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# Stillbirths: ending preventable deaths by 2030

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#### **Abstract**

(word count: 149/150)

The number of annual stillbirths remains unchanged and unacceptably high, 2.7 million in 2015. Efforts to achieve the new global goals for maternal and child survival will also prevent stillbirth and improve health and developmental outcomes. However, failure to consistently include global targets or indictors for stillbirth in post-2015 initiatives shows this issue remains hidden in the global agenda. This paper summarises findings from previous papers in this Series, presents new analyses, and proposes specific criteria for successful integration of stillbirths into post-2015 initiatives for women's and children's health. Five priority areas to "change the curve" include: (1) intentional leadership; (2) increased voice, especially of women; (3) implementation of integrated interventions with commensurate investment; (4) indicators to measure impact and especially to monitor progress; and (5) investigation of critical knowledge gaps. The post-2015 agenda represents opportunities for all stakeholders to act together to end all preventable deaths including *stillbirths*.

## **Keywords**

Stillbirth, Maternal health, Newborn health, Prenatal health, Prevention, Antenatal care, Perinatal, Birth, Intrapartum, Bereavement, Integration, Health priorities, Health policy, Health information systems, Indicators, Research priorities

#### **Key messages**

- 1. Too many women and children die in pregnancy and childbirth despite the existence of evidence-based solutions. Stillbirths comprise a huge part of this burden an estimated 2.7 million third trimester stillbirths worldwide, 1.3 million occurring during labour with minimal reductions in the past decade. Efforts to end preventable stillbirths as well as maternal and newborn deaths will improve maternal and newborn morbidity outcomes and have positive long term effects on development and non-communicable diseases.
- 2. **Stillbirths remain hidden** in global data tracking, social recognition and also in investment and programmatic action as demonstrated in the previous papers in this Series. The burden on families, especially women, is severe and long lasting, yet stigma and taboo hides this burden even in high income countries.
- 3. **Five priority actions can "change the curve" for stillbirths**, integrating with relevant action for women's and children's health: (1) intentional leadership; (2) increased voice, especially of women; (3) implementation of integrated interventions with commensurate investment; (4) indicators to measure impact and especially to monitor progress; and (5) investigation of critical knowledge gaps.
- 4. **Leadership is a critical pre-requisite for progress.** The network of organisations working on stillbirth issues has the **potential to improve collaboration and cooperation through existing connections** with maternal and newborn health activities, but deliberate efforts are needed to strengthen the role and involvement of affected parents within this network.
- 5. **Increasing community and women's voices will be essential** for preventing these deaths by improving quality of life and health care as well as addressing issues of stigma around stillbirth and supporting those affected. In the event of any death in pregnancy or childbirth, contextual respectful and supportive care is an important yet still neglected component of care.
- 6. **Indicators to measure impact and especially monitor progress are needed** to count every stillborn baby, track programmes and measure coverage including improvement of data to track content and quality of care for relevant programmes and interventions with the greatest impact on stillbirths, such as intrapartum monitoring and management and syphilis treatment in pregnancy. Stillbirth rate is a marker of quality of care in pregnancy and childbirth, as well as a sensitive marker of a health systems' strength.
- 7. **Implementation of the post-2015 health agenda** through the Sustainable Development Goals, and the *Global Strategy for Women's, Children's, and Adolescents' Health* will be maximised by acknowledging, incorporating and counting stillbirths.

#### Introduction

This is the final paper in *The Lancet* Ending Preventable Stillbirth series, aimed to elevate the concern of the global community on this neglected area in public health and identify actions for accelerated progress. Since 1990, under-five and maternal deaths have decreased more rapidly than ever, yet not enough to achieve Millennium Development Goals (MDGs) 4 and 5 for women's and children's health; newborn mortality and stillbirths, health indicators external to the MDGs, have seen much slower progress. In September 2015, countries committed to a post-2015 framework – the Sustainable Development Goals (SDGs) — which includes the unfinished agenda for maternal and child health supported by the *Global Strategy for Women's, Children's and Adolescents' Health* (Global Strategy). 5

The new Global Strategy also focuses on additional priorities, including newborns and stillbirths, family planning, and adolescent health. Their inclusion reflects the 'obstetric transition,' where countries shift from a pattern of high to low maternal mortality, from predominance of direct obstetric causes of maternal mortality to an increasing proportion of indirect causes and other relevant health and non-health factors. Relevant global plans reflect this transition, e.g. Strategies for Ending Preventable Maternal Mortality, and countries have followed suit, albeit at differing paces. Countries further along on the obstetric transition pathway have sub-specialisations, such as maternal-fetal medicine or perinatology, which consider fetal health outcomes predominantly in high-risk pregnancies. However, specific attention to improve the baby's health and survival along with the mother should not have to wait for an obstetric transition since common preventive measures are linked, in particular quality midwifery and obstetric care, which should occur in all settings.

The progress for maternal and child mortality has resulted in greater attention on morbidity, stillbirths, newborn deaths and the long term effects of adverse birth outcomes on development and non-communicable diseases. <sup>10-14</sup> Tackling these challenges requires optimising the health of the mother-baby dyad. The global epidemiological transition for under-5 child mortality led to a shift in focus to newborn health, <sup>15</sup> and the resulting Every Newborn action plan with specific targets for ending preventable stillbirths and maternal and newborn mortality. <sup>16</sup>

#### **Objectives**

This final paper aims to:

- 1. Synthesise evidence from the Series on actions to accelerate progress for ending preventable stillbirths and promoting respectful, supportive care;
- 2. Assess opportunities for greater integration of stillbirth prevention and care in relevant global health initiatives and reports and national plans;
- 3. Report on an organisational network analysis examining relationships among 33 organisations working to prevent stillbirths; and
- 4. Renew a measurable call to action for integrating stillbirth prevention and response as part of women's and children's health.

Data and methods are summarised in panel 2 and the webannex.

