RE: Response to the Consultation about the Draft Stillbirth Clinical Care Standard

The Australian Psychological Society (APS) is pleased to have been invited by the Australian Commission on Safety and Quality in Health Care (ACSQHC, the Commission) to provide a response to the consultation survey regarding the national Draft Stillbirth Clinical Care Standard and associated supporting resources. The APS acknowledges that conception heralds a period of enormous psychological change for people who are pregnant and their partners and families. The perinatal period brings many gains but also losses, such as stillbirth and increased vulnerability for mental ill-health.

At the APS we embed social impact and sustainability in our operations, advocacy, and initiatives guided by the United Nations global Sustainable Development Goals (SDG)\(^1\). The APS commends the Commission and stakeholders on the development of the Draft Stillbirth Clinical Care Standard (the Draft) as a critical element for optimising health and wellbeing outcomes for individuals and families who are at risk of, or experience, stillbirth and helping to realise SDG 3 which aims to ensure healthy lives and promote well-being for all at all ages. In addition, the work of the standards is relevant to the SDG target 5.6 in its endeavour to ensure access to sexual and reproductive health and reproductive rights.

The Draft addresses a breadth of clinical matters related to preventing and responding to stillbirth, however, this APS submission does not make comment on all aspects. Rather, we have endeavoured to provide a response that highlights the most salient issues and recommendations from a psychological health perspective. In preparing this submission, the APS has consulted broadly across our national membership base of 27,000 psychologists with specialist knowledge relevant to the area.

If any further information is required from the APS I would be happy to be contacted through my office on (03) 8662 3300 or by email at z.burgess@psychology.org.au

Dr Zena Burgess, FAPS FAICD
Chief Executive Officer

The APS would like to acknowledge and sincerely thank the members who so kindly contributed their time, knowledge, experience and evidence-based research to this submission.
Survey Questions Responses

Quality statement 1: Risk assessment before conception

A woman planning pregnancy is offered preconception care to identify and manage stillbirth risks and improve her likelihood of giving birth to a healthy, liveborn baby.

1. This quality statement adequately describes the quality of care that should be provided
   Disagree

2. How could this quality statement be improved?
   Comprehensive assessment and management of psychological factors must be identified and managed as part of contemporary preconception care for a person planning pregnancy². Healthcare services and clinicians offering preconception advice should be aware of the burden of perinatal mental health disorders and other psychological vulnerabilities such as adverse childhood experiences (ACES) or trauma and personality difficulties which can make the perinatal period particularly challenging for people and partners planning pregnancy¹.

   As per our general comments, there is an opportunity to increase the inclusiveness of the language of the quality statement as well as emphasising the importance of evidence-based care. The clinical implications of the statement, however, are outside the scope of the APS.

3. Would you like to provide feedback on the proposed indicator for this quality statement?
   No

Quality statement 2: Comprehensive risk assessment during pregnancy

A woman’s clinical and social risk factors for stillbirth are identified early and monitored throughout her pregnancy care. She is offered evidence-based care according to her risks, including the most appropriate available model of maternity care in line with her clinical, personal and cultural needs.

4. This quality statement adequately describes the quality of care that should be provided
   Agree

5. How could this quality statement be improved?
   As per our general comments, there is an opportunity to increase the inclusiveness of the language of the quality statement as well as emphasising the importance of evidence-based care. The clinical implications of the statement, however, are outside the scope of the APS.

6. Would you like to provide feedback on the proposed indicator for this quality statement?
   No

Quality statement 3: Stillbirth awareness and information provision

During the antenatal period, a woman is informed about stillbirth as a potential pregnancy outcome. Throughout the pregnancy, she is supported to implement interventions that may reduce her risk of stillbirth, including smoking cessation, using a side going-to-sleep position from 28 weeks’ gestation, and being aware of her normal foetal movements.

7. This quality statement adequately describes the quality of care that should be provided
   Neither Agree or Disagree
8. How could this quality statement be improved?

In general, the APS is supportive of preventative initiatives and increasing awareness of health risks and is, therefore, broadly supportive of the statement. As per our general comments and comments regarding Quality statement 9, there is an opportunity to increase the inclusiveness of the language of the quality statement as well as emphasising the importance of evidence-based care. The clinical implications of the specific statement, however, are outside the scope of the APS and we will not, therefore, provide further comment.

