



Report on the Development of the NACEL Patient and Carer Public Facing Tool

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1. Introduction

The National Audit of Care at the End of Life (NACEL) developed the Patient and Carer Tool (a public facing tool) to improve transparency and accessibility of care at the end of life data for patients, carers, and the general public. The tool enables users to understand how care providers perform, highlights areas of good practice, and identifies opportunities for quality improvement.

The initiative was led by the team from NACEL, NHS Benchmarking Network (NHSBN), in collaboration with NHS England, Wales and Jersey. They were tasked with creating an interactive platform that allows open access to NACEL data without requiring user authentication. The overarching aim is to support informed public engagement and drive improvements in patient outcomes.

2. Objectives of the Tool

The primary objectives of the NACEL Patient and Carer Tool are:



- To present care at the end of life data in an accessible and user-friendly format
- To inform patients, carers, and the public about the quality of care provided at a hospital level
- To support quality improvement initiatives within healthcare services
- To incorporate Patient and Public Involvement (PPI) in the development and refinement of the tool
- To enable transparency while ensuring appropriate safeguards around sensitive data

3. Data Sources

The tool draws upon three of the core components of NACEL data collection:

- Patient-level data from clinical records
- Bereavement survey responses
- Organisational-level data from hospitals and care providers

Participation in NACEL is high, with approximately 99% of eligible hospitals contributing data, ensuring robust and representative findings.

4. Phase 1 Development (Published August 2025)

4.1 Initial Design and Consultation

Phase 1 of the tool was launched in August 2025 following consultation with 10 people with lived experience of bereavement. Early engagement ensured that the tool reflected the needs and sensitivities of its primary audience.

4.2 Key Design Decisions

The first phase focused on simplicity and accessibility. Key decisions included:

- Displaying five core metrics:
 - Availability of specialist palliative care (7 days a week)
 - Adequacy of pain relief for the dying person
 - Overall rating of hospital care and support
 - Evidence of personalised care discussions
 - Assessment of spiritual, religious, or cultural needs



- Limiting data granularity to regional and national levels (rather than hospital-level data)
- Including explanatory text and expandable guidance to aid interpretation
- Providing comparison options by country and region

4.3 User Interface Design

The interface was designed with:

- A clear presentation of key metrics
- Simple navigation and dropdown filtering
- Collapsible explanatory sections for additional detail
- Introductory guidance to support user understanding
- Feedback mechanism
- Accessibility tool to support those with additional needs

5. Phase 2 Scoping and Development (Planned Publication August 2026)

5.1 Stakeholder Engagement

A structured scoping process was undertaken to inform Phase 2 development:

- 35 professionals were nominated by NHS England, NHS Wales, and Jersey
- 22 participants were selected to join Task and Finish (T&F) groups. These professionals represented differing roles, system levels and geographies.
- T&F groups met in November and December 2025

5.2 Task and Finish Group Outputs

Key outputs from the T&F groups included:

- Identification of main risks (see below, section 6)
- Identification of mitigation strategies (see below, section 6)
- Development of a comprehensive communications plan (see below, section 7)
- Stakeholder mapping across national, regional, system, and local levels
- Recommendation to establish a co-production group including professionals and people with lived experience of bereavement from Phase 1 scoping.



5.3 Co-Production Approach

A co-production group met in February 2026, bringing together:

- Participants (people with lived experience of bereavement) from Phase 1
- Professionals from the T&F groups

This group:

- Reviewed and refined the tool's design and content (including metrics)
- Scenario tested public response to hospital/level data
- Discussed feedback mechanisms
- Assessed embedded resources and support materials
- Produced recommendations for the Phase 2 redesign

6. Risk Assessment and Mitigation

6.1 Identified Risks

The development process highlighted several potential risks:

- Misinterpretation of data by the public
- Emotional distress for those dying, families/ carers and bereaved people
- Reputational damage and loss of public trust
- Negative impact on staff morale and wellbeing

6.2 Mitigation Strategies

To address these risks, the following measures were proposed:

- Clear guidance and explanatory materials
- Engagement with hospitals and communications teams
- Signposting to bereavement and emotional support services
- Transparency regarding quality improvement actions

7. Communications Strategy

A four-stage communications plan was developed:

Step 1: Approval (February 2026)



- Submission of proposal to the NACEL Steering Group, approved February 2026.