### Synthesising the evidence from the 2015 Ending Preventable Stillbirth Series

Strategies for maternal and newborn health emphasise universal access to quality care. <sup>8, 16</sup> This Series argues that stillbirth prevention and response is founded on respectful, quality care for prenatal health (a term defined by Frøen and colleagues referring to antenatal and intrapartum care that protects and

supports the mother-baby dyad), which must be part of women's and children's health programmes.<sup>17</sup> At the same time, specific attention to stillbirths in advocacy, policy formulation, research and monitoring is required as countries move through the obstetric transition. Stillbirths in the United States, for example, now outnumber infant deaths,<sup>18</sup> and therefore the issue is gaining greater attention.<sup>19</sup>

Building from *The Lancet* Stillbirth Series 2011, <sup>11</sup> this Series presents new evidence, updated stillbirth estimates, and a call to action in the post-2015 era (panel 1). The estimated 7,500 stillbirths that occur every day remain hidden in global public health and women's rights initiatives, <sup>17, 20, 21</sup> despite the evidence presented in 2011. <sup>22, 23</sup> Nearly half are intrapartum stillbirths, which are highly preventable with quality care at birth <sup>24-26</sup> and early identification of at-risk pregnancies. <sup>27</sup> The high numbers and slow progress reflect that the 2011 Call to Action <sup>28</sup> remains mostly unrealised despite impressive global media visibility; <sup>29</sup> Frøen and colleagues examine the reasons for lack of attention or effective action. <sup>17</sup> Use of the term 'stillbirth' remains infrequent in reporting, research, and funding with some exceptions. <sup>13, 16, 8, 30, 25</sup> Countries committed to ending preventable stillbirths with the adoption of the Every Newborn action plan (ENAP), <sup>16, 31</sup> yet few have taken this forward nationally. <sup>17</sup> Stillbirths received less political attention than other important public health issues, such as HIV or malaria, even though the burden is greater, <sup>32</sup> and solutions would also benefit women and children.

Stillbirth rate data are increasingly available through national Civil Registration and Vital Statistics (CRVS), birth registry and Health Management Information Systems, <sup>20, 33</sup> and the indicator is included in core health indicator lists. <sup>34</sup> Lawn and colleagues summarise the burden of stillbirths, with updated national and global stillbirth rates and numbers for 2015 and a focus on intrapartum stillbirths, risk factors (e.g. infections in pregnancy, especially syphilis, and with non-communicable diseases and lifestyle risks) and other metrics for disadvantaged populations. <sup>35</sup> The majority of stillbirths occur in low-income countries, and most in rural settings. In high-income countries (HIC) marginalised groups are particularly affected. <sup>33</sup> Unlike previous *Lancet Series* on maternal, newborn and child health, <sup>13, 30</sup> the importance of supportive care following a stillbirth is elevated and examined. Heazell and colleagues assess stillbirths' economic and social costs, especially for women, including stigma surrounding stillbirth. Flenady and colleagues identify challenges of stillbirth prevention in HIC including socioeconomic disparities, the need to improve data quality, and provision of bereavement care. <sup>33</sup> A matrix of themes from the papers in the Series is available in the webannex.

## A mother-baby dyad approach to stillbirth prevention and response

A healthy mother and baby are the markers of successful management of pregnancy, labour and childbirth. Stillbirth prevention and response cannot be a stand-alone issue and requires an integrated programmatic approach. Likewise, neglecting stillbirths would limit the full potential of an integrated approach for women, children and fetal health alike, averting deaths (maternal, newborn and stillbirth)<sup>11</sup> and improving child neurodevelopmental outcomes<sup>12</sup> and maternal morbidities.<sup>36-38</sup> Investment in and effective implementation of high-quality care and health promotion along the continuum of women's and children's health is one of the most effective ways to protect mother and baby and promote healthy child development outcomes.<sup>39</sup> This approach strengthens with functioning health systems womancentred and compassionate care, and trusting relationships between women and their care providers.<sup>40</sup>

<sup>&</sup>lt;sup>a</sup> Political attention is defined by Hafner and Shiffman [2013] as occurring when "leaders of organisations express concern about issues publicly and privately, and when they back up this concern by allocating resources."

The stillbirth rate is a key indicator of quality care during pregnancy and childbirth, defined by World Health Organization (WHO) as: 'the extent to which health care services provided to individuals and patient populations improve desired health outcomes ... health care needs to be safe, effective, timely, efficient, equitable and people-centered." The Lancet Series on Midwifery presented a framework for quality maternal and newborn care which incorporates the values upon which care should be based—respect, open communication and tailored to women's needs—and the components of the health system required to enable the provision of quality care—adequate resources, accessible and acceptable quality services, and integration between communities and facilities. Quality is necessary throughout the continuum of care and can only be ensured when appropriately educated and skilled health care professionals are in place and well supported by a functional heath system.

Table 1 shows the interventions and requirements at each stage of the continuum<sup>43</sup> including in the case of a death. Heazell and colleagues provide an updated review of evidence based interventions.<sup>21</sup> High-impact interventions in pregnancy, such as syphilis detection and treatment, and during labour and birth, such as assisted vaginal delivery and caesarean section for fetal indication, are critical for stillbirth prevention.

Prevention of stillbirths starts with protection of the girl child through addressing hunger, violence, and discrimination and ensuring equal access to education and health care. <sup>44</sup> In adolescence, comprehensive sexuality education, delayed marriage, access to sexual and reproductive health information and services including family planning, and access to safe abortion services when legal, are critical. Access to primary health care before pregnancy help address nutritional deficiencies and enable diagnosis of hypertensive disorders and diabetes, which can help to reduce stillbirths. Community mobilisation and gender empowerment, including engagement with men on women's health issues, play a role in women's general health and wellbeing. Care in pregnancy, labour and birth requires attention to both mother and baby – the principle of "survival convergence". <sup>45</sup>

Though most stillbirths, like most neonatal deaths, do not have death certificates yet, <sup>20</sup> they count to women and their families. <sup>21, 33, 46</sup> When any death happens, bereaved persons will typically need some form of support; however, evidence shows that mothers of babies who are stillborn are at greater risk of negative psychological symptoms, including depression. <sup>21</sup> Evidence also shows that families may be stigmatised, <sup>21, 33</sup> and that, despite evidence-based solutions <sup>21, 24</sup> and guidelines, <sup>47</sup> there is a sense of fatalism whereby women and even health workers do not see stillbirths as preventable; therefore societies continue to accept these deaths as inevitable. <sup>33</sup>

# Integration that truly addresses stillbirths - proposed criteria

Promotion of women's and children's health inherently includes the prevention of stillbirths. Frøen and colleagues<sup>17</sup> identified themes relating to stillbirths in global women's and children's health platforms since the 2011 Lancet Stillbirth series. Based on their findings, we propose three ways to effectively and appropriately incorporate stillbirths in post-2015 initiatives for women's and children's health in order to meet the full potential of efforts. These criteria include: 1) acknowledge the burden of stillbirths; 2) address actions needed to prevent stillbirths with antenatal and intrapartum care; and 3) monitor stillbirths with a target and/or outcome indicator. We assessed relevant post-2015 initiatives for these criteria (panel 2, webannex). The ENAP meets the criteria, though the component on antenatal care is not emphasized sufficiently for stillbirths. Seven initiatives, including the Global Strategy, mentioned quality care and acknowledge the burden, but do not include a target or indicator to monitor progress for stillbirth prevention. About half the initiatives reviewed met only one or none of these criteria. The

inclusion of these criteria need to be linked to the continuum of women's and children's health promotion, but specific advocacy for the inclusion of stillbirth prevention within new initiatives may be needed in order not to miss the opportunities.

