



Stillbirth in Australia 4: Breaking the Silence: Amplifying Public Awareness of Stillbirth in Australia



Adrienne Gordon^{a,b,c,*}, Lillian Chan^{c,d}, Christine Andrews^a, Keren Ludski^e, Jacquelyn Mead^f, Leigh Brezler^g, Claire Foord^h, Justin Mansfield^e, Philippa Middleton^{a,i}, Vicki J. Flenady^a, Adrian Bauman^{c,d}

^a Centre of Research Excellence in Stillbirth, Mater Research Institute, The University of Queensland, Brisbane, Australia

^b Sydney Institute of Women, Children and their Families, Sydney Local Health District, NSW Australia

^c Charles Perkins Centre, University of Sydney, NSW, Australia

^d Prevention Research Collaboration, Sydney School of Public Health, University of Sydney, Australia

^e Red Nose Australia

^f SANDS Australia

^g Stillbirth Foundation Australia

^h Still Aware

ⁱ SAHMRI Women and Kids, South Australian Health and Medical Research Institute, Adelaide, Australia

ARTICLE INFO

Article history:

Received 20 June 2020

Received in revised form 7 September 2020

Accepted 11 September 2020

Keywords:

Stillbirth

Public awareness

Mass media

Prevention

ABSTRACT

Prevention of stillbirth remains one of the greatest challenges in modern maternity care. Despite this, public awareness is low and silence is common within families, the community and even healthcare professionals. Australian families and parent advocacy groups given a voice through the Senate Enquiry have made passionate and articulate calls for a national stillbirth awareness campaign. This fourth paper in the Stillbirth in Australia series outlines why stillbirth needs a national public awareness campaign; and provides an overview of good practice in the design, development and evaluation of public awareness campaigns. The cognitive and affective steps required to move from campaign awareness to action and eventually to stillbirth prevention are described. Using these best practice principles, learning from previous campaigns combined with close collaboration with aligned agencies and initiatives should assist a National Stillbirth Prevention Campaign to increase community awareness of stillbirth, help break the silence and contribute to stillbirth prevention across Australia.

© 2021 Published by Elsevier Ltd on behalf of Australian College of Midwives.

1. Introduction

Prevention of stillbirth remains one of the greatest challenges in modern maternity care. Stillbirth affects 2.64 million babies globally each year and has well documented psychosocial and economic impacts on parents and families, caregivers and society [1–3]. Stillbirth in late pregnancy (>28 weeks) is more likely to occur in normally developed babies whose mothers have had uncomplicated pregnancies, thus offering real potential for prevention. Despite this, public awareness is low [4,5] and silence is common within families, the community and even health professionals [6–9]. In the 2011 Lancet Stillbirth Series Professor

Joy Lawn stated that “Almost no burden affecting families is so big and yet so invisible both in society and on the global public health agenda”. Meta-syntheses of studies of bereaved families show that raising public awareness of stillbirth is a common priority [10]. If stillbirth prevention campaigns are to have any impact they need to resonate with whole communities, not only with those who have experienced a loss. They also need to learn from and build upon previous successful campaigns.

Increased awareness and prevention messaging created through mass media public health campaigns for the similarly tragic outcome of sudden infant death syndrome, have shown substantial benefit. These campaigns build on the epidemiological evidence for prevention and communicate that to whole populations. The widely recognised “back to sleep” campaign/s resulted in an 85% reduction in sudden infant death syndrome within Australia and New Zealand [11,12]. The message was simple - a devastating outcome that could be substantially prevented by a key action from parents and carers. Stillbirth is also an incomprehensible event with some known risk

* Corresponding author at: Charles Perkins Centre, D17, The Hub, NSW 2006, Australia.

E-mail address: adrienne.gordon@sydney.edu.au (A. Gordon).

@adriennoz (A. Gordon)

factors that are amenable to public health messaging, but not necessarily well known by the community [5]. An effective campaign for stillbirth needs to address these known behaviour-evidence gaps using simple, consistent and unified messages to reach the target audience.

Effective communication alone does not replace adequate maternity care, and intractable health challenges such as smoking remain a huge challenge for public health campaigns. Thus, knowledge and skills in communicating effectively are essential for bridging the gap between what is known, what is said, and what is done in both health policy and health delivery.

