

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

QUALITY STANDARD TOPIC OVERVIEW

1 Quality standard title

End of life care for infants, children and young people.

2 Introduction

2.1 *NICE quality standards*

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care.

The standards are derived from high-quality guidance, such as that from NICE or [accredited](#) by NICE. They are developed independently by NICE, in collaboration with health, public health and social care practitioners, their partners and service users. Information on priority areas, people's experience of using services, safety issues, equality and cost impact are considered during the development process.

NICE quality standards are central to supporting the government's vision for a health and social care system that is focused on delivering the best possible outcomes for people who use services, as detailed in the [Health and Social Care Act \(2012\)](#).

The quality standard development process is described in detail on the [NICE website](#).

2.2 *This topic overview*

This topic overview describes core elements of the quality standard. These include the population and topic to be covered, key source guidance to be used to underpin potential quality statements, any related quality standards,

published current practice information and national or routine indicators and performance measures.

If the source guidance is not NICE guidance, it should meet the minimum quality criteria defined in NICE's [accreditation programme](#).

3 This quality standard

This quality standard is expected to publish in October 2017.

3.1 Population and topic to be covered

This quality standard will cover end of life care for infants, children and young people aged up to 18 years who have a life-limiting condition. It will also cover providing support to family members and carers.

3.2 Key development sources (NICE and NICE-accredited sources)

Primary source

- [End of life care for infants, children and young people: planning and management](#) (2016), NICE guideline NG61

Key policy documents, reports and national audits

Relevant policy documents, reports and national audits will be used to inform the development of the quality standard.

- Department of Health (2016), [Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care](#)
- National Palliative and End of Life Care Partnership (2015), [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#)
- NHS England (November 2014), [Actions for End of Life Care: 2014-16](#)
- Royal College of General Practitioners (March 2013) [RCGP commissioning guidance in end of life care : guidance for GPs, clinical commissioning group advisers](#)

- Royal College of Nursing (November 2012) [RCN competences : palliative care for children and young people](#)
- Together for Short Lives (August 2012) [A Guide to End of Life Care Care of children and young people before death at the time of death and after death](#)

3.3 Related NICE quality standards

In March 2012, the Department of Health referred a library of quality standard topics for the NHS to NICE for development.

This quality standard will be developed in the context of all topics in the NICE [library of quality standards](#). End of life care for infants, children and young people is relevant to a wide range of conditions and diseases.

Published

- [End of life care for adults](#) (2011). NICE Quality Standard 13.

In development

- [Care of dying adults in last days of life](#) NICE quality standard (expected March 2017).

4 Existing indicators

- 2016/17 Quality and Outcomes Framework, [PC001: The contractor establishes and maintains a register of all patients in need of palliative care/support irrespective of age](#)
- 2016/17 Quality and Outcomes Framework, [NM11: The contractor has regular \(at least 3 monthly\) multi-disciplinary case review meetings where all patients on the palliative care register are discussed.](#)
- 2016/17 CCG improvement and assessment framework (CCG IAF): 105c: Of people who die, the proportion who die in hospital.

5 Further information

See the NICE website for more information about [NICE quality standards](#) and the [progress of this quality standard](#).

NICE quality standard: End of life care for infants, children and young people overview (November 2016)