## Priorities based on evidence, opportunities and gaps

Findings from this Series show that stillbirths should be integrated and tracked within initiatives for women's and children's health as well as women's rights and empowerment. <sup>17, 21, 33, 35</sup> Building on existing calls to action from *The Lancet's* Every Newborn Series and the Midwifery Series, which called for women's right to available, accessible, acceptable and good quality care, <sup>13, 30</sup> and supplemented by evidence from this Series, five issue areas were identified to "change the curve" for stillbirths: (1) intentional leadership; (2) increased voice, especially for women; (3) implementation of integrated interventions with commensurate investment; (4) indicators to measure impact and especially to monitor progress; and (5) investigation of critical knowledge gaps. Integration into women's and children's health as measured by the "three criteria" cuts across all these areas.

#### 1. Intentional leadership

Global health issues are prioritised in part because of "actor power" exercised by individual champions, "guiding organisations" that facilitate development of networks and movements, and a mobilised civil society. <sup>48</sup> An Organisational Network Analysis (ONA) was conducted to better understand how a group of 33 organisations working in maternal and newborn health are interacting related to stillbirths and how to maximise their relationship to advance stillbirth prevention and response (see panel 2, webannex).

Our results indicate that these organisations have dense interactions around maternal, newborn, and/or stillbirths issues (61% of potential interactions realised). However, they are missing opportunities to collaborate more effectively around stillbirth prevention and response: stillbirth-specific interactions are much less dense (21%) (Figures 1a and 1b). The marked centralisation of the stillbirth only network makes it highly dependent upon the most central actors (see webannex). The network could be strengthened by: a) building on existing inter-organisational work on maternal or newborn issues, which likely already include interactions relevant to stillbirth prevention; b) increasing the level or intensity of interactions on stillbirth issues; and c) increasing the ties of highly connected maternal or newborn organisations with stillbirth-focused organisations.

In order to build a stronger network, the few central organisations responsible for much of the interaction on stillbirths must serve as "connectors", bringing in less connected organisations (Figure 1b), especially the main global organisations with relevant mandates and also parent groups which are more peripheral. If connections are not intentionally forged, the network of those working on stillbirth related issues will remain weak.

Intentional leadership requires that agencies assume responsibility, with adequate capacity, skills and funding to lead policy and programme change and support countries. WHO should develop guidelines, set priorities for research and conduct large-scale research; UNFPA should lead scale-up of midwifery and emergency obstetric services; the professional associations (i.e. the International Federation for Obstetrics and Gynaecology and the International Confederation of Midwives) should enable their national organisations to speak up for improved services. Academic institutions should lead on research. Civil society should be advocating for policies to hold global and national stakeholders accountable for ending preventable deaths, including stillbirths, providing respectful care and support to bereaved families, and leading behaviour change and community engagement. Specific efforts will be required to

support agencies in leadership roles including funding, strategy assessments and adaptable implementation approaches. A powerful advocacy mechanism will be through efforts to open dialogue around the issue and count stillbirths as deaths.

There is limited information on leadership or champions for stillbirth. Countries that have adopted a national stillbirth target often have done so through the efforts of a few individual champions. All interested stakeholders, including parent-based organizations, should be given opportunity to regularly convene and exchange information on new evidence, funding and prevention strategies, increasing the strength of the network.

Culturally appropriate supportive care in the case of a death is particularly lacking leadership. The WHO joint statement on respectful maternity care, <sup>49</sup> echoed by the UN Women's 2015-2016 progress report, calls for protecting a woman's "right to dignified, respectful health care" and "ending disrespect and abuse during childbirth." While this agenda does not include care following a death, <sup>50</sup> post-mortem respectful maternity care should be considered part of required care along the life course of women and children.

#### 2. Increased voice, especially of women

The Lancet Stillbirth Series in 2011 provided evidence of stigma and marginalisation of women who had stillbirths<sup>46</sup> and called for empowerment of communities and families.<sup>28</sup> This new Series shows that there has been no specific or notable action against stigma or for support of affected families,<sup>17</sup> and stigma persists.<sup>21, 35</sup> Change requires inclusion of women's and parents' voices to call for change,<sup>17, 20, 21, 35</sup> demanding accountability, taking action against stigma and providing support to the bereaved, as culturally appropriate.<sup>21, 35</sup>

To enable women to demand quality health care, they must be supported to realise their fundamental human rights, <sup>44</sup> including "the highest attainable standard of physical and mental health." <sup>51</sup> Cultural barriers often disempower women; for example, young brides may have to get pregnant early to 'prove' their fertility, and expectant mothers may be delayed from care seeking. Sustainable development requires that women be healthy, valued, enabled and empowered. <sup>44</sup> Empowerment of women, through education, equitable decision making, woman-focussed care and access to resources, can improve health outcomes, including preventing stillbirths, yet more research is needed to understand these linkages.

The norms of complacency and fatalism around pregnancy and childbirth for health workers as well as communities need to be addressed. Community based interventions are one method of changing norms and should be tested for scale up.<sup>52, 53</sup>

Respectful support is fundamental to increasing women's voices, starting with acknowledgement of death and enabling families to respond in their own ways. The respectful maternity care agenda is an entry point for support following any death – maternal, newborn or stillbirth. Dignified care matters to grieving families and communities, and culturally acceptable support should be an integral part of it. Parents should be given the option to hold a baby who has died, yet the bodies of stillborn babies are often disposed of without any recognition, name, clothes or funeral. Context specific approaches are required for post-mortem respectful, supportive care in pregnancy and childbirth. Little knowledge is available from low- and middle- income countries (LMIC) but in some settings, there is some support for affected families from the community. Around half of families affected by stillbirth in high-income countries reported substandard levels of bereavement care. Acknowledging a family's right to

respectful care during and after childbirth can lay the foundation for a common understanding of and commitment to respectful care during and after death as well. Programmes are also needed to support affected health workers and avoid the "blame culture" often associated with stillbirth. 54

Parent groups have the potential to raise awareness, for example as seen for preterm birth, <sup>55</sup> but the network of stillbirth-affected families remains limited, disconnected and under-resourced. Only a handful of parent organisations are active in more than one country. <sup>56</sup> The ONA suggests that parent-based organisations are poorly connected with the broader global maternal and newborn heath community. Parent groups primarily focus on local provision of information, advice and support, or advocacy locally or nationally, for instance lobbying for legal recognition of stillbirths, or seeking to raise awareness of stillbirth's burden. Successful examples of stillbirth parent group advocacy in the United States, <sup>57,58</sup> provide some lessons learned but these are small scale and more engagement is needed especially in low- and middle- income countries (LMIC).

