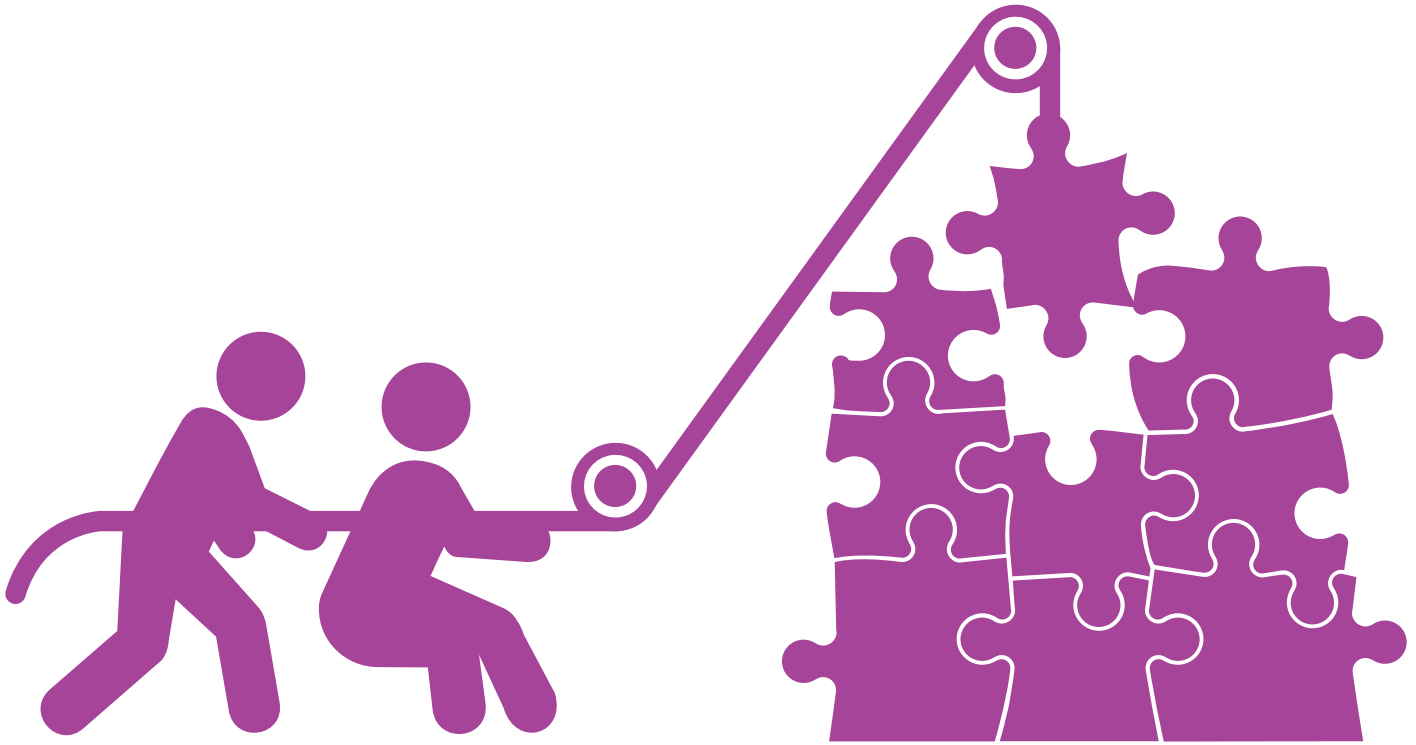


# Introduction



## Who are we talking about? A working definition

For the purposes of this toolkit people are ‘approaching the end of life’ when they are likely to die within the next 12 months. This definition is used by NCPC, the National End of Life Care Programme, the General Medical Council and the NICE End of Life Care Quality Standard. It includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

**Note:** Although it adopted this definition, the NICE Quality Standard also recognised that many people can benefit from palliative care before the last 12 months, and this must be kept in mind when commissioning services. **It is particularly important that people with dementia and other conditions which affect capacity are given the opportunity to plan ahead long before the last year of life.**

