NICE National Institute for Health and Care Excellence

2024 exceptional surveillance of antenatal care (NICE guideline NG201)

Surveillance report

Published: 27 December 2024

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Surveillance proposal

Topic area: end of life care

We propose to update section 1.2 on routine antenatal clinical care in the NICE guideline on antenatal care to include a reference to end of life care, directing practitioners to the NICE guideline on end of life care for adults: service delivery (NG142).

Background

End of life care for pregnant women is complex, requiring sensitive management of care. While NICE provides guidance on end of life care through the NICE guidelines on end of life care for adults (NG142) and care of dying adults in the last days of life (NG31), NICE maternity guidelines do not address the specific requirements of terminally ill pregnant women. This oversight needs to be addressed to respect the mother's wishes while balancing the potential outcomes for the baby, ensuring compassionate support for both women and their families during this difficult time.

Triggers for the exceptional review

The current MBRRACE report, Saving Lives, Improving Mothers' Care (October 2024), suggests that NICE update its end of life care guidance to include recommendations for appropriate service delivery to pregnant or recently pregnant women. This should cover recognising deterioration, supporting time spent with their baby, and holding conversations around the provision of consent for advanced resuscitation.

The current MBRRACE report highlights a case involving a pregnant refugee with a delayed cancer diagnosis at 20 weeks. She chose to end the pregnancy to begin palliative care, receiving compassionate and well-coordinated support. However, the report also observed that, in similar cases, late recognition of disease progression and a focus on pregnancy sometimes delayed essential end of life planning, leading to unnecessary interventions and missed opportunities for meaningful time with loved ones.

Methods

The exceptional surveillance process consisted of:

- Considering the new evidence and intelligence that triggered the exceptional review.
- Examining related NICE guidance and quality standards.
- Examining the NICE event tracker for relevant ongoing and published events.

For further details about the process and the possible update decisions that are available, see the section on ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual.

Relevant NICE guidance

The NICE guideline on antenatal care (updated 2023) covers organising and delivering antenatal care, routine clinical care, and support for pregnant women and partners but does not include recommendations for end of life care.

NICE guideline NG142 provides general guidelines on end of life care. The guideline covers organising and delivering end of life care services, which provide care and support in the final weeks and months of life (or for some conditions, years), and the planning and preparation for this. It aims to ensure that people have access to the care that they want and need in all care settings. It also includes advice on services for carers. The guideline is intended to be used alongside the NICE guideline on care of dying adults in the last days of life, which covers clinical care for people who are considered to be in the last days of life.

Relevant guidance/guidelines produced by external organisations

The American College of Obstetricians and Gynaecologists (ACOG) guideline on End-of-Life Decision Making (updated 2018) addresses the ethical difficulties of providing end of life care to pregnant women. It highlights the importance of respecting patient autonomy and involving multidisciplinary teams in the decision making process. The guideline also

emphasises the need for advance care planning, clear communication, and adherence to both ethical and legal standards when making end of life decisions in pregnant women. Royal College of Obstetricians and Gynaecologists (RCOG) does not have a specific guideline on end of life care. However, RCOG published relevant guidance on Managing Events Surrounding a Maternal Death and Supporting the Family and Staff (February 2024), which offers guidance for healthcare professionals on supporting families and staff following a maternal death.

New published evidence considered in this exceptional surveillance review

Previous surveillance review

Non-applicable. This is a topic area that has not been prioritised in the guideline scope.

Ongoing studies

No ongoing studies were identified.

Budget impact/Economic considerations

End of life care for pregnant women presents financial challenges due to the need for specialised maternal and fetal care, which can increase healthcare costs. This financial burden may affect the stability and quality of life for family members, underscoring the need for targeted healthcare policies to better support these women and their families.

System impact

The system impact includes increased strain on hospital resources, the need for specialised care, and the necessity for highly trained healthcare professionals.

Population impact

In the UK, indirect maternal deaths, which are deaths from pre-existing medical conditions or conditions that develop during pregnancy but are not directly caused by it, account for a significant portion of maternal mortality. According to the latest MBRRACE-UK report, indirect deaths make up about 58% of all maternal deaths. This highlights the importance of comprehensive healthcare that addresses both pregnancy related and non-pregnancy related health issues.

Health inequalities

There is evidence from the MBRRACE report that women from marginalised groups (e.g., Black, Asian, those from deprived areas) face worse maternal health outcomes due to systemic barriers. These include delayed diagnoses, limited access to high quality care, and less timely treatment. For terminally ill women, especially those pregnant, these factors likely exacerbate the challenges, leading to delayed recognition of their condition and more complications with end of life care planning.

Impact of new evidence and intelligence

The current NICE guideline on antenatal care (NG201) does not specifically address the needs of terminally ill pregnant women, despite increasing recognition of the challenges they face. The latest MBRRACE report highlights instances where delayed recognition of deterioration and a focus on pregnancy have hindered timely end of life care, particularly for women from marginalised groups. This highlights the need for a statement that addresses the complexities of end of life care, recognising the importance of identifying deterioration, providing compassionate care, and ensuring equitable access to services for all women, regardless of their background. These topics are covered in the NICE guideline on end of life care for adults (NG142), which aims to ensure high quality end of life care, focusing on holistic care and the needs of individuals and their families.

Overall proposal

We propose to update section 1.2 on routine antenatal clinical care in the NICE guideline on antenatal care to add a reference to the NICE guideline on the end of life care for adults: service delivery (NG142).

ISBN: 978-1-4731-6739-1