Monitoring progress on respectful, supportive care and raising the voice of affected parents requires a clear definition of models and content of care, as well as indicators. However concepts such as stigma and taboo for these deaths have not yet been well quantified, making measurement of progress a challenge.

#### 3. Implementation of integrated interventions with commensurate investment

Health services for women and children, including those with most impact on stillbirth prevention and response, should be delivered together whenever possible without compromising quality of care for either mother or baby. 8,45 Evidence-based, cost effective interventions exist<sup>21,24</sup> despite reports of a knowledge gap on interventions and low awareness of risk factors among some providers and women themselves.<sup>33</sup> Linking programmes for HIV, malaria prevention and treatment, nutrition, immunisation, and antenatal care package to stillbirth prevention is critical. Programmatic and clinical guidance as well as additional research are necessary to design appropriate and innovative policies and implement interventions. These could include prevention of unwanted pregnancies, especially in adolescents, or changing environments (obesity), 59 health promotion before and in pregnancy (pre-conception care, 60 early and focused antenatal care visits, ultrasounds), labour surveillance (fetal monitoring)<sup>61, 62</sup> and correct use of interventions during labour and birth (labour induction, amniotomy, fetal monitoring, assisted delivery or caesarean–section when appropriate<sup>63</sup>). Some maternal and newborn interventions reduce stillbirths;<sup>24,64</sup> although not always,<sup>53,65</sup> and more research is needed to better understand why. For example, the number of antenatal care visits does not give an accurate assessment of quality of care, the effective provision of critical interventions or whether stillbirths and other adverse outcomes are being reduced (Table 1 includes list of interventions; webannex).

Stillbirth prevention does not require a separate set of interventions. The Saving Mothers, Giving Life Program (SMGL) programme demonstrates that stillbirths can be prevented when improving quality maternal and newborn care with declines in stillbirth rates of 20% in Uganda and 19% in Zambia (webannex). 66 Countries recognised as "fast-progressing", e.g. Peru and Nepal, 67 and other case studies, 68 demonstrate there are multiple pathways to improvement, from investing in the workforce and family planning to community leadership, health insurance and greater accountability. 20 Reducing stillbirth rates with implementation of select essential interventions has also been substantial and cost effective in the South African setting. 69

Successful integrated interventions for prenatal care require inclusion of essential indicators in guidelines and intervention lists. Implementation requires a full range of competent and motivated health professionals, including midwives and specialists, within functioning health systems. Major bottlenecks of quality care around birth include health financing, workforce and service delivery. for demand creation and strengthening implementation must also be explored. The service of the service delivery are serviced by the service delivery.

Incorporating stillbirths into the investment cases for women's and children's health strengthens the cost-effectiveness argument;<sup>25</sup> however, often supporting programmes do not use stillbirth rates to monitor progress and document the full return on investment.<sup>72</sup> Limited reporting on stillbirth in the Organisation for Economic Cooperation and Development's database of donor funding reflects another missed opportunity to integrate stillbirth into existing programmes for women's and children's health.<sup>17</sup> The hidden costs to families and societies may partially explain why the investment case for stillbirth is not more widely used.<sup>21</sup>

#### 4. Indicators to measure impact and especially to monitor progress

Data are crucial for accelerating progress for implementation efforts as well as advocacy for more political attention and funding.<sup>73</sup> Efforts to improve antenatal, intrapartum and postnatal care data are underway through the Every Newborn metrics work,<sup>74</sup> and quality improvement will benefit from the forthcoming WHO Perinatal mortality audit and review tool. It is recommended to associate stillbirth review with maternal death and near-miss reviews, when appropriate, within the Maternal Death Surveillance and Response (MDSR) mechanism.

There has been some improvement in stillbirth reporting, with more national level data available and advancements in worldwide updates. Data for intrapartum stillbirths are the weakest of all outcome-level data assessed. Recent investment in CRVS and MDSR provides a key opportunity to improve counting of births and deaths, including stillbirths. A "Perinatal mortality rate indicator", based on intrapartum stillbirths and pre-discharge neonatal deaths, requires more research as a measure of quality of care at birth in low income settings. Recording all birth outcomes, using comparable definitions and details on timing (intrapartum versus antepartum) would increase data, quality and accountability, and can be used to drive change when linked to clinical review and audit discussions without blame on staff. The new ICD PM proposed classification of causes of death is a step towards developing a global classification system including programmatically relevant stillbirth conditions as called for in the 2011 Stillbirth series. The WHO should harmonize its ICD-PM efforts with a rerevision of the Verbal Autopsy Tool, as well as the ICD, to ensure greater relevance of ICD to stillbirth.

While evidence exists for effective interventions, programmatic coverage indicators are lacking.<sup>17</sup> Identifying and tracking intrapartum and antenatal care, including content, quality, coverage and equity, is urgently needed. Indicators must address specific actions to prevent stillbirths and monitor care after death. Data disaggregation, including by timing, cause, and for marginalised groups, may enable countries to target strategies to reach the most vulnerable. Data collected via routine health management information systems or intermittent heath facility quality assessmentscan strengthen accountability when used in national/subnational score cards and quality improvement initiatives.

#### 5. Investigation of critical knowledge gaps

The 2011 Stillbirth Series prioritised research themes to lower stillbirth rates in different settings. Frøen and colleagues found only 11% of new research studies could be linked to themes from the call. Since 2011, some research on effective interventions to prevent stillbirth has emerged e.g. obesity prevention and diabetes screening. Many themes remain under-researched, with new gaps identified.

Although the volume of implementation research is increasing, investigation of the generalizability of current interventions to different settings is needed to avoid unintended consequences and reach scale, particularly regarding obstetric emergencies. Relevant research should record multiple adverse outcomes, including stillbirth and preterm birth. Identification of additional knowledge gaps and reprioritisation of research questions is critical for increasing support and funding, such as better understanding of causes, stillbirth predictors, and placental pathologies. Many key questions, such as frequency of stillbirth with obstetric fistula, remain unknown.

