



# Maternal mortality surveillance: Getting it right is essential to drive preventive actions

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A country's maternal mortality ratio (MMR) is widely considered to be a barometer for the performance of its healthcare system. Nevertheless, few countries have routine data systems that are sufficiently robust to generate accurate MMR data, and many global estimates are developed based on algorithms incorporating adjustment of rates calculated from vital registration data based on predictor variables such as the country's gross domestic product per capita, the general fertility rate and the proportion of births attended by skilled health personnel.<sup>1</sup> Established methods to generate global estimates recognise the role of specialised studies on maternal mortality that 'triangulate information from multiple sources...to estimate the true number of maternal deaths in a specific geographic area'.<sup>1</sup>

These methods are all designed to enhance ascertainment of maternal deaths and compensate for underestimation, but a recent US analysis has suggested some approaches may lead to over-estimation of maternal mortality.<sup>2</sup> Joseph et al. propose revised criteria to generate more accurate maternal mortality estimates based on data from national vital registration systems (NVSS). While the current NVSS approach identifies as maternal deaths women aged 17–44 with a positive 'pregnancy check box' on death registration certificates to indicate recent pregnancy status<sup>2</sup>, Joseph et al. propose to identify maternal deaths only as those with at least one cause of death on the death certificate mentioning pregnancy, regardless of the checkbox.

We argue that neither of these approaches is appropriate, as both rely exclusively on the content of the death certificate to identify maternal deaths. While the first approach probably over-estimates maternal mortality as supported by Joseph et al.'s analysis, experience from established enhanced surveillance systems

in Europe and individual US states would nevertheless argue that the approach proposed by Joseph et al. is unduly restrictive, substantially underestimates deaths, notably those from medical or mental health conditions made worse by pregnancy or the care received during pregnancy, and has the potential to derail efforts to tackle a rising and increasingly inequitable maternal mortality rate.<sup>3</sup> In addition, beyond simply counting maternal deaths, the causes of these deaths need to be accurately characterised in order to identify where to target actions. Excluding deaths inappropriately could, therefore, potentially lead to the wrong prioritisation of efforts to prevent women from dying in the future. Previous studies have shown that relying only on death certificate content to determine the profile of causes of maternal deaths led to inaccurate conclusions, as compared to an enhanced surveillance system.<sup>4</sup>

## 1 | WHAT IS AN ENHANCED SURVEILLANCE SYSTEM?

An enhanced ascertainment maternal death surveillance and response system (eMDSR) can be described in several successive stages, all of which are necessary and complementary.

The first stage is the multisource identification of *pregnancy-associated deaths*, that is having a temporal link with pregnancy because they occurred during pregnancy or in the 42 days (or 1 year) following its end, whatever the cause, and therefore without prejudging at this stage the causal involvement of the pregnancy in the death. This stage must include several sources to be as inclusive as possible (e.g. death certificate content and direct notification), and

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an essential element is the linkage between the death and birth registers, which makes it possible to identify all deaths occurring with or after a birth, the absence of which is associated with significant under-identification.<sup>4,5</sup> Within these pregnancy-associated deaths (those with a temporal link with pregnancy), the sub-group of those in which pregnancy or delivery or the care they received played a causal role, that is *maternal deaths*, is identified on the basis of subsequent steps. Enhanced systems use these additional steps specifically to secondarily identify maternal deaths (which have both a temporal and causal link with pregnancy) within the broad group of pregnancy-associated deaths. One difficulty in reading the literature is that the term 'pregnancy-related' deaths is used in the United States by the CDC to designate deaths causally related to pregnancy up to 1 year after pregnancy end, that is deaths defined as maternal deaths (including late maternal deaths) by WHO and the ICD-MM. In contrast, the term 'pregnancy-related' as defined by the WHO refers to deaths temporarily associated with pregnancy, whatever the cause (See Table 1).

The *second stage* of enhanced surveillance involves documenting each pregnancy-associated death. The aim is to collect the information needed to reliably characterise any causal link with pregnancy and the cause of death. This step requires going beyond the content of the death certificate and including data from the birth certificate, birth register, medical records, hospital discharge database, or at best, a confidential inquiry. The content of the death certificate alone is often insufficient to make this assessment, particularly for diseases exacerbated by the pregnancy or for which pregnancy was an obstacle to optimal management.<sup>4</sup>

Finally, in the *third stage*, confidential case review is carried out by a committee that audits each death to fully identify maternal deaths, and classify the cause according to ICD-MM,<sup>6</sup> the classification system intended to ensure harmony and international comparability. This is also the most crucial stage for identifying opportunities to improve the healthcare system, as evidenced by the case histories of the women who died.

