Ending preventable stillbirths 4

Stillbirths: recall to action in high-income countries

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Variation in stillbirth rates across high-income countries and large equity gaps within high-income countries persist. If all high-income countries achieved stillbirth rates equal to the best performing countries, 19 439 late gestation (28 weeks or more) stillbirths could have been avoided in 2015. The proportion of unexplained stillbirths is high and can be addressed through improvements in data collection, investigation, and classification, and with a better understanding of causal pathways. Substandard care contributes to 20–30% of all stillbirths and the contribution is even higher for late gestation intrapartum stillbirths. National perinatal mortality audit programmes need to be implemented in all high-income countries. The need to reduce stigma and fatalism related to stillbirth and to improve bereavement care are also clear, persisting priorities for action. In high-income countries, a woman living under adverse socioeconomic circumstances has twice the risk of having a stillborn child when compared to her more advantaged counterparts. Programmes at community and country level need to improve health in disadvantaged families to address these inequities.

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This is the fourth in a Series of five papers about ending preventable stillbirths

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Introduction

Stillbirth rate is a key indicator of women's health and quality of care in pregnancy and childbirth.[1,2] Although rates for high-income countries (HICs) are relatively low compared with low-income and middle-income countries (LMICs), stillbirth is a major health burden, with rates of more than double neonatal mortality,[3] and often equal to all deaths of infants younger than 1 year.[4] Neonatal mortality continues to reduce,[4] whereas stillbirth rates are steady, and have increased in some regions.[5] The death of any child is a tragedy for families, often with profound, longlasting psychosocial and economic effects.[6] The *Lancet* Stillbirths Series in 2011 drew attention to the slow progress in the rate of reduction across HICs and emphasised prevention.[7] In this fourth paper of the *Lancet*'s Ending preventable stillbirths Series, we summarise the status of stillbirths in HICs and suggest strategies to accelerate momentum in the reduction of stillbirths and to meet parents' needs when their baby is stillborn.

Stillbirth rates: is progress good enough?

Worldwide, estimates[8] show an average stillbirth rate (28 weeks gestation) in 49 HICs of 3·5 per 1000 total births. Country-specific rates varied widely from 1·3 to 8·8 (figure 1). The average annual rate of reductions (ARR) from 2000 to 2015 varied,[8] with eight countries showing ARRs of less than 1%, and five countries with ARRs of more than 4%. Cross-country comparisons are hindered by data capture issues, including reporting practices for termination of pregnancy after the gestational age threshold; variation in data capture mechanisms, such as the use of cross-linkages between birth and death certificate data and birth registry data; and variation in definitions for reporting.[8] Use of the WHO definition of stillbirth for the lowest gestational age limit of 28 weeks probably reduces the effect of these issues on reported stillbirth rates. Irrespective of data capture issues, real epidemiological variation in rates is present[9] and shows that further reduction is possible. Stillbirth rates for disadvantaged groups are about double of those who are more advantaged,[3,10–12] with evidence suggesting that these gaps can be narrowed.[10] Although intrapartum stillbirths comprise a small proportion (less than 10%) of all stillbirths across HICs, variability in this indicator is also evident.[9] Nonetheless, countries must monitor and understand their own temporal stillbirth trends rather than assess performance based on rankings with other countries.

Six of 49 countries (12%) showed third trimester stillbirth rates of 2·0 per 1000 births or lower, showing that this level is achievable (figure 1). If all countries had achieved a stillbirth rate in 2015 of 2·0 or less, 19 439 late gestation (28 weeks or more) stillbirths could have been avoided.

Early gestation stillbirth

Depending on the definition, 35%[13] to 50%[14] of stillbirths in HICs occur below the WHO recommended cutoff for the international comparison of 1000 g (or 28 weeks).[13] Due to variability in definitions (eg, inclusion of terminations), comparisons of early gestation stillbirth rates are difficult between and even within countries. When overall stillbirth rates (including early and late gestation stillbirths) were compared between 28 HICs, Sweden ranked third best and Australia last (28th), but Sweden dropped to tenth and Australia improved to 11th when rank was based on stillbirths who weighed 1000 g or more.[15] Under-reporting of stillbirths less than 28 weeks is also evident in some regions.[3] Ascertainment of data might be affected by perceptions of viability.[8]

Key messages

Variation in stillbirth rates
Late gestation (28 weeks or more) stillbirth rates vary across high-income countries (HICs) from 1·3 to 8·8 per 1000 total births, showing that further reduction in stillbirths is possible. Setting and monitoring of targets in all HICs are important to reduce preventable stillbirths.

Disadvantage and marginalisation
Socially marginalised and disadvantaged women often have twice or more the risk of stillbirth when compared to their more advantaged counterparts. Social determinants of maternal and fetal wellbeing should be monitored in all HICs, and addressed through education and alleviation of poverty, as well as improved access to health care, especially timely, culturally appropriate antenatal care.

Stigma and fatalism
Stigma and fatalism continue to exacerbate trauma for families and impede progress in stillbirth prevention. Strong parent and care provider partnerships are needed to dispel misperceptions and negative attitudes that persist in communities.

Measurement for progress
All countries have the responsibility to implement high quality national audits for perinatal mortality, which translate into improvements in quality of care. Key performance indicators of quality maternity care should be measured and reported with the aim to eliminate substandard antepartum and intrapartum care, which is too often present when a stillbirth occurs.

Bereavement care
Bereavement care frequently does not meet the needs of parents, often with devastating consequences. Immediate bereavement care should be provided by appropriately trained health-care professionals with a sensitive and seamless transition to community support services in all settings.

Improvements to data quality
Poor-quality data for stillbirths is a major problem across HICs. Access to high quality investigation into the causes of stillbirth, including autopsy and placental histopathology by a skilled perinatal pathologist, should be made available to all parents after stillbirth. Consensus on a classification system for stillbirth, which addresses the contribution of placental pathology, and a standard definition for reporting stillbirths that makes comparison possible for reports of early and late stillbirth rates across HICs, are needed.

Future research
Future research must focus on stillbirth prediction, understanding placental pathways to stillbirth and causal pathways to unexplained stillbirth. Effective strategies are needed to reduce the prevalence of obesity and smoking in women of reproductive ages. Understanding pathways leading to early stillbirth and spontaneous preterm birth at early gestation is also important to pursue.

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Despite these difficulties, stillbirth rates of those less than 28 weeks in HICs are not reducing, and some increases are evident.[5,13,14,16] In Canada, recent increases in pregnancy terminations for prenatally diagnosed congenital anomalies at 20–23 weeks gestation explain the increasing overall stillbirth rate.[5] In the USA, spontaneous preterm birth at early gestation made a substantial contribution to high stillbirth rates in black non-Hispanic women.[17] Thus, in HICs, stillbirths at less than 28 weeks comprise an important component of all adverse pregnancy outcomes, particularly in some racial and ethnic groups.

Perceptions of stillbirth: are harmful attitudes holding back progress?

Fatalism and stigma about stillbirth persist in HICs, both across communities and in the health-care workforce.[18] In the International Stillbirth Alliance (ISA) surveys (panel 1), two in three respondents felt their community believed that most stillbirths are not preventable (figure 2). About one in two parents felt their community believed that "parents should not talk about their stillborn baby because it makes people feel uncomfortable". One parent said "...many women told me that my son's death was likely 'nature taking care of mistakes'". Perceptions and actions that denigrate grief, dismiss the importance of a stillborn child, or support notions that a child was never supposed to live, are harmful to bereaved parents and devalue efforts towards stillbirth prevention.[18] Parent organisations provide powerful mechanisms to challenge stigma and fatalism about stillbirth (appendix pp 45–51).

Risk factors leading to stillbirth

Is there sufficient awareness of the risks?

Risk factors including demographic and lifestyle factors and medical or pregnancy disorders were reported in the *Lancet* Stillbirths Series.[7] In the ISA survey of care providers, we asked respondents to select ten of 23 risk factors and associated disorders they believed posed the highest risk for stillbirth. We show the survey rankings alongside the adjusted odds ratio as reported in the *Lancet* Stillbirths Series[20] and systematic reviews (appendix p 35).[21–23] Perceptions were generally consistent with the evidence, but care providers underestimated the risks of advanced maternal age (older than 35 years), in-vitro fertilisation, multiple gestations, and overestimated the risk of pre-eclampsia, smoking, and substance misuse.

Risks associated with maternal obesity were also underestimated. In the survey of community members (n=1113), 72% of respondents felt that there was only very low to moderate community awareness that overweight and obesity increases the risk of stillbirth (appendix p 36). With increasing prevalence of overweight and obese people, interventions to increase the number of women beginning pregnancy with a normal bodyweight are crucially important to improve pregnancy outcomes and longer-term health. Modelling of a large Canadian cohort[24] of about 225 000 pregnancies showed that a 10% decrease in prepregnancy body-mass index (across a range of prepregnancy body-mass indexes) could decrease stillbirth risk by 10%. However, targets to behavioural change alone fail to recognise the complexity of this issue, resulting in ineffective interventions and added stigma for women who are overweight.[25] Antenatal care that labels women as problematic by focusing on bodyweight rather than a healthy pregnancy can produce feelings of embarrassment, guilt, and shame in the mother,[26,27] leading these women to avoid or delay care.

Classification of causes: where to focus?

Despite the call in the *Lancet* Stillbirths Series for a uniform approach to the definition and classification of stillbirths,[28] a systematic review of worldwide causes of stillbirth showed continued use of disparate approaches across HICs (appendix p 34), rendering interpretation between countries difficult. Irrespective of this challenge, placental pathologies were clearly important, accounting for about 40% of stillbirths in systems designed to capture these pathologies. Wide variation was evident in capture and definition of these pathologies, consistent with a review.[29] The contribution of other important factors varied widely: congenital abnormalities were noted in 6–27% of stillbirths, infection in 5–22% of stillbirths, and spontaneous preterm birth or preterm ruptured membranes in 1–15% of stillbirths. In one high quality study,[17] spontaneous preterm birth or preterm ruptured membranes were key factors in 41% of stillbirths less than 28 weeks.

Studies with hierarchical approaches showed higher proportions of fetal growth restriction[30] and congenital abnormalities,[11,14] depending on the classification system used. The categories other unspecified (up to 46%) and unexplained (up to 76%) showed the widest variation and highest proportions.

Diagnostic tests for finding the cause of stillbirth

The evidence for many routinely implemented stillbirth investigations is scarce. Although studies in progress in the Netherlands and Australia will help to address this scarcity of data, the value of placental histopathology, autopsy, and genetic analysis is clear.[31,32] Nonetheless, in the ISA parent survey (n=3503), 23% reported not being counselled or given information about autopsy. Failure to offer autopsy denies parents a chance to understand the cause of their baby's death, increases the proportion of unexplained stillbirths, and hinders the effectiveness of subsequent audits. A crucial shortage of perinatal pathologists also hampers efforts.[33,34] Such a shortage was shown in our surveys, where only 26% of care providers reported that autopsies were undertaken or supervised by perinatal or paediatric pathologists. Resources continue to be diverted away from perinatal pathology services,[33,35] despite stillbirths and neonatal deaths outnumbering all deaths from cancer.[9,36] In our survey of care providers, only 33% reported that autopsy was routinely completed after consent (appendix p 37). Parental consent and cost were frequently cited as barriers to investigations (appendix p 38), despite evidence that identification of the cause of stillbirth might reduce costs in subsequent pregnancies. As stated by Heazell and colleagues,[6] the cost of care for subsequent pregnancies after a stillbirth with an assigned cause is less than for women whose stillbirths were of an unknown cause.[37]

Changes in diagnostic testing might lead to revisions of causes of stillbirths. Use of chromosomal microarray is now preferred to karyotyping because the microarray overcomes the issue of non-viable tissue. Microarrays also identify abnormalities that are not identified by karyotyping, such as microdeletions and micro-duplications.[38] However, adoption of diagnostic advances is slow, with 30% of care providers from the ISA survey unsure how frequently microarray was used; only 4% said that microarray was routine. Whichever test is used, a perinatal pathology service is important to establish stillbirth phenotype and to assess the meaning of newly described genetic variations.[39,40]

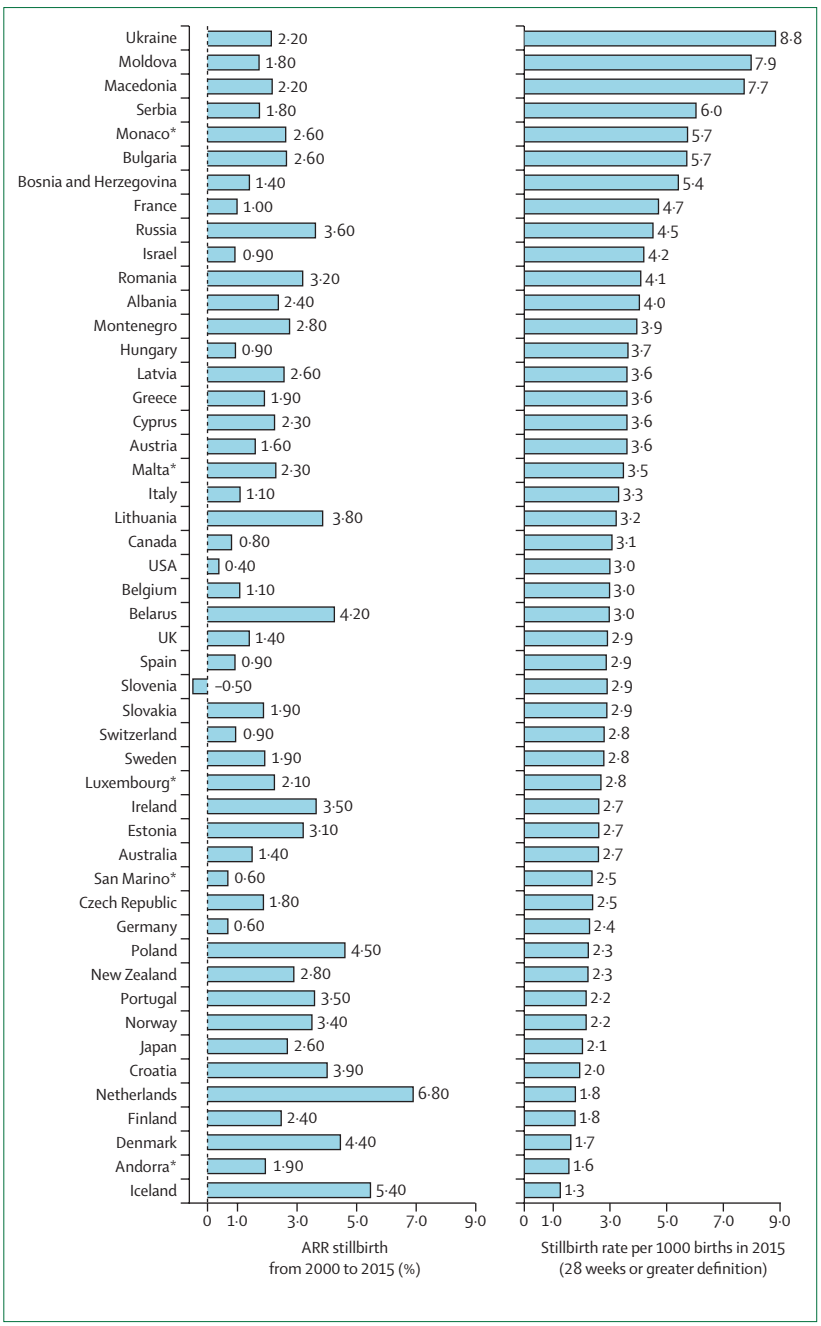

Figure 1: **Present stillbirth rates and reductions since 2000 in high-income countries**
ARR=annual rate reduction. *Countries with less than 5000 annual births.

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Panel 1: Methods

International Stillbirth Alliance web-based surveys

We developed three web-based, multilanguage surveys of bereaved parents, care providers, and general community members to assess practices in stillbirth prevention, awareness of stillbirth risk factors, quality of antepartum and bereavement care, uptake of stillbirth investigations, audit and classification of stillbirths, and more. A mix of categorical items, open-ended items, ranking items, and rating scales were included. Surveys were disseminated chiefly through the International Stillbirth Alliance member organisations and additional relevant professional societies (appendix) between December, 2014, and February, 2015. Surveys were available in English, Dutch, German, Italian, Spanish, and Portuguese. The survey of care providers was also available in French and Japanese.