This fourth paper in the Stillbirth in Australia series outlines why stillbirth is a public health issue that needs a national public awareness campaign; and provides an overview of good practice in the design, development and evaluation of public awareness campaigns using the Flowproof model [13]. We will describe the cognitive and affective steps required to move from campaign awareness to action and eventually to stillbirth prevention.

2. Rationale for a public awareness campaign about stillbirth

The size and reach of any awareness campaign depends on the scope of the problem being addressed. Campaigns that seek to change behaviour on a national scale need to address more social-ecological levels than targeted communications to address a health problem specific to a health service or a small localised target population.

Stillbirth rates in Australia have remained largely unchanged for several decades [14]. Rates of late stillbirth (≥ 28 weeks) differ between high-income countries, ranging from 1.7/1000 to 8.8/1000 births, with Australia at 2.7/1000 births [15]. These between country variations suggest it is possible to further reduce late-gestation stillbirth and achieve rates on par with the lowest

countries of <2 late stillbirths/1000 births by 2030 [15]. Such reductions can only be achieved by identifying and acting on modifiable risk factors.

Previous campaigns regarding risk factors in similar settings have contributed to significant reductions in late pregnancy stillbirths [16,17]. So far most of the experience of public awareness campaigns in stillbirth prevention is related to improving awareness of the importance of DFM and what to do when women are concerned.

As described in paper two of this series [18] increased awareness of the importance of DFM and clinical management protocols was a key component included in previous stillbirth prevention bundles of care. In England and Wales the Saving Babies' Lives Care Bundle (SBLCB) evaluation demonstrated a 20% reduction in stillbirth rates [17,19]. In fact, this important reduction occurred despite only 42% of frontline hospital staff being aware of the SBLCB, indicating that even further reduction in stillbirths may be possible with uplift through both targeted health professional campaigns and closely aligned mass media public health facing campaigns for the broader community.

In Australia, suboptimal awareness and delayed reporting of DFM is commonplace [20]. However, the Movements Matter Campaign in Victoria – a partnership between the Stillbirth CRE and Safer Care Victoria – demonstrates that improving knowledge and behaviour change for both pregnant women and clinicians is possible [21]. 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 around 1500 women across 5 sites showed that pregnant women's knowledge of fetal movements as pregnancy progresses and recognising the importance of contacting their healthcare provider immediately if baby was moving less was 50% more likely following the campaign [22]. Post campaign, women were two and a half times as likely to

