

Co-designing Compassion: Inclusive Feedback that Drives Change

Support for Caregivers, Friends, and Family

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Barts Health NHS Trust

- One of the **largest NHS trusts in England**, serving a population of **>2.5 million people** in East London
- **Five hospitals** seeing an average of 7,250 patients per day
- 22,000+ staff
- Over **60% of residents** from a non-White British background
- Significant deprivation
- **3,500+ adult deaths annually**



Why the survey matters

Formal feedback tools bring both data and humanity into care improvement



Grief has real and measurable health impacts

Bereaved individuals experience significant reductions in health-related quality of life¹



Gathering family feedback enhances care quality and compassion

Survey formally captures crucial aspects of care experience seemingly informally



Human connection in bereavement outreach makes a difference

Evidence that direct contact after death positively impacts grieving. Personalised approach important²



Personalised, appreciative learning transforms care culture

Narrative of positive practice and areas for improvements prompting reflection

1. Stroebe, M., Stroebe, W., & Schut, H. (2007). *Health outcomes of bereavement*. *The Lancet*, 370(9603), 1960–1973.

2. Morris, S. E., Littlefield, M., & Mendu, M. L. (2023). *Survey Study of a Hospital-Based Bereavement Program During COVID-19: Insights to Improve Support of the Bereaved*. *Journal of Palliative Medicine*, 26(11), 1542–1546

Evolution of the survey

A journey of refinement to co-design, resulting in a survey that listens with empathy

2011

A simple survey
launched to
understand EOL
Experience

Refined and
developed based
on feedback and
developing
needs, integrating
more voices into
the process

2023

Fully co-designed with
families and staff.
Focused on compassion,
inclusivity, and increasing
accessibility.
Reviewed timeline,
process and contents.



The 2025 Bereavement Survey 1/2

Built together with families and staff to create inclusive feedback that drives change



Dear relative or friend,

Please accept our condolences at this difficult time.

We understand this is a sensitive time for you, but we would be most grateful if you could take part in this survey. Understanding your experience will help us improve the care we provide.

The feedback that we receive from this survey is invaluable and has directly changed the way that we look after and return patient's belongings, have conversations about end of life and support families when a loved one has died.

Completing the survey

On the following page, there are titles along with space to write about your thoughts and feeling. The thought bubble contains words which may help prompt your responses.

The survey is anonymous, however, should you wish to speak to someone or require a follow up call, please leave your contact details in the space provided on the back page.

Please return the survey at your convenience in the freepost envelope provided. Alternatively, you can scan the QR code below.

Thank you.

David Curran - Director of nursing
Andrew Wragg - Medical director



Online survey St Bartholomew's Hospital



Helping us to understand your experience

Using the titles below, please describe your experience and feelings in the spaces provided or on a separate sheet of paper. The thought bubble above can be used to prompt your thinking, if needed.

Care - please rate your overall experience of care:

☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very poor

Please comment...

Staff - please rate your overall experience of our staff:

☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very poor

Please comment...

Communication - please rate your overall experience of communication:

☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very poor

Please comment...

Respect - did people respect your beliefs, religion, culture, and spirituality? Please rate your overall experience:

☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very poor

Please comment...

Experience at the time of death - please rate your overall experience at the time of death:

☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very poor

Please comment...

Information - please rate your overall experience of receiving practical information from the ward staff after the death, (examples of this could be receiving the booklet What to do when someone close to you dies and the return of personal items):

☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very poor

Please comment...

Contact after death - please rate your overall experience of contact after death (examples of this could be contact with the Bereavement Office or Medical Examiners Service):

☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very poor

Please comment...

Overall experience - please rate your overall experience:

☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very poor

Is there anything else you would like to share with us?

Please comment...

Ward name

Date of death Age Gender

Thinking of your loved one and their circumstances, did they die in the right place?

Please comment...

What was the deceased's ethnic background?

☐ Asian or Asian British
☐ Bangladeshi ☐ Indian ☐ Pakistani
☐ Chinese ☐ Other Asian background
☐ Black or Black British
☐ African ☐ Caribbean ☐ Other Black background
☐ Mixed
☐ White/ Asian ☐ White/Black African ☐ White/ Black Caribbean
☐ Other mixed background
☐ White
☐ White British ☐ Irish ☐ Gypsy or Irish Traveller
☐ Other White background
☐ Other ethnic group
☐ Arab ☐ Any other ethnic group ☐ I would rather not answer

*If you have stated 'Any other ethnic group' please state:

What was the deceased's religion, if any?

☐ Buddhist ☐ Christian ☐ Hindu ☐ Muslim ☐ Jain ☐ Jewish ☐ Sikh
☐ None ☐ Other ☐ I would rather not answer

The 2025 Bereavement Survey 2/2

Personalised, compassionate outreach

If you would like to speak to someone about your experience. Please include your name and contact number, a member of the bereavement team will call you.

