

6 January 2026

Perinatal / Children's Palliative Care Pathways (2022-2025)

Under the Freedom of Information Act 2000, please provide:

- 1. Total # of children under 5 placed on perinatal/paediatric palliative care pathways (withdrawing/withholding life-sustaining treatment, e.g., nutrition/hydration) from Jan 2022–Oct 2025.**

Maternity / Neonatology Response:

Belfast Health and Social Care Trust had 110 deaths during this period in Neonatal Intensive Care. In almost all of these cases, the babies would be moved to comfort measures and withdrawal of treatment.

Paediatric Service Response:

The service do not have data for all 4 years. To provide this would require a manual trawl of individual clinical records for that period, which would take more than 18 hours to complete.

Belfast Trust considers that the cost of retrieving the information would be above the 'Appropriate Limit', as defined by the Freedom of Information Act under Section 12. Section 12 of the Freedom of Information Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit. The limit has been specified as £450 for public authorities such as Belfast Trust. This represents the cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.

Data has been collected from 2025 regarding those children receiving palliative care in Belfast Trust. There have been 12 deaths in children under 5 years known to the Palliative Care Team (note there may be some overlap with the neonatal figures).

- 2. % of those where parental consent was explicitly documented vs. implied/deemed.**

Maternity / Neonatology Response:

Parental consent would always be sought explicitly in terms of care provided or withdrawn.

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Paediatric Service Response:

Parental consent is always sought and is explicitly documented.

3. #/% where parents objected, and outcomes (e.g., court involvement).

Maternity / Neonatology Response:

No parents objected during this period.

Paediatric Service Response:

Ongoing dialogue is usually what happens if there are any initial parental objections, working with families in the best interests of the child.

The service is not aware of any court involvement for withdrawal of care in the specified period.

4. Anonymised summary of decision criteria used (per RCPCH/NICE guidelines).

Maternity / Neonatology Response:

Decision criteria does not exist. However, clinicians will consider the life limitations of the condition and ongoing support required when discussing options with parents.

Paediatric Service Response:

The Northern Ireland Perinatal Palliative Care Pathway is used for babies who are referred in the perinatal period. This is regional guidance based around benchmarking elsewhere and from NICE Guidance / Together for Short Lives (TFSL) / Association of Paediatric Palliative Medicine (APPM) guidance.

No specific criteria used for those not referred under perinatal pathway: Association of Paediatric Palliative Medicine (APPM) criteria for defining life limiting illness and decisions embedded in principles and guidance from APPM / Royal College of Paediatrics and Child Health (RCPCH) / Together for Short Lives (TFSL).

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5. Any internal audits/reviews on consent processes since 2022.

Maternity / Neonatology Response:

Since September 2022, Belfast Health and Social Care Trust review any deaths in maternity using the Perinatal Mortality Review Tool (PMRT).

This is a systematic, multi-disciplinary, high quality review of the circumstances and care leading up to and surrounding each stillbirth and neonatal death, and the deaths of babies who die in the post-neonatal period having received neonatal care.

Importantly, parents are consented to their care being reviewed in this way and their perspectives are sought to contribute to the review.

Prior to September 2022, all deaths were reviewed via the Morbidity and Mortality Review process.

Paediatric Service Response:

There have been no specific audits undertaken in relation to palliative care. The service have since begun data collection on palliative care deaths and for 2025 - 2026 period can confirm that consent is explicitly sought from families as a standard of care.