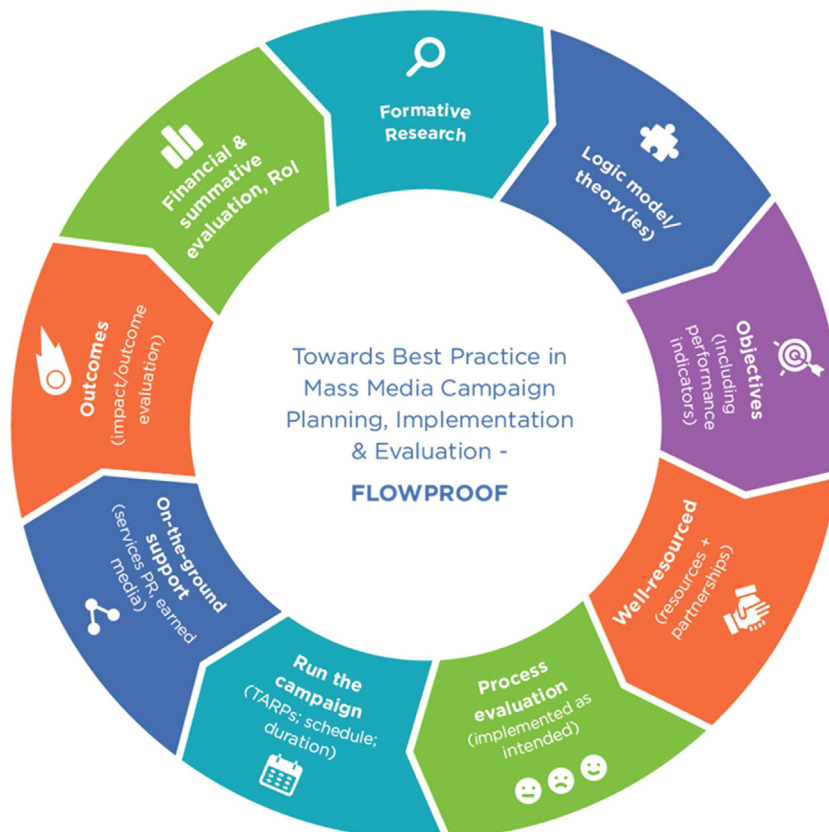


Fig. 1. Flowproof model for mass media campaign planning, implementation & evaluation (adapted with permission from The Australian Prevention Partnership Centre [13]).

report having received both written and verbal information about the importance of babies' movements compared to before the campaign. They were also significantly more likely to report that their clinician had explained this risk. These early data demonstrate that a multi-pronged approach using a combination of social media and hospital posters and flyers was a cost-effective method in raising awareness of DFM as a risk factor for stillbirth and could be trialled on a larger scale. National stillbirth message development, delivery and evaluation are the natural and needed next step to inform and empower women, families and community about stillbirth and related preventive actions.

3. Designing a national stillbirth public awareness campaign

Careful attention to design and delivery of a National Stillbirth Public Awareness Campaign is essential to align and bring together initiatives with the same goal and to deliver consistent clear messages to the women and the community. The Australian Stillbirth Senate Inquiry Report [23] recommended a *national stillbirth public awareness campaign that educates parents and the general public about the risks of stillbirth, and encourages public conversations about stillbirth as a public health issue*. Such a campaign needs to both increase whole-of-community understanding and encourage health-enhancing behaviours for pregnant women. Key considerations for a National Stillbirth Public Awareness Campaign based on published recommendations [13] include:

3.1. Campaigns should be part of an integrated, system-wide approach to stillbirth prevention

As stated in earlier papers in this series, the increasing National focus on stillbirth, the recent Senate Inquiry and the SBB are all part

of an Australian National coordinated approach to stillbirth prevention which is supported by the Stillbirth Centre of Research Excellence, its partners and collaborators and parent advocacy groups. A stillbirth mass media campaign will contribute to population-wide prevention by building upon this approach and the current momentum, to enhance community understanding about stillbirth, reduce stigma and reinforce behaviour change messaging included in other initiatives such as the SBB.

Integration with multi-sectoral strategies and on-the-ground programs is essential for mass media campaigns to be effective. Therefore, implementing a stillbirth prevention campaign needs concomitant supportive health policies, environments, government and non-government organisations working in partnership. Integration enhances collaboration, reduces confusion and contributes towards a common goal. As such a National Public Stillbirth Awareness Campaign should align with, and be integrated into the delivery of the SBB [18], account for other existing campaigns and messages to the community such as other smoking cessation programs, and be included as an accountable component of overarching stillbirth prevention strategies.

3.2. Campaigns and main messages should be consistent across Australia

For a National Campaign to be effective, messages need to be developed that are accepted, relevant and motivating to women in the target group. Message themes and taglines should be consistent across Australia. Aligned messages allow community perceptions and social norms to be influenced in a cohesive way. A recent Australian example is the COVID 19 pandemic where unprecedented national consensus on key messages such as handwashing and physical distancing occurred and was one of key contributors to suppression of the pandemic in Australia [24].



Fig. 2. Hierarchy of effects model.

3.3. Campaigns should follow a campaign planning and evaluation protocol

The FLOWPROOF protocol (Fig. 1) described by the Australian Prevention Partnership Centre is suggested as a model of best practice for the development and implementation of mass media campaigns [13]. The next section of this paper will describe the approach to planning a National Stillbirth Public Awareness Campaign through the stages of this protocol.

4. Best practice in mass media campaign design and planning

4.1. Campaigns should draw upon formative research and past lessons

Formative research should occur prior to any campaign to develop and test the campaign themes, messages and communication elements. For a National Stillbirth Public Awareness campaign the importance of including the community voice, in particular families with lived experience of stillbirth, in the formative work and message development cannot be overstated [25]. In addition, lessons from previous stillbirth campaigns should be incorporated. For example, the Movements Matter Campaign in Victoria demonstrated that post campaign, more clinicians felt that providing women with information about DFM would increase anxiety. This suggests that public awareness campaigns need to be closely linked and supported by clinical practice and aligned with clinician education resources.