We suggest, however, that there is an opportunity to provide general information about stillbirth that may later help families cope with late pregnancy loss. When providing information about interventions, it is important to also recognise that approximately 30-40% of stillbirths are still ‘unexplained’ \(^4,5\). Over reliance on the pregnant person’s own behaviour as the main (or only) avenue for stillbirth prevention risks increased anxiety and unhelpful self-surveillance in the pregnant person. It also can lead to anxiety and self-blame issues should a still birth occur. Furthermore, if the pregnancy does end in stillbirth, this may lead to self-blame or guilt (which are common feelings post-stillbirth)\(^6\).

Given that many pregnant people are already anxious about the health of their foetus\(^7\) or experience obsessive-compulsive symptoms during pregnancy\(^8\), it is important to balance communication carefully to encourage healthy monitoring and behaviours without leading to undue pressure and feelings of sole responsibility for the outcome of the pregnancy.

9. Would you like to provide feedback on the proposed indicator for this quality statement?

Yes

10. This indicator captures information that can be used to support local clinical quality improvement activities

Disagree

11. How could this/these indicator be improved?

As discussed previously, there is a need to strike a balance between appropriate information provision to encourage healthy behaviours and the risk of unnecessarily alarming prospective parents, which could be counter-productive. This is particularly important, given the high number of ‘unexplained’ stillbirths\(^4\). It is important, therefore, that the indicators recognise that the information provided is balanced and provide an understanding of factors outside of the pregnant person’s control which may determine pregnancy outcome\(^9\).

Quality statement 4: Obstetric ultrasound

A woman receives high-quality obstetric ultrasound at recommended intervals, including to assess fetal development and morphology at 18–20 weeks’ gestation, that is performed and reported on in line with current best practice guidelines.

12. This quality statement adequately describes the quality of care that should be provided

Neither Agree or Disagree

13. How could this quality statement be improved?

As per our general comments, there is an opportunity to increase the inclusiveness of the language of the quality statement as well as emphasising the importance of evidence-based care. The clinical implications of the statement, however, are outside the scope of the APS.

14. Would you like to provide feedback on the proposed indicator for this quality statement?

No
Quality statement 5: Change in fetal movements

A woman who contacts her clinician or health service with concerns about a change in the frequency, strength or pattern of her baby’s movements from 28 weeks’ gestation is offered timely assessment and care according to a locally approved pathway.

15. This quality statement adequately describes the quality of care that should be provided
   Neither Agree or Disagree

16. How could this quality statement be improved?
   As per our general comments, there is an opportunity to increase the inclusiveness of the language of the quality statement as well as emphasising the importance of evidence-based care. The clinical implications of the statement, however, are outside the scope of the APS.

17. Would you like to provide feedback on the proposed indicator for this quality statement?
   No

Quality statement 6: Informed decision-making about timing of birth

A woman is provided with information that enables her to make informed decisions about timing of birth in line with her individual risks and preferences. Whenever a planned birth before 39 weeks’ gestation is being considered because of concerns about maternal or fetal health, the potential benefits and harms are discussed with the woman and documented appropriately.

18. This quality statement adequately describes the quality of care that should be provided
   Neither Agree or Disagree

19. How could this quality statement be improved?
   As per our general comments, there is an opportunity to increase the inclusiveness of the language of the quality statement as well as emphasising the importance of evidence-based and shared decision making in care. The clinical implications of the statement, however, are outside the scope of the APS.

20. Would you like to provide feedback on the proposed indicator for this quality statement?
   No

Quality statement 7: Discussing investigations for stillbirth

When a stillbirth is diagnosed, the availability and anticipated value of investigations, including autopsy, are discussed with the parents. They are provided with an opportunity to share information about factors they perceive may have contributed to the stillbirth.

21. This quality statement adequately describes the quality of care that should be provided
   Disagree

22. How could this quality statement be improved?
   It is important to consider that any investigations that take place as a result of stillbirth are by nature occurring during the very acute time of loss for the parents. Although in parts respectfully written, the current conceptualisation of the Draft misses an important opportunity to properly acknowledge the trauma these discussions may evoke. The APS acknowledges that clinicians are busy and some of the interventions are 'time sensitive' (p. 40) but we must emphasise the importance of clear and empathetic communication, as well as being respectful of cultural and religious needs.
Respectful, empathic, and clear communication are critical to the delivery of ‘person-centred care’\textsuperscript{11}. Despite the emphasis of communication and empathy in medical schools, there is evidence to show that graduates adapt to their new working environment where these skills are often not practiced by role models in the profession\textsuperscript{12}. Stillbirth constitutes an area of medicine which is incredibly emotional, distressing and potentially psychologically damaging\textsuperscript{13}. It is essential that health care providers ease (or do not add to) the psychological burden as much as possible by discussing all aspects of investigations in an evidence-based, empathetic way\textsuperscript{10}.

