Palliative and end of life care health needs assessment: Guidance document

The NHS Long Term Plan commits to improving personalised palliative and end of life care for all and to address inequity. This will require action across health and care systems and key to driving these improvements is an understanding of local need, existing service provision and identifying any gaps in access or provision. **We recommend that undertaking a comprehensive health needs assessment for palliative and end of life care underpins this improvement activity.** The health needs assessment should consider palliative and end of life care and support provided by specialist NHS services, community and primary health care, social care services (including care homes) and the voluntary and community sector.

This guidance and accompanying template are provided to assist places and/or systems to carry this out.

What is a health needs assessment?

Health needs assessment is a systematic approach to understanding the needs of a population. It enables local health systems to assess whether the provision and use of health services are equitable. It is an essential tool to inform service planning including forecasting future service demand and should form part of the commissioning process. Crucially, the process of health needs assessment needs to include more than just the collection and analysis of the data; developing a robust action plan to address gaps and inequalities identified through the assessment is essential to ensure that it isn't simply an academic exercise.

Health needs assessment provides the opportunity for:

- Profiling the population's health status and describing patterns of disease
- Learning more about the needs and priorities of patients and the local population
- Highlighting unmet need and providing objectives to work towards meeting these needs
- Rational decision making on use of resources to improve the health of the local population in the most effective and efficient way
- Influencing policy, collaboration and research priorities [i]

There are three main types of health needs assessment:

- 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.

Higginson et al[ii] conducted a systematic appraisal of needs assessments for palliative and end of life care and concluded that the three main categories of needs assessment are all appropriate to be undertaken alone or in combination, depending on the aims of the work, and made a recommendation to use the NHS Executive definition of need: 'the ability to benefit from health care', where benefit includes both clinical benefit and reassurance, supportive care and relief of carers[iii]

What should we consider before undertaking a health needs assessment?

There are some key questions that will inform the most appropriate approach to take.

- What is the purpose of the health needs assessment? Is it to increase understanding of the issue, to identify areas for action or to inform commissioning?
- What age group are you considering and are services delivered differently for children, adults and older adults?
- Would considering the needs of people on different disease pathways be useful (eg is the cancer care end of life pathway different to that for people without cancer)?
- Where will commissioning decisions be made? Region/ICS/Place?

If you are intending to undertake engagement with patients, carers and families, seeking advice from your patient engagement team and local support organisations is recommended given the sensitive nature of the services and that carers and family members may be recently bereaved.

What resources are needed to undertake a health needs assessment?

Conducting a health needs assessment is only worthwhile if it leads to changes that benefit the population in need. It is therefore essential to have **commitment from local system leaders** to consider and act on the findings of the assessment. Agree at the outset the governance arrangements for implementing recommendations: which board will act as sponsor for this piece of work, receive the final report and have responsibility for oversight of the action plan. It is important to note that despite the identification of a sponsor board, *all organisations* in the health and care system need to engage with the process and are recommended to have identified senior leadership accountability for end of life care.

You will need to work with partners across the system involved in the commissioning and delivery of palliative and end of life care and organisations that represent patients and families. It is recommended that **commitment from all stakeholders** to supporting the process and implementing findings is sought prior to beginning the work. A suggested list of stakeholders to include in the work can be found at Appendix 1.

It is important to ensure there is sufficient **capacity to undertake the needs assessment**. In most cases one person will take overall responsibility for the needs assessment, either carrying out the data collection and analysis and writing the report themselves, or coordinating a team carrying out different aspects of the work; this is often a public health specialist within the local authority public health team or, more recently, in the Integrated Care System, but if they are not leading the work public health input remains essential to the health needs assessment. Sufficient data and intelligence capacity must be identified to enable meaningful analysis and interpretation of the local information.

If the needs assessment includes community engagement, you will need to secure **financial resources** to fund venues and out of pocket expenses for attendees.

What data sources might we need?