4.2. Underpinning theory/logic models need to be made explicit and applied

A logic model is part of the planning process for a campaign that links activities and communications with a series of intermediate and endpoint outcomes. Campaign logic models are recommended as good practice but are rarely used in planning mass media campaigns [13]. Theoretical frameworks are helpful to guide both campaign planning and evaluation. The hierarchy of effects model [26] (Fig. 2) provides a useful conceptual framework for a national stillbirth prevention campaign, is particularly suited to evaluation of behaviour change interventions and will be used to guide design and evaluation for mapping national stillbirth campaign performance indicators and outcomes. The outcomes of a stillbirth campaign are not only to raise awareness, but to influence attitudes and relevance of the messages, ultimately to change behaviour, and thereby reduce the incidence of stillbirth in Australia.

4.3. Clear, measurable campaign goals and objectives should be specified

A National Stillbirth Public Awareness Campaign needs specific goals and quantitative targets to assess population level change. Campaign objectives of campaigns need to be specific, measurable, and can be influenced by a mass-reach campaign. The 'hierarchy of effects' model (Fig. 2) allows for performance indicators corresponding to each level to be clearly mapped to stillbirth awareness, specific message recall (eg "smoking increases the risk of stillbirth"), knowledge enhancement, attitudinal change (eg "stillbirth can happen to anyone"), confidence/intention to change behaviour (eg making plan to get help to quit smoking) or behavioural trialling/maintenance (eg stopping smoking).

4.4. Campaigns require sufficient resources to reach a defined impact threshold

Well-resourced campaigns are more likely to succeed. This includes both the financial and human resources required to

manage and implement a campaign as well as campaign partnerships with government and non-government organisations. All too often public awareness campaigns attempt to do too much with too little, either through budget or time constraints. Although impact can be demonstrated with short implementation schedules such as the previous Movements Matter Campaign, the most successful public health campaigns [27] such as road safety [28], sun protection [29], smoking [30] take the "long view" and have overarching goals and sufficient budget to be able to focus on clear messages in a rolling fashion sustained over time. The Australian Government have allocated \$3 m for an education and awareness campaign for women, as part of its response to the Senate Inquiry into Stillbirth Research and Education.

4.5. Implementing the campaign with appropriate on-the-ground support

Once the campaign begins, process evaluation allows assessment of whether campaign components were implemented as intended and what elements were planned versus opportunistic. This allows reflection and potential improvements of campaigns that follow. Running the campaign refers specifically to the volume of media purchased and delivered. Often this is measured as target audience rating points (TARPs) which describes the expected audience reach in relation to the amount of media delivered. On-the-ground support for a National Stillbirth Prevention Campaign refers to infrastructure, services associated with the campaign, public relations and earned media are needed to support the campaign. This includes provision of resources to the public or health care professionals, free access to information or tools to support behaviour change, public events and related campaign promotion activities.

4.6. Campaign evaluations should be made publicly available

Evaluation documents need to include description of the campaign execution, dose (i.e. target audience rating points (TARPs), range of media delivery channels and frequency of exposure) and effects on proximal and distal impact measures. Campaign expenditure, including a breakdown for media purchased, should also be made available.

4.7. Sustained campaign efforts over years are required to achieve population impact

Campaigns involving sustained, multi-phase efforts over several years are more likely to influence their target population [13]. Australia has some excellent examples in the long standing effective and innovative anti-tobacco and sun protection campaigns [29–31], both combined with environment and regulatory support, that have contributed to sustained declines in smoking and skin cancer. As increased evidence about stillbirth risk and prevention strategies is gained, support for sustained funding for stillbirth prevention campaigns with sequences of relevant messages developed under an overarching theme will be needed.

5. Conclusions

Australian families and parent advocacy groups given a voice through the Australian Senate Enquiry have made passionate and articulate calls for a national stillbirth awareness campaign, and the government has responded by allocating funding to a national campaign. Using best practice principles to design, implement and evaluate such a campaign, learning from previous campaigns, close collaboration with aligned agencies and initiatives including the Stillbirth CRE and its Safer Baby Bundle should assist a National

Stillbirth Prevention Campaign to increase community awareness of stillbirth, help break the silence and contribute to stillbirth prevention across Australia.