The APS would be pleased to partner with the Commission to assist in the development of communication training for health professionals working with people who are affected by perinatal loss.

23. Would you like to provide feedback on the proposed indicator for this quality statement?

Yes

24. This indicator captures information that can be used to support local clinical quality improvement activities

Disagree

25. How could this/these indicator be improved?

Given the importance of doctor-patient communication in health outcomes\textsuperscript{14}, and the specific need of parents to have their loss acknowledged by their health care provider\textsuperscript{10}, empathetic communication must be monitored via an appropriate indicator.

Quality statement 8: Reporting and documenting stillbirth investigation results

The results of stillbirth investigations are reported in a timely manner, documented appropriately, and discussed with the parents along with any information they have provided about perceived contributors to the loss. The stillbirth is classified according to the Perinatal Society of Australia and New Zealand classification system, and is reviewed both locally and as part of a perinatal mortality audit process.

26. This quality statement adequately describes the quality of care that should be provided

Disagree

27. How could this quality statement be improved?

As discussed previously with respect to Quality Indicator 7, empathy and respectful communication are critical features of ‘person-centred care’\textsuperscript{11}. The APS acknowledges that ideally the results of investigations of stillbirth are delivered in a timely fashion, however, we also want to emphasise the importance of them being delivered in a sensitive and empathetic fashion\textsuperscript{10}. Given the potentially distressing nature of the news to be communicated, it is essential that healthcare providers do not add to the psychological burden already facing parents in these circumstances\textsuperscript{13}.

28. Would you like to provide feedback on the proposed indicator for this quality statement?

Yes

29. This indicator captures information that can be used to support local clinical quality improvement activities

Disagree

30. How could this/these indicator be improved?

For the reasons previously described, it is essential that results are communicated in a sensitive and empathetic fashion. As such, this should be reflected in the indicator, which appears to emphasise timeliness.
Quality statement 9: Bereavement care and support after perinatal loss

After a perinatal loss, parents and their support people are provided with respectful, culturally appropriate bereavement care that recognises their specific needs and preferences and ensures follow-up support is available after discharge.

31. This quality statement adequately describes the quality of care that should be provided
- Disagree

32. How could this quality statement be improved?

The APS has identified three main ways the quality statement could be improved:

1. Make clear the expectation that quality bereavement care and support is evidence-based

As noted on p. 27 of the Draft, the clinical care standards “aim to support the delivery of evidence-based clinical care and promote shared decision making between patients, carers and clinicians” (lines 2-3) and “reduce unwarranted variation” in care (lines 3-4). The APS commends this commitment to evidence-based practice.

Clear reference to the expectation that bereavement care and support be evidence-based, is however, missing from Quality statement 9. The APS strongly recommends the inclusion of “evidence-based bereavement care and support” as part of Quality statement 9 and in addition to respectful and culturally appropriate bereavement care.

The APS also strongly recommends developing the Draft discussion for Quality statement 9 to ensure evidence-based bereavement care and support is correctly described and clarifies the responsibilities of health services, health staff, clinicians and bereavement care and support experts. Consensus about evidence-based principles for bereavement care after stillbirth notes that consumers should expect care delivered with compassion; that their health care providers have up-to-date training in bereavement care; and that clinicians will provide evidence-based bereavement care and referral to expert bereavement care options when needed.

On p. 46 (lines 16-17), the suggestion is that bereavement care is general care for physical, emotional, and psychological wellbeing. Evidence-based bereavement care and support for pregnancy loss and stillbirth is, however, not general care. The Sands Australian Principles of Bereavement Care note the need to provide specific training for all staff working with stillbirth loss:

“Principle I: Health Professionals Trained in Bereavement Care All health professionals who interact with bereaved parents should be aware of the Sands Australian Principles and should aim to attend professional development opportunities on bereavement care to ensure that the goal of consistent bereavement care across Australia is achieved” (p. 16).