In total, 6636 responses were received across 32 high-income countries (HICs). Quantitative data were analysed in SPSS and were weighted to account for an uneven distribution of responses across countries (appendix). Qualitative data were sorted in NVivo.

Surveys were approved by the Mater Health Services Human Research Ethics Committee, within the guidelines of the Australian National Statement on Ethical Conduct in Human Research, and the University of British Columbia Office of Research Ethics (Vancouver, Canada).

Stillbirth rates in high-income countries and analysis of avoidable deaths

The number of potentially preventable stillbirths across all HICs for the year 2015 was calculated from stillbirth rates and total births in Blencowe and colleagues' study[8] by subtracting the anticipated numbers of stillbirths applying the 2015 stillbirth rates from the numbers derived with a rate of 2 per 1000 births for all countries with a rate of more than 2 per 1000 births.

Summary of disparities in stillbirth rates

Socioeconomic disparities in stillbirth rates in HICs were investigated with a narrative review, searches were done for papers of health inequities and social disadvantage because these topics relate to stillbirth, expansion from those papers, and from citations made to the *Lancet* Stillbirths Series HICs paper.[7] We also consulted the wider author group for details of relevant programmes addressing disparities and ways of reducing stillbirths in HICs.

National policies on perinatal mortality audit

We searched for national policies of perinatal mortality audit across the top 36 HICs according to number of annual stillbirths (equating to 99% of the known stillbirth burden in HICs). Perinatal audit was defined as per Dunn and McIlwaine[19] as "The systematic, critical analysis of the quality of perinatal care, including the procedures used for diagnosis and treatment, the use of resources and the resultant outcome and quality of life for women and their babies". Specifically, we searched for policies for national perinatal data collection that are coupled with mandatory in-depth review of care by a multidisciplinary team after a stillbirth (appendix).

National clinical practice guidelines

National clinical practice guidelines and recommendations addressing stillbirth prevention and investigations were identified across the top five developed countries according to number of annual stillbirths (Russia, USA, Japan, France, and UK). Guidelines included those addressing the key messages of the 2011 *Lancet* Stillbirths Series HICs paper,[7] namely overweight and obese people, alcohol and substance use, smoking cessation, training of health professionals to provide care to disadvantaged pregnant women, and stillbirth investigations protocols to assess cause of death. A structured search was done for each country with a customised list of websites providing national health-care guidelines (appendix).

Addressing data quality in causes of stillbirth

Classification of cause of death in stillbirth needs to be standardised, especially with regard to placental pathologies. Collective agreement of definitions of placental lesions and their importance is also needed.[41] Although the same lesions might be seen in stillbirths and in livebirths, placental lesions are more frequently noted in cases of stillbirth.[42] Similarly, other causes of stillbirth can be seen in livebirths. In one review (Leisher SH, Teoh Z, Reinebrant HE, et al, unpublished), not one classification system met the criteria of a quality system, as defined by an expert panel. Development of WHO's International Classification of Diseases-Perinatal Mortality,[43] aims to address these standards. Although HICs are likely to continue with detailed classification of stillbirths on the basis of sophisticated diagnostics not accessible in LMICs, approaches must be consistent with the International Classification of Diseases-Perinatal Mortality system, and HICs must reach consensus on such a system. The availability of thorough medical history and diagnostic testing underpins accurate data for stillbirth causes. Standardised perinatal death datasets are essential. Such datasets are in place nationally in the UK, Ireland, and New Zealand, and are in pilot-testing in Australia.

Understanding and tackling disparities in stillbirth risk

Disparities in stillbirth rates suggest larger systems of structural inequality exist, including racism and systematic inequities in opportunities and power.[44] Accordingly, health disparities reflect social and political determinants rather than biological origins.[45,46] Within HICs, stillbirth rates for disadvantaged groups are often

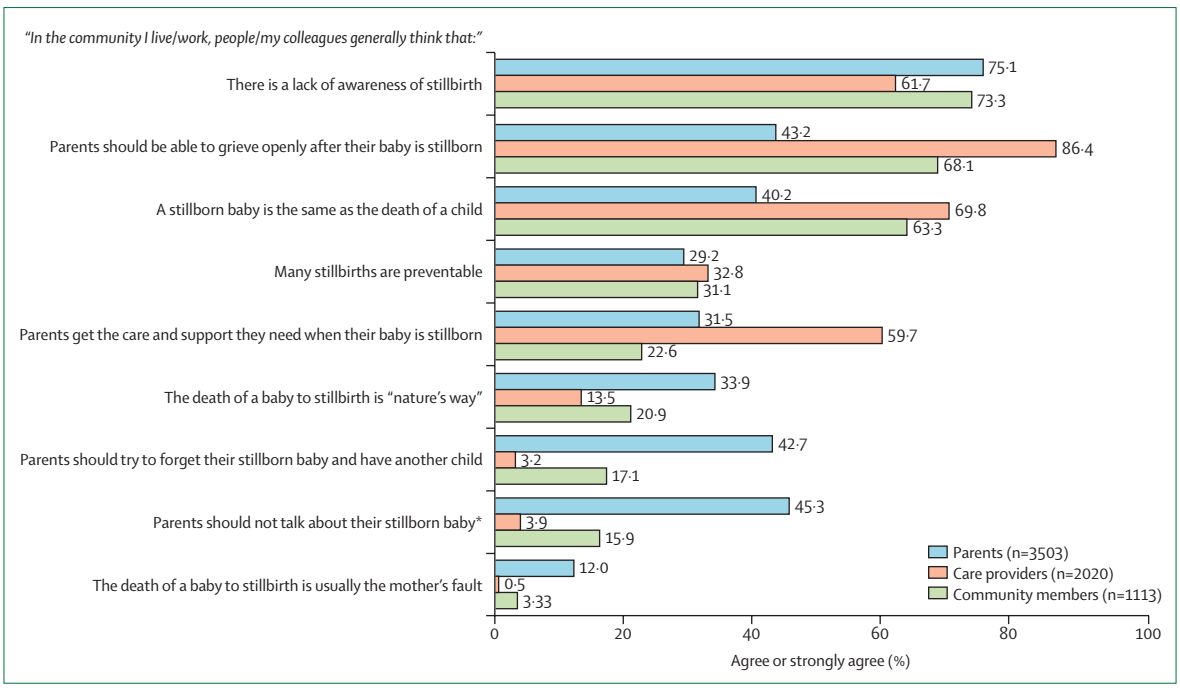

Figure 2: **Survey data for perceptions of stillbirth in high-income countries**
*Full statement: "Parents should not talk about their stillborn baby because it makes people feel uncomfortable".

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See **Online** for appendix

double those of more advantaged groups, and are likely to be underestimated, because health disparities are often only measured with comparison of the most advantaged with the least advantaged.[47] The relationship between stillbirth and social disadvantage is complex, with probable links across preconception, pregnancy pathways, and risk factors (figure 3).

Access to and quality of antenatal and maternity care

Disadvantaged women are less likely to receive adequate antenatal care.[54] Access to, and quality of antenatal care also differs by populations[55] and among ethnicities.[56] Clear and specific circumstances have been noted where differential access or uptake of services contributes to disparities. These include antenatal diagnosis and pregnancy termination for congenital anomalies, timely diagnosis and treatment of pre-eclampsia, and labour induction for post-term pregnancy. Rural–urban differences in access to services are also likely to contribute, especially in populations in remote areas that are most at risk of stillbirth.[50,57] Institutionalised racism is often reported by women accessing antenatal care.[58]

Beyond health-care delivery

Health disparities are only partly explained by disparities in maternity care.[47] Complex social determinants, termed causes of the causes, include: poverty; experiences of discrimination; incarceration; addiction; chronic stress; and inadequate education, child care, employment, transportation, and living conditions.[59] Intimate partner violence,[60] mental health issues,[61] and the cumulative

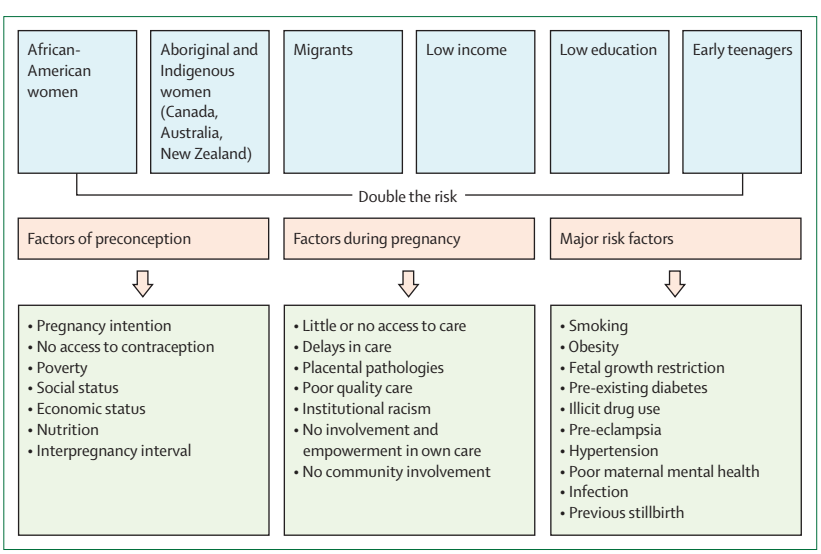

Figure 3: **Disparity pathways for stillbirth**
Complex relationships and associations for social disparity in stillbirth rates.[10,12,48–53]

effect of stressful life events[62] are also hidden but potent risks. In a systematic review[63] of nearly 1 000 000 births in the UK from 1993 to 2005, stillbirth rates were 1·5–2·0-fold greater in the lowest area deprivation quintiles compared with the highest.

In one study,[53] women migrating to HICs had stillbirth rates double the average proportion of the host country, particularly when their country of birth was a humanitarian source country. Adjusted for age, parity,

socioeconomic status, and body-mass index, these differences disappeared,[53] suggesting ethnicity might not always be a pathway to increased stillbirth. However, disparities in pregnancy outcomes continue between women of differing racial or ethnic background accessing the same health-care services.[64–66] Stillbirth rates for women of south Asian and African origin giving birth in Europe or Australia are two to three times higher than white women.[64–66] The challenge is to understand why and how we can manage the excess risk of stillbirth correlated with ethnicity within routine and comprehensive antenatal care.

Addressing disparity

To understand and address socioeconomic disparities in stillbirth, all HICs must monitor and report socioeconomic status in vital statistics.[12] Maternal education is one relevant and feasible indicator for comparisons within a country and across a country.[12] Across 19 European countries with a median population attributable risk of 26% (IQR 16–31), Zeitlin and colleagues[12] showed 1606 of 6447 stillbirths would not have occurred in 2010 if rates for all women were the same as for women with post-secondary education (appendix p 39). School completion for pregnant women could therefore have a substantial effect on the reduction of disparities. Structural issues such as housing, employment, and food security policies must also be addressed.

Antenatal care, home visiting services, and financing of contraceptive services are examples of interventions with capacity to address reproductive health strategies[67] and therefore to prevent stillbirths. Universal service platforms should be supplemented with efforts to engage populations especially at risk of stillbirth, including outreach strategies and transportation to health services. In 2011, we nominated quality, accessible, culturally responsive, and appropriate preconception care as one of the top priorities to reduce disparity.[7] Improvements in preconception care are an enormous challenge. Innovative community programmes addressing refugee maternal and child health inequalities[68] and antenatal care programmes associated with partnerships between midwives and Aboriginal health workers are underway in Australia.[69,70] Universally, women whose first language differs from the dominant national languages should be offered care and information in their own language,[71] with a choice of the gender of the interpreter.[68] The US Affordable Care Act[72] will provide services such as free contraception, screening for infections, and programmes for alcohol and smoking cessation.[73]

Quality of care

Uptake of interventions in stillbirth prevention

Through the ISA survey of care providers we assessed uptake and perceived barriers to implementation of the *Lancet* Stillbirths Series recommended interventions in stillbirth prevention (appendix pp 40, 41). Only 60% of respondents said their facility always provided smoking cessation advice. The most frequently cited barriers were scarcity of time or resources, or both (20%) and acceptance by women (35%). Only 36% of respondents said their facility always provided care that was culturally appropriate, with time and resources noted as the most frequent barrier (17%). Serial fundal height measurements were not done at all or only sometimes according to 14%, with 10% of care providers identifying absence of high quality evidence of effectiveness as a barrier. Most providers said their facility always or mostly used early ultrasound assessment of gestational age (83%), with cost and acceptance by women cited as barriers by about 12%. Screening for gestational diabetes at 28 weeks was always or mostly done according to 77% of respondents, with 12% citing acceptance by women as a barrier. Use of Doppler velocimetry in high-risk pregnancies had reasonably high usage (68%), with absence of high quality evidence of effectiveness (11%) and cost (9%) as the most regularly cited barriers. The least frequently used intervention (used always or mostly according to 43% of respondents) was low-dose aspirin for high-risk pregnancies, with 13% of care providers reporting absence of evidence as a barrier. Low-dose aspirin and heparin have been used to improve placental function and decrease stillbirth, but a high number needed to treat with aspirin and uncertain efficacy has prevented widespread adoption of these interventions.[74] Although evidence is incomplete, preconception care is a potentially valuable intervention in stillbirth prevention, yet only 28% of care providers said that preconception care for women with risk factors was implemented mostly or always in their facilities.

Antenatal and bereavement care: information, communication, and support

In addition to clinical care, quality maternity care incorporates interpersonal and emotional aspects of care.[75] Because stillbirth is an indicator of quality of care, women's experiences of care associated with stillbirth can be deemed to be an indicator of quality of care processes. Just as actions can be taken to prevent stillbirth, actions can be taken to prevent adverse psychosocial outcomes after stillbirth and, in both instances, suboptimum interpersonal care can undermine even the best clinical care and lead to harm.[6] The ISA surveys asked parents and care providers eight questions designed to capture components of quality care consistently identified as important to women (appendix). The data (appendix p 42) show that care providers viewed various aspects of care more positively than bereaved parents. At least four in five providers (83–95%), but only three in five parents (54–70%), judged these aspects of quality care to be present always or most of the time. Not spending enough time with parents in antepartum care was a point of agreement for parents and care providers. Importantly,

more than a third of parents believed their concerns were not taken seriously or felt not listened to, either before or after their baby was stillborn.

Ratings of information provision and parental involvement in decision making after stillbirth were lower for parents and care providers compared with before stillbirth, underscoring the challenge of providing quality bereavement care. Parents' views of the comprehensibility of information were also less positive than the views of care providers; barely half of the parents felt the time spent with care providers was adequate. Many of the questions parents had could be readily answered and procedures to answer such questions would be easy to implement (appendix p 25). Missed opportunities to answer parents' questions might be avoided by measures that recognise parents' need to know more about their child.

These survey findings corroborate the results of a systematic review on parents' and care providers' experiences of bereavement care.[76] Care providers were reported to hide behind ritualising guidelines and checklists. These care providers were frequently not trained to expect and manage parents' reactions and individual needs. In our survey of care providers, only 23% reported being satisfied with training opportunities in bereavement care at their facility, and 30% had no opportunities. As reported in the meta-analysis, care providers urgently need emotional, knowledge, and system-based support, and training in verbal and non-verbal communication skills.