In the United States, national surveillance of maternal mortality, whether by the National Vital Statistics System (NVSS) or the CDC's Pregnancy-related mortality surveillance system (PMSS), does not

fully meet these enhanced system criteria. NVSS does not include Stages 2 and 3, and Stage 1 is incomplete since it does not include linkage and relies only on the death certificate content, whether following the current procedure based on the checkbox or the alternative one proposed by Joseph et al. based on the wording of the causes of death. PMSS includes Stages 1 (with linkage) and 2 but not for the whole country and does not include Stage 3. At the state level, Maternal Mortality Review Committees (MMRCs) provide regional maternal mortality statistics, some relying on enhanced systems.

## 2 | ROBUST SURVEILLANCE IN THE CONTEXT OF THE PREGNANCY CHECKBOX

The pregnancy checkbox in the death certificate is a possible tool at Stage 1, which aims to achieve broad identification of pregnancy-associated deaths, provided that any false positives can be rectified at subsequent stages, which is not the case in the current US NVSS.

Scotland, as one of the four UK nations covered by the MBRRACE-UK Confidential Enquiry into Maternal Deaths, recently introduced a pregnancy checkbox in its death registration certificates. This change resulted in a small increase in the number of deaths notified to MBRRACE-UK from the National Records of Scotland, which was managed through usual case-checking procedures (Stage 2 described above). Deaths identified from all routine data sources are further investigated to determine whether women were pregnant at the time of death or in the year preceding their death. Some deaths are evidently false positives, based on the assessment of the woman's age at death, coupled with causes of death indicating conditions typical of older age, such as dementia. These deaths are excluded without further investigation. Medical records of other women not already notified to MBRRACE-UK are examined by primary care staff or staff at the maternity units closest to their residence at the time of death to confirm evidence of recent pregnancy.<sup>7</sup>

Relying solely on a checkbox to identify pregnancy-associated deaths is also notoriously unreliable, as false negatives are also frequent. A study conducted in France showed that more than half of

Definition	WHO	USA
Deaths of any cause during pregnancy and up to 42 days or 1 year after pregnancy	Pregnancy-related mortality	Pregnancy-associated mortality
Deaths for which the cause of death is causally related to pregnancy		
Up to 42 days after pregnancy	Maternal mortality	Maternal Mortality (NVSS and NCHS)
Up to 42 days after pregnancy	Maternal mortality (including late maternal mortality)	Pregnancy-related mortality (PMSS)

TABLE 1 Maternal mortality definitions and denominations.

Abbreviations: NCHS, National Center for Health Statistics; NVSS, National Vital Statistics System; PMSS, Pregnancy-Related Mortality Surveillance System.



pregnancy-associated deaths and about one-quarter of maternal deaths did not have the pregnancy check box ticked.<sup>4</sup>

### 3 | CAUSES OF MATERNAL DEATH IN HIGH-INCOME SETTINGS AS IDENTIFIED BY ENHANCED SURVEILLANCE SYSTEMS

Joseph et al. propose excluding from NVSS maternal mortality estimates all deaths of women who do not have a mention of pregnancy amongst any of the multiple causes of death on the death certificate.<sup>2</sup> Decades of data from the UK Confidential Enquiry have shown the substantial underestimation of deaths that result from such exclusions. In 2018–20, only 129 of the confirmed 229 maternal deaths in the UK had a pregnancy or a pregnancy-related diagnosis listed on the death certificate.<sup>7</sup> Thus, more than 40% of maternal deaths would have been under-counted using the approach proposed by Joseph et al., and the maternal mortality ratio substantially underestimated as 6.04 per 100,000 live births compared with the true rate of 10.72 per 100,000 live births. Figures for France for 2016–18 show that this process would exclude a similar 39% proportion of maternal deaths.<sup>8</sup>

The deaths underestimated by such exclusions are those due to medical and mental health conditions, which have been made worse by pregnancy, or by the altered care received because women were pregnant or recently pregnant. In high resource settings with eMDSR, figures show that deaths from medical and mental health conditions outweigh those due to obstetric causes.<sup>3</sup> Approaches that do not use enhanced ascertainment or which exclude any deaths without a pregnancy-specific diagnosis on the death certificate substantially underestimate these deaths and hence would miss key learning points for future care, as illustrated in [Box 1](#). Such underestimation is evident in the alternative NVSS data analysis proposed by Joseph et al., in which most maternal deaths are due to obstetric conditions and contrasts with the findings of US state-based enhanced surveillance, which identified cardiovascular disease as the leading cause of pregnancy-associated death (34% of pregnancy-related deaths in California for 2017–2018<sup>9</sup> versus 16% in the alternative national NVSS data analysis). These state-level enhanced data could be used to externally validate the national data.