## What does good look like? The End of Life Care Quality Standard

NICE issued a Quality Standard for end of life care in November 2011, which NCPC and other organisations helped to develop and endorsed. It is made up of 16 “aspirational but achievable” statements about what comprehensive end of life care services should include. Quality standards are a key part of delivering the Government’s new system, and will be used by:

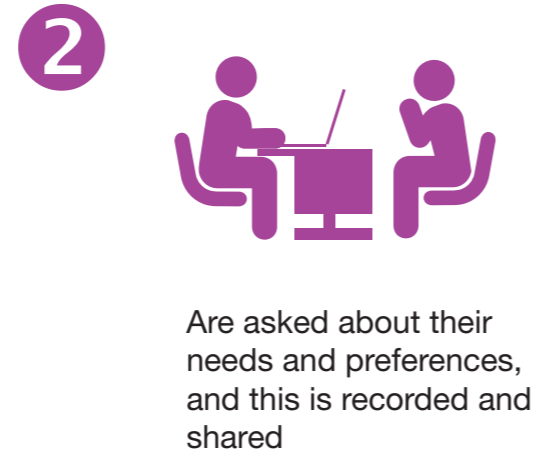
- Health and social care professionals to make decisions about care based on the latest evidence and best practice
- People using services and their carers to understand what they can expect
- Service providers to examine the performance of their organisation and assess the standards of care they provide
- Commissioners to be confident that the services they are purchasing are high quality and cost effective

The Quality Standard (including an easy-to-read version) is available to download at [www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp](http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp) or by calling 0845 003 7780.

## Five priority outcomes

This toolkit has been produced to enable different actors within the new landscape to identify clear actions they need to take to ensure high-quality end of life care is provided to the people who need it. Commissioners, providers, scrutinisers and champions need to consider their role in delivering specific outcomes for people approaching the end of life. We suggest the following five as a starting point:

### People approaching the end of life...



### Carers of people approaching the end of life...



## Measurement & intelligence

- The National End of Life Care Strategy and NICE Quality Standard include a range of suggested markers and measures.

[www.endoflifecareforadults.nhs.uk/tools/evaluation](http://www.endoflifecareforadults.nhs.uk/tools/evaluation)

[www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp](http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp)

- The national survey of bereaved people (VOICES) collects data from people who have recently registered a death and is the current indicator for end of life care under the NHS Outcomes Framework.

[www.dh.gov.uk/health/2012/07/voices](http://www.dh.gov.uk/health/2012/07/voices)

- The National End of Life Care Intelligence Network (NEoLCIN) can offer a range of national, regional and local data, for example on HES data monitoring hospital admissions at the end of life.

[www.endoflifecare-intelligence.org.uk](http://www.endoflifecare-intelligence.org.uk)

- Death in place of choice: the numbers of people dying in their usual place of residence (i.e. at home or in a care home) is a new indicator in performance management