Addressing quality of care

Stillbirth prevention needs emphasis on quality maternity care that is respectful of a woman's rights and tailored to her needs.[75] Quality can be improved through better communication and information provision, and timely delivery of evidence-based interventions. Quality bereavement care must also be emphasised, with greater access than at present to training being a crucial first step. Maternity units must decide whether this level of care is best accomplished through training and certification of competencies for all staff, or whether to assign the role of bereavement support to a dedicated group. Access to clinical practice guidelines is imperative, but active implementation and evaluation of clinical practice guidelines is needed.[77] The UK provides an extensive range of national clinical guidelines acknowledging every aspect of the key messages of the *Lancet* Stillbirths Series HICs paper but, for other HICs with a high stillbirth burden, such resources are far less comprehensive (appendix). Publicly available reports of maternal satisfaction with care and other indicators of women's maternity care experiences should be developed, as was done in Australia,[78] New Zealand,[79] and the UK.[80] Audit and feedback and benchmarking programmes that include explicit targets for change and suggestions for how change can be achieved are also effective.[81]

Panel 2: **Essential steps to establish perinatal mortality audit at the national level**

- Execute an information plan to make clear that stillbirths are not inevitable and that many stillbirths can be prevented by improving quality of care, particularly near term.
- Obtain support and budget from national bodies, including ministries of health and professional colleges.
- Develop a national network to coordinate data collection and identify missing cases of stillbirth in the data through a system to check birth and death certificates, and to lead timely reporting and analysis.
- Establish a national multidisciplinary leadership or steering group to drive the process, agree on national priorities, develop and monitor formal audit methodology, establish consistent and robust definitions of stillbirth, ensure consistency across jurisdictions, and ensure perinatal audit is on the national agenda when the topic is relevant.
- Identify clinical champions at service delivery level.
- Develop a system for clinical and process data collection, preferably web based, to be completed by the clinical staff.
- Ensure that the underlying philosophy of data collection is based on shared ownership of the data to optimise data quality. This idea includes the ability of units to access their own data in a format that they can use for their own surveillance and perinatal mortality reviews.
- Allocate human resources to support local or regional audit initiatives.
- Complete a local review of perinatal cases with multidisciplinary teams that have a specific allocated amount of time.
- Develop a method to provide useful, automatically generated feedback to clinicians and facilities of the suggested improvements to support local quality and audit processes.
- Implement effective monitoring and evaluation of the audit programme with relevant and feasible performance indicators.
- Implement processes to ensure that disclosure of information cannot be used for disciplinary action.

Perinatal mortality audit: why and how?

Perinatal audit has been described as: "The systematic, critical analysis of the quality of perinatal care, including the procedures used for diagnosis and treatment, the use of resources and the resultant outcome and quality of life for women and their babies."[19] Audits in the Netherlands,[82] the UK,[83] and New Zealand[11] show substandard care factors are present in an unacceptably high proportion of cases (20–30%, and up to 60% for intrapartum stillbirths). In New Zealand, stillbirth rates at term have reduced over the 7 years since the national perinatal audit began[11] (appendix p 43). This reduction was specifically attributed to a decrease in stillbirth at a gestation of 37–41 weeks or more. Despite the value of the perinatal audit programmes at the national level, few countries have implemented these schemes (appendix). Norway, which originally introduced its national perinatal audit programme in 1984, has now abandoned this practice because of changes in the national organisational structure of its care systems. Among the care providers we surveyed, only 37% reported that their facility completes regular perinatal audit meetings; these meetings were most often held only monthly (34%) or quarterly (26%), and used only case discussion (61%) as opposed to formal audit methodology (12%).

The need for a greater focus on effective, sustainable implementation of perinatal audit is clear to ensure health services identify areas with suboptimum care. Establishment of the perinatal mortality audit needs both service-level support and ministerial-level support, and quarantined time for multidisciplinary team engagement. Other crucial components include an agreed set of definitions, adoption of a formal audit methodology, appropriate indicators for monitoring and evaluation, and effective data systems (panel 2). Innovative solutions for electronic health and mobile health that are being implemented hold promise,[84] as well as structured education programmes about institutional perinatal mortality audit and classification, such as the IMPOVE (IMproving Perinatal Mortality Review and Outcomes Via Education) programme (Gardiner P, Kent AL, Rodriguez V, et al, unpublished).

Antenatal screening and interventions to prevent stillbirth

Early delivery

Routine induction of labour at term and post-term reduces the risk of perinatal mortality and caesarean birth.[85] However, birth before 39 weeks increases the risk of morbidity[86] and is associated with increased risk of long-term mortality.[87] Therefore, before 39 weeks, early delivery needs to balance any reduction in stillbirth risk against morbidity and long-term mortality of the offspring, and should only be considered in the presence of a substantial risk for maternal or neonatal complications. For induction of labour, provision of adequate information to women is essential, because women have reported not being aware of the risks of induction or the implications for future pregnancies until after the induction had been completed.[88]

The ARRIVE trial (NCT01990612) in the USA, comparing elective induction of labour at 39 weeks with expectant management in singleton uncomplicated term pregnancies, might help to clarify the risks and benefits of term induction.

Ultrasonic and biochemical prediction of stillbirth risk

Various pathophysiological processes result in stillbirth, making prediction difficult.[89] A test is likely to do poorly when assessed against all stillbirths, but might be more specific for a particular cause of stillbirth. A systematic review[90] of biomarker and ultrasonic tests noted that none of 16 single, or five combined, tests did well as predictors of stillbirth. However, stillbirth attributed to placental dysfunction was moderately to strongly associated (positive likelihood ratios between five and 15) with low first-trimester pregnancy associated plasma protein A and abnormal uterine artery Doppler velocimetry in the second trimester. More studies are needed to establish whether close vigilance or any treatment is effective to prevent stillbirth in this group who are at an increased risk.

Routine late pregnancy ultrasound to screen for fetal growth restriction

Of the estimated 30–50% of stillbirths related to fetal growth restriction, most are undetected and many occur in women who do not have risk factors.[91] Ultrasonic fetal biometry is widely used in high-risk pregnancies as a means of detecting fetal growth restriction, thus universal ultrasound is one potential approach to screening low-risk women.[91] Until recently, high quality evidence of the diagnostic effectiveness of ultrasound was absent.[92] However, a prospective cohort study[93] has recently reported that universal scanning was associated with about a three-fold increase in the detection of fetuses who were small for their gestational age (from 20% to 57%). Further, these small fetuses with reduced growth velocity of the abdominal circumference were at an increased risk of morbidity, whereas those small fetuses with normal growth velocity were not. This study confirms universal ultrasound is effective in the identification of fetal growth restriction. However, the costs and potential adverse iatrogenic consequences of implementing such an intervention need consideration.[94]

Challenges in gaining high quality evidence for screening

Sample size calculations suggest that even if a screening test has a positive likelihood ratio of ten and was coupled with an intervention that reduced stillbirth by 50%, a study of screening and intervention would still need about 130 000 women to be adequately powered (appendix p 44). Possible approaches to address this issue are the inclusion of stillbirth as part of a composite outcome and the use of study designs with randomisation at the hospital level, including cluster randomised controlled trials or stepped wedge randomised controlled trials,[89] such as those of fetal movement awareness interventions (NCT01777022 and ACTRN12614000291684).

Promising antenatal interventions?

Raising awareness of decreased fetal movements might aid stillbirth prevention through timely detection and reporting, although concerns exist about the potential to increase anxiety and use of health services.[95] Two large-scale trials of fetal movement awareness interventions are in progress in Australasia (ACTRN12614000291684), and Ireland and the UK (NCT01777022). In a large non-randomised study,[96] an educational programme of standardised measurement of fundal height, plotting on customised charts and referral protocols, has also been associated with reduced stillbirth. Data from randomised controlled trials are needed to confirm or refute these findings.[97] The adverse effect of supine sleep position in late pregnancy has been emphasised as a potentially modifiable risk factor for stillbirth.[98–101] Although these findings are biologically plausible, results from further studies in the UK[102] and New Zealand[99] study are awaited.

The research agenda

The *Lancet* Stillbirths Series identified 30 questions derived from opinions of professionals and researchers. Methods for setting research priorities have since developed to include patient and public views. As part of the ISA surveys, more than 7000 parents, care providers, and community members provided stillbirth action and research priorities. Although the ISA project is in progress, preliminary data support the *Lancet* Stillbirths Series and a recent UK project.[103] Major topics included: stillbirth prevention by application of tests and development of novel investigations for optimum timing of delivery, the need to increase understanding of placental pathways in stillbirth and the causes of unexplained stillbirth, optimum bereavement care, and subsequent pregnancy care.

Perinatal mortality audit programmes, interventions to reduce the prevalence of overweight and obesity, and initiatives to increase the coverage of programmes for smoking cessation in pregnancy are also priorities. With static rates of stillbirths less than 28 weeks across HICs, and with spontaneous preterm labour or preterm ruptured membrane as major contributors, continuing efforts in prediction and prevention of preterm birth are important in stillbirth prevention. Strengthening of collaboration between researchers and parents to address priorities with similar protocols is key to address stillbirths in HICs.

Conclusions

Stillbirths are a major public health issue in HICs and reductions in rates have not matched those for neonatal mortality. Variation and socioeconomic disparities in stillbirth rates, suboptimum uptake of interventions, low proportions of stillbirths attributed to congenital abnormality and high proportions classified as unexplained, and the contribution of substandard care factors suggest stillbirths are not inevitable, and that further reduction in HICs is possible. Ending preventable stillbirths in HICs can be achieved through improvements in the health status of women, through improvements in quality of maternity care, and with reductions in social inequities. High quality perinatal mortality audit informed by thorough investigation is attainable in all HICs and holds the key to fairly rapid reductions in stillbirth rates. The death of a child before birth is a tragedy for families, and stigma and fatalism must be eliminated to optimise bereavement care and to reduce the number of these deaths.

Contributors

VF was responsible for the overall development and writing of the manuscript. AMW assisted with the development and writing of the manuscript and coordination of author contributions. DE and PM assisted in editing. VF, AMW, DE, FMB, DH, AV, CR, JC, PC, JFF, LF, MMG, PM, JJE, GS, TYK, RMS, SHL, LM, DS, AEPH, and SP contributed to the development and dissemination of the web-based surveys. AMW coordinated the dissemination of surveys and SHL and AMW coordinated the survey translations. AMW led the quantitative survey data analyses with VF and MC. FMB and DH undertook qualitative survey data analysis. JEL and HB did data analyses for stillbirth rates and risk factors. TYK, RMS, SHL, and JJE developed the diagnostic test section. DE developed the risk factor and interventions sections. VF, MC, and HER undertook the causes of stillbirth analysis. JJE, CF, and LS developed the perinatal mortality audit section. PM, LF, SJB, KSJ, JZ, and EW developed the disparity section. DS, AEPH, and CS contributed a meta-synthesis on experiences of bereavement care. GS and LM developed the antenatal screening and interventions to prevent stillbirth section. FB, GS, JFF, and RLG drafted the manuscript. JC participated in conceptualisation, instrument development, data curation, writing, review, and editing. All authors read and approved the final version of the manuscript.

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Supplementary appendix

This appendix formed part of the original submission and has been peer reviewed. We post it as supplied by the authors.

Supplement to: Flenady V, Wojcieszek AM, Middleton P, et al, for The Lancet Ending Preventable Stillbirths study group and The Lancet Stillbirths In High-Income Countries Investigator Group. Stillbirths: recall to action in high-income countries. *Lancet* 2016; published online Jan 18. http://dx.doi.org/10.1016/S0140-6736(15)01020-X.

Supplementary webappendix
Stillbirths: Recall to action in high-income countries

Table of contents

Methods

ISA web-based surveys

We developed three multi-language, web-based surveys of bereaved parents, care providers, and general community members to assess practices around stillbirth prevention, awareness of stillbirth risk factors, quality of antepartum and bereavement care, stillbirth investigations, audit and classification of stillbirths, priorities for research and action in stillbirth prevention and bereavement care, and more (full surveys are available from the authors on request). Surveys were available in English, Dutch, German, Italian, Spanish and Portuguese. The survey of care providers was also available in French and Japanese. Surveys were developed in English and then translated by Translators Without Borders, a translation service available for non-governmental organisations. Completed translations were checked for accuracy and appropriateness of language and tone by a member of the authorship team or the Lancet stillbirths in high-income countries investigator group.

Target audiences for the surveys were parents in HIC who had had a stillborn baby at any time, health-care professionals in HIC providing maternity care and care to parents who have had a stillborn baby (including maternity care professionals, pathologists, pastoral care and social workers, psychologists and others), and general community members HIC. The care provider survey was tailored to respondents' professional discipline with clinical questions around stillbirth restricted to midwives, obstetricians and/or gynaecologists, and nurses (providing maternity care). The study was approved by the Mater Health Services Human Research Ethics Committee, within the guidelines of the Australian National Statement on Ethical Conduct in Human Research and the University of British Columbia Office Of Research Ethics. We used the country income classifications provided by the World Bank (http://data.worldbank.org/about/country-and-lending-groups).

Surveys were disseminated between December 2014 and February 2015 via the International Stillbirth Alliance (ISA) member organisations (see http://stillbirthalliance.org/about-us/member-organisations). The survey of care providers was also disseminated via the International Confederation of Midwives (ICM), International Federation of Gynaecology and Obstetrics (FIGO) and other national professional societies. Due to the recruitment method adopted in this study, we could not determine the number of men and women who were exposed to the study advertisement, and therefore the overall response rate is unknown. Analyses were performed using SPSS V22 (Version 22) and Microsoft Excel. We report descriptive statistics only.

Weighting of quantitative data

To account for uneven distribution of responses across countries, quantitative data were weighted using following formula:

$$\frac{\text{Annual number of stillbirths/births in country}}{\text{Annual number of stillbirths/births in all participating countries}} \times \frac{\text{Number of respondents from country}}{\text{Total number of respondents}}$$

For the first term, annual number of stillbirths was used when the analysis pertained to a stillbirth population (e.g. investigations following stillbirth, provision of autopsy counselling to bereaved parents), and annual births was used when the analysis pertained to a pregnancy population (e.g. risk factors for stillbirth, interventions for stillbirth prevention). Countries that contributed only a few responses (e.g., <20) were omitted from the weighted analysis because the weights derived from such small numbers were imprecise. This meant that, in total, depending on the survey question, 1-5% of responses were omitted. Sensitivity analyses on the unweighted results showed that omission of responses from countries that contributed only a few responses made no material difference to the results.

Antenatal and bereavement care - information, communication and support

Eight items measuring quality of antenatal and bereavement care were developed specifically for the ISA surveys. These items were derived from the QUICK mnemonic as presented by Small and colleagues,[1] which captures components of quality care consistently identified as important to women in population studies of experiences of maternity care. These questions were asked in reference to antenatal care prior to stillbirth, as well as after the occurrence of stillbirth (where applicable). Items were measured on a 4-point categorical scale ("Never" / "Some of the time" / "Most of the time" / "Always").

Care providers were asked each question in relation to the care provided at their facility to all families in general, and parents were asked each question in relation to the care they themselves received in the pregnancy of their stillborn baby.

The QUICK mnemonic is:[1]

Q = Quality *care that promotes wellbeing for mothers and babies with a focus on individual needs.*

U = Unrushed *caregivers with enough time to give information, explanations and support.*

I = Involvement *in decision-making about care and procedures.*

C = Continuity *of care with caregivers who get to know and understand women's individual needs and who communicate effectively.*

K = Kindness *and respect.*

Qualitative data analyses

Responses to open-ended questions included in quantitative surveys present challenges for analysis as the data generated are neither strictly qualitative nor quantitative.[2] The purpose of including such questions should be clear and should guide the strategy for analysis. Our purpose in including open-ended questions in the survey was to give respondents opportunity to elaborate their responses or emphasise aspects they felt were not fully captured in the quantitative survey items. Our intention was to elicit comments and perspectives to illustrate and explain the survey data from the viewpoints of parents and health professionals. This approach does not necessarily provide a representative account of respondents' experiences but does give insight into different perceptions of events around the experience of stillbirth. We treated data in the open-ended questions qualitatively. We used guided content analysis focussed on the intent of each question using the qualitative software package NVivo. Following review of all qualitative responses, information-rich quotes were selected to complement and 'bring to life' key survey results.

What do parents want to know after their baby is stillborn?

Units of analysis included more than 1500 responses to the open-ended questions *"Were there things you wanted to know after your baby was stillborn? What were the most important things you wanted to know?".* There were also data relevant to this issue in responses to the questions *"If you would like to, please add anything else you want to tell us about general investigations/tests to find out why your baby died and the information you were given*", and *"Is there anything else you would like to tell us about having an autopsy/post-mortem examination of your baby?".* Some parents referred back to previous answers in their response to these questions. A coding frame was developed from an initial content analysis of a random data sample, which identified four broad areas around which many parents' questions were posed. These were: the baby; the birth; immediate care for mother and family; and future options. This coding frame was used for guided content analysis with responses grouped under these four broad headings and common themes identified under each heading. Data were sorted in NVivo.