A commitment to consistent, evidence-based bereavement care and support for pregnancy loss and stillbirth, therefore, requires healthcare services to ensure all health professionals are trained to reduce stigma, establish respectful care, provide information with compassion, appropriately acknowledge and support grief responses, and provide for physical and psychological needs. This training should also be extended to operational staff (e.g., food services, cleaners) who also routinely come into contact with bereaved parents, and often at times when other formal and informal supports may not be present.

On p. 47 (line 13), the information for parents about post-discharge care states: “Your clinician will also refer you to your general practitioner for follow-up care and support”. In many cases people do not have a consistent GP, and most GPs have limited to no training in evidence-based bereavement care. The APS is deeply concerned that a referral only to a GP may mean that some parents who require appropriate psychological support may not receive it.

This is addressed in part on p. 48 (line 10) of the clinician’s section which notes that as part of post-discharge care clinicians may refer to psychologists or counsellors with expertise or experience in bereavement care. The APS commends the inclusion of consideration being given to referral to psychologists on discharge, and requests the Commission also include this as part of the parents’ section.
of the Draft, but with some amendments as described in the next paragraph. We note that some information may have been omitted from the parents’ section as part of plain language considerations. We understand the need for plain language from a health literacy perspective, however this must not be at the cost of ensuring the Stillbirth Clinical Care Standard provides complete information to consumers to enable them to fully participate in shared decision-making with healthcare staff.

Due to the unique and potentially traumatic experience of stillbirth, the APS strongly recommends that psychologists, as regulated health professionals with advanced expertise in human behaviour, are the main avenue of appropriate bereavement care provision. In particular, in the guidelines, we strongly suggest referral to psychologists with “specific training and expertise in bereavement care for pregnancy loss and stillbirth” and remove the word “experience”. It is demonstrable professional expertise, rather than experience, that is associated with high quality stillbirth care for all health care staff. High quality bereavement care and support for stillbirth requires advanced-level case formulation and intervention that reflects, not only the losses that are part of stillbirth, but potential future impacts on pregnancies and later parenting. There are services such as those in the Centre of Perinatal Excellence who can direct affected people to appropriately skilled psychologists and other avenues of support.

A definition of bereavement care and support that recognises the role of all healthcare staff and professionals with expertise in bereavement care and support is currently absent from the Draft Glossary (from p. 58) and should be included.

2. Acknowledge the bereavement support and care needs for partners, families and support people

Partners, family members and support people can be impacted by stillbirth beyond their role as a support to the person who has experienced pregnancy loss. For example, partners are not only expected to support the person who has experienced pregnancy loss; they may have to care for older grieving children and return to work all whilst often grieving themselves. Similarly, grandparents may experience their own grief, while supporting their children and grandchildren. The Sands Australian Principles of Bereavement Care note:

“Principle E: Acknowledging a Partner’s and Family’s Grief Recognition that a partner’s and family’s grief can be as profound as that of the mother and that their need for support should be considered and met. It should be clearly communicated to both the mother and her partner that support services are available to them individually and that it is helpful to talk to someone if they require support” (p. 12).

The APS commends the Commission on the inclusion of support people and their bereavement care and support needs in Quality statement 9. The discussion about Quality statement 9, however, focuses almost exclusively on the bereavement support and care needs for the person who has experienced the stillbirth.

The APS highly recommends more consideration be given in the standards to addressing the bereavement care and support needs of partners, family members and other support people. Who constitutes a partner, family or support person should be defined by the person who has experienced the pregnancy loss and be inclusive of diverse families including those who are culturally diverse or identify as LGBTQIA+.

It is particularly important to recognise the strain the trauma of stillbirth loss can place on the partner, family and other relationships and recognise the need for individual as well as family systems support.

3. Awareness of and addressing stigma

As acknowledged in the Draft, many families who experience stillbirth feel isolated and, because it is not discussed widely in the public discourse, may suffer in silence and intensify their distress. This may be due to many reasons, but one particular cause of this isolation may be the stigma that is currently attached to stillbirth. It is important for healthcare providers to openly discuss the stigma associated with stillbirth and talk through any feelings of shame or guilt that the affected families may experience. Not addressing these very common reactions risks not acknowledging and validating their experience which has been identified as an important need by patients.
Despite stillbirth-related stigma reduction being identified as a priority by the scientific community, current research is still lacking\(^26\) and stigma reduction needs to be emphasised more clearly in the Draft. An APS psychologist, consulted for this submission, recommended healthcare providers assist affected parents’ articulate their experiences by providing 2-5 short template statements that explains what happened, without inducing shame and/or guilt. For example, use of the phrase ‘I lost the baby’ suggests that somehow it was the birthing parent’s fault and could be rephrased as ‘the baby wasn’t strong enough to live’. This would be particularly helpful to explain the experience to other family members such as young children who would be expecting a baby to be born.

