1
	20-24	9.0	2.7
	25-29	7.2	2.4
	30-34	6.6	2.2
	35-39	7.8	2.3
	40 or over	11.9	4.1
	Not stated	n.p.	n.p.
Remoteness of mother's usual residence[(d)(e)(f)]	Major cities	7.2	2.4
	Inner Regional	8.1	2.3
	Outer Regional	8.2	2.7
	Remote	9.0	2.9
	Very remote	11.5	3.5

Disaggregation	Description	Stillbirths (at or from 20 weeks gestation) *Rate/1000 births*	Stillbirths (at or from 28 weeks gestation) *Rate/1000 births*
Socioeconomic area of mother's usual residence[f][g]	Q1 (most disadvantaged)	8.9	2.9
	Q2	8.4	2.8
	Q3	7.1	2.2
	Q4	6.7	2.2
	Q5 (least disadvantaged)	6.6	2.0
	Not stated	30.5	6.1
Smoking status[h]	Smoking at any point during pregnancy	12.1	3.9
	Did not report smoking	7.0	2.2
	Not stated	23.6	5.5
Previous stillbirth[i]	Had a previous stillbirth	17.2	5.9
	No previous stillbirth	7.9	2.3
	Not stated	19.3	2.3

n.p. Not published because of small numbers, confidentiality or other concerns about the quality of the data. Cells based on very small numbers (fewer than 5 events) are not published (n.p.), except for not stated categories. Consequential suppression (n.p.) has been applied to prevent back-calculation of small numbers. Rates based on denominators of less than 100 are not published (n.p.) for reliability reasons.

(a) In 2020, there was 1 death reported to the National Perinatal Mortality Data Collection (NPMDC) that was unable to be matched to a record in the National Perinatal Data Collection (NPDC) due to the lack of common identifier information. This means that some demographic information cannot be retrieved from the NPDC for this death and are recorded as 'not stated' where information is not available.

(b) The stillbirth rate is the number of deaths per 1,000 births. Births include live births and stillbirths.

(c) Data were mapped to the ABS 2016 Standard Australian Classification of Countries (SACC), major categories.

(d) Remoteness area was derived by applying ABS 2016 Australian Statistical Geography Standard (ASGS) to area of mother's usual residence. Remoteness area was only calculated where geographic area of usual residence was provided.

(e) The remoteness of mother's area of usual residence indicator has been calculated differently to annual web report of *Stillbirths and neonatal deaths* released using 2020 data. The current methodology provides a more accurate measure and aligns with the methodology used in the *Australia's mothers and babies* web reports, which also uses data from the NPDC. This methodology will be applied to future reporting of stillbirths and neonatal deaths.

(f) Data excludes Australian non-residents, residents of external territories and records where state/territory of residence was 'Not stated'.

(g) Socioeconomic status was derived by applying ABS 2016 Socio-Economic Indexes for Areas Index of Relative Socio-Economic Disadvantage (SEIFA IRSD). Socioeconomic status was only calculated where geographic area of usual residence was provided.

(h) Mother's tobacco smoking status during pregnancy is self-reported.

(i) Data for previous pregnancies resulting in stillbirth are not available for NSW and WA and have been excluded from the numerator and denominator.

Note: The scope of the NPMDC and the NPDC is limited to births occurring from 20 weeks gestation or at least 400 grams birthweight. Stillbirths may include a small number of births of less than 20 weeks gestation where birthweight was 400 grams or more.

Source: AIHW analysis of the National Perinatal Mortality Data Collection and the National Perinatal Data Collection.

Table 21 | Timing and number of antenatal visits by maternal risk factors and demographic information (percentage of women), 2020

		Timing of first antenatal visit[a]		Number of antenatal visits[b][c]	
Disaggregation	**Description**	**Before 10 weeks gestation**	**After 10 weeks gestation**	**7 or more**	**10 or more**
Australia	Total	59.4%	40.6%	85.8%	55.0%
Mother's First Nations status	First Nations	51.9%	48.1%	74.2%	47.2%
	Non-First Nations	59.8%	40.2%	86.5%	55.4%
	Not stated	50.4%	49.6%	81.3%	56.1%
Mother's country of birth[d]	Australia	60.2%	39.8%	86.4%	57.6%
	Other Oceania and Antarctica	57.4%	42.6%	79.5%	47.1%
	North-West Europe	58.1%	41.9%	88.6%	56.7%
	Southern and Eastern Europe	58.5%	41.5%	86.4%	53.0%
	North Africa and the Middle East	57.6%	42.4%	81.5%	43.5%
	South-East Asia	55.4%	44.6%	83.7%	47.9%
	North-East Asia	57.1%	42.9%	88.3%	56.6%
	Southern and Central Asia	61.1%	38.9%	85.2%	48.9%
	Americas	59.3%	40.7%	86.8%	54.1%
	Sub-Saharan Africa	52.3%	47.7%	83.3%	50.4%
	Not stated	52.3%	47.7%	84.3%	50.3%
Maternal age at birth	Under 20	51.9%	48.1%	78.0%	49.6%
	20-24	58.6%	41.4%	81.8%	51.0%
	25-29	60.3%	39.7%	84.8%	53.4%
	30-34	60.1%	39.9%	87.0%	56.1%
	35-39	58.7%	41.3%	87.3%	56.7%
	40 or over	56.0%	44.0%	87.7%	58.9%
	Not stated	47.6%	52.4%	82.9%	61.0%
Remoteness of mother's usual residence[e][f]	Major cities	59.0%	41.0%	85.9%	53.5%
	Inner Regional	62.6%	37.4%	86.3%	59.4%
	Outer Regional	60.2%	39.8%	85.8%	60.6%
	Remote	50.1%	49.9%	82.7%	56.5%
	Very remote	47.9%	52.1%	78.4%	54.1%
Socioeconomic area of mother's usual residence[f][g]	Q1 (most disadvantaged)	56.9%	43.1%	82.4%	50.2%
	Q2	58.6%	41.4%	83.8%	53.3%