Care providers' reported barriers to performing stillbirth investigations

In relation to a prepared list of stillbirth investigations, care providers were asked *"Do you think that there are any barriers/impediments to completing the above investigations?"* Free text responses were recorded and exported to an excel spreadsheet. Non-English responses were translated into English using Google Translate software. Typographical errors were corrected and commonly used abbreviations of words were updated (e.g. 'amnio' was converted to 'amniocentesis'). Due to variability in the way care providers discussed the issue of parental consent (e.g. 'parents may refuse', 'parents may not want'), we ensured the word 'consent' was present in these responses. A Wordcloud of responses (Figure 4) was then generated using the standard setting of Tagul (http://tagul.com). Plurals were converted to the singular term to enhance interpretability (e.g. 'protocols' was converted to 'protocol', 'costs' to 'cost', and 'guidelines' to 'guideline').

Search of national policies on perinatal audit

Evidence of progression towards or implementation of national perinatal auditing was investigated across the top 36 HIC according to number of annual stillbirths (which equated to 99% of the known stillbirth burden in HIC): Russian Federation, United States, Saudi Arabia, Japan, France, United Kingdom, Germany, Korea Republic, Spain, Italy, Poland, Canada, Chile, Australia, Israel, Netherlands, United Arab Emirates, Oman, Uruguay, Belgium, Equatorial Guinea, Kuwait, Czech Republic, Austria, Greece, Sweden, New Zealand, Portugal, Ireland, Slovak Republic, Switzerland, Bahrain, Qatar, Trinidad and Tobago, Denmark, Lithuania, Norway, Croatia, Finland.

Perinatal audit was defined as per Dunn and McIlwaine as *"The systematic, critical analysis of the quality of perinatal care, including the procedures used for diagnosis and treatment, the use of resources and the resultant outcome and quality of life for women and their babies".*[3] Specifically, we searched for policies for national perinatal data collection that is coupled with mandatory in-depth review of care by a multidisciplinary team following a stillbirth.

Using the key phrases: 'stillb*', 'maternal', 'perinat*' and 'perinatal audit', the following websites were searched for relevant documents or evidence of national health care programs:

- The Country Planning Cycle Database (WHO resource): http://www.nationalplanningcycles.org/planning-cycle
- The PAN American Health Organization (WHO resource): http://www.paho.org/hq/
- The Health Systems and Policy Monitor (European Observatory on Health Systems and Policies): http://www.hspm.org/countries/unitedstatesofamerica18112013/countrypage.aspx
- The WHO MiNDbank: http://www.mindbank.info/collection/country

The key words in conjunction with the country of interest were then applied to a Google, Google Scholar and PubMed search. Again, this search aimed to identify evidence of progression towards or evidence of an established national auditing policy and system. Documents were translated where required and all relevant articles identified and a summary of findings were recorded (full database of findings is available from the authors on request). We also consulted with a local key informant if we felt that our online search did not appear to capture all relevant information and resources.

Search of clinical practice guidelines addressing stillbirth prevention and investigations

We performed a systematic search of national clinical practice guidelines and recommendations addressing stillbirth prevention and investigations across the top five developed countries according to number of annual stillbirths (Russian Federation; United States, Japan, France, The United Kingdom). Guidelines of interest included those addressing the key messages of the 2011 Lancet's Stillbirths Series HIC paper,[4] namely overweight and obesity, alcohol and substance use, smoking cessation, training of health professionals to provide care to disadvantaged pregnant women, and stillbirth investigations protocols to assess cause of death.

A structured search was conducted specific for each country using a customised list of organisational websites providing national health care guidelines. For each site key phrases were searched in conjunction with both 'pregnant' and 'pregnancy' (both English and translated equivalent where required). The key phrases included: diet; nutrients; exercise; physical activity; supplements; folic acid; smoking; cigarette; drug use; alcohol; disadvantaged care and disadvantaged education. Additional searches were conducted for: investigations; audit; stillbirth; stillbirth audit and stillbirth investigations. An additional resource, the Maternal and Child Health Handbook (2015), which is given to all women in Japan on commencement of their pregnancy, was searched for evidence of health care advice during the prenatal period. Key recommendations, articles or links identified that were relevant to these health care guidelines were recorded for each site. The relevant websites are listed for each country below. We also consulted with a local key informant if we felt that our online search did not appear to capture all relevant information and resources.

Russian Federation (key informant: Anna Usynina, Northern State Medical University, Arkhangelski)

- Russian Health Ministry: http://www.rosminzdrav.ru
- Russian Society of Obstetrics and Gynaecology: http://www.ncagip.ru/en/rsog/

United States (key informant: Robert M Silver, University of Utah Health Sciences Centre, Salt Lake City)

- Country planning cycle database (WHO resource): http://www.nationalplanningcycles.org/planning-cycle/USA
- The health systems and policy monitor (European Observatory on Health Systems and Policies): http://www.hspm.org/countries/england11032013/countrypage.aspx

- American College of Obstetricians and Gynecologists (accessed via the Agency for Healthcare Research and Quality (AHRQ) guidelines clearinghouse): http://www.guideline.gov/browse/by-organization.aspx?orgid=85
- American college of nurse-midwives: http://www.midwife.org/
- Society for Maternal Fetal Medicine: https://www.smfm.org/
- National Institutes of Health (US Department of Health and Human Services): http://www.nih.gov/

Japan (key informant: Stephanie Fukui, SIDS Family Association)

- Japan Society of Obstetrics and Gynaecology: http://www.jsog.or.jp/english/
- Japan Association of Obstetricians and Gynaecologists: http://111.87.74.44/404.php
- Japan Ministry of Health, Labour and Welfare: http://www.mhlw.go.jp/english/
- Japan Society of Obstetrics and Gynaecology 2014, clinical guidelines: http://www.jsog.or.jp/activity/pdf/gl_sanka_2014.pdf
- The Maternal and Child Health Handbook. Published by Mothers' and Children's Health Organization, Tokyo (2015).

France (key informants: Jennifer Zeitlin, Paris-Descartes University, Paris and Beatrice Blondel, Institut National de la Santé et de la Recherche Médicale, Paris)

- Ministry of Social Affairs and Health France: http://www.social-sante.gouv.fr/
- French College of Obstetricians and Gynaecologists (CNGOF): http://www.cngof.asso.fr/
- French College of Obstetricians and Gynaecologists (CNGOF) link for Haute autorité de santé: http://www.has-sante.fr/portail/jcms/fc_1249588/fr/accueil

United Kingdom

- Country planning cycle database (WHO resource): http://www.nationalplanningcycles.org/planning-cycle/GBR
- The health systems and policy Monitor (European Observatory on Health Systems and Policies): http://www.hspm.org/countries/unitedstatesofamerica18112013/countrypage.aspx
- The National Institute for Health and Care Excellence (NICE) Guidelines: https://www.nice.org.uk/
- The Royal college of obstetricians and gynaecologists: https://www.rcog.org.uk/

- Department for International Development: https://www.gov.uk/government/organisations/department-for-international-development

Documents were translated where required and all relevant articles identified were recorded (full database of findings is available from the authors on request).

Review of major reported causes of stillbirth across high income countries, 2009-2014

To identify the causes of stillbirth across high income countries, we drew on a systematic search conducted as part of a review on classifications systems reported over the period 1 January 2009 to 31 December 2014 by Leisher et al.[5] A single population based study (with the largest numbers of stillbirths) reporting causes of stillbirths was selected for each country. Where two or more annual reports were identified from a single country using the same classification system, we extracted and combined the data. Data on systems used, causes of stillbirth, and population characteristics were extracted independently by two authors. Reported causes were mapped into common clinically meaningful groupings.

Results

Web-based surveys

Characteristics of survey respondents

Bereaved parents

A total of 4184 women and men completed the survey of bereaved parents, 3504 from HIC and 680 from middle-income countries (MIC) (data from low- and middle-income countries are reported in the third paper of this series – *Stillbirths: Global Impact, Cost, and Value)*.[6] After removing two ineligible participants who were not bereaved parents, there were 3503 responses from bereaved parents across 26 HIC (92% female; 56% aged 30-39 years) and 679 responses from bereaved parents across 18 MIC (97% female; 53% aged 30-39 years). Table 1 presents demographic and other characterises of respondents.

Care providers

A total of 2138 women and men completed the survey of care providers. One respondent who did not indicate their country of work was removed leaving 2137 respondents, 2020 respondents across 30 HIC (83% female; 45% midwives or obstetricians and/or gynaecologists) and 117 respondents across 34 LMIC[1] (data from low- and middle-income countries are reported in the third paper of this series – *Stillbirths: Global Impact, Cost, and Value)*.[6] Table 2 presents demographic and other characterises of respondents.

General community members

A total of 1431 women and men completed the survey of general community members, 1113 respondents across 23 HIC (93% female; 49% aged 30-39 years) and 117 respondents across 14 MIC (data from low- and middle-income countries are reported in Paper 3 of the series – *Stillbirths: Global Impact, Cost, and Value)*.[6] In both income regions the large majority of respondents knew someone who had had a stillborn baby at the time of completing the survey (92% from HIC and 96% from MIC). Table 3 presents further demographic details and other characterises of respondents.

[1] 36 respondents completed a survey specifically designed for LMIC. Items were equivalent for the data presented.

What do parents want to know after their baby is stillborn?

The survey of bereaved parents asked parents what were the most important things they wanted to know after their baby was stillborn. Parents' responses reflected the complexity of having a stillborn baby; stillbirth involves birth and death, the past and the future (Panel 1).

Overwhelmingly, parents wanted to know why their stillbirth happened, a question that included both cause of death, reasons for its occurrence and whether it could have been prevented. These questions were associated with questions about their pregnancy and labour and a pervading sense of guilt among mothers, who asked whether they had done something wrong and if their baby had suffered. Other questions could be more readily answered and procedures to ensure that they are answered are likely to be easy to implement. These include questions about the baby's appearance and location and information about the immediate care of the mother. Missed opportunities to answer parents' questions might be avoided by simple measures that recognise parents' need to know about their child. As one parent said *"I was only given guesses".* Another parent said:

> *Why? Why did this happen? She was perfect. We will never know why. Also? Her eyes? What colour were her eyes? Both her twin brother and our baby born after the twins have blue eyes while both my husband and I have brown eyes. Was she our little brown eyed girl? (Mother in USA)*

> *I was given all the information but I had to chase the hospital to find out. And after chasing them to fix all the information about my children i.e. weight, height, time of birth etc I found it really stressful and unnecessary (Mother in Australia)*

Parents also had to deal with immediate, practical issues; how to care for themselves and their families, how to get support, what the future held.

> *I wanted to know that my health was ok after the stillbirth - I was very confused since we didn't have any information about her death, and I was nervous that something would subsequently happen to me as I was healing and my body was changing. I had a superficial blood clot and wasn't given any information that was helpful or reassuring. I recommend medical professionals focus more on the health of the mother following a stillbirth. Once the baby is gone, mothers need reassurance and guidance. (Mother in USA)*

I wanted to know WHY! My baby had been 100% normal and healthy and in a five minute window she got very active and then died. I wanted to know what the hell I was supposed to do now?? I mean how do you go on living after something like this? I wanted to know how to explain to my two year old that her sister had died, and how to help her through it. I very much wanted to know where to turn for help. All they did was keep handing us pamphlets and telling us to refer to them. The support groups etc either didn't see people until at least 3 months after the death, or were 1-800 numbers from the USA. It was ridiculous. I also was very concerned about the possibility of an autopsy, but as she died before birth one was not needed. (Mother in Canada)

We needed to know the statistics -that it wasn't just us. We wanted to know the cause or reason he was stillborn. I needed to know if it was something I did wrong or if there was something I could have done to prevent it I didn't know what to do for paperwork I wanted to know how to get time off work We wanted to know when we would get autopsy results I wanted to know what happened exactly--it was in labour and all happened so fast and I was in medical shock and knew they were poking and prodding me but didn't know what was going on. I wanted to know what they did to me while they were trying CPR on my baby. I wanted to know when we could try again for another baby. It was almost right after that my brain needed to think about that. I know someone else who had that too. (Mother in Canada)

I wanted to know what had happened and if it could happen again. If I could have children. (Mother in Sweden)

Barriers to finding out possible causes, particularly by agreeing to autopsy, included issues such as how parents were asked, whether parents could afford to pay, and possibly stigma associated with the decision:

(w)e were offered an autopsy, but in very discouraging tones. Which ultimately led to us not agreeing to it. At the time the idea of cutting my child open was absolutely devastating. But if we had been spoken to differently about it, given compelling reasons for it, we most likely would have had it done. He was cremated, so it wasn't like we were going to have to see the scars anyway. (Mother in USA)

I wish I had an answer about the reason of the death, which still do not know. Specifically that in the rush of the situation for my wife we decided not to perform an autopsy (Father in Italy)

Making the decision to have or not have an autopsy performed on your unborn dead baby is so incredibly difficult. Yes, you want as much information as possible, but you also want to protect that baby in any way you can. I found it very difficult and in the end agreed to a partial autopsy to be performed on our daughter, in my mind she had already endured so much, the thought of her being cut open and examined was too much for me at the time and to be honest still is now, 18 months on (Mother in Australia)

During my labour I was given the option to have a post mortem performed on my baby. I was not encouraged to do so. It was not explained to me why this test was essential. During my labour was not the right time to raise this question with me. Due to me being distressed by the situation, and distracted by labour, and the importance of post mortem not being stressed to me I opted to not have a post mortem. I deeply wish that I had made a different decision as I believe it is vital to better understand stillbirth to help others. (Mother in the United Kingdom)

The cost of doing an autopsy on my baby was prohibitive, so we chose not to do it, but I think that would have given us a more definitive answer. They tested the placenta and did a lot of analyses of my blood and we think we have an answer, but it's not 100% certain. It is extremely important to find out an answer both emotionally and for practical reasons. This is the worst thing that has ever happened to me and I definitely don't want it to happen again, so I need to know the reason it happened. (Mother in USA)

I felt guilty about getting an autopsy done, as no one else in my support group did it. But now we're all pregnant again, I take comfort in knowing I can prevent the same thing happening the other girls don't know what caused their stillbirths. (Mother in Australia)

Where autopsies were performed, many parents were left to interpret the information they did provide:

I did not have an appointment to find out the results. They were posted to my house and I had to google what it all *meant (Mother in Australia)*

The meeting with the hospital when we got the results of the autopsy was very brief and we didn't feel the doctor "saw" us at all. (Mother in Denmark)

We had to actively ask (several times) for the result of the autopsy. We also had to ask for an appointment to get the information, and we finally got it more than 6 months after the stillbirth. I know that many others get this automatically, and within shorter time after birth, so I guess this is not the rule. (Mother in Norway)

The information following the post-mortem was highly medicalised (which is to be expected) however, the consultant made no attempt to translate that into something that I could properly understand (especially in terms of a future pregnancy). There was no definitive cause for my baby's death, but the results could have been presented to me more clearly. (Mother in the United Kingdom)

Search of national policies on perinatal audit

As in 2011, national audit including confidential enquiries of perinatal death occurs the Netherlands, New Zealand and The UK, but not in the other 33 countries. In Australia, while high quality guidelines for perinatal mortality audit,[7] which include recommendations to conduct perinatal audit to identify suboptimal care, these have not been widely implemented. In the UK, comprehensive investigation of maternal deaths, stillbirths and infant deaths is now undertaken via the MBRRACE-UK program *(Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK).* In addition, The 'Each Baby Counts' initiative started in 2015 collecting data from all UK units on stillbirths, neonatal deaths and neonatal brain injuries. The aim is to identify lessons learned to improve future care.