Much of the data used in a health needs assessment is already in the public domain from

- Palliative and End of Life Care Profiles
- Place of Death Factsheets
- Care Home Factsheets
- Dementia Profile
- Productive Healthy Ageing Profile
- Office for National Statistics
- NHS Digital

Some will be routinely available to public health and NHS intelligence teams in your area and for others you may want to run bespoke queries on clinical systems. **Data sharing agreements** may be required between participating organisations if you will be using data that is not in the public domain. A detailed list of sources of routine data can be found at Appendix 2.

Palliative and End of Life Care services may have previously undertaken self-assessments and/or clinical audits and these can provide useful additional data. It should be noted, however, that health needs assessment is not a process for benchmarking performance of local services, but an objective appraisal of unmet health and healthcare needs.

If you are consulting with patients, relatives and carers to provide qualitative data you will need to ensure appropriate consent forms are completed for participants outlining how their data will be used and securely stored.

After the health needs assessment has been written

The impact of a health needs assessment relies on the action taken on its recommendations. It is recommended that an implementation group be established to develop a comprehensive action plan with SMART objectives, actions with clear timescales for delivery and a responsible lead officer. The impact of change should be evaluated in terms of operational indicators and outcome indicators.

Group members should be working at a level where they can influence and effect change and should represent the range of stakeholders involved in the palliative and end of life care pathway.

The implementation group should report on progress on the action plan to its 'sponsor' board (eg Health and Wellbeing Board) and to the senior leaders accountable for end of life care.

Project review
In addition to implementing the changes recommended in the needs assessment, a reflective review of the needs assessment process is recommended to provide learning for future assessments.

Useful resources for 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?

Useful resources for 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

Appendix 1: Stakeholders to engage in the HNA
- Public health specialists (local authority and/or ICS)
- Public health intelligence/health intelligence
- Accountable leaders, clinicians, health and care professionals, managers and practitioners at:
  - Specialist palliative and end of life care providers
  - Generalist palliative and end of life care providers (including those providing domiciliary health and social care)
  - NHS provider services including primary care, community services, acute trusts, mental health trusts, children's services, pharmacy. Engage providers of other services where patients/service users may need palliative and end of life care, particularly where the patients/service users are likely to experience inequality (eg substance misuse services, services for those who are homeless and/or sleeping rough, learning disability services)
  - NHS commissioners (CCGs and ICSs until July 2022; ICSs post July 2022)
  - Social care provider services (local authority and commissioned providers)
  - Social care commissioners
  - Hospices and hospice at home services
- Voluntary and faith sector organisations
- People with lived experience and organisations providing support

Appendix 2: data sources for the HNA
- Office for National Statistics https://www.ons.gov.uk/

- Fingertips Public Health Profiles https://fingertips.phe.org.uk/
- NHS Digital https://digital.nhs.uk/data
- POPPI https://poppi.org.uk/
- PANSI https://pansi.org.uk/
- Hospice UK: https://popnat.hospiceuk.org/
- Shape Atlas https://shapeatlas.net/

In addition to the sources listed above, the National End of Life Care Intelligence Network maintains a comprehensive resource directory within its Palliative and End of Life Care Profile, which includes data and intelligence, information on inequalities and policy and guidance. This directory is updated quarterly.

[i] Kawachi I, Lang I, Ricchiardi W (Eds). 2020. Oxford Handbook of Public Health Practice. Oxford. OUP

[ii] Higginson IJ, Hart S, Koffman J, Selman L, Harding R. Needs assessments in palliative care: an appraisal of definitions and approaches used. J Pain Symptom Manage. 2007 May;33(5):500-5. doi: 10.1016/j.jpainsymman.2007.02.007. PMID: 17482037. https://www.jpsmjournal.com/article/S0885-3924(07)00109-1/fulltext

iii Stevens A, and Gillam S. Needs assessment: from theory to practice. *Br Med J.* 1998; **316**: 1448-1452