Heazell and colleagues find large gaps in the evidence base for interventions to mitigate the effects of stillbirth for women and other family members and call for research to establish stillbirth's costs, particularly in LMIC and amongst marginalised families. Research is needed to quantify all stillbirth-related costs, including economic, psychosocial and years of life lost, and both direct and indirect costs, to communicate effectively to the public, funders, national governments and others the personal cost of stillbirth borne by parents, caregivers and others. Other issues requiring additional research include more respectful, woman-centred care, le. choice of companion, choice of position during labour, and respectful, supportive care for the bereaved in both high and low income settings. There is very limited evidence on interventions; agreement on definitions and indicators is a prerequisite to research that could build the evidence base (see Table 1).

Increasing research capacity requires investment and an integrated approach. A harmonised set of criteria for context, population, inputs, outputs, outcome, and impact will improve interpretation of study findings to inform programme design g. Collaboration among organisations should be expanded to align and increase resources. The extent of parent involvement in the research agenda has not been assessed but needs serious consideration.

# 2015: A turning point for stillbirths

As the MDGs come to a close, 2015 must be a turning point for ending preventable deaths – stillbirths, maternal, newborn, and child deaths. We outline a renewed call to action to end preventable stillbirths based on the evidence (Panel 3, webannex), in support of women's and children's health, including criteria for successful integration.

Leadership, coordination and accountability are needed at all levels to address health system failures and denials of the human right to health which cause preventable deaths. One of the most important contribution to ending preventable stillbirths will be the intentional incorporation of stillbirths into global, regional and national policy frameworks for women's and children's health. This will help break the silence and will cause a ripple effect of adding stillbirth outcomes to research, policies, and programmes. Training and support for healthcare workers, particularly midwives; strengthening health systems; funding research that strengthens prenatal interventions; and educating and empowering women are all examples of investments to prevent deaths. In addition, the movement for respectful care during childbirth provides a framework upon which to build supportive care when death occurs; indicators for respectful care and reduction of stigma still need to be developed, validated and

launched. Stillbirth rate is a marker of high-quality antenatal and intrapartum care, <sup>17</sup> as well as a sensitive marker of a health systems' strength. <sup>1</sup>

Strengthening the network of organisations working on stillbirth prevention and care has potential to move forward the agenda. Stillbirth prevention and response must involve women themselves and thus depends upon their health, education and equality. Intensive efforts are required to improve support to women, men, and others after stillbirth as well as to bring the voice of affected parents and communities into global and national policy platforms.

Every Woman Every Child called for prioritizing stillbirths post-2015<sup>2</sup> and has included stillbirth in the vision for "ending preventable maternal, newborn and child deaths, and stillbirths"<sup>87</sup> Stillbirth prevention and response will need to be done differently to reach the full potential of 2030 with 126 million more mothers and children alive, including 21 million stillbirths prevented.<sup>72</sup>

#### **Contributors**

The manuscript was drafted by MK, LdB, SL, PH, WS, JEL. LF led the organisational network analysis. SL conducted the review and analysis of reports and initiatives. All authors commented and contributed to the content of the report, and read and approved the final version. MK coordinated the paper contents and consultation with the advisory group. LdB and MK had full access to all the data in the study and had final responsibility for the decision to submit for publication.

#### **Conflicts of interest**

We declare that we have no conflicts of interest.

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## PANELS/TABLES/FIGURES

#### Panel 1: Debunking myths about preventability of stillbirths

# Myth 1: Stillbirth is not an important global health problem in comparison to maternal and child mortality, and other more pressing health issues.

**Fact**: There are an estimated 2.7 million stillbirths every year, <sup>20</sup> which should be added to the global burden of deaths for women and children: 6.3 million under-5 child deaths (including 2.8 million newborn deaths) and 289,000 maternal deaths. <sup>88,89</sup> In high-income countries, stillbirth numbers outnumber infant deaths. <sup>18</sup> The costs of stillbirth go beyond the loss of life and include maternal depression and financial costs to parents as well as long-term economic costs to society. <sup>21</sup> Even in countries where the overall stillbirth burden is low, there are great equity divides (rural/urban, ethnic, age, poverty, etc.) in terms of stillbirth rates. <sup>33</sup>

**Action**: Intentional leadership requires that global and country leaders count the global burden of stillbirths together with maternal and child deaths. Not only will this acknowledge stillbirths as a death to families and help to break the silence, it will also accurately measure the full potential of investing in preventable deaths. Indicators to monitor progress and measure inputs will ensure every death is counted and actions to prevent them can be tracked and monitored.

#### Myth 2: Stillbirth is inevitable.

**Fact**: Nearly half of stillbirths occur during birth, of which three-quarters are preventable with equitable access to quality of care<sup>24</sup> and early detection of at-risk pregnancies.<sup>27</sup> Stillbirths due to non-preventable congenital abnormalities account less than 10% of stillbirths after 28 weeks.<sup>20</sup> Infections during pregnancy remain important preventable factors, especially in sub-Saharan Africa where malaria in pregnancy is estimated to be associated with around 20% of stillbirths and syphilis 11%. Addressing other risk factors such as non-communicable diseases, nutrition and lifestyle factors, fetal growth restriction, preterm labour, and post-term birth will also reduce preventable stillbirths.

**Action**: Implementation of high-quality care for every woman during pregnancy, labour and birth will prevent most intrapartum stillbirths now. Family planning and safe abortion will prevent unintended pregnancy and promote adequate birth spacing. Social and political actions to address poverty and discrimination as well as health care in adolescence and before pregnancy also reduce stillbirths.

We must focus on delivering what we know works, especially in the highest burden settings, reducing equity gaps, and scaling up evidence-based interventions through strengthening national capacity, removing health system bottlenecks and supporting health workers. Investigation of critical knowledge gaps will improve understanding of stillbirth prevention and increase effective innovation. Data are crucial for accelerating progress. Quality of care during labour also relates to data collection because the capacity for effective data collection implies a level of functionality that is associated with good quality of care (and vice versa). Data especially for intrapartum stillbirths is urgently needed.