Surprisingly, while Norway had previously conducted national perinatal audit (since 1984), this practice how now been abandoned. We identified progression towards national perinatal audit in Poland, with an explicit call for compulsory multidisciplinary audit made by Troszyński and colleagues.[8] Chile's National Health Strategy for 2011-2020 also calls for a system to monitor fetal morbidity and mortality through audits of perinatal deaths.[9] In Canada, perinatal audit operates at the provincial level in Alberta, Nova Scotia and Manitoba, and there is discussion amongst stakeholders about the feasibility of implementation at the national level. In Italy, one of the proposed strategic areas for progress of perinatal medicine is the adapting of quality standards for perinatal care services.[10]

Several of the remaining countries carry out national perinatal data collection, but without mandatory in-depth review of care. These countries include Ireland (see below), The Russian Federation, Sweden, Finland, Slovakia, and Qatar. In Sweden, various regional studies have been conducted to review care and determine whether suboptimal care contributed to perinatal deaths, including among immigrant groups.[11] The Russian Federation has in place a surveillance system of perinatal, early neonatal mortality and stillbirths and publishes annual reports of these findings. The potential to further reduce maternal and perinatal death rates in The Russian Federation is acknowledged in the literature and strategies for improving care are outlined. In Qatar, there is research dedicated to investigating causes for mortality using data obtained from the Qatar Perinatal Registry, but no explicit recommendations for perinatal audit were identified.

In Ireland the National Perinatal Epidemiology Centre has gradually developed a national audit of perinatal mortality statistics and, since 2011, has moved from a minimum dataset through to the completion of a detailed audit form by all maternity units in the country. The 2012 report from the

centre was published in 2014 and noted that in-depth review of perinatal deaths of intrapartum origin may be warranted.[12] For the remaining HIC, we found no evidence of national perinatal audit or explicit progression towards this. It is important to note that there is a lack of databases purposefully designed to monitor progress on these national initiatives; the evidence identified in this search was most commonly retrieved via Google, and via scientific literature through Google Scholar and PubMed.

Search of clinical practice guidelines addressing stillbirth prevention and investigations

Our search demonstrated that The United Kingdom provides a nationally consistent definition of stillbirth in addition to an extensive range of publicly accessible recommendations and clinical guidelines for health professionals, predominantly via the National Institute for Health and Care Excellence (NICE) guidelines. These guidelines and recommendations acknowledge every aspect of the key messages of the 2011 Lancet Stillbirths Series HIC paper;[4] that is, overweight and obesity, alcohol and substance use, smoking cessation, training of health professionals to provide care to disadvantaged pregnant women, and stillbirth investigations protocols to assess cause of death. For the remaining four countries, guidelines (and other initiatives) addressing stillbirth prevention and investigation were far less comprehensive.

France has a nationally accepted definition of stillbirth and provides government supported community accessible recommendations as an alternative to clinical guidelines. These recommendations include adequate folic acid intake and smoking and alcohol cessation during pregnancy. However, we did not identify recommendations addressing other key messages, such as training of health professionals to provide care to disadvantaged pregnant women, or stillbirth investigations.

In Japan, the official clinical guideline of the Japan Society of Obstetrics and Gynecology (2014) addresses weight gain during pregnancy; folate level; exercise during pregnancy; smoking and passive smoking during pregnancy; and care for mothers and families whose baby has died.[13] Further, it is standard care for all pregnant women in Japan to be given the Maternal and Child Heath Handbook, which includes advice about smoking and alcohol cessation. The handbook also includes a section for pregnant women to comment on their child care and household support. However, again, we did not identify recommendations addressing other key messages, such as training of health professionals to provide care to disadvantaged pregnant women, or stillbirth investigations.

The Russian Federation Ministry of Health provides a national definition of stillbirth. In addition, a legal order and protocol for stillbirth investigations states that post-mortem examinations are compulsory. The ministry of health recommends the future reduction of infant mortality, however, articles specific to pregnancy care for the community were rarely identified.

In the United States, the American College of Obstetrics and Gynecology (ACOG) has developed a practice bulletin on clinical management guidelines for obstetrician-gynecologists.[14] This practice bulletin includes a comprehensive section on the essential components of an evaluation of a fetal death, which notes that autopsy and placental histopathology should be offered in all cases,

consistent with the LSS. A table of alternative investigations to complete autopsy is also provided, with the strengths and limitations of each method outlined. In its 2015 Annual Meeting, the ACOG include a post-graduate course on stillbirth, management and prevention. Aside from these positive initiatives, our search demonstrated an absence of both national clinical guidelines for health care professionals and readily accessible recommendations for the public regarding stillbirth prevention in the United States.

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Panels

Panel 1. What do parents want to know after their baby is stillborn? Summary of qualitative survey data (n=3503)

WHY AND HOW

- Why did it happen?
- How did it happen?

ABOUT THE BABY

- Where is my baby? What is happening to my baby?
- Did my baby suffer?
- Details about the baby – weight, eye colour, gender and length
- How can we create memories of our baby (including holding and caring for the baby and taking the baby home)
- What are we "allowed" to do (e.g. baby care, funerals, birth certificates and taking the baby home)

ABOUT CARE IN PREGNANCY AND LABOUR

- Did I do something wrong?
- Why didn't they listen to me? (voiced by women who felt that concerns raised in pregnancy were ignored or dismissed)
- Why not sooner? This related to a range of care decisions made in their pregnancy.

ABOUT THEIR OWN CARE

- How do I cope?
- How do I tell other children?

ABOUT THE FUTURE

- Can we have another baby? How soon?
- What are the chances of stillbirth happening again?
- How long will it take to get over this?

Tables

Table 1. Characteristics of parents responding to ISA survey by income region (N=4182)

		HIC (n=3503) n (%)	MIC (n=679) n (%)
Age			
	>20 years	16 (.5)	12 (1.8)
	20-24	131 (3.7)	86 (12.7)
	25-29	462 (13.2)	147 (21.6)
	30-34	953 (27.2)	212 (31.2)
	35-39	991 (28.3)	148 (21.8)
	40-44	603 (17.2)	52 (7.7)
	≥45 years	343 (9.8)	22 (3.2)
	Not stated	4 (.1)	-
Gender			
	Female	3223 (92)	659 (97.1)
	Male	272 (7.8)	18 (2.7)
	Not stated	8 (.2)	2 (.3)
Country			
	Australia	444 (12.7)	-
	Austria	13 (.4)	-
	Belgium	25 (.7)	-
	Canada	62 (1.8)	-
	Chile	56 (1.6)	-
	Denmark	52 (1.5)	-
	France	7 (.2)	-
	Germany	206 (5.9)	-
	Italy	720 (20.6)	-
	Netherlands	125 (3.6)	-
	New Zealand	52 (1.5)	-
	Norway	126 (3.6)	-
	Portugal	37 (1.1)	-
	Republic of Ireland	130 (3.7)	-
	Spain	297 (8.5)	-
	Sweden	133 (3.8)	-
	Switzerland	11 (.3)	-
	United Kingdom	576 (16.4)	-
	United States	402 (11.5)	-
	Puerto Rico	5 (.1)	-
	Uruguay	19 (.5)	-
	Other (in HIC)[β]	5 (.1)	-

		HIC (n=3503) n (%)	MIC (n=679) n (%)
	Argentina	-	423 (62.3)
	Bolivia	-	7 (1.0)
	Brazil	-	9 (1.3)
	Colombia	-	25 (3.7)
	Costa Rica	-	8 (1.2)
	Dominican Republic	-	3 (.4)
	Ecuador	-	6 (.9)
	Guatemala	-	5 (.7)
	Mexico	-	168 (24.7)
	Paraguay	-	3 (.4)
	Peru	-	9 (1.3)
	Venezuela	-	5 (.7)
	Other (in MIC)[β]	-	8 (1.2)
Religion			
	None	1125 (32.1)	98 (14.4)
	Christianity	2142 (61.1)	422 (62.2)
	Judaism	14 (.4)	1 (.1)
	Islam	8 (.2)	1 (.1)
	Buddhism	13 (.4)	3 (.4)
	Catholicism	36 (1)	109 (16.1)
	Other	65 (1.9)	9 (1.3)
	Not stated	100 (2.9)	36 (5.3)
Highest education level			
	No formal qualifications	24 (.7)	3 (.4)
	Primary school	30 (.9)	13 (1.9)
	Secondary/high school	935 (26.7)	157 (23.1)
	Undergraduate university/college degree	1506 (43)	418 (61.6)
	Trade or apprenticeship	243 (6.9)	1 (.1)
	Post-graduate degree	623 (17.8)	65 (9.6)
	Other	87 (2.5)	11 (1.6)
	Not stated	55 (1.5)	11 (1.6)
Employment			
	Not employed	228 (6.5)	87 (12.8)
	Employed part-time	839 (24)	175 (25.8)
	Employed full-time	1718 (49)	250 (36.8)
	Homemaker, student or retired	597 (17)	155 (22.8)
	Self-employed	10 (.3)	-
	Other	86 (2.5)	4 (.6)
	Not stated	25 (.7)	8 (1.2)
When stillbirth occurred[α]			
	Less than 6 months ago	491 (14)	99 (14.6)

		HIC (n=3503) n (%)	MIC (n=679) n (%)
	6-11 months ago	385 (11)	103 (15.2)
	1-2 years ago	868 (24.8)	183 (27.0)
	3-5 years ago	738 (21.1)	176 (25.9)
	5-9 years ago	1015 (29)	117 (17.2)
	Not stated	6 (.1)	1 (.1)
Gestation at stillbirth			
	<20 weeks	320 (9.1)	46 (6.8)
	20-24 weeks	637 (18.2)	138 (20.3)
	25-29 weeks	450 (12.8)	142 (20.9)
	30-34 weeks	480 (13.7)	116 (17.1)
	35-37 weeks	456 (13)	95 (14.0)
	38-40 weeks	755 (21.6)	106 (15.6)
	>40 weeks	396 (11.3)	31 (4.6)
	Not stated	9 (.3)	-
Deaths of other children from any cause			
	Yes	721 (20.6)	127 (18.7)
	No	2027 (57.9)	453 (66.7)
	Not applicable (no other children)	748 (21.4)	91 (13.4)
	Not stated	7 (.2)	8 (1.2)

[α] *Parents who had had more than one stillborn baby were asked to respond to question in relation to their first stillborn baby*

[β] *No more than 2 responses received from countries within this group*

HIC: High income countries; MIC: Middle-income countries

Table 2. Characteristics of care providers responding to ISA survey by income region (N=2137)

		HIC (*N*=2020) n (%)	LMIC (*N*=117) n (%)
Age			
	<24 years	41 (2)	4 (3.4)
	25-29	167 (8.3)	14 (12.0)
	30-34	254 (12.6)	17 (14.5)
	35-39	301 (14.9)	12 (10.3)
	40-44	265 (13.1)	17 (14.5)
	45-49	285 (14.1)	14 (12.0)
	≥55 years	414 (20.5)	16 (13.7)
	Not stated	11 (.5)	23 (19.7)
Gender			
	Female	1682 (83.3)	95 (81.2)
	Male	327 (16.2)	22 (18.8)
	Not stated	11 (.5)	-
Country			
	Australia	519 (25.7)	-
	Austria	9 (.4)	-
	Belgium	3 (.1)	-
	Canada	148 (7.3)	-
	Chile	4 (.2)	-
	Denmark	13 (.6)	-
	France	2 (.1)	-
	Germany	355 (17.6)	-
	Greece	2 (.1)	-
	Hong Kong	4 (.2)	-
	Italy	186 (9.2)	-
	Japan	43 (2.1)	-
	Netherlands	70 (3.5)	-
	New Zealand	119 (5.9)	-
	Norway	11 (.5)	-
	Republic of Ireland	21 (1)	-
	Spain	164 (8.1)	-
	Sweden	26 (1.3)	-
	Switzerland	11 (.5)	-
	United Kingdom	195 (9.7)	-
	United States	102 (5)	-
	Uruguay	4 (.2)	-
	Other (in HIC)[β]	9 (.4)	-
	Argentina	-	35 (29.9)
	Brazil	-	2 (1.7)

		HIC (*N*=2020) n (%)	LMIC (*N*=117) n (%)
	Guatemala	-	8 (6.8)
	Iraq	-	3 (2.6)
	Mexico	-	21 (17.9)
	Peru	-	6 (5.1)
	Ethiopia	-	5 (4.3)
	Kenya	-	5 (4.3)
	Pakistan	-	3 (2.6)
	Other (in MIC)[β]	-	29 (24.8)
Discipline			
	Midwifery	987 (48.9)	27 (23.1)
	Obstetrics and/or Gynaecology	778 (38.5)	26 (22.2)
	Nursing (providing maternity care)	75 (3.7)	15 (12.8)
	Neonatology or paediatrics[α]	25 (1.2)	8 (6.8)
	Family physician providing maternity care[α]	8 (.4)	-
	Pathology[α]	36 (1.8)	-
	Social work[α]	12 (.6)	5 (4.3)
	Psychology or Psychiatry[α]	30 (1.5)	13 (11.1)
	Pastoral care[α]	3 (.1)	-
	Other[α]	66 (3.3)	23 (19.7)
Number of annual births in facility			
	Less than 10	28 (1.4)	8 (6.8)
	10-99	71 (3.5)	8 (6.8)
	100-999	434 (21.5)	23 (19.7)
	1000-1999	449 (22.2)	13 (11.1)
	2000-4999	611 (30.2)	12 (10.3)
	5000 or more	356 (17.6)	26 (22.2)
	Unsure	46 (2.3)	23 (19.7)
	Not stated or invalid	25 (1.2)	5 (3.4)
Experience caring for parents of stillborn baby			
	>5 times	416 (20.6)	33 (28.2)
	5-10 times	400 (19.8)	22 (18.8)
	11-20 times	333 (16.5)	10 (8.5)
	21-30 times	186 (9.2)	3 (2.6)
	≥30 times	674 (33.4)	29 (24.8)
	Unsure	-	19 (16.2)
	Not stated	11 (.5)	1 (.9)
Last cared for parents of a stillborn baby[γ]			
	Less than one week ago	224 (11.1)	8 (6.8)
	1-2 weeks ago	189 (9.4)	9 (7.7)
	3-4 weeks ago	193 (9.6)	8 (6.8)
	1-3 months ago	337 (16.7)	7 (6.0)

		HIC (*N*=2020) n (%)	LMIC (*N*=117) n (%)
	4-6 months ago	208 (10.3)	5 (4.3)
	6-11 months ago	194 (9.6)	10 (8.5)
	1 year or more ago	655 (32.4)	29 (24.8)
	Not stated	20 (1)	5 (4.3)

[α] *Asked selected questions only*

[β] *No more than 2 responses received from countries within this group*

[γ] *Data available for 81 LMICs only*

HIC: High income countries; LMIC: Low and middle-income countries

Table 3. Characteristics of community members responding to ISA survey by income region (N=1431)

		HIC (n=1113) n (%)	MIC (n=318) n (%)
Age			
	>20 years	13 (1.2)	6 (1.9)
	20-24	57 (5.1)	30 (9.4)
	25-29	132 (11.9)	67 (21.1)
	30-34	300 (27)	90 (28.3)
	35-39	244 (21.9)	57 (17.9)
	40-44	147 (13.2)	36 (11.3)
	≥45 years	218 (19.6)	29 (9.1)
	Not stated	2 (.2)	3 (.9)
Gender			
	Female	1033 (92.8)	300 (94.3)
	Male	76 (6.8)	18 (5.7)
	Not stated	4 (.4)	-
Country			
	Australia	147 (13.2)	-
	Austria	6 (.5)	-
	Belgium	3 (.3)	-
	Canada	60 (5.4)	-
	Chile	7 (.6)	-
	Denmark	9 (.8)	-
	Germany	85 (7.6)	-
	Italy	373 (33.5)	-
	Netherlands	23 (2.1)	-
	New Zealand	4 (.4)	-
	Norway	15 (1.3)	-
	Republic of Ireland	28 (2.5)	-
	Spain	99 (8.9)	-
	Switzerland	7 (.6)	-
	United Kingdom	109 (9.8)	-
	United States	99 (8.9)	-
	Uruguay	32 (2.9)	-
	Other (in HIC)[α]	7 (.6)	-
	Argentina	-	214 (67.3)
	Brazil	-	5 (1.6)
	Colombia	-	12 (3.8)
	Costa Rica	-	3 (.9)
	Guatemala	-	3 (.9)
	Mexico	-	71 (22.3)
	Peru	-	2 (.6)
	Venezuela	-	2 (.6)