Name (optional): _____

Relationship to deceased: _____

Contact number: _____

Where to find support

Bereavement Lead Nurse
Offering support, information and guidance for bereaved relatives or carers. If you have questions about the survey, the care your loved one received or require sign posting to support. Please call the number below for help and advice.
Call us on 020 3594 6532

Multi-faith Chaplaincy Team
Spiritual, pastoral or religious care: the Trust has a Multi-faith team of chaplains to support you whatever your faith or beliefs.
Tel: 020 3465 7220

Patient Advice and Liaison Service (PALS)
Please contact us if you need general information or advice about Trust services, visit: www.bartshealth.nhs.uk/pals
St Bartholomew's Hospital:
Call us on 020 3465 5919
Email us: SBHpals.bartshealth@nhs.net

Child Bereavement UK Stratford
Help children and young people (up to age 25), parents and families, to rebuild their lives when a child grieves or when a child dies.
Call us on 020 8519 7025

City and East London Bereavement Service
Offer free bereavement counselling to family and friends whose loved one died at Barts Health after the death of a child of any age and from any cause.
Call us on 020 3022 5177

The Good Grief Trust
Bring all bereavement services from around the country together in one place, to ensure that everyone receives the support they need.
Visit: www.thegoodgrieftrust.org



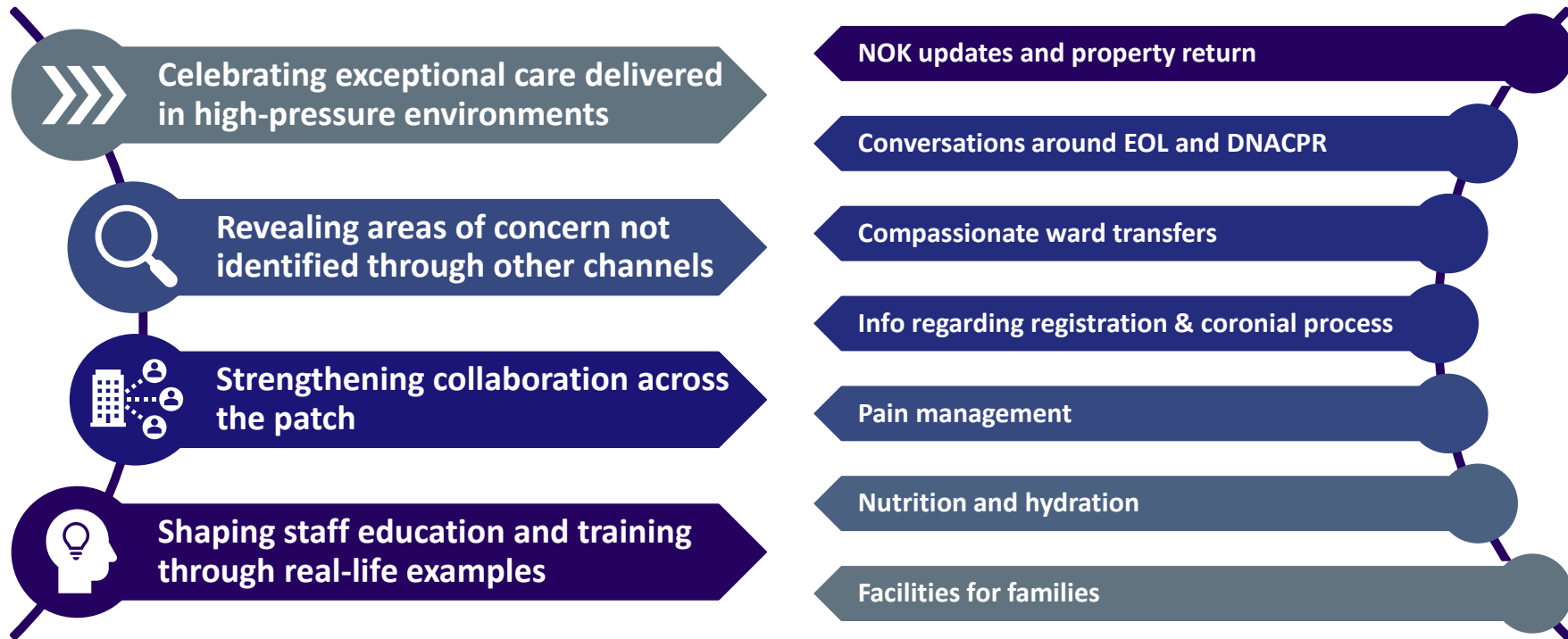
- Explanation about how the feedback has been used
- Opportunity to explain reasoning without pressure
- Option to leave details for follow-up
- Signposting to bereavement support
- Personal notes included in bereavement card

Outcomes

- ↑ response rate: 4% in 2022 to 10% in 2024
- Acceptable to include all deaths

Impact and results

Turning bereaved families' voices into meaningful change



Voices and learning

Normalising honest, compassionate feedback, ensuring that lessons are learnt

"Thank you for sending this form. I can now lay to bed my experience."

Bereaved family respondent



"The annual bereavement survey gives us current information about the care and experience relatives receive in the Trust and forms a key part of our assurance about our services."

Macmillan Director of Nursing for Cancer & Palliative Care

"The feedback is incredibly powerful. These are the real voices of people who have recently experienced our care, offering honest, constructive reflections on what went well and what could be improved. We've seen students really engage with the narratives, showing empathy and a genuine willingness to learn from the feedback."

Education lead

Key takeaways:

Overcoming fears & family response:

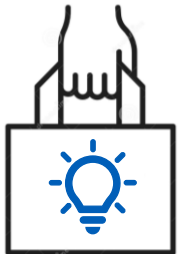
- Initial fears of being intrusive overcome through compassionate, anonymous approach
- Families found it “healing” and “cathartic”
- Valued chance to reflect and influence care

Insights driving change

- Highlighted poor care where high standards were assumed
- Surfaced unexpected praise
- Shown to be a powerful tool for cultural and service change
- The tool is adaptable, paediatric and maternity services adopting the model

Ensuring inclusivity & honest feedback

- All bereaved families offered the opportunity, not just a select few
- Consistent contact fosters equality and openness
- Anonymity encouraged candid, meaningful responses
- Allows the bereaved to choose how they reply
- Straightforward and easy to complete



This is not only a technical tool, but a cultural one.

It normalises honest, compassionate feedback and helps ensure that lessons are learned from every patient, even after death.

Thank you for listening

For more information:

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