Step 2: Advance Notice (February–March 2026)

- Distribution of briefing packs
- Early notification was sent to healthcare providers including:
 - Participating organisations in England, Wales and Jersey – CEOs, Medical Director, Nursing Director, NACEL Project Lead. Dissemination was recommended to Communications, Chief nurse/ Clinical Director Nursing, Palliative Care and End of Life Care Clinical Leads, Medical Examiners, Quality and Governance Leads, Patient Experience/ PALS. Welsh translation was provided for Welsh organisations.
 - System stakeholders including: in England – NHS England Regional Leads, Regional Clinical Networks, ICB Leads, and in Wales - Health Boards and Trusts. Dissemination was recommended to Palliative Care and End of Life Care Clinical Leads, Palliative Care and End of Life Programme Lead, Communications Lead, Patient & Carer Experience Leads, (ICB) Chief Nurse, Medical Director, Senior Responsible Officer. Welsh translation was provided for Welsh organisations.
 - National Stakeholders including: National leaders in England, Wales and Jersey, National Communications Team, HQIP, NACEL steering group Palliative Care and End of Life Ambitions Partners.
- Guidance on reviewing and preparing data

Step 3: Preparation Support (May–July 2026)

- Communication toolkits and templates and FAQs sent to same list of healthcare providers listed in Step 2 above.
- Drop-in sessions for stakeholder queries
- Webinar titled “Improving Patient and Carer Experience”
- Preview access to data presentation
- Final readiness checklist

Step 4: Post-Launch Evaluation (Post August 2026)

- Feedback surveys at 6 months and annually thereafter

8. Phase 2 Design Enhancements



Phase 2 builds upon Phase 1 with several enhancements:

- Inclusion of hospital/site-level data
- Inclusion of 2025 data,
- Inclusion of year-on-year comparisons
- Inclusion of quintiles to better illustrate variation
- Dynamic text to support data interpretation
- Retention of the five core metrics (reordered for clarity)
- Improved accessibility and navigation
- Expanded guidance and contextual information
- Enhanced feedback mechanisms
- Enhanced support resources, including:
 - Bereavement support
 - Information on the dying process
 - Links to national support organisations

Data Characteristics

- Granularity: National, regional, and hospital-level
- Coverage: England, Wales, and Jersey
- Update frequency: Annual
- Data suppression applied for small sample sizes

9. Stakeholder Engagement

Engagement was undertaken across multiple levels:

- **National:** NHS leadership, regulators, and partner organisations
- **Regional/System:** Clinical networks, integrated care boards, and programme leads
- **Local:** Hospital leadership, clinical teams, and patient experience groups

This ensured alignment, preparedness, and effective dissemination.



10. Implementation Timeline

The development followed a structured timeline:

- Phase 1 development and launch: February–August 2025
- Phase 2 scoping and consultation: November 2025 – February 2026
- Phase 2 build, testing, and communications: February -July 2026
- Planned publication of Phase 2 tool: August 2026

11. Conclusion

The NACEL Patient and Carer Tool represents a significant step towards transparency in care at the end of life. Its development has been underpinned by extensive stakeholder engagement, patient and public involvement, and a structured quality improvement approach.

Phase 1 established a foundation of accessible, high-level data, while Phase 2 introduces greater detail and functionality. The iterative, co-produced design ensures that the tool remains sensitive, informative, and aligned with user needs.

Ongoing evaluation and feedback will be critical to ensuring the tool continues to support meaningful improvements in care quality and patient outcomes.

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