		HIC (n=1113) n (%)	MIC (n=318) n (%)
	Other (in MIC)[α]	-	6 (1.9)
Religion			
	None	354 (31.8)	58 (18.2)
	Christianity	678 (60.9)	202 (63.5)
	Judaism	8 (.7)	1 (.3)
	Islam	4 (.4)	1 (.3)
	Buddhism	9 (.8)	2 (.6)
	Catholicism	7 (.6)	33 (10.4)
	Other	27 (2.4)	8 (2.5)
	Not stated	26 (2.3)	13 (4.1)
Highest education level			
	No formal qualifications	3 (.3)	-
	Primary school	7 (.6)	6 (1.9)
	Secondary/high school	250 (22.5)	71 (22.3)
	Undergraduate university/college degree	513 (46.1)	205 (64.5)
	Trade or apprenticeship	71 (6.4)	1 (.3)
	Post-graduate degree	230 (20.7)	31 (9.7)
	Other	25 (2.2)	3 (.9)
	Not stated	14 (1.3)	1 (.3)
Employment			
	Not employed	66 (5.9)	28 (8.8)
	Employed part-time	241 (21.7)	66 (20.8)
	Employed full-time	556 (50)	145 (45.6)
	Homemaker, student or retired	208 (18.7)	67 (21.1)
	Other	34 (3.1)	8 (2.5)
	Not stated	8 (.7)	4 (1.3)
Knows a parents who has had a stillborn baby			
	Yes	1023 (91.9)	304 (95.6)
	No	70 (6.3)	8 (2.5)
	Unsure	19 (1.7)	5 (1.6)
	Not stated	1 (.1)	1 (.3)

[α]*No more than 2 responses received from countries within this group*

HIC: High income countries; MIC: Middle-income countries

Table 4. Major reported causes of stillbirth across high income countries, 2009-2014

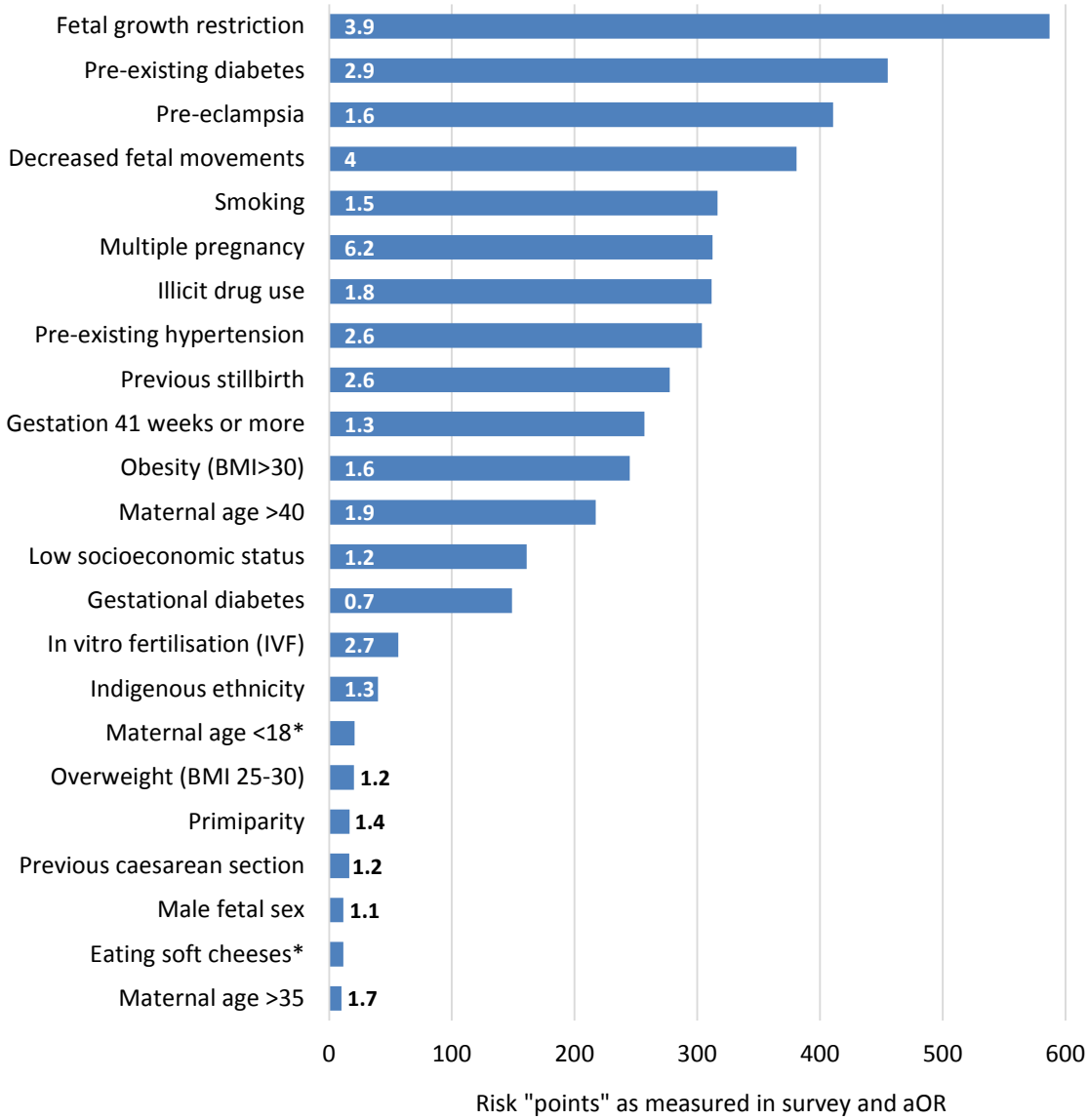
Country	SB rate	Stillbirth Definition	TOP	Stillbirths n	System	Aut %	PlacP %	Unexp %	Other %	CA %	SGA /FGR %	Plac %	Umb %	SP %	Hyp %	SPF %	HT %	Mat %	Inf %
Canada[± 15]	4.2	≥24 weeks	no	7339	ICD	70.9	NS	25.9	14.5	11.3	6.3	-	-	-	-	-	3.2	1.5	-
Croatia[€ 16-19]	4.2	≥22 weeks	yes	553	ICD	NS	NS	24.1	45.9	10.3	2.5	-	-	-		6.5	-	-	10.7
Lithuania[20]	5.2	≥22 weeks	NS	144	ICD	NS	NS	52.8	0.1	5.6	-	-	-	-	40.2	0.1	-	-	-
Poland[8]	4.0	>500 g	yes	2225	ICD	NS	NS	22.3	12.3	23.0	-	12.0	6.8	3.3	-	-	2.1	4.5	-
Portugal[21]	3.7	≥22 weeks	NS	736	ICD	NS	NS	-	44.7	18.2	21.3	-	-	-	15.6	-	-	-	-
Kuwait[22]	5.9	≥28 weeks	NS	355	ICD	NS	NS	71.0	13.8	8.2	-	-	-	-	-	-	-	0.7	-
Qatar[23]	6.7	≥28 weeks	yes	123	ICD	NS	NS	75.6	6.5	11.4	-	1.6	-	-	1.6	0.8	-	-	-
Australia[24]	7.5	≥20 weeks or ≥400 g	yes	8367	PSANZ-PDC[¥]	40	NS	20.2	-	22.6	3.2	14.6	2.1	7.7	1.9	4.2	3.2	2.9	7.0
New Zealand[€25-30]	5.6	≥20 weeks or ≥400 g	no	2107	PSANZ-PDC[¥]	38.4	NS	22.6	-	8.8	2.0	28.9	3.9	4.5	3.7	7.2	4.0	4.8	9.7
France[31]	3.8	≥22 weeks or 500 g	no	969	ReCoDe[¥]	NS	NS	10.5	-	14.7	38.2	13.0	7.1		1.2	3.2	-	1.6	7.1
Ireland[32]	3.9	≥24 weeks or ≥500 g	NS	300	Irish NPEC 2011	42.3	96	24.5	1.4	26.6	2.1	33.3	8.5	-	-	3.2	1.1	-	5.7
Sweden[± 33]	4.1	≥22 weeks	yes	1089	Stockholm	71.4	95.1	12.3	3.1	10.3	-	35.5	7.8	-	1.0	0.5	5.2	2.4	22.0
US[Σ 34]	NS	≥20 weeks	no	512	INCODE	100	100	23.8	-	13.7	-	38.7	9.8	15.2	1.8	11.1	9.2	8.0	15.4
UK[35]	5.2	>23+6 weeks	no	3373	CMACE modified	44	78.3	30.7	-	9.1	6.6	22.7	7.4	1.6	1.5	4.4	5.9	5.0	5.1

Table includes a single selected study from each high-income country reports we identified. Reported causes of death were re-grouped into clinically meaningful consistent categories to enable comparisons (see methods for further details).

SB rate: stillbirth rate per 1000 births; TOP: Termination of pregnancy included (yes or no); NS: Not stated; ¥: Hierarchical system; €: Includes data from multiple annual reports; *±: Excludes births from a multiple pregnancy; Σ: Multiple causes assigned; ICD: International Statistical Classification of Diseases and Related Health Problems; PSANZ-PDC: Perinatal Society of Australia and New Zealand Perinatal Death Classification; ReCode: Relevant Condition at Death; INCODE: Initial Causes of Fetal Death; CMACE: Centre for Maternal and Child Enquiries; Aut: Autopsy; PlacP: Placental Histopathological examination; Unexp: Unexplained; Other: Other unspecified conditions; CA: Congenital abnormality; SGA/FGR: Small for gestational age/Fetal Growth Restriction; Plac: Placental pathologies; Umb: Umbilical cord complications; SP: Spontaneous preterm labour and birth; Hyp: hypoxia (usually defined as birth related); SP: Specific Pregnancy/fetal conditions; HT: Hypertension; Mat: Maternal conditions; Inf: Infection.*

Figures

Figure 1. Risk factors and associated conditions: adjusted odds ratios and perceived risk according to survey data from care providers



aOR: Adjusted odds ratio
**aOR not available*
Respondents (n=1840) were given a list of 23 potential risk factors and associated conditions and were asked to select the 10 that they believe pose the highest risk to stillbirth. Items ranked 1st were assigned 10 points, items ranked 2nd were assigned 9 points, and so on. Non-ranked items were assigned 0 points. Blue bars show the weighted sum of risk points for each risk factor and associated condition across all respondents. Risk factors and associated conditions are sorted from highest to lowest according to survey risk points. aOR are presented inside or outside bars.
All aORs taken from LSS[36] bar male fetal sex,[37] decreased fetal movements,[38] gestational diabetes[39] and smoking[40]
aOR for small for gestational age is used here as a proxy for fetal growth restriction and aOR for prolonged pregnancy (>42 weeks) is used as a proxy for gestation 41 weeks or more.

Figure 2. Survey data on community members' self-rated awareness of risk factors for stillbirth (n=1113)

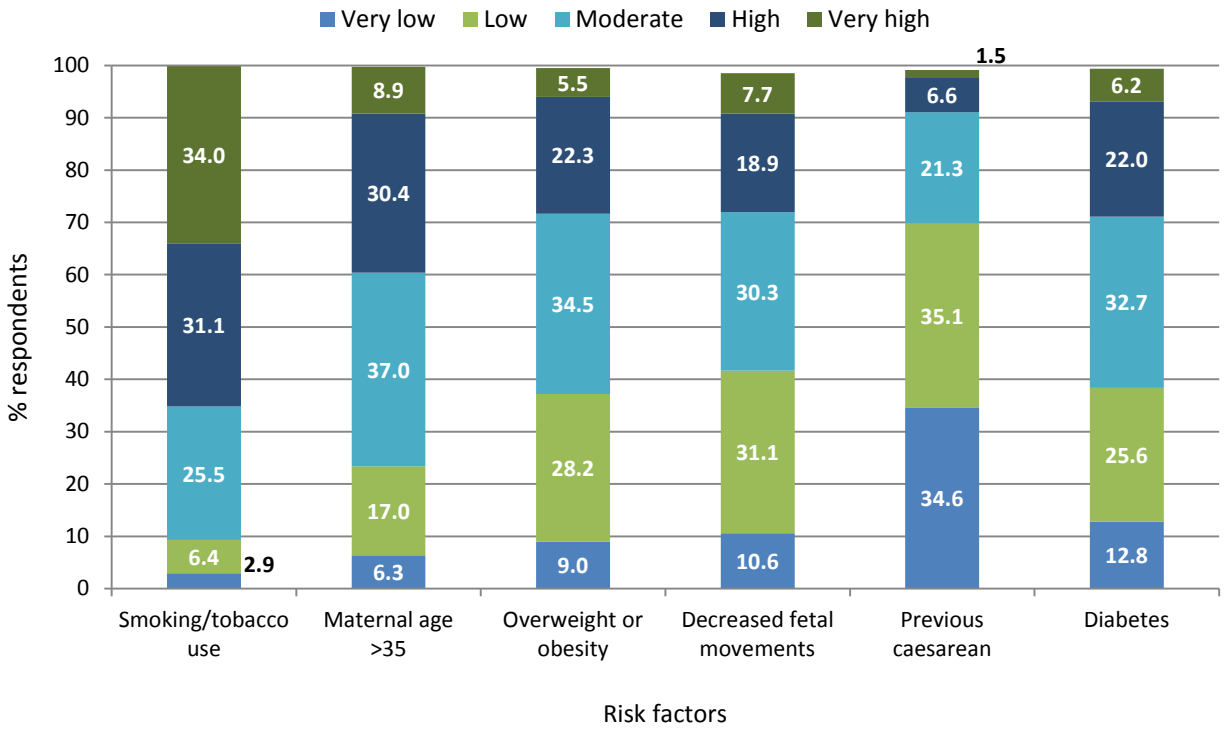


Figure 3. Survey data from care providers on frequency of uptake of stillbirth investigations at facility (n=1884)