		Timing of first antenatal visit[a]		Number of antenatal visits[b][c]	
	Q3	59.9%	40.1%	86.6%	56.3%
	Q4	61.7%	38.3%	87.5%	56.9%
	Q5 (least disadvantaged)	60.2%	39.8%	89.2%	58.7%
	Not stated	41.5%	58.5%	78.1%	42.8%
Smoking status[h]	Smoking at any point during pregnancy	55.3%	44.7%	75.2%	46.0%
	Did not report smoking	59.9%	40.1%	86.9%	55.8%
Previous stillbirth[i]	Had a previous stillbirth	59.6%	40.4%	86.3%	61.5%
	No previous stillbirth	58.4%	41.6%	86.6%	57.2%
	Not stated	55.3%	44.7%	81.2%	54.1%

n.p. Not published because of small numbers, confidentiality or other concerns about the quality of the data. Cells based on very small numbers (fewer than 5 events) are not published (n.p.), except for not stated categories. Consequential suppression (n.p.) has been applied to prevent back-calculation of small numbers. Rates based on denominators of less than 100 are not published (n.p.) for reliability reasons.

(a) The first antenatal visit refers to the first contact with a midwife, medical practitioner, or other registered health professional where antenatal care was provided. It does not include contact if it was to confirm the pregnancy only or those contacts that occurred during pregnancy that related to other non-pregnancy-related issues. It does not include first contact after the onset of labour.

(b) Antenatal visits relate to care provided by skilled birth attendants for reasons related to pregnancy. Data recorded about antenatal visits is based on visits recorded in the woman's clinical record and may not include all antenatal visits outside the hospital setting, such as with a general practitioner or private obstetrician. Therefore, caution should be used when interpreting these numbers.

(c) Women who gave birth at 32 weeks or more gestation (excluding unknown gestation).

(d) Data were mapped to the ABS 2016 Standard Australian Classification of Countries (SACC), major categories.

(e) Remoteness area was derived by applying ABS 2016 Australian Statistical Geography Standard (ASGS) to area of mother's usual residence. Remoteness area was only calculated where geographic area of usual residence was provided.

(f) Data excludes Australian non-residents, residents of external territories and records where state/territory of residence was 'Not stated'.

(g) Socioeconomic status was derived by applying ABS 2016 Socio-Economic Indexes for Areas Index of Relative Socio-Economic Disadvantage (SEIFA IRSD). Socioeconomic status was only calculated where geographic area of usual residence was provided.

(h) Mother's tobacco smoking status during pregnancy is self-reported.

(i) Data for previous pregnancies resulting in stillbirth are not available for NSW and WA and have been excluded.

Source: AIHW analysis of the National Perinatal Data Collection.

Table 22 | Smoking status by maternal risk factors and demographic information (percentage of women), 2020

		Smoking status[a]	
Disaggregation	**Description**	**Smoking at any point during pregnancy**	**Did not report smoking**
Australia	Total	9.2%	90.8%
Mother's First Nations status	First Nations	43.4%	56.6%
	Non-First Nations	7.5%	92.5%

