

Reference:	FOI.18872.25
Subject:	Children's palliative care pathways
Date of Request:	18 November 2025

Requested:

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.
2. % of those where parental consent was explicitly documented vs. implied/deemed.
3. #/% where parents objected, and outcomes (e.g., court involvement).
4. Anonymised summary of decision criteria used (per RCPCH/NICE guidelines).
5. Any internal audits/reviews on consent processes since 2022.

Response:

1. Hywel Dda University Health Board (UHB) confirms there were a total of eight (8) patients under the age of 5 placed on perinatal/paediatric palliative care pathways, during the timeframe requested.
2. & 3. Due to the nature of the subject matter, the information in question could cause significant harm to the parents of those patients detailed within question 1 if they were to be identified. Therefore, the UHB is withholding the information requested, as it relates to personal information of third parties. This decision has been made as it is not within the reasonable expectations of these individuals, that their personal data would be put into the public domain by the UHB. This information is classed as personal data of a third party. Therefore, it is being withheld in accordance with the exemption set out in section 40(2) of the Freedom of Information Act 2000 (FoIA), by virtue of section 40(3)(a) of the FoIA, which permits a public authority to withhold personal data other than the requestor's where the disclosure would breach Data Protection principles.

This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations, as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

The responsibility for assessing and evaluating benefits and harm is shared between all those involved in caring for the child. Additionally, a child's parents are not expected to give or refuse consent to withholding or withdrawing a medical intervention. This is because children lack capacity and decisions regarding whether or not to introduce or continue a medical intervention, must be made on the basis of whether or not the intervention is, on balance, in the child's best interests.

In Wales, there is a formalised process for recording discussions with parents about their preferences around end of life care. Details of this formalised process can be found within the link below:

[All-Wales-PAC-Plan.pdf](#)

4. The UHB is a member of the All Wales Paediatric Palliative Care Network, which operates in accordance with the Royal College of Paediatrics and Child Health (RCPCH) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice'. All decisions are made on an individual clinical needs basis, jointly between Senior Clinicians and the parents, in line with RCPCH, British Association of Perinatal Medicine (BAPM) and National Institute for Health and Care Excellence (NICE) guidance. Additional support is provided by the UHB's Paediatric Palliative Care team where required.
5. The UHB confirms zero (0) internal audits/reviews on consent processes have taken place since 2022. However, the UHB utilises the All Wales Paediatric Advance Care Plan (PAC-Plan) and results are disseminated amongst the various agencies that need to know that such discussions have taken place.