Contribution to authorship

All authors read and approved the final manuscript.

Adrienne Gordon conceived the design of the paper supported by Adrian Bauman. All authors read and approved the final manuscript.

Funding

This initiative falls within the work program of the Stillbirth CRE. Core funding to support the Stillbirth CRE is provided by the National Health and Medical Research Council (NHMRC, AP1116640). The National Stillbirth Public Awareness Campaign is supported by the Australian Government Department of Health “Stillbirth Education and Awareness Grant Opportunity” (GO2536) awarded to RedNose Australia in collaboration with planned evaluation by the Stillbirth CRE.

Details of ethics approval

Not required.

Disclosure of interests

Adrienne Gordon, Vicki Flenady and Phillipa Middleton are all chief investigators on the NHMRC Stillbirth Centre of Research Excellence. Keren Ludski, Jackie Mead, Leigh Brezler and Claire Foord are CEOs of the NGOs Red Nose, SANDS, Stillbirth Foundation Australia and Still Aware.

References

- [1] S. Cousens, H. Blencowe, C. Stanton, et al., National, regional, and worldwide estimates of stillbirth rates in 2009 with trends since 1995: a systematic analysis, *Lancet* (London, England) 377 (9774) (2011) 1319–1330.
- [2] H. Blencowe, S. Cousens, F.B. Jassir, et al., National, regional, and worldwide estimates of stillbirth rates in 2015, with trends from 2000: a systematic analysis, *Lancet Glob. Health* 4 (2) (2016) e98–e108.
- [3] A.E. Heazell, D. Siassakos, H. Blencowe, et al., Stillbirths: economic and psychosocial consequences, *Lancet* (London, England) 387 (10018) (2016) 604–616.
- [4] B.A. Winje, A.M. Wojcieszek, L.Y. Gonzalez-Angulo, et al., Interventions to enhance maternal awareness of decreased fetal movement: a systematic review, *BJOG* 123 (6) (2016) 886–898.
- [5] D. Nuzum, S. Meaney, K. O'Donoghue, The public awareness of stillbirth: an Irish population study, *BJOG* 125 (2) (2018) 246–252.
- [6] J. Scott, Stillbirths: Breaking the silence of a hidden grief, *Lancet* (London, England) 377 (9775) (2011) 1386–1388.
- [7] M.C. Kelley, S.B. Trinidad, Silent loss and the clinical encounter: parents' and physicians' experiences of stillbirth—a qualitative analysis, *BMC Pregnancy Childbirth* 12 (2012) 137.
- [8] D.M.S. Nuzum, K. O'Donoghue, The impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study, *BJOG* 121 (8) (2014) 1020–1028.
- [9] D. Pollock, T. Ziaian, E. Pearson, M. Cooper, J. Warland, Understanding stillbirth stigma: a scoping literature review, *Women Birth* 33 (3) (2020) 207–218.
- [10] A. Ellis, C. Chebsey, C. Storey, et al., Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences, *BMC Pregnancy Childbirth* 16 (2016) 16.
- [11] F. de Luca, A. Hinde, Effectiveness of the 'Back-to-Sleep' campaigns among healthcare professionals in the past 20 years: a systematic review, *BMJ Open* 6 (9) (2016)e011435.
- [12] R.S.C. Horne, Sudden infant death syndrome: current perspectives, *Intern. Med. J.* 49 (4) (2019) 433–438.
- [13] A.B.B. Grunseit, E. Goldbaum, J. Gale, A. Bauman, Mass Media Campaigns Addressing Physical Activity, Nutrition and Obesity in Australia: an Updated Narrative Review, The Australian Prevention Partnership Centre, Sydney, 2016.
- [14] A.H.K. Monk, N. Donnelly, L. Hilder, M. Humphrey, A. Gordon, G.M. Chambers, in: AIHW (Ed.), *Perinatal Deaths in Australia, 1993–2012. Perinatal Deaths Series No. 1. Cat. No. PER 86*, AIHW, Canberra, 2016.
