

# National Audit of Care at the End of Life – family/carer perspective

SDM

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Head of involvement



# Background and context

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- **Contacts**
  - The Patients Association
  - Compassion in Dying
  - HQIP Service User Network
- **Questionnaire**
  - Individuals and organisational responses
- **Focus Group**
  - SUN members



# What we asked about

- The Quality Survey
- Main concerns
- Greatest benefits
- Areas for improvement
- Resources

**IMPORTANT: This document is a template only. The Quality Survey is an online survey. Not a paper survey.**

National Audit of  
Care at the End of Life

Don't know

**8. Did staff at the hospital involve the person in decisions about care and treatment as much as he/she would have wanted in the last two to three days of life?**

He/she was involved as much as he/she wanted to be

He/she would have liked to be more involved

He/she would have liked to be less involved

He/she was not able to be involved

Not sure

**9. Did the person have an advance care plan in place prior to their last admission?**  
An advance care plan might describe future treatment plans, the place they would prefer to be cared in, the use of life saving treatments, their values and beliefs and end of life care wishes and goals

Yes

No

Don't know

How much do you agree or disagree with the following statements about the care received by the person who died during their final admission in hospital? Please indicate using the answers below.

Strongly disagree      122%      Strongly agree

nor disagree

# The Quality Survey

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- Not received it
- Free text options from earlier on
- Too many questions
- Repetitive
- Too general

## **More questions about**

- Power of attorney
- Where person wanted to die

## **Improvement**

- Co-pro with carers and staff

# Main areas of concern

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- Advance care plans followed
  - Advance decisions - DNACPR
  - ReSPECT - Lasting Power of Attorney
- Cross checking with families
- Their pain, confusion and fear
- Kept informed
- Key contact
- Access to palliative care team
- Bereavement care
- Care in the weekends
- Surrounding environment

# Greatest benefit

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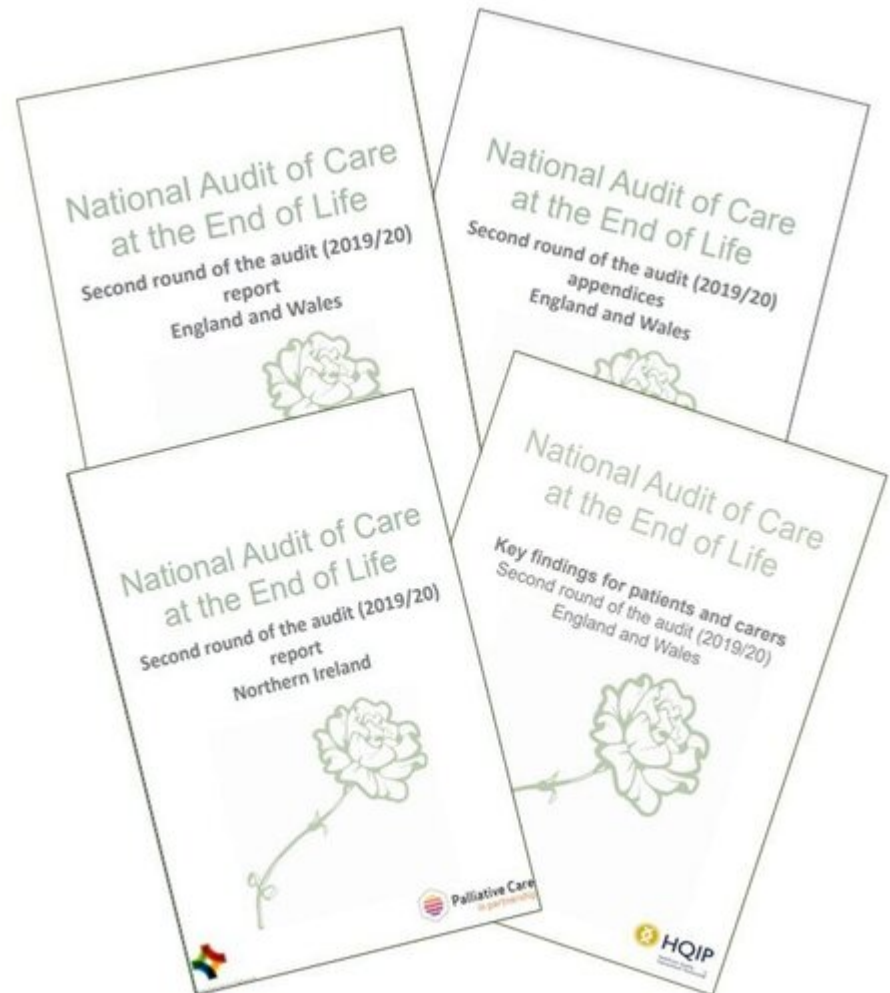
- Information sharing
- Documented decisions
- Rapid discharge for dying at home
- Pain relief
- Private room
- Specialist scans
- Family presence
- Supportive and compassionate staff
- Open and honest consultant

# Areas for improvement

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- Making decisions for the patient under the Mental Capacity Act 2005
- Understanding of Health and Welfare Attorneys rights
- Fast track forms and referrals recorded
- Staff training and communication
- Facilities for families
- Information on Delirium
- Dedicated key worker
- After death experience
- Ability to see loved one
- Access to consultant
- Ward movement
- Care in the community

- No awareness
- Good infographics
- Understandable
- Right questions
- Each section explained
- Would support them in their experience
- Help to influence services





# Improvements

**About NACEL**

The National Audit of Care at the End of Life (NACEL) is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute hospitals, community hospitals and mental health inpatient providers in England, Wales and Northern Ireland

NHS Benchmarking Network have been commissioned by HQIP to provide NACEL. Three cycles of the audit have been commissioned to be undertaken over three consecutive years. The aim of the audit is to improve the quality of care at the end of their life. NACEL covers NHS funded inpatient care provided to adults (18+).

NACEL is featured on NHS England's [Quality Accounts](#) list for 2021/22. For further information about the statutory function of this list please refer to HQIP's [Guidance on Quality Accounts](#).

**Audit Outputs**      **Audit Guidance**      **Steering Group**      **NACEL Mental Health**

- More accessible - easy read
- Recommendations too vague
- Local recommendations
- Hospice arrangements

- More information on
  - Care plans
  - Wills and power of attorney
  - Up to date signposting

- Individualised care plans
  - Existing forms
  - Pro-longing life vs quality of life
  - Who they want involved
- Improved and more available Quality Survey
- Dedicated team
- Shared decision making
- Improved dissemination of the resources