33. **Would you like to provide feedback on the proposed indicator for this quality statement?**
   
   Yes

34. **This indicator captures information that can be used to support local clinical quality improvement activities**
   
   Disagree

35. **How could this/these indicator be improved?**
   
   The locally approved policy referred to in this indicator should make clear that the policy and associated procedures reflect evidenced-based bereavement care and support principles and procedures. In addition, the indicators should reflect the importance of referring affected people to psychosocial support service providers with appropriate expertise. Given the impact that stillbirth-related stigma can have on the social and psychological health and wellbeing of the parents and their families\(^26\), it is important that information and discussion of stigma is included as a quality indicator.

**Quality statement 10: Subsequent pregnancy care after perinatal loss**

*During a subsequent pregnancy after a perinatal loss, a woman receives antenatal care that recognises factors that may have contributed to the previous loss, and ensures she has access to appropriate clinical expertise and psychosocial support as required.*

36. **This quality statement adequately describes the quality of care that should be provided**
   
   Neither Agree or Disagree

37. **How could this quality statement be improved?**
   
   There is clear evidence which suggests that the psychological impact of stillbirth is significant and can have a profound impact on functioning\(^13,27,28\). Bereavement care and support should be proactive and available across the short- (immediate reaction and telling family members), medium- (for example returning to work) and longer-term for the person experiencing the pregnancy loss as well as partners, family and support people\(^20,27\). Despite the positive impact that interventions and empathic care can have\(^13\), less than 50% of parents receive ‘follow-up’ contact from their hospital\(^27,29\). Given this, and our previous responses, it is essential that the appropriate psychosocial expertise is provided throughout all stages of bereavement.

   The APS notes that there are no proposed quality indicators for this quality statement. Given the importance of ongoing psychological care for future pregnancies, we recommend a quality indicator is created to ensure this vital part of bereavement care is appropriately monitored.

**Feedback on supporting resources: Consumer Guide**

48. **Is the draft resource useful?**
   
   Yes
How could this resource be improved?

- Make clear to consumers that they should expect that bereavement care and support is evidence-based.
- Demonstrate a strong commitment to inclusive, person-centred care for all consumers by avoiding cisgendered and heteronormative language in this resource.
- Acknowledge the additional bereavement support and care needs for partners, families and support people.
- Demonstrate a strong commitment to culturally appropriate models of care, inclusive of Aboriginal and Torres Strait Islander people, by properly acknowledging Indigenous knowledge of pregnancy and birthing, and the importance of birthing ‘on country’.
- Balance the language in this resource carefully to encourage healthy monitoring and behaviours in consumers, but without creating undue pressure and feelings of sole responsibility and stigma associated with the outcome of the pregnancy.

Feedback on supporting resources: Information for Clinicians

49. Is the draft resource useful?
   Yes

How could this resource be improved?

- Make clear the expectation that bereavement care and support is evidence-based.
- Strengthen the commitment to inclusive, person-centred care for all consumers by avoiding cisgendered and heteronormative language in this resource.
- Acknowledge the additional bereavement support and care needs for partners, families and support people.
- Strengthen the expectation that clinicians adopt culturally appropriate models of care, inclusive of Aboriginal and Torres Strait Islander people, by properly acknowledging Indigenous knowledge of pregnancy and birthing and the importance of birthing ‘on country’.
- Strongly encourage clinicians to carefully balance their language and communication to encourage healthy monitoring and behaviours in consumers, but without creating undue pressure on consumers and feelings of sole responsibility and stigma associated with the outcome of the pregnancy.
- Use consistent, direct and empathic language and tone similar to that used in the Consumer guide – the tone in this guide reads as dry and impersonal.

Feedback on supporting resources: Information for Healthcare Services

50. Is the draft resource useful?
   Yes

How could this resource be improved?

- Make clear to health services that quality bereavement care and support is evidence-based.
- Strengthen the commitment to inclusive, person-centred care for all consumers by avoiding cisgendered and heteronormative language in this resource.
- Acknowledge the additional bereavement support and care needs for partners, families and support people.
- Strengthen the expectation that health services adopt culturally appropriate models of care, including for Aboriginal and Torres Strait Islander people, by properly acknowledging indigenous knowledges of pregnancy and birthing and the importance of birthing ‘on country’.
• Use consistent, direct and empathic language and tone similar to that used in the Consumer guide – the tone in this guide reads as dry and impersonal.