- [15] V. Flenady, A.M. Wojcieszek, P. Middleton, et al., Stillbirths: recall to action in high-income countries, *Lancet* (London, England) 387 (10019) (2016) 691–702.
- [16] K. Widdows, H.E. Reid, S.A. Roberts, E.M. Camacho, A.E.P. Heazell, Saving babies' lives project impact and results evaluation (SPiRE): a mixed methodology study, *BMC Pregnancy Childbirth* 18 (1) (2018) 43.
- [17] Healthcare Improvement Scotland, Scottish Patient Safety Program Maternity and Children, End of Phase Report August 2016. Scotland, (2016) .
- [18] C.J. Andrews, D. Ellwood, A. Gordon, P.F. Middleton, C.S.E. Homer, E.M. Wallace, M.C. Nicholl, C. Marr, K. Sketcher-Baker, M. Weller, S.K.M. Seeho, V.J. Flenady, on behalf of the Safer Baby Bundle collaborators, Stillbirth in Australia 2: working together to reduce stillbirth in Australia: the Safer Baby Bundle initiative, *Women Birth: J. Aust. Coll. Midwives* (2020).
- [19] K.R.H. Widdows, S.A. Roberts, E.M. Camacho, A.E.P. Heazell, Saving babies' lives project impact and results evaluation (SPiRE): a mixed methodology study, *BMC Pregnancy Childbirth* 18 (1) (2018) 43.
- [20] V. Flenady, G. Gardener, F.M. Boyle, et al., My baby's movements: a stepped wedge cluster randomised controlled trial to raise maternal awareness of fetal movements during pregnancy study protocol, *BMC Pregnancy Childbirth* 19 (1) (2019) 430.
- [21] A.C.L. Gordon, K. Warrilow, A. Wojcieszek, T. Firth, F. Loxton, A. Bauman, V. Flenady, #Movementsmatter: evaluation of a public awareness campaign in Victoria, *J. Paediatr. Child Health* 55 (S1) (2019) 20-.
- [22] A.C.L. Gordon, K. Warrilow, A. Wojcieszek, T. Firth, F. Loxton, A. Bauman, V. Flenady, Movements Matter – Evaluation of a Public Awareness Campaign in Victoria, Australia, International Stillbirth Alliance, Madrid, 2019.
- [23] Australia. Co, The Senate Select Committee on Stillbirth Research and Education Report ISBN 978-1-76010-76882-3, (2018) .
- [24] J.M. McNulty, K. Ward, Suppressing the epidemic in New South Wales, *N. Engl. J. Med.* 382 (21) (2020) e74.
- [25] L. de Bernis, M.V. Kinney, W. Stones, et al., Stillbirths: ending preventable deaths by 2030, *Lancet* (London, England) 387 (10019) (2016) 703–716.
- [26] N.B.A. Cavill, Changing the way people think about health-enhancing physical activity: do mass media campaigns have a role? *J. Sports Sci.* 22 (8) (2004) 771–790.
- [27] M.A. Wakefield, B. Loken, R.C. Hornik, Use of mass media campaigns to change health behaviour, *Lancet* (London, England) 376 (9748) (2010) 1261–1271.
- [28] I.M. Lewis, B. Watson, K.M. White, R. Tay, Promoting public health messages: Should we move beyond fear-evoking appeals in road safety? *Qual. Health Res.* 17 (1) (2007) 61–74.
- [29] J.F. Aitken, D.R. Youlden, P.D. Baade, H.P. Soyer, A.C. Green, B.M. Smithers, Generational shift in melanoma incidence and mortality in Queensland, Australia, 1995–2014, *Int. J. Cancer* 142 (8) (2018) 1528–1535.
- [30] A. Havard, D.T. Tran, A. Kemp-Casey, K. Einarsdóttir, D.B. Preen, L.R. Jorm, Tobacco policy reform and population-wide antismoking activities in Australia: the impact on smoking during pregnancy, *Tob. Control* 27 (5) (2018) 552–559.
- [31] Q. Luo, J. Steinberg, D.L. O'Connell, et al., Lung cancer mortality in Australia in the twenty-first century: how many lives can be saved with effective tobacco control? *Lung Cancer* 130 (2019) 208–215.