### 4 | CAN WE LEARN FROM 'COINCIDENTAL' DEATHS?

Deaths due to malignancy in pregnant or recently pregnant women are typically excluded from investigations of pregnancy-associated deaths. The UK Confidential Enquiry and the French ENCM have nevertheless identified many areas where women received a lower quality of cancer care simply because they were pregnant. The most frequent theme identified concerned making a diagnosis; in particular, recognising worrying symptoms and avoiding normalisation bias.<sup>10,11</sup> Follow-up, notably postnatally, to ascertain whether symptoms resolve, was noted to be an important safety net and could

#### BOX 1 Example lessons for improving care identified from a maternal death by suicide identified through enhanced surveillance

A woman died by violent suicide a few weeks after a termination of pregnancy. She had a history of self-harm, though this was not identified at her first prenatal visit. Within 2 weeks of the termination, she presented to her primary care physician with low mood and suicidal thoughts. Over the following weeks, beginning with thoughts of not wanting to be alive, she moved on to specific ideas of suicide, followed by actual self-injury, attempted drowning, overdose and attempted hanging. On the last three occasions that she was seen by different healthcare providers, she described recent significant self-harm and, on two occasions, the inability to keep herself safe. None of these encounters resulted in any plan for her immediate safety. In her last presentation, she described the recent onset of psychotic symptoms and thoughts of violent suicide. She said that she could not keep herself safe. Despite this being documented by the assessor, the assessment describes her as having no 'actual plans or intent' and that there was no evidence of a mental health crisis warranting hospital admission. She was discharged from the Emergency Department and died the following day.

This woman would not have been identified as a maternal death from her death certificate alone, yet her care illustrates several areas for improving services and preventing future maternal deaths by suicide. Her prior history had not been identified during antenatal care, hence her risk was not identified and risk management was not considered. Despite her acute presentation and documented risks, there was no active planning to ensure her immediate safety. Her symptoms were downplayed. She was seen by multiple health professionals and no one recognised the overall pattern of her deterioration. The recommendation from the 2021 UK Confidential Enquiry emphasised a need to consider previous history, pattern of symptom development and ongoing stressors when assessing immediate risk and management of women with mental health symptoms and highlighted that plans should address immediate, short-term and long-term risk.<sup>10</sup>

help ensure earlier diagnosis and treatment. For women known to have cancer, the strongest theme was a need for early planning—ensuring appropriate contraceptive advice prior to treatment, and enabling a consultant obstetric or obstetric medicine appointment in early pregnancy to plan management. Involvement of the wider multidisciplinary maternal medical team, including in early pregnancy, was recommended to help ensure that women with cancer get the investigation and treatment they need.

## 5 | CONCLUSION

Accurate and comprehensive surveillance and review of all deaths of pregnant and recently pregnant women is essential to produce the underpinning information to drive appropriate improvements to healthcare services and wider actions to prevent future deaths. Sole use of routinely collected data cannot achieve this purpose and enhanced systems of maternal death surveillance and review are essential. As has long been recognised, we need to think 'Beyond the numbers'.<sup>12</sup>

### AUTHOR CONTRIBUTIONS

Marian Knight and Catherine Deneux-Tharoux conceived the content, drafted and revised the manuscript. They approved the final manuscript and agree to be accountable for its content.

### ACKNOWLEDGEMENTS

None.

### CONFLICT OF INTEREST STATEMENT

MK and CDT lead national maternal mortality surveillance and confidential enquiry programmes in the UK and France, respectively.

### DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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**How to cite this article:** Knight M, Deneux-Tharoux C. Maternal mortality surveillance: Getting it right is essential to drive preventive actions. *Paediatr Perinat Epidemiol*. 2024;00:1-4. doi:[10.1111/ppe.13140](https://doi.org/10.1111/ppe.13140)