51. The quality statements focus on areas identified by the Commission as being a priority for quality improvement. If there are other areas or aspects of care that you think should be included, please provide details below.

Not applicable.

52. If you are aware of any current or planned initiatives that could support the implementation of this clinical care standard, please provide details below.

- **Logan Maternity Child Health Hubs** (Metro South Health HHS) are an innovative, best-practice model of care developed by the community, for the community which provides high quality healthcare that is responsive to, as well as sensitive and accepting of, cultural needs and preferences. The service aims to:
  - increase the number of women accessing the recommended number of antenatal visits
  - improve pregnancy outcomes including reducing perinatal deaths
  - better coordinate and connect women to the health, community and social support services they need for a healthy pregnancy
  - determine why women birthing in the Logan catchment are not currently accessing the recommended number of antenatal visits and put strategies in place to improve this.

- Research undertaken at Charles Darwin University’s **Molly Wardaguga Research Centre** is committed to a vision of “returning birthing services to Indigenous Communities and Indigenous control” 30. In partnership with First Nations industry partners and working side-by-side with communities, the research centre is focussed on the first 2,000 days of life (conception to age 5), underpinned by “a social justice framework that actively addresses inequality and discrimination”31. One notable example is a maternity program for Indigenous families was associated with a 50% reduction of preterm birth rates (which is associated with stillbirth)32.

- In partnership with Aboriginal Elders, communities and service providers, Aboriginal health researcher Associate Professor Carrington Shepherd from Curtin University and Professor Rhonda Marriott, Director of Murdoch University’s **Ngangk Yira Research Centre for Aboriginal Health and Social Equity**, are undertaking the first ever multidimensional, mixed methods study of Aboriginal stillbirth supported by a $1.4 million NHMRC grant. This work is in collaboration with the Telethon Kids Institute, the **Centre of Research Excellence in Stillbirth** at the Mater Research Institute, **Still Aware**, and the Department of Health.

- **Heartfelt Australia and New Zealand** is a volunteer organisation of professional photographers dedicated to giving the gift of photographic memories to families who have experienced stillbirth or have children with serious or life-threatening illness with all services free of charge.

53. Please provide any other comments below.

The APS is generally supportive of the guidelines and broad consultation conducted by the Commission. Beyond the previous recommendations, we have identified the following four ways by which the guidelines could become more inclusive and meet the needs of a more diverse audience:

1. **Strengthen the commitment to person-centred care by embedding gender inclusivity into the Stillbirth Clinical Care Standard and accompanying resources**

   The APS commends the Commission for a commitment to person-centred care in the General Principles (p. 13, line 11) of the Draft, and specifically in Quality Statement 9 which refers to providing people who have experienced stillbirth bereavement care and support that is respectful, culturally appropriate and that recognises specific needs and preferences.

   Of concern, however, is that throughout the Draft and accompanying resources this commitment to person-centred care is contradicted for gender and sexually diverse people.
The APS notes the Commission’s statement early in the Draft: “The Commission acknowledges that individuals have diverse gender identities. Although the terms ‘woman’, ‘mother’ and ‘maternity’ are used throughout this clinical care standard, this is not intended to exclude those who give birth and do not identify as a woman” (p. 11, lines 9-12). Throughout the Draft, women/woman is repeated approximately 150 times while intersex, transmasculine, gender fluid and non-binary people who are or were pregnant is absent.

The APS strongly encourages the Commission to consider the unintended consequences of taking this disclaimer approach to gender inclusivity and failing to include direct acknowledgment of people with diverse sexualities. As identified throughout the Draft, access to quality routine and responsive clinical care is essential for improving stillbirth prevention and care. Yet, evidence suggests that many LGBTQIA+ people, especially transgender people, avoid or delay healthcare or do not disclose to avoid discrimination, resulting in poorer health outcomes. 33,34,35