#### Myth 3: Stillbirth prevention is not affordable, especially for lower-income countries.

**Fact:** Investing in stillbirth prevention *is* investing in prenatal health, which will also prevent maternal and newborn deaths<sup>90</sup> as well as improve child neurodevelopmental outcomes, and maternal morbidities,<sup>36-38</sup> and long-term adult wellbeing.<sup>12</sup> An integrated programmatic approach is required for preventing and responding to stillbirths. **Action:** Increased investment for quality antenatal and intrapartum care must be strengthened and targeted in order to achieve the bold targets for ending preventable deaths in the Global Strategy for Women's, Children's and Adolescents' Health – including stillbirths and newborn and maternal deaths.

# Myth 4: It is inappropriate and insensitive to talk about stillbirth. Stigma and taboo associated with stillbirth are part of culture that must be accepted.

**Fact**: No mother in any society can "forget" that she had a baby who was stillborn. Some may not even want to forget. Moreover, many parents and other family members find it is easier to go forward if given the opportunity to share their stories and remember their babies in "safe" settings. Addressing loss forthrightly can help bring stillbirth out of the shadows and reduce the stigma. Culture changes constantly. For example, maternal deaths

were accepted a century ago as a "normal" outcome of pregnancy and childbirth. As countries have advanced along the obstetric transition, maternal deaths are no longer viewed as inevitable and accepted. This same shift must take place for stillbirths as well as neonatal deaths which likewise are deemed acceptable in some societies. When deaths do occur, respectful care is necessary during the remainder of the pregnancy, as well as during childbirth and after.

**Action:** Increased voice, especially of women, will support women to demand improved quality of life and health care. Cultural change requires intentional leadership, coordinated partnerships, nurtured champions and robust data and evidence to build a case. We need to develop and implement culturally appropriate protocols and support programmes for respectful care following a death in pregnancy and childbirth. We must define, assess and track stigma relating to stillbirth at country, regional and global levels, and support coordinated action to reduce stigma.

#### Myth 5: A vertical approach is needed to end preventable stillbirths.

**Fact**: Ending preventable stillbirths is not achievable without an integrated approach. Stillbirth prevention and response is respectful quality care antenatal and intrapartum care that must be integrated and cannot be vertical programmes. To ensure inclusion of stillbirth in global and national policy formulation, research and monitoring for women's and children's health, specific advocacy and attention are required.

**Action**: Intentional leadership is needed to raise the profile of stillbirth prevention and care within the continuum for women's and children's health, making the case for the full potential of returns on investment and presenting stillbirth from the perspectives of rights, equity and vulnerability. Increased accountability will result from utilizing key indicators of relevance to stillbirth, including quality of antepartum and intrapartum care, and especially incorporating the stillbirth rate as a marker of quality maternity care. Investigation of effective and recommended interventions, focusing on what works in different settings e.g. low-resource and conflict settings, as well as for marginalised groups and under-researched countries and regions, is also key.

#### Panel 2: Analyses and methods

#### Mapping of post-2015 women's and children's health initiatives

The objective of this mapping exercise was to review all relevant global post-2015 initiatives to explore content for recommended criteria for inclusion of stillbirths based on the themes identified in the first paper of the Series. Documentation selection streamlined with the first paper in this Series including the following selection criteria: (1) created to support Every Woman Every Child and/or (2) mentioned in the 2011 Lancet Stillbirth Series' Call to action. In addition, several themes were identified by the Advisory and Study Series Groups as important yet underrepresented—global mental health, raising women's voices, stigma, and human rights—and related documents identified for each.

For each initiative, the original action plan or most recent updated report was selected, resulting in a total of 16. Each document was reviewed in full to identify: (1) number of mentions of stillbirth and other relevant terms; (2) evidence of the criteria identified for inclusion of stillbirth; and (3) opportunities for the future to incorporate these criteria.

#### **Organisational Network Analysis**

Organisational network analysis examines the structure of relationships between actors in a network. This organisational network analysis, conducted to better understand current patterns and develop the way forward for strengthening momentum and action, included 33 organisations involved directly or indirectly in stillbirth-related issues, selected by *The Lancet* Stillbirth Study Group. Respondents from multilateral agencies, professional associations, academia/research organisations, the donor community, non-governmental organisations, partnerships, parent groups, and the private sector provided structured information on their organisation's interactions in the last year with each of the other 32 organisations, and qualitative information on successes and challenges for the community of organisations working on stillbirth issues. Similar analyses have been used in recent years for the community of organisations working on newborn health globally. <sup>91</sup>

Analysis, using UCINET version 6.547, included network density (measuring realised versus potential connections between organisations), degree centrality (measuring the number of direct links each organisation has, weighted for interaction level), betweenness centrality (the extent to which an actor is "connecting" two actors not currently interacting) and network centralisation (measuring how equally/unequally degree and betweenness centrality are distributed in the network). With the study's 100% response rate, analysis results are based on confirmed ties (those in which both organisations stated they had interacted in the last year).

Limitations to this analysis include its limited sample size, distinction between individuals and their organisation, respondent knowledge, and inability to capture changes over time (data reflect interactions in the last year only). We intentionally sampled globally affiliated organisations rather than country specific organisation given the global nature of the analysis. However, this limitation prevented the consideration of some active country-based organisations which engage at global level as well. The 33 organisations included are a sample of the global network and not inclusive of all critical organisations working in this sphere.

More details for both analyses available in webappendix

#### Panel 3: Call to Action: An integrated approach for Ending Preventable Stillbirths

#### **MORTALITY TARGETS**

- National stillbirth rate: As called for in the Every Newborn Action Plan, every country to achieve a rate of 12 stillbirths or fewer per 1000 total births (resulting in a global average of 9 stillbirths per 1000 total births) by 2030.
- Equity stillbirth rate: As called for in the Every Newborn Action Plan, every country, particularly those where stillbirth rates are already <12 per 1000, to have set and met a national target for reducing equity gaps in stillbirth rates by 2030.

#### **COVERAGE TARGETS**

- Universal healthcare coverage:
  - Family planning: By 2025, universal access to services and rights; 75% fewer pregnancies among adolescent girls below 16 years of age
  - Antenatal care: By 2025, universal quality, comprehensive antenatal care for all women in all countries (see Table 1)
  - Care during labour and birth: By 2025, effective intrapartum care for all women in all countries, with particular attention to eliminating intrapartum stillbirths, including high quality intrapartum monitoring and timely/appropriate obstetric interventions, including caesarean section, as well as adequate, context-appropriate clinical and respectful management of stillbirth.

#### **MILESTONES**

- Every Newborn global and national milestones by 2020 (full list in webannex)<sup>16</sup>
- **Post-mortem respectful, supportive care:** By 2025, all countries to have in place a respectful and supportive care programme following a death during pregnancy, childbirth, neonatal periods or beyond for families, communities, and caregivers, including a protocol after death.
- **Reduce stigma:** By 2025, all countries to acknowledge the impact of stillbirth and identify mechanisms to reduce associated stigma among all stakeholders, particularly health workers and communities.

