Public Health
England

Protecting and improving the nation's health

Developing data and intelligence for end of life care

Outcomes from workshops held with Strategic Clinical Networks and the National End of Life Care Intelligence Network

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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The intelligence networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

National Cardiovascular Intelligence Network

The National Cardiovascular Intelligence Network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Network provides information and intelligence to improve decision-making for high-quality, cost-effective services. Its work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children’s, young people’s and maternal health.

National Mental Health, Dementia and Neurology Intelligence Network

The National Mental Health Intelligence Networks (NMHDNIN) brings together the distinct National Mental Health Intelligence Network, the Dementia Intelligence Network and the Neurology Intelligence Network under a single programme. The Networks work in partnership with key stakeholder organisations. The Networks seeks to put information and intelligence into the hands of decision makers to improve mental health and wellbeing, support the reduction of risk and improve the lives of people living with dementia and improve neurology services.

Contents

About Public Health England 2

The intelligence networks 2

Executive summary 5

Introduction 6

Top priorities for SCNs 7

1. Joined up across provider, person-centric data which is up-to-date, accurate, appropriately accessible, and able to tell us about outcomes and quality of care 8
2. Reporting levels (more depth, more detail, wider scope) 9
3. Care home data – indicator detail 9
4. Minorities and 'hard to hear' groups 10
5. Developing skills and understanding of data 10
6. Timeliness 10
7. Hospital data – indicator detail 11
8. Presentation format/information context 12
9. Social care data 12
10. Cause of death 13
11. Funding data 13

Executive summary

Most of all, Strategic Clinical Network (SCN) delegates called for:

a) Centrally mandated systems to be implemented which would provide front line staff, caring for the dying person with relevant, accurate, up-to-date, joined up information, that is consistent across organisational boundaries, especially regarding outcomes and quality of care, (almost 30% of responses).

b) More detailed end of life care data and intelligence, reported more often, in ways that facilitate local investigation and, where possible, benchmarking within smaller geographies and peer group organisations, while still providing comparisons with national and other larger geographic/organisational perspectives, or best practice targets, such as provided in NICE guidelines (70% of responses).

Eleven top priorities, raised by all or most participant SCNs are summarised in this document to provide a national overview. More detail is available for the national outcome and each participating SCN in the accompanying workbook.

We are very grateful to all the Strategic Clinical Network (SCN) delegates who planned and attended the end of life care workshops and participated in the activities and discussions about how to develop end of life care, in particular the data and intelligence requirements. Your insight and expertise is invaluable to us.

The Public Health England (PHE) National End of Life Care Intelligence Network (NEoLCIN) is committed to working with other people and organisations to help address these priorities and to bring about improvements which are most relevant and beneficial for people who are dying and the bereaved in their localities.

Introduction

Between September 2014 and March 2015, members of PHE's NEoLCIN team offered an opportunity for consultation to all 12 Strategic Clinical Networks in England through one-day workshops. These were an opportunity to learn from one another and build understanding about how best to improve data and intelligence for end of life care, and provided a platform for local and national leadership on relevant issues.

Each workshop offered the opportunity for sessions to:

- highlight public health approaches to end of life care and information
- update delegates regarding about the new palliative care data set
- show current end of life care data available nationally and at local level
- discuss data and intelligence for end of life care through a workshop activity session
- present and discuss other key information identified by local SCN leadership
- provide updates on the local response to 'One Chance to Get it Right'

In all, eight Strategic Clinical Networks took up the offer and negotiated workshop designs for their localities. Over 630 non-NEoLCIN delegates took part, representing wide ranging backgrounds and skills, including various kinds of health and management professionals from primary and secondary care, including hospices, and sometimes prisons and patient representatives.

This document offers a national summary of outcomes from the workshop activities. We hope it will provide Strategic Clinical Networks with a useful perspective on the priorities for developing end of life care data and intelligence, and we are considering how they relate to our future NEoLCIN work programme.

The first workshop activity explored types of data the delegates were familiar with, what their intended purposes were, and what proportion of these were based around the care experiences, outcomes and wishes of dying people and their bereaved. Following this exploratory session, a question framework was developed to ask delegates:

> What data/intelligence sources for EoLC do you currently find useful?
> Why do you think it is useful? (What can we learn from that?)
> How do you think EoLC data and intelligence can be improved?
> What do you think the priorities are?