The discrimination, stigma and negative impacts on wellbeing faced by LGBTQIA+ people is perpetuated not only by healthcare professionals but also the systemic cisgenderism and heteronormativity in healthcare as reflected in culture, polices and, in this case, standards of care. The APS strongly encourages the Commission to consider how it can strengthen the commitment to person-centred care for gender and sexually diverse people who are at risk of, or who may experience, stillbirth. Statements encouraging clinicians and healthcare professionals to be sensitive to and reflect this diversity in their interactions with care recipients is important, but insufficient. Other considerations could include changing “a woman” to “a pregnant person”, or “pregnant people”, or “people who are pregnant” throughout the standard and accompanying resources. Pronouns could be changed from “she/her” to “they/them” as recommended in key obstetric position statements about gender inclusive language. 36,37

2. **Strengthen the commitment to the practice of culturally appropriate care within the Stillbirth Clinical Care Standard and accompanying resources**

The APS is deeply concerned about findings demonstrating the continued health inequity experienced by Aboriginal and Torres Strait Islander people, including those who experience stillbirth.

For example, Indigenous people who are pregnant and experience stillbirth have been found to access fewer general practitioners, allied health, specialist, obstetrics, and outpatient services, and fewer pathology and diagnostic test compared to non-Indigenous counterparts.38

The APS understands that implementation of the clinical care standards will occur at the local health service level and commends the Commission for inquiring about current or planned initiatives that could support the implementation of this clinical care standard at the local level (Q 52).

We have provided information about Logan Maternity Child Health Hubs which are an innovative, best-practice model of care developed by the community, for the community which provides high quality healthcare that addresses perinatal and stillbirth risks referred to in the Draft while also being responsive to, as well as sensitive and accepting of, cultural needs and preferences for people from Aboriginal and Torres Strait Islander, Maori and Pacific Islander, and culturally and linguistically diverse (CALD) or non-English speaking backgrounds. In addition, we have provided information about “Birthing in our community service” and research and initiatives conducted by Charles Darwin University’s Molly Wardaguga Research Centre which have had dramatic success in reducing the rates of preterm birth (which is associated with stillbirth)30,32,39.

Using this evidence, and other research, the APS strongly recommends the Commission provide more guidance to clinicians and health services about culturally appropriate care as part of the Stillbirth Clinical Care Standard. For example, the Commission could consider developing a supplementary Aboriginal and Torres Strait Islander guide with proper acknowledgement of indigenous knowledges of pregnancy and birthing and importance of birthing ‘on country’.

3. **Strengthen the commitment to health equity for people in regional, rural and remote locations**

The APS understands that implementation of the clinical care standards will occur at the local health service level.
We are concerned, however, about how the standards will be applied fully in the regional, rural and remote Australian context. Risk of still birth is higher in regional, rural and remote areas and perinatally bereaved parents report access to health care services and bereavement care and support is less than in metropolitan areas.\textsuperscript{40,24} We also note that Aboriginal and Torres Strait Islander people who are pregnant and living in regional, rural and remote locations are especially vulnerable as noted in the previous section.

The APS recommends that the gap between service availability and access for people who are at risk of, or experience stillbirth in regional, rural and remote Australia be addressed as a matter of urgency. State, Territory and Federal Governments should work with local communities to develop responses that meet the needs of local families where possible.

4. **Use consistent, direct, and empathic language throughout the Stillbirth Clinical Care Standard and accompanying resources**

The Draft sections for parents, clinicians and health services are each written in a different tone and person (second compared to third) which is jarring when reviewing the entire document. It appears to assume that each group (parents, clinicians, health services) will read only their section which we consider to be unlikely. The APS also recommends checking for consistency of key information across the various audiences/stakeholder sections.

The APS commends the direct and empathic language used in the Consumer guide resource that accompanies the Draft. We wonder whether this tone could be incorporated into the clinician and health services sections of the Draft and guides, which currently read as dry and impersonal in tone. For example, the following line from the Consumer guide for Quality statement 9 about bereavement care and support could be incorporated into the health service and clinician information: “The death of a baby can be a devastating and difficult experience for parents, their families and support people. This is regardless of when the death occurs, or the reasons for the loss.”

54. **Are you submitting your response to this survey as an individual, or on behalf of your organisation?**

Organisation – Australian Psychological Society

55. **What is your role in the organisation?**

Executive (CEO)

56. **Which of the following best describes the capacity in which you are responding?**

Other – Professional association for psychologists

57. **Which of the following best describes where you are located?**

Not applicable (e.g., national organisation)

58. **In which state or territory are you based?**

Not applicable (e.g., national organisation)

59. **If you would like to receive updates from the Commission about the latest resources, advisories and consultations, please enter your email address below:**

policy@psychology.org.au
References