#### **PRIORITY ACTIONS**

These actions must be taken in order to achieve national and global stillbirth targets:

- 1. **Intentional leadership**: maximise existing leadership, ensure global organisations include stillbirths when taking action for women and children.
  - 1.1. Ensure relevant global organisations act on their mandates related to stillbirths
  - 1.2. Intentionally nurture champions especially from high burden settings, and from professional organisations, including building technical capacity to implement and to research
  - 1.3. Convene regular stakeholder events, including affected parents
  - 1.4. Raise the profile of stillbirth prevention and healthy start in life within the continuum for women's and children's health, making the case for the full potential of returns on investment and presenting stillbirth from the perspectives of rights, equity and vulnerability.
- 2. **Increased voice, especially among women:** empower women to demand quality of life and health care, and support those affected by the burden of stillbirth to raise their voices for change.
  - 2.1. Engage women, families, and communities in research, prevention, support, and convening opportunities

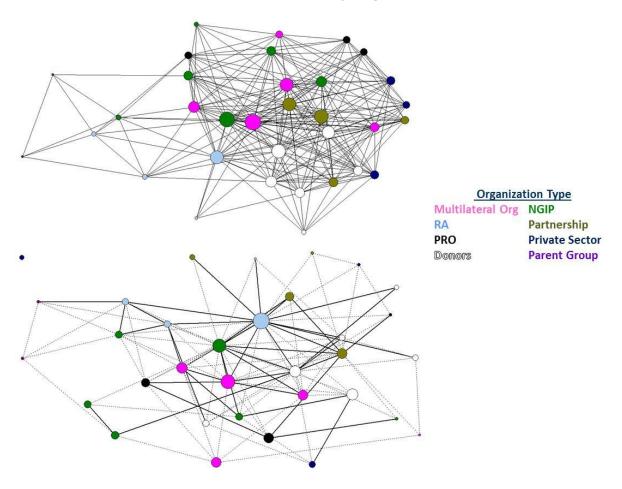
- 2.2. Develop and implement culturally appropriate protocols and support programmes for respectful care following a death in pregnancy or childbirth
- 2.3. Reach consensus on how best to define, assess and track stigma relating to stillbirth at country, regional and global levels, and support coordinated action to reduce stigma.
- 3. Implementation of integrated interventions with commensurate investment: ensure high-quality care for every woman during pregnancy, labour and birth; focus on what works, especially in the highest burden settings, reducing equity gaps, and scaling up; strengthen national capacity to end preventable stillbirths, maternal and child deaths and severe morbidity; focus on removing bottlenecks and supporting health workers; ensure funding commensurate with the scale of 2.7 million deaths a year.
  - 3.1. Increase quality coverage of priority interventions for respectful maternity care and promotion of prenatal health to prevent ante- and intrapartum stillbirths and provide culturally appropriate, post-mortem respectful after death
  - 3.2. Promote innovation for interventions to improve prenatal, maternal and neonatal health
  - 3.3. Scale up and act on mortality review/audit data by adopting national perinatal review/audit policies
  - 3.4. Increase investment for quality antenatal and intrapartum care
  - 3.5. Focus on overcoming health system bottlenecks especially related to the health workforce, , particularly midwives, and the enabling working environment.
- 4. **Indicators to measure impact and especially to monitor progress**: count every stillborn baby, track programmes and measure coverage.
  - 4.1. Institutionalise stillbirth registration in every country as part of the routine information system
  - 4.2. Promote the use of comparable definitions of stillbirth (based on gestational age before weight) and of causes
  - 4.3. Support the completion and wide use of a global classification system for causes of stillbirth
  - 4.4. Identify and track coverage and content indicators for stillbirth prevention and post-mortem supportive respectful care
  - 4.5. Strengthen accountability by utilizing key indicators of relevance to stillbirth, at minimum including stillbirth rate, intrapartum stillbirth rate, antenatal care, syphilis prevention, intrapartum management and management of hypertension.
  - 4.6. Promote stillbirth investigation as part of maternal/perinatal death review and response mechanism
- 5. **Investigation of critical knowledge gaps**: Address gaps in knowledge by setting research priorities of what is needed to prevent, manage and monitor stillbirths; build the evidence through increased investment in discovery, translational and implementation science to drive better understanding and effective innovation; learn as we go forward with what we know through implementation research; develop research capacity.
  - 5.1. Revisit research priorities for prenatal, maternal and newborn health to address knowledge gaps for both stillbirth prevention and respectful, supportive care
  - 5.2. Build the research evidence on outstanding questions related to effective and recommended interventions, focusing on what works in low-resource and conflict settings, for marginalised groups in all settings, and under-researched countries and regions
  - 5.3. Support and invest in implementation research and robust monitoring and evaluation of programme activities, ensuring to integration of stillbirth outcomes as well as other pregnancy and birth outcomes, as appropriate

- 5.4. Develop research capacity that serves specific contexts and communities with emphasis on highest burden settings
- 5.5. Research and assess needs for women and families after death due to pregnancy or childbirth complications (maternal and newborn deaths and stillbirths), and for best practices in supporting healthcare workers affected by their care for women undergoing stillbirth.

Figure 1: Visualisation of organisational interactions among the 33 organisations in the last year

1a: Any reported interactions related to maternal, newborn and/or stillbirth issues

1b: Stillbirth interactions only: medium and high level of interactions depicted with bold lines, low level interactions in dotted lines -- - nodes additionally weighted for level of interaction



Note: Placement of organisations varies between the plots and nodes sised for degree centrality

Legend: Blue – Research and academic organisations, Pink – international organisations, Black – professional organisations, White – donors, Green – non-governmental implementing partners, Navy – private sector, Brown – partnerships, Purple – parent groups

Table 1: Interventions and action to preventing and responding to stillbirth along the continuum of care

Sources: adapted from the State of the World's Midwifery Report 2014: Midwifery 2030; A pathway to Health, page 47. Essential interventions, commodities and guidelines for RMNCH. PMNCH, 2012. "Survive, Thrive, Transform" The Global strategy for Women's, Children's and Adolescents' Health, 2016-2030. A. Heazell et al. Moving from cost to value (Ending Preventable Stillbirths Lancet series, 2016)<sup>21</sup>

In red italics are the 10 interventions proven as reducing stillbirth (Stillbirth Lancet series 2011)<sup>90</sup>

