Palliative and End of Life Care

Health Needs Assessment Template

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Executive Summary

- Key findings
- Recommendations

Aim and scope of the HNA

- Describe the aim of the HNA
  - What is the purpose of doing the HNA? Is it just for increasing understanding of the issue, for identifying areas for action or informing commissioning?
  - Where will commissioning decisions be made? Region/ICS/Place level?
  - Are services delivered differently for different age groups (children, adults, older adults) and/or disease pathways?
  - Identify where responsibility for delivery of resultant actions sits
- Describe the type of HNA you are doing and why
  - Epidemiological. This approach considers the epidemiology of the condition, current service provision, and the effectiveness and cost-effectiveness of interventions and services.
  - Comparative. This approach compares service provision between different populations. Large variations in service use may be influenced by a number of factors, and not just differing needs.
  - Corporate. This approach is based on eliciting the views of stakeholders - which may include professionals, patients and service-users, the public and politicians - on what services are needed. Elements of the corporate approach (i.e. community engagement and user involvement) are important in informing local policy.
  - Will it be a participatory HNA, where the voice of residents/people with lived experience is incorporated?

Definitions - comprehensive

End of Life [1]

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

Advance Care Planning [2]

Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and healthcare providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they at some point be unable to make their own decisions.

Palliative Care [1]

The World Health Organisation has defined palliative care as follows: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

1. Leadership Alliance for the Care of Dying People. June 2014. One Chance to Get it Right
2. Rietjens J et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *The Lancet*.

Definitions - concise

- **Palliative Care** [1]

Active, holistic care of people with advanced progressive illness, involving management of pain and other symptoms and the provision of psychological, social and spiritual support. Palliative care aims at ensuring the best possible quality of life for individuals at end of life or with advanced illness and their families.

- **End of Life Care** [1]

Refers specifically to care provided in the last phase of life. This is often defined as approximately the last year, but end of life care can also sometimes be used to refer to the last weeks or even days of life and, for carers, can include care into bereavement.

- **Care of the dying patient** [1]

Generally refers to care in the last days or hours of life to ensure comfort and dignity.

- **Advance care planning** [2]

Enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate.

1. Dixon et al. 2015. Equity in the Provision of Palliative Care in the UK: Review of Evidence

2. Rietjens J et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *The Lancet*.

Palliative and End of Life Care: a timeline of key policy drivers

2008: First End of Life Care Strategy published and contained three key findings:

- People didn't die in their place of choice
- Need to prepare for larger numbers of dying people
- Not everybody received high quality care

2009: Dying Matters Coalition established

2015: Independent review of Choice in End of Life Care

2015: Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020

2016: Government response to independent review, making six commitments to end variation in end of life care by 2020

2019: NHS Long Term Plan

2021: Updated Ambitions for Palliative and End of Life Care

2022: NHS National Delivery plan for palliative and end of life care (for details contact england.palliativeandendoflife@nhs.net)

Ambitions for Palliative and End of Life Care

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and wellbeing
- Care is coordinated
- All staff are prepared to care
- Each community is prepared to help

The HNA findings are structured around these Ambitions.

Policy and guidance context

describe national and local policy influencing palliative and end of life care in your area

National policy and guidance

- Ambitions for Palliative and End of Life Care 2021-2026

- NHS Long Term Plan and delivery plan

- People at the Heart of Care: Adult Social Care Reform White Paper. 2021

- NICE Guidance/Quality Standards
  - NG31 Care of dying adults in the last days of life
  - NG61 End of life care for infants, children and young people
  - NG142 End of life care for adults
  - QS13 End of life care for adults
  - QS144 Care of dying adults in the last days of life
  - QS160 End of life care for infants, children and young people

  In addition, NICE Guidance relating to specific conditions/diseases consider end of life care

Local policy and strategy

- Add local policies/strategies that may be relevant – eg health and wellbeing strategy

Epidemiology 1

- Data on demographics in your area
  - Population size, M/F, age, ethnicity, religion (may influence end of life practices), language, unpaid care, lone person households, self-reported health status, LTCs/disabilities, deprivation. Data can also be found on POPPI (Projecting Older People Population Information System), PANSI (Projecting Adult Needs and Service Information) and on ONS

- Data on end of life
  - Palliative and End of Life Care Profiles (including resource directory of intelligence and guidance, place of death factsheets for CCGs and care home factsheets for upper tier local authorities) Dementia Profile, Productive Healthy Ageing Profile,
  - Comparative data can be found on the Atlas of Variation, PopNAT (Hospice UK's Population-based needs assessment tool) and on ONS
  - Crude and age standardised death rate, underlying causes of deaths in area, place of death (hospital, care home, home, other, hospice), percentage of deaths with 3 or more emergency admissions in the last 3 months of life

Epidemiology 2

- Comment on trends over time
- What does modelling suggest will change in the future
- Are there notable differences between your area and the national average, a comparator place and/or statistical neighbours?
- Consider and outline underlying reasons for any differences (are there issues with other service provision/delivery – eg screening – that may have resulted in somebody being on an end of life care pathway)

Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

Examine data and services to identify any inequalities. Consider:

- Proportion of those with a life limiting diagnosis with advance care planning in place
- The [Quality and Outcomes Framework](#) (QOF) may provide some useful data. Local systems can also be interrogated to identify performance information
- Extent of training in advance care planning and end of life conversations among non-specialist health and care teams. Is such training mandated and/or a requirement in commissioning processes?
- Provision of end of life care and bereavement information in a range of accessible formats and takes account of ethnicity, culture and faith

- Include feedback from service users and carers and case studies

Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

- Examine data and services to identify any inequalities. Consider:
  - [Protected characteristics](#)
  - [Deprivation](#)
  - Employment status
  - Housing status (eg people who are homeless)
  - Diagnosis/illness type
  - Co-existing conditions (eg sensory impairment, mental illness, learning disability, cognitive impairment, substance misuse)
  - Inclusion health groups (eg migrant communities, sex workers)
  - Geographical access to services – using [Shape](#) tool
  - Information from self-assessments and clinical audits already undertaken by palliative and end of life services and from bereaved relative and carer surveys may be useful, eg [Ambitions self-assessment](#) and the [National Audit of Care at the End of Life](#) (NACEL) results
- Include feedback from service users and carers and case studies

Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

Examine data and services to identify any inequalities. Consider:

- Proportion of those with life-limiting diagnosis offered and provided with specialist palliative care

- Provision of medication, equipment and care to maximise comfort in the place of their choosing. You may want to access self-assessments and clinical audits providers of palliative and end of life care have previously completed.

- The Quality and Outcomes Framework (QOF), patient reported outcome measures and patient centred outcome measures may provide some useful data. Local systems can also be interrogated to identify performance information.

- Include feedback from service users and carers and case studies, particularly around acceptability of currently offered interventions and services

Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

Examine data and services to identify any inequalities. Consider

- Is there access to specialist and/or generalised palliative and end of life care advice 24 hours a day, 7 days a week (NACEL includes information on specialist services)? Are these services provided remotely or face to face? Specialist palliative care services are described in the NHS England Service Specification.

- Are shared records routine for all patients (who have consented)?

- Are IT systems effective at enabling shared records?

- Are data sharing agreements in place with all organisations? Eg: Children's services, mental health services, learning disability services, social care, third sector provision

- Is care and support for family members offered? Which organisations? How is this organised?

- Are regular reports on palliative and end of life care provided to appropriate boards across the health and care system (eg Health and Wellbeing Board, Council's Health Scrutiny panel, trust boards)? NB palliative and end of life care is a responsibility for all providers, not just the acute trust.

- Include feedback from service users and carers and case studies

All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

Examine data and services to identify any inequalities. Consider

- Workforce training plans for end of life care across health and social care (including private and voluntary sector provision) – what training is recommended for which groups of staff?
  - Awareness training of local services to facilitate appropriate referral
  - Advance care planning and end of life conversations
  - Care of people who are nearing death
  - Legislative requirements at end of life (eg Children and Families Act, Mental Capacity Act, safeguarding of adults and children)
- Pastoral and peer support for staff working with those at end of life.
- What governance arrangements and executive accountability for end of life care are in place in all organisations in the local health and care system.
- Include feedback from service users and carers and case studies

Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Examine data and services to identify any inequalities. Consider

- Provision of community bereavement support (consider requirements for those from all ethnic groups, cultures and faiths) – emotional and practical support offers from NHS, social care, private and voluntary sector providers
- Findings from bereaved relatives and carer surveys
- Provision of death cafes
- Adoption of the Compassionate Cities Charter
- Promotion of Dying Matters resources and awareness week
- Include feedback from service users and carers and case studies

Conclusions

- Note key findings and observations

- Identify gaps and celebrate good practice

- Make appropriate comparisons:
  - Between place-based systems
  - Between place or system and statistical neighbours or region

Recommendations

Robust and appropriate recommendations and subsequent action planning will transform the HNA from an academic exercise into a quality improvement activity.

Make recommendations

- To improve inequalities
- To close gaps in service provision and access
- To make changes in resourcing
- To extend and share good practice
- To enhance data collection, analysis and monitoring to facilitate ongoing improvement in the local system

They should:

- Be clearly specified
- Be practical, realistic and acceptable
- Be capable of being monitored and evaluated
- Have an agreed timeline and identified resources to deliver improvements

Additional useful resources

On palliative and end of life care:

- [NHS End of Life Care](#) resources
- [RCN End of Life Care](#) resources
- [Homeless and inclusion health standards](#)
- [NICE impact](#). End of Life Care

On health needs assessment:

- Health Development Agency (2005) [Health Needs Assessment: a practical guide](#)
- Health Knowledge Public Health Textbook. [The uses of epidemiology and other methods in defining health service needs and in policy development](#)
- Public Health England (2021). [Population health needs assessment: a guide for 0-19 health visiting and school nursing services](#). (this has some useful general principles for health needs assessment, despite being written for a different service).
- Coursera. [What is health needs assessment?](#)