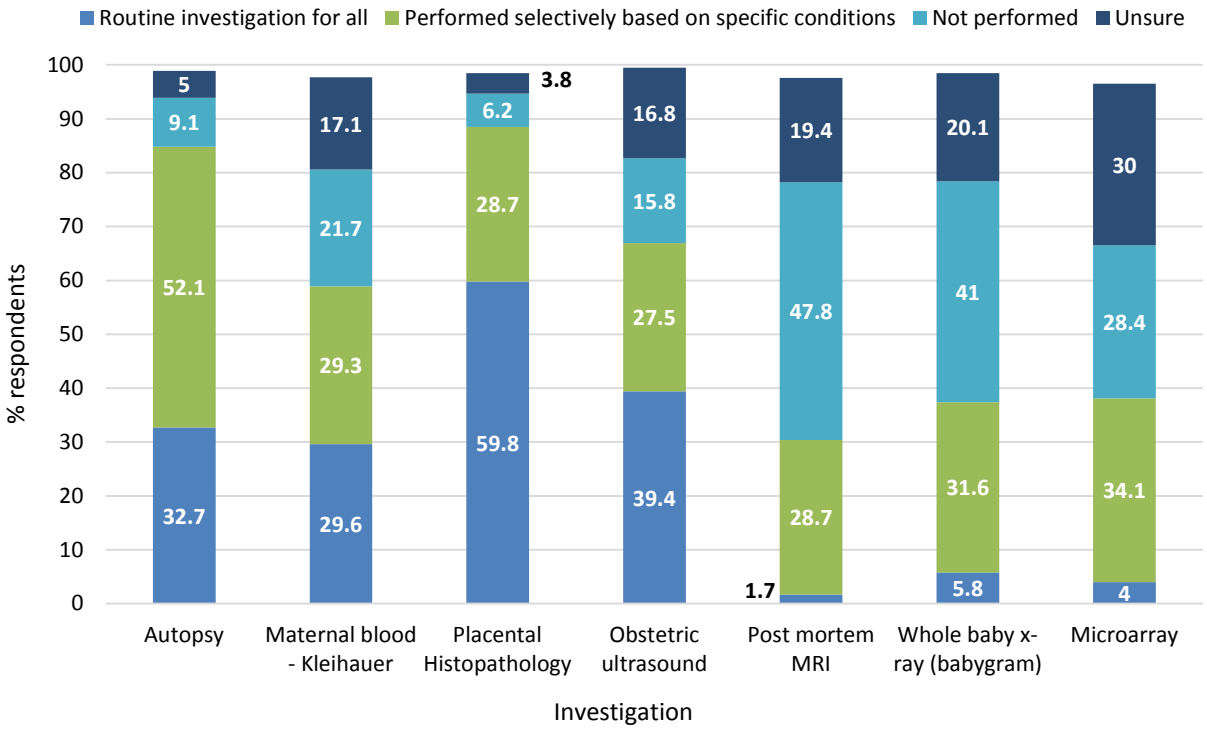
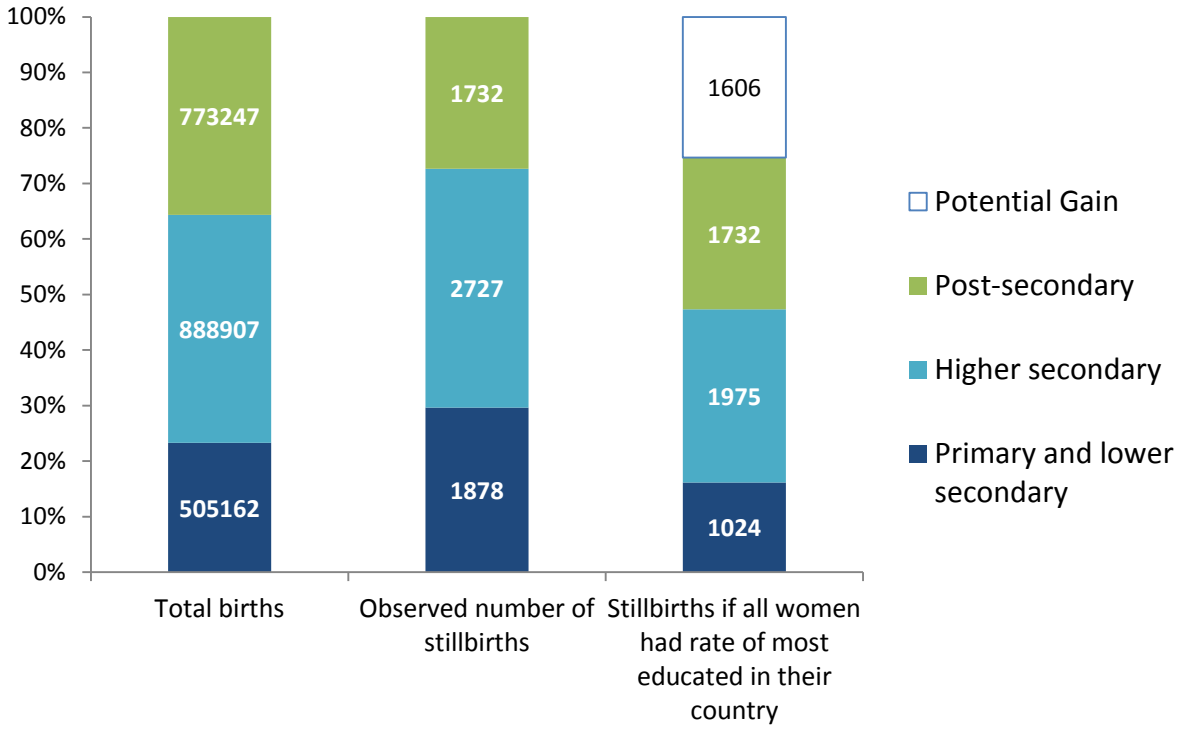


Figure 4. Qualitative survey data on barriers to performing stillbirth investigations according to care providers

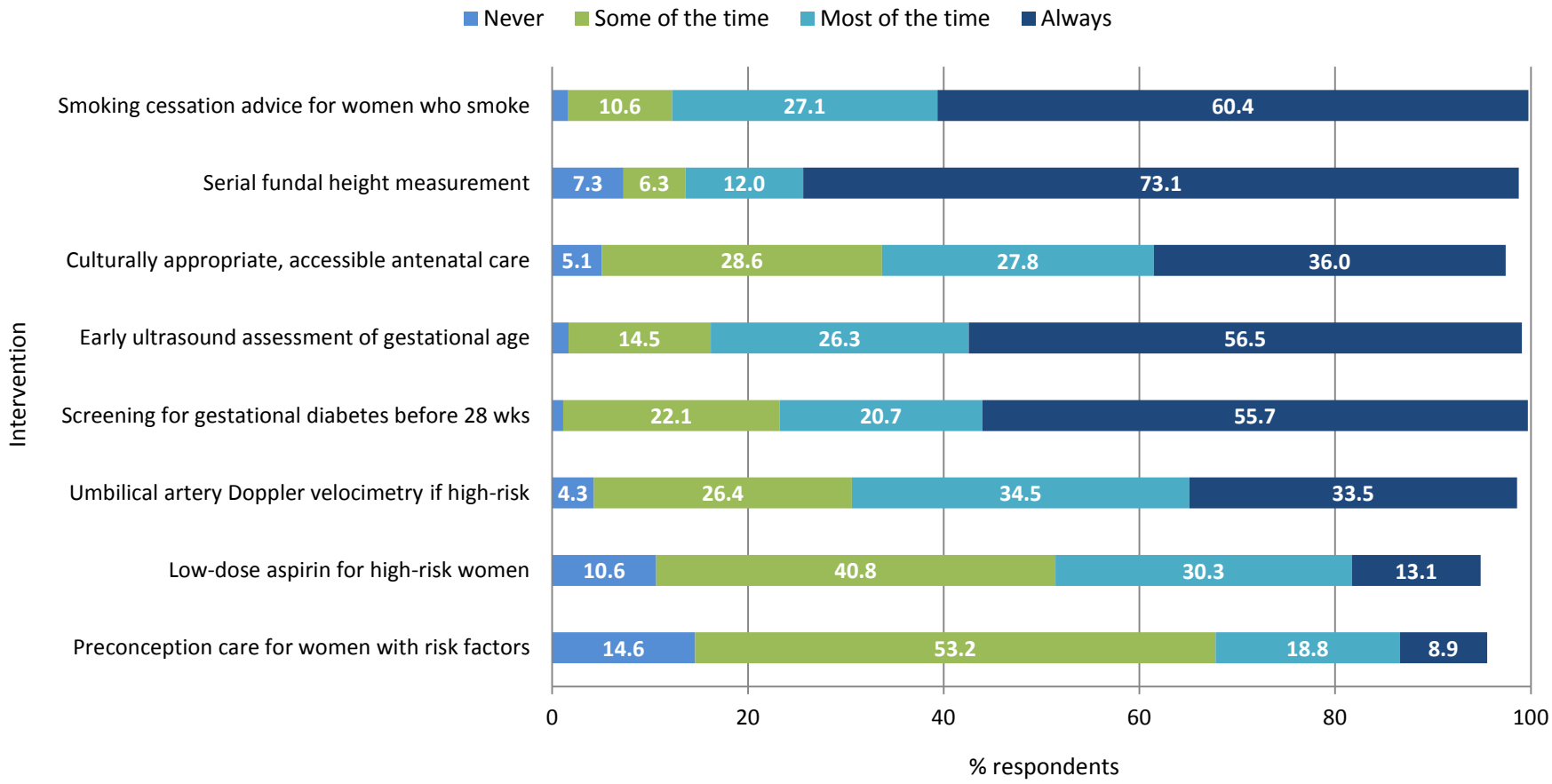
Word cloud depicts responses to open-ended survey item asking care providers what they believed were the barriers/impediments to performing stillbirth investigations including autopsy, as well as other alternative stillbirth investigations. As shown, parental consent (particularly for autopsy) and cost were frequently mentioned barriers. Time and availability of resources and equipment (particularly magnetic resonance imaging (MRI) were also frequently cited.

Figure 5. Total births, observed stillbirths and predicted stillbirths if all women experienced the stillbirth rates of women with post-secondary schooling in 21 European countries in 2010



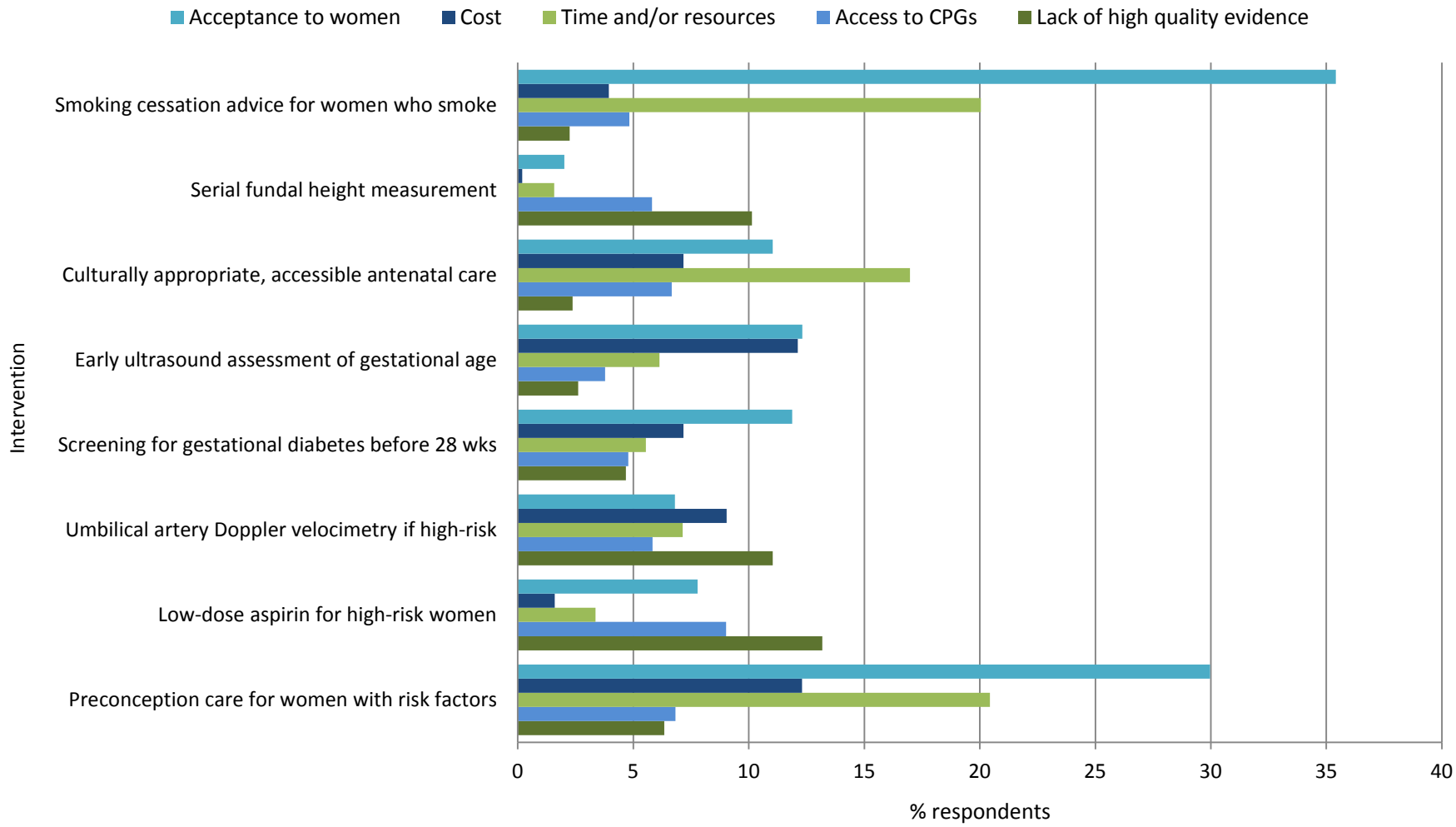
Source: Zeitlin J, Mortensen L, Prunet C, et al. Socioeconomic inequalities in stillbirth rates in Europe: measuring the gap using routine data from the Euro-Peristat Project. BMC Pregnancy Childbirth (in press).[41]

Figure 6. Survey data from care providers on frequency of uptake of recommended interventions for stillbirth prevention at facility (n=1848)



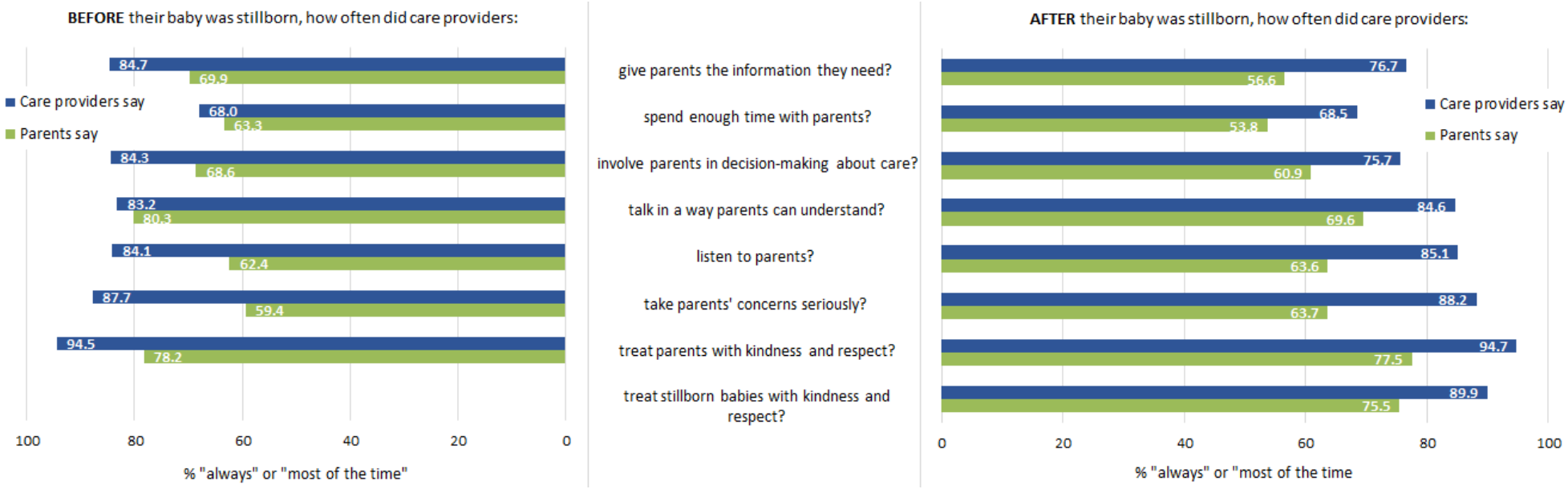
Percentages may not equal 100. Remainder of respondents were either unsure or did not respond

Figure 7. Survey data from care providers on barriers and impediments to uptake of recommended interventions for stillbirth prevention at facility (n=1884)



CPGs: Clinical practice guidelines

Figure 8. Quality antenatal and bereavement care – survey data from parents (N=3503) and care providers (N=2020)



Data from parents refers to the care parents, themselves, received in the pregnancy in which their baby was stillborn. Data from care providers refers to the care provided to all parents, in general, at each care provider's facility