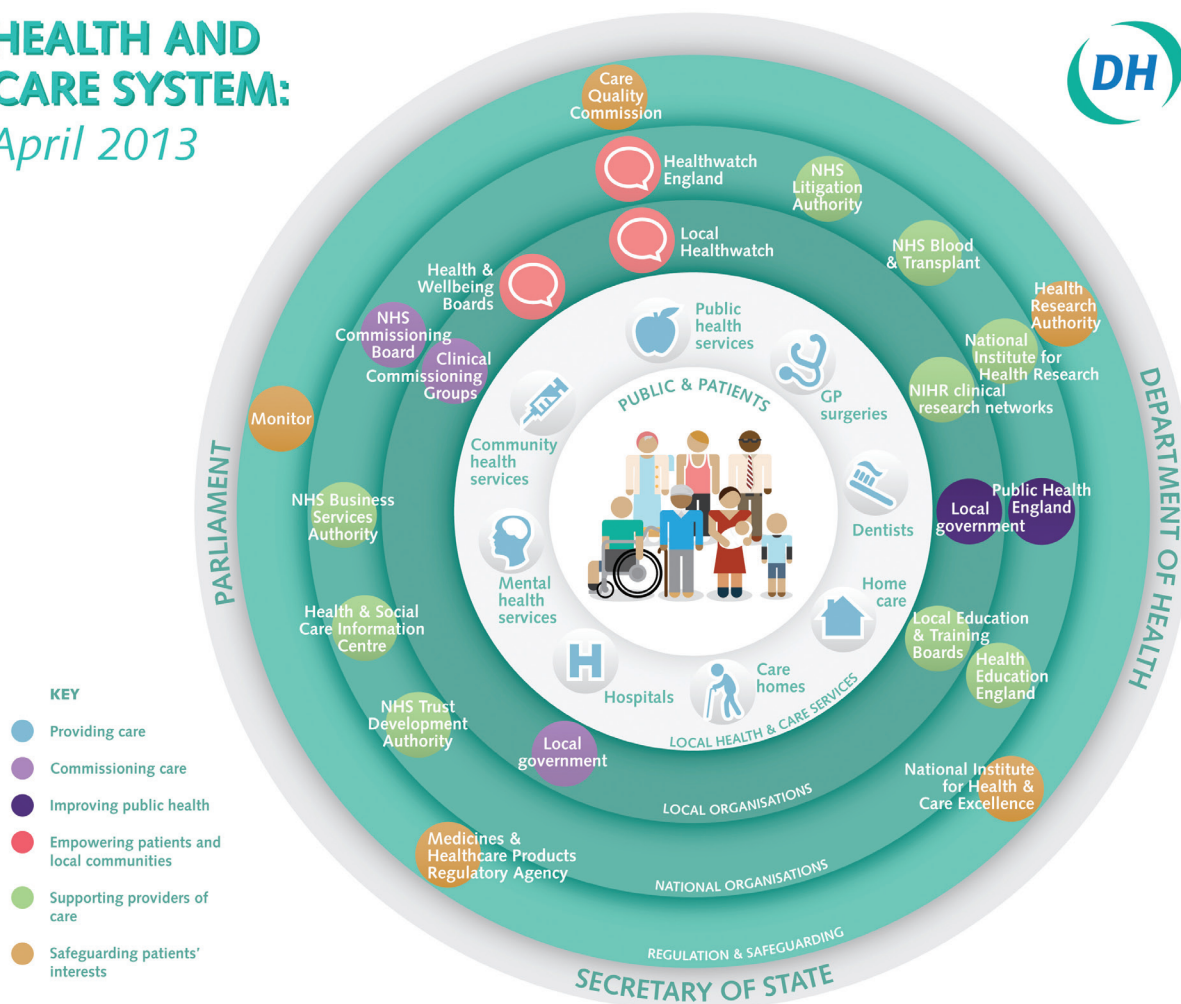
- NCPC can offer ways of measuring the impact of involving people with personal experience of end of life care and the Dying Matters coalition on the public’s attitudes and behaviours towards dying, death and bereavement. [www.ncpc.org.uk](http://www.ncpc.org.uk) and [www.dyingmatters.org](http://www.dyingmatters.org)

## The new system

The government's reformed system, as laid down in the Health & Social Care Act 2012, looks like this:

## HEALTH AND CARE SYSTEM:

April 2013



Reprinted with permission from the Department of Health. Please note this is a developing overview of the new health and care system.

## Need more detail?

Take a look at *Health and Social Care Act Explained*, Department of Health, June 2012, available at [www.healthandcare.dh.gov.uk/act-factsheets](http://www.healthandcare.dh.gov.uk/act-factsheets)

## What you need to know about the Health & Social Care Act 2012

Look out for the coloured boxes on the Action Sheets which highlight some of the duties and responsibilities in the Health & Social Care Act that you need to know about.