TIMING ALONG PATHWAY	PACKAGE OF INTERVENTIONS WITH PROVEN IMPACT ON STILLBIRTH PREVENTION	PACKAGE OF INTERVENTIONS WITH POTENTIAL EFFECTS ON STILLBIRTH PREVENTION AND CARE	LEGISLATIVE AND POLICY ACTIONS
REPRODUCTIVE HEALTH: PLANNING AND PREPARING	<ul> <li>Family planning information and services, including for adolescents (reduction of &lt;16 and &gt;35 years pregnancies, birth spacing)</li> <li>Folic acid fortification/supplementation<sup>a</sup></li> <li>Prevention, testing and management of Syphilis</li> </ul>	<ul> <li>Maintaining good health and nutrition, promoting of healthy behavior such as nutrition, physical activity, no tobacco, alcohol and drugs</li> <li>Pre-pregnancy checking for hypertensive disorders, cardiac disease, anemia, under nutrition and obesity<sup>b</sup></li> <li>Prevention, testing and management of STIs (Hepatitis B) and HIV</li> <li>Prevention of early and forced marriage</li> <li>Detection and management of hazardous and harmful substance use</li> <li>Pre-pregnancy detection and management of risks factors (nutrition, tobacco, alcohol, environmental toxins) and genetic conditions</li> </ul>	<ul> <li>Legislative and programmatic interventions to delay age of marriage</li> <li>Legislative and programmatic interventions to ensuring completion of secondary education, for girls and boys</li> <li>Provision of comprehensive sexuality education to boys and girls</li> <li>Planning pregnancies using modern contraceptive methods</li> <li>Strategic thinking about quality of care, including availability, equitable access, acceptability and quality</li> </ul>
PREGNANCY: ENSURING A HEALTHY START	Effective ante-natal care and support visits <sup>c</sup> • Folic acid supplementation • Prevention and management of malaria, including insecticidetreated bed nets or intermittent preventive treatment • Prevention and management of Syphilis • Interventions for cessation of	<ul> <li>Iron supplementation</li> <li>Calcium supplementation (prevention of hypertension)</li> <li>Dietary counselling for healthy weight gain and adequate nutrition</li> <li>Detection and management of risks factors (nutrition, tobacco, alcohol, environmental toxins) and genetic conditions</li> <li>Management of chronic medical conditions (e.g. hypertension, diabetes)</li> <li>Low dose aspirin to prevent pre-eclampsia</li> </ul>	<ul> <li>Maintaining good health and preparing for pregnancy, childbirth and the early months as a new family</li> <li>Receiving at least four quality antenatal care visits, which include essential clinical components<sup>c</sup></li> </ul>

	<ul> <li>smoking</li> <li>Screening for and management of maternal illness (obesity, hypertensive disorder, diabetes)</li> <li>Detection and management of fetal growth restriction</li> </ul>	<ul> <li>Antihypertensive drugs</li> <li>Magnesium sulphate for severe pre-eclampsia/eclampsia</li> <li>External Cephalic Version</li> <li>Counselling for domestic violence</li> </ul>	
CHILDBIRTH: SUPPORTING A SAFE BEGINNING	Facility childbirth with a skilled birth attendant  Antibiotics for PPROM  Induction of labour to manage PROM at term  Surveillance of labour (Partograph) including fetal monitoring  Post-term labour induction  Assisted vaginal delivery and caesarean section for fetal indication (comprehensive emergency obstetric care – EmOC)	Psycho-social support and companion of choice during labour     Appropriate procedures for delivery following stillbirth diagnosis (induction of labour, Embryotomy, caesareansection)	<ul> <li>Accessing midwifery services with the companion of choice</li> <li>Mothers participating in decisions about how they and their baby are cared for</li> <li>Having the privacy and space to experience birth without unnecessary disturbance and interventions</li> </ul>
WHEN A DEATH OCCURS: RESPECTFUL AND SUPPORTIVE CARE		<ul> <li>Provide quality postnatal care to the mother, including management of the complications (haemorrhage, eclampsia, sepsis, anaemia), and prevention, early detection and management of obstetric fistula, family planning advice and contraceptives, initiation or continuation of antiretroviral therapy for HIV, nutrition counselling, postnatal contact with a skilled health care provider, at home or in the health facility, around day 3, day 7 and at 6 weeks after birth</li> <li>Screening and management for postpartum depression</li> <li>Maternal and perinatal death or near-miss case review or audit</li> <li>Compassionate support and counselling for all family members following a stillbirth,</li> </ul>	<ul> <li>Respectful support to all the family members after death as appropriate in context. This may include accurate information on options (seeing, holding, etc.) and decisions to make (funeral arrangements, autopsy, etc.)</li> <li>Ongoing support after a death: information on where to go for help; counselling support; financial support for lost income and extra expenses; listening</li> <li>Information and education to reduce the stigma and taboo associated with stillbirth, maternal or newborn death</li> <li>Support to community groups which can reduce stigma and</li> </ul>

maternal and/or neonatal death  • Provision of emotional support and specific information to assist in decision-making and access to financial support when possible	support bereaved families  Education and training of healthcare workers in respectful care for bereaved parents  Creation of "safe spaces" to support healthcare workers caring for the bereaved  Encouraging autopsy where feasible
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<sup>&</sup>lt;sup>a</sup>WHO Guideline: Intermittent iron and folic acid supplementation in menstruating women, Geneva 2011. http://apps.who.int/iris/bitstream/10665/44649/1/9789241502023\_eng.pdf?ua=1&ua=1

<sup>&</sup>lt;sup>b</sup>We are suggesting studying the effectiveness of primary health care pre-pregnancy visit aimed to detect health problems having a potential impact on the maternal mortality and morbidity and stillbirth, to adapt treatments (anti-hypertensive drugs) and discuss post-partum contraception.

<sup>&</sup>lt;sup>c</sup>Quality antenatal care visits should include assessment of gestational age and definition of the estimated date of delivery (first half of the pregnancy), body mass index (BMI) measurement, blood pressure measurement, urine test (Albumin), Syphilis and HIV screening, and information provision for birth preparedness (danger signs, including fetal movements, decision-making to reach a health care professional competent in midwifery) and, as needed, context specific interventions like intermittent presumptive treatment for malaria and repeated HIV test in late pregnancy. The impact on stillbirth of using ultrasounds in poor settings to measure gestational age, to monitor fetal growth and inform on possible complications (placenta location, fetus number and position, amniotic liquid) should be tested.