		Smoking status[a]	
	Not stated	4.1%	95.9%
Mother's country of birth[b]	Australia	12.6%	87.4%
	Other Oceania and Antarctica	15.2%	84.8%
	North-West Europe	3.8%	96.2%
	Southern and Eastern Europe	4.4%	95.6%
	North Africa and the Middle East	3.7%	96.3%
	South-East Asia	1.6%	98.4%
	North-East Asia	0.9%	99.1%
	Southern and Central Asia	0.3%	99.7%
	Americas	2.0%	98.0%
	Sub-Saharan Africa	2.0%	98.0%
	Not stated	4.3%	95.7%
Maternal age at birth	Under 20	34.3%	65.7%
	20-24	21.4%	78.6%
	25-29	10.5%	89.5%
	30-34	5.9%	94.1%
	35-39	5.8%	94.2%
	40 or over	6.7%	93.3%
	Not stated	0.0%	100%
Remoteness of mother's usual residence[c][d]	Major cities	6.9%	93.1%
	Inner Regional	14.3%	85.7%
	Outer Regional	16.2%	83.8%
	Remote	19.0%	81.0%
	Very remote	36.4%	63.6%
Socioeconomic area of mother's usual residence[d][e]	Q1 (most disadvantaged)	17.6%	82.4%
	Q2	12.3%	87.7%
	Q3	8.2%	91.8%
	Q4	5.3%	94.7%
	Q5 (least disadvantaged)	2.8%	97.2%
	Not stated	5.0%	95.0%
Previous stillbirth[f]	Had a previous stillbirth	17.3%	82.7%
	No previous stillbirth	9.6%	90.4%
	Not stated	20.3%	79.7%

n.p. Not published because of small numbers, confidentiality or other concerns about the quality of the data. Cells based on very small numbers (fewer than 5 events) are not published (n.p.), except for not stated categories. Consequential suppression (n.p.) has been applied to prevent back-calculation of small numbers. Rates based on denominators of less than 100 are not published (n.p.) for reliability reasons.

(a) Mother's tobacco smoking status during pregnancy is self-reported.

(b) Data were mapped to the ABS 2016 Standard Australian Classification of Countries (SACC), major categories.

(c) Remoteness area was derived by applying ABS 2016 Australian Statistical Geography Standard (ASGS) to area of mother's usual residence. Remoteness area was only calculated where geographic area of usual residence was provided.
(d) Data excludes Australian non-residents, residents of external territories and records where state/territory of residence was 'Not stated'.
(e) Socioeconomic status was derived by applying ABS 2016 Socio-Economic Indexes for Areas Index of Relative Socio-Economic Disadvantage (SEIFA IRSD). Socioeconomic status was only calculated where geographic area of usual residence was provided.
(f) Data for previous pregnancies resulting in stillbirth are not available for NSW and WA and have been excluded.

Source: AIHW analysis of the National Perinatal Data Collection.

Table 23 | Investigation rates for stillbirths by investigation type, 2020

		For stillbirths at or from 20 weeks gestation		For stillbirths at or from 28 weeks gestation	
Disaggregation	**Description**	**Number**	**Percentage[(a)]**	**Number**	**Percentage[(a)]**
Autopsy performed[(b)]	Yes	867	40.6%	313	47.9%
	No	1,269	59.4%	341	52.1%
	Not stated	137	. .	58	. .
Placental histopathology performed[(c)]	Yes	1,047	77.8%	380	89.0%
	No	306	22.2%	47	11.0%
	Not stated	893	. .	285	. .

. . Not applicable
n.p. Not published because of small numbers, confidentiality or other concerns about the quality of the data. Cells based on very small numbers (fewer than 5 events) are not published (n.p.), except for not stated categories. Consequential suppression (n.p.) has been applied to prevent back-calculation of small numbers. Rates based on denominators of less than 100 are not published (n.p.) for reliability reasons.
(a) Percentages calculated after excluding records with 'Not stated' values. Care must be taken when interpreting percentages.
(b) Autopsy performed includes full and limited autopsies, external examinations and records where an autopsy was performed but type is unknown.
(c) Placental histology data were not available for Qld, WA and NT for 2020. These records have been included as 'Not stated'.
Note: The scope of the National Perinatal Data Collection (NPMDC) is limited to births occurring from 20 weeks gestation or at least 400 grams birthweight. Stillbirths may include a small number of births of less than 20 weeks gestation where birthweight was 400 grams or more.

Source: AIHW analysis of the National Perinatal Mortality Data Collection.

Table 24 | PSANZ perinatal causes of death for stillbirths, 2020

Disaggregation	Description	Percentage of stillbirths at or from 20 weeks gestation	Percentage of stillbirths at or from 28 weeks gestation
PSANZ Perinatal Death Classification	Congenital anomaly	31.5%	19.5%
	Perinatal infection	5.1%	6.7%
	Hypertension	2.3%	2.5%
	Antepartum haemorrhage	5.8%	9.6%
	Maternal conditions	13.6%	6.6%

Disaggregation	Description	Percentage of stillbirths at or from 20 weeks gestation	Percentage of stillbirths at or from 28 weeks gestation
	Complications of multiple pregnancy	4.0%	5.1%
	Specific perinatal conditions	4.8%	8.3%
	Hypoxic peripartum death	1.2%	3.1%
	Placental dysfunction or causative placental pathology	10.3%	16.3%
	Spontaneous preterm labour or rupture of membranes	7.6%	1.4%
	Unexplained antepartum fetal death	12.7%	18.4%
	Not stated	1.2%	2.5%

Source: AIHW analysis of the National Perinatal Mortality Data Collection