Figure 9. Perinatal related mortality rates in New Zealand from 2007–2013

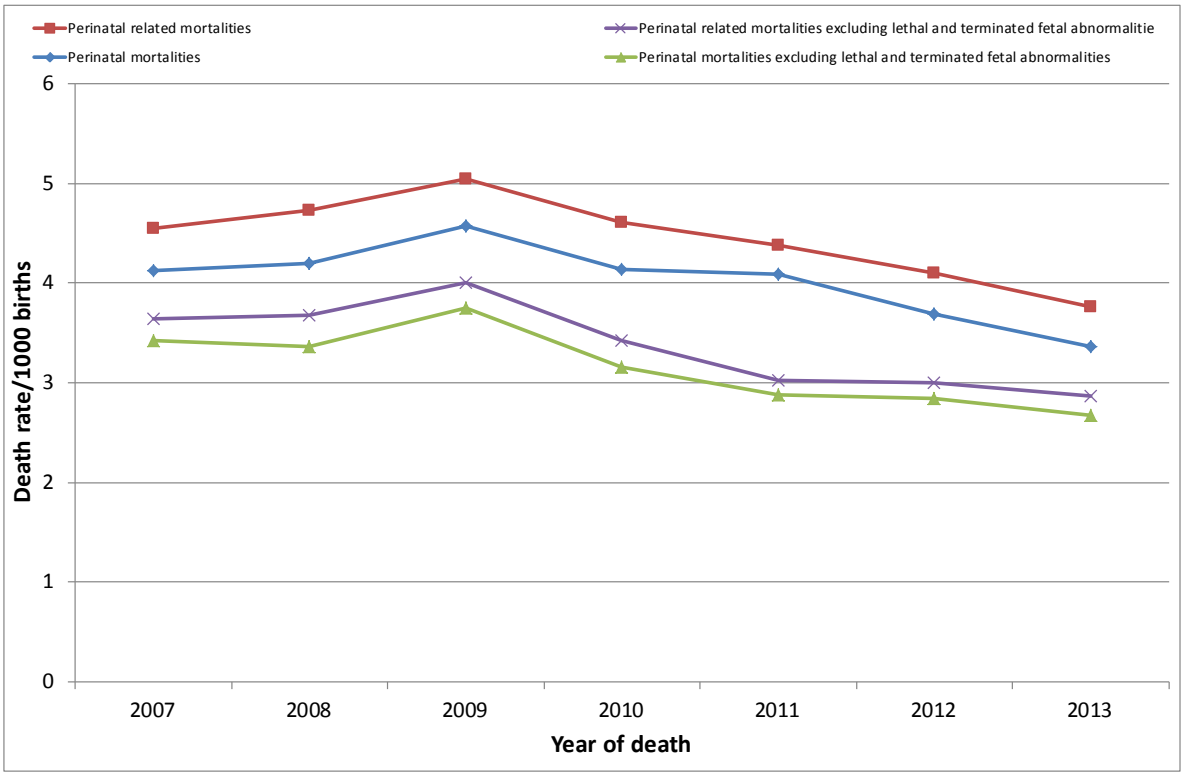
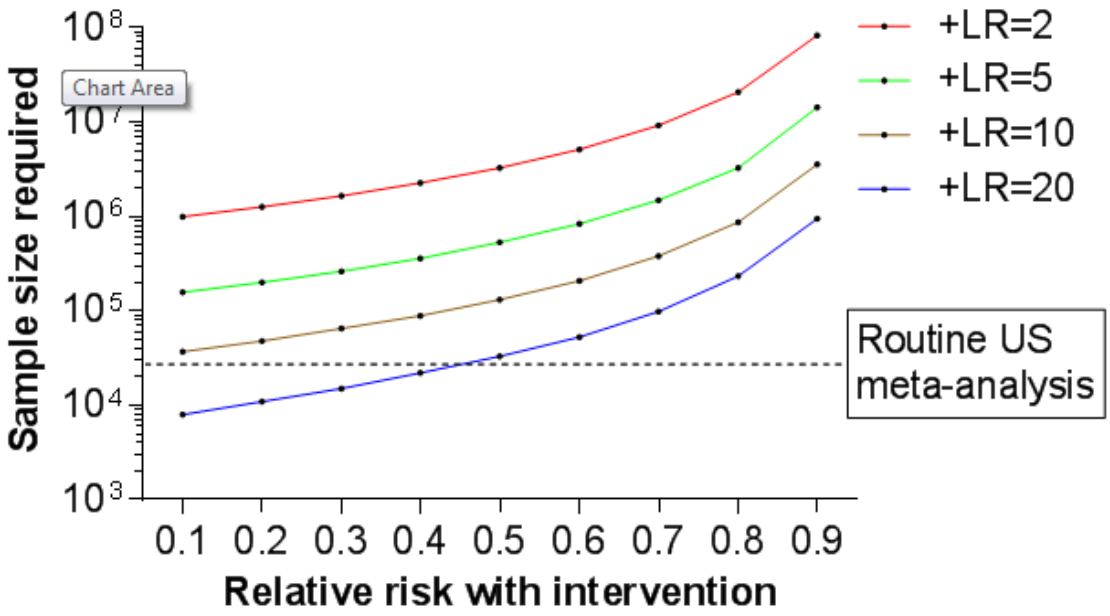


Figure shows significant reduction in perinatal mortality from 2007-2013 using the WHO international definition (births from 1000g or 28 weeks) following the introduction of national perinatal mortality review with mandatory reporting. The greatest reduction in stillbirths at term (≥37 weeks at birth) occurred in hypoxic peripartum deaths (80 percent reduction from 2007-2009 rates) and unexplained antepartum deaths (30 percent reduction from 2007-2009 rates). There was also a significant reduction in stillbirth at 37 or more weeks from antepartum haemorrhage (p=0.003) and from perinatal infection (p=0.018).[42]

Figure 10. Sample size calculations for RCTs of screening



Sample size calculations for randomised controlled trials (RCTs) of screening and intervention compared with routine care. The calculations assumed a 5 per 1000 incidence of the outcome (which is approximately the incidence of stillbirth in the UK and USA) and all models assume a 5% screen positive rate. The positive likelihood ratio and the relative risk associated with intervention were varied (from 2 to 20 and from 0.1 to 0.9, respectively). The odds of stillbirth in the screen positive group were calculated using the prior odds and the given positive likelihood ratio (LR). The posterior odds were converted back into a probability, and this was used to estimate the expected number of stillbirths in the 5% of women who screened positive in the absence of intervention. This number was subtracted from the total number of stillbirths in the whole population to yield the number of stillbirths expected in the screen negative group. Hence, the expected incidence in the remaining 95% (i.e. screen negative) could be calculated. The number of stillbirths in the screen positive rate was then reduced by the given effect of the intervention, yielding a reduced incidence in the screen positive group. By combining the expected incidence in the two groups (i.e. screen positive and screen negative), the expected incidence of stillbirth in the screened arm of a trial could be calculated. Sample size calculations were then performed comparing this estimated incidence from screening with the assumed background incidence (5 per 1000). The other statistical assumptions in the calculation were 90% power and a two sided P value threshold of 0.05.

Appendix: "Parents bringing about change"

Case studies of parent-based action to address stillbirth and bereavement care across HIC.

Australia

Bears of Hope

Bears of Hope Pregnancy and Infant Loss provides care and support to parents who experience a loss through pregnancy, stillbirth and infancy. The organisation was established in 2006 and changed its name in August 2008. Members of the board are bereaved parents and are driven by providing the support they know was missing at the time of their loss. The support begins within the hospital through the Bear Giving program, a bear donated from one bereaved family to another in honour of their own child who has died. Along with the bear is information on support available, a photo frame, a candle and other small mementos.

The support offered by Bears of Hope is diverse. There is an online forum and quarterly newsletter through to annual remembrance days to commemorate specific events. Email support and free phone and face to face counselling, all with a qualified and experienced counsellor who has experienced her own stillbirth is also offered. Support groups are run across Australia and facilitated by trained professionals as well as providing social coffee catch ups and playgroups. Workshops on grief and loss are also provided to parents at various times throughout the year as well as in-services and professional development talks to hospitals.

In 2015 Bears of Hope began research into the support needs of men who experience a loss of child and how they feel the current level of support sustains their needs. A similar project for woman was also launched to ensure that the needs of both mothers and fathers are not just being met but exceeded.

Bears of Hope is a not for profit organisation where the majority of staff are volunteers. The organisation relies on fundraising to continue to provide the support and the major event is the Annual Ball – a time for parents to come together in a social environment and commemorate their child. Bears of Hope advocates for loss to be treated with equality and compassion.

Sands Australia

Sands is the voice for bereaved parents and their families across Australia, promoting healthy grieving and bringing understanding and hope when a baby dies.

We are a community of bereaved parents providing support, information and education to other bereaved parents and their families across Australia that have experienced pregnancy loss or a newborn death. We also work in partnership with healthcare professionals to improve the quality of care and support for bereaved parents.

Our services include a national 24 hour Support Line; LiveChat which gives parents the opportunity to speak to a trained Volunteer Parent Supporter live through our website; local face to face Support Groups engaging with parents in their local communities and free information brochures. In addition, we also provide training, information and resources to Healthcare Professionals to improve the care and support for bereaved parents.

SIDS and Kids Australia

SIDS and Kids purpose is to save the lives of babies and support bereaved families and we are very proud to be a part of an international community working to make a difference to stillbirth rates and improved care for those experiencing the incomprehensible loss of a baby.

Raising community awareness of the impact of stillbirth, advocating for changes in bereavement care for families experiencing stillbirth, funding research in the area of stillbirth and providing community services to support families and others impacted by the death of a baby are key priority areas.

Since the Lancet 2011 Stillbirth Series SIDS and Kids has worked in partnership with stillbirth researchers, health care professionals, families, government and supporters of the cause to bring about positive change at the international and national levels.

We continue to provide bereavement care to families in every state and territory of Australia and offer a suite of supports and information including professional counselling, trained parent supporters, support groups, sibling programs, internet support programs, memorial services, newsletters and publications. Over 70% of the families we support have experienced the perinatal death of a child.

The Stillbirth Foundation Australia

The Stillbirth Foundation Australia was founded in 2005 by the parent of a stillborn baby girl who died unexpectedly in utero. It was established in order to raise awareness of the too-high incidence of stillbirth in Australia and is the first and only charity in Australia solely dedicated to raising funds for stillbirth research.

Over 2000 babies are stillborn each year in Australia, a figure that has not significantly reduced over the last two decades. The Lancet Stillbirth Series in 2011 continues to be a driving force behind the mission of the foundation: *To reduce the incidence of stillbirth through research, education and advocacy.* The Stillbirth Foundation Australia is a conduit for the Lancet Stillbirth Series recommendations to be pushed out into the public arena and urge Australia to include stillbirth in its national health agendas.

Canada

Still Life Canada

Still Life Canada: Stillbirth and Neonatal Death Education, Research and Support Society was founded in 2012 by bereaved families in Vancouver, Canada (traditional territories of the Coast Salish peoples). As a fledgling organization, Still Life Canada drew inspiration from the 2011 Lancet Stillbirth Series. Through community-based participatory research activities, Still Life Canada carries forward the Stillbirth Series' calls to action of reducing stigma and improving supports for families by building the capacity of its members and forging meaningful intersectoral collaborations. The Lancet 2011 Stillbirth series continues to serve as a tool that buoys the work of this grassroots organisation.

Italy

CiaoLapo Onlus

CiaoLapo is the first Italian charity dealing with pregnancy at risk, stillbirth and perinatal loss. CiaoLapo promotes medical and psychological research, training for professionals, social awareness campaigns, and offers free psychological support to pregnant women and bereaved parents.

Since 2006, CiaoLapo developed the very first Italian network of professionals and parents interested in perinatal loss, as well as a strong relationship with the main international groups involved in stillbirth research and grief support. The involvement of CiaoLapo as the Italian partner in the Lancet 2011 Stillbirth Series was an event of paramount importance for the charity. Papers from the Series rapidly became points of reference for epidemiological data and clinical guidelines, and significantly improved everyday work with parents and professionals.

Japan

The SIDS Family Association Japan

The SIDS Family Association Japan was founded in 1993 to help families who have suffered a loss of a baby for any reason including SIDS, miscarriage, stillbirth, perinatal death or infant death. Other goals are to support research as well as educate Japanese medical professionals about how to care for bereaved families.

The SIDS Family Association Japan has 12 chapters nationwide that hold regular meetings where bereaved parents can meet and support each other. These chapters and meetings are navigated by our network of trained befrienders who also respond to the newly bereaved families by email or phone.

The SIDS Family Association Japan has developed materials in Japanese that support bereaved parents and educate health professionals. We maintain a website at www.sids.gr.jp that also offers support for bereaved families, information on SIDS and stillbirth, and prevention through education on child care practices and kick count. We hold biennial conferences in different locations throughout Japan, most recently in Hokkaido in 2014. We give regular workshops on how to care for the bereaved that are aimed at medical professionals.

In 1995 The SIDS Family Association Japan started a SIDS prevention campaign that lead to more than a 50% reduction of SIDS in Japan. We held the 9th SIDS International Conference in 2006 and remain active in the network of international organizations concerning SIDS and stillbirth.

New Zealand

Sands NZ

Sands New Zealand (NZ) is a network of voluntary groups made up of bereaved parents and family members providing support, information and resources to other bereaved families. Sands was established in New Zealand 29 years ago and is the country's leading non-profit provider of support and information on pregnancy, baby and infant loss, especially as it relates to families.

Sands NZ has been involved in the national Perinatal and Maternal Mortality Review Committee (PMMRC) since its inception in 2005. The PMMRC's latest data from 2013, released on 23 June 2015, shows a continued decrease in the number of stillbirths. In 2007 there was one stillbirth for every 180 births but in 2013 there was one stillbirth for every 200 births which is a small but significant improvement. Sands NZ has also been a consultant organisation in the first national maternity consumer survey of bereaved women in 2011 and a follow up survey in 2014.

Sands groups across New Zealand continue to provide much needed community support for bereaved parents and families and work to raise awareness around stillbirth, perinatal and infant loss. Sands NZ supports research by acting as a conduit between bereaved families and research agencies, and provides advice and support for researchers and government agencies when required. Sands also provides training and support to health professionals through its biennial conference and various workshops held throughout the country.

Baby Loss Awareness Week, held from 9-15 October every year, is a focus for all Sands groups across the country. Many activities and events are held to both support families and to raise awareness in the community.

Spain

Umamanita

Umamanita is a Spanish Stillbirth and Neonatal Death Charity founded in 2008 by Jillian Cassidy and Juan Castro after the stillbirth of their daughter Uma. Through small team of volunteers, Umamanita provides support families through its website, facebook page, monthly group meetings, and annual babyloss awareness event Balloons to Remember. Seminars and professional training are also offered to health care professionals and other sectors that work with bereaved families. In 2012, Umamanita established its research department, which carries out analysis of perinatal mortality statistics, and both quantitative and qualitative research with parents. In June 2013 Umamanita launched the first national online survey for mothers who gave birth to a stillborn baby within the Spanish health care system. The research focused on care quality, developing indicators such as the number of parents who have post-mortem contact and also mothers' evaluations of their interactions with health professionals, so that parents' needs might be better understood.

Umamanita advocates for changes to social and health policy, and to create awareness about the importance of social recognition for stillborn babies' lives, whatever their gestational age. A vital objective is that a baby who has died or is about to die is treated with the love and respect he or she deserves, and that his or her parents are treated as parents and their grief recognised being as deserving of support as any other.

The United Kingdom

Sands UK

The Lancet's 2011 Stillbirth Series was a significant milestone in Sands' campaign to influence governments. By demonstrating the UK's poor stillbirth record relative to other HICs, it powerfully supported the call for action. Parents have been central to shifting attitudes, refusing to accept that their child's death was inevitable and forcing stillbirth onto the public agenda.

> *I'm not an expert but I know her death was avoidable, that if she'd been taken out sooner she'd have survived. After Erin died I got a letter from the hospital and it described all the scans I'd have if I got pregnant again... But it's too little too late. I wanted Erin. She wasn't a test run. Erin's mum, Louise*
>
> *Some of the pain emerges years later, when having gone on to have two loved daughters, you realise you'll never have your son. That void is constant. But I never forget the instant and overwhelming pain when he died, coupled with the guilt of what could or should I have done'? The pragmatics of having to arrange a funeral doesn't touch the heart and spirit-breaking pain of losing your baby. That his death was avoidable only adds to it. There's no solace; no-one can say 'it wasn't meant to be'." Asahi's dad, Adrian*

USA

First candle, Star Legacy Foundation, Action of Stillbirth Awareness and Prevention, March of Dimes

Stillbirth awareness and prevention messaging in the United States have greatly been influenced by parent organizations lobbing to increase awareness. First Candle, an organization formed to help parents who have lost their babies to SIDS were quick to embrace the stillbirth community in 2002. The Lancet Stillbirths Series in 2011 has buoyed the focus on stillbirth. Newer parent groups such as the Star Legacy Foundation and the Action of Stillbirth Awareness and Prevention (ASAP) have worked collaboratively with recent good success. In 2015 the March of Dimes, an organization initially founded to focus on preterm birth recently introduced information on stillbirth and stillbirth prevention. In addition the Centers for Disease Control (CDC) introduced the Stillbirth Project information and resources for stillbirth parents. Getting corporate support for stillbirth groups is difficult because messaging can be difficult to sell. However, efforts from a collaboration of the above groups have just recently developed (May 2015), a Pregnancy and

Empowered program which links web-based tools promoting healthy habits in pregnancy, tool for fetal movement awareness, and safe sleep habits, and messaging to empower women to ask questions have secured support from Babies -R -us and Boppy-Pillows.