A final workshop (South East Coast) offered a brief opportunity for us to ask for peer review of the top priorities gathered.

Top priorities for SCNs

We collected over 600 written suggestions for improvements to end of life care data and intelligence, and over 100 top priorities. Top priorities were aggregated into 11 main categories, using qualitative analysis. These are shown below in descending order of the approximate frequency with which they were suggested:

1. Joined up across provider, person-centric data which is:
   - up-to-date
   - accurate
   - appropriately accessible
   - able to tell us about outcomes and quality of care
2. Reporting levels (more depth, more detail, wider scope)
3. Care home data - indicator detail
4. Minorities and 'hard to hear' groups
5. Developing skills and understanding of data
6. Timeliness (how frequently and how up-to-date reporting is available)
7. Hospital data – indicator detail
8. Presentation format/information context
9. Social care data
10. Cause of death
11. Funding data

Although the collection process was intended to encourage involvement and contribution from a wide range of stakeholders, it is still likely that some delegates may have preferred to take time before providing reflective feedback, some will have felt more able to contribute to the discussion and written frameworks than others, and some will not have been able to be present to contribute at all.

The prioritisation and categorisation processes were not exact sciences, but involved some qualitative assessment of the main issues and suggestions that delegates reported most frequently. Several key issues were mentioned in most workshops, but there was some variation in the level of priority expressed for each SCN area, and this is likely to be highly relevant as SCNs consider the implications for their future plans.

An explanation summarising the sorts of comments received is provided in the following pages, and more detail is available, including at participant SCN level, in the appendices.

1. Joined up across provider, person-centric data which is up-to-date, accurate, appropriately accessible, and able to tell us about outcomes and quality of care

Practitioners called for fundamental improvements in end of life care data collection and use, particularly at the point of care. The main concern at every workshop was that the data collected should help us to focus on and improve quality of care and outcomes for people who are dying and those who are bereaved. There was a strong sense that such far-reaching changes were required to enable:

- better informed, timely care plan development
- better use of resources
- better reporting that highlights keys to best practices

Delegates cited benefits in terms of end of life care provision for:

- each person involved in the process of death
- people with specific conditions and co-morbidities
- people requiring particular interventions
- commissioning of improved, more relevant and equitable services
- developing better understanding of effective service interactions
- understanding value for money in delivering patient outcomes

Comments identified the importance of collecting and using information about how people, who are dying, view their various care experiences and what their wishes are (including when they change). There was concern that this needs to be done in a consistent way that would also improve communication and understanding across various providers of care and allow better comparative analysis, including nationally.

Another common concern was the importance of ensuring that this, and other relevant end of life care information, is communicated more efficiently across organisational boundaries as needs change and develop, often with little time to spare. There is an urgent need to resolve issues that are perceived as currently preventing timely access to end of life care information, including information governance, across and within organisational boundaries. The key role of improved communication, including through advance care plans and more appropriate assessment of the mental capacity was emphasised to varying extents

There is an understanding that implementation of such fundamental changes would assist those providing care at the frontline in their many efforts to do so in more appropriate, effective and timely ways.

2. Reporting levels (more depth, more detail, wider scope)

There were many requests for more detailed reporting levels in terms of geography, organisational type and cause of death. So many suggestions were made for improvements in care home, hospital and causes of death data, with specific reference to indicator design, that these have been placed in special indicator detail categories of their own (3, 7 and 10 below)

Delegates most frequently requested reports for general practice, primary and community care, district authority and lower tier locality level. They also requested detail for out of hours services, and specialist palliative care (SPC) team catchment areas.

Requests for greater detail regarding cause of death ranged from: more detail within the main groups currently used in the profiles, to providing groupings for specialty level profiles and even specific underlying cause. There were also frequent suggestions that profiles be produced for specific age groups, and with more detailed age breakdowns.

Other suggestions in this category included requests for more detail about variations in outcomes for people who had undergone similar interventions and procedures, reports by commissioning health resource groups (HRGs) for palliative care (including clearer definition of palliative care), and showing types of community intervention so that we can better understand their role in improving care, including the role of advance care plans.

3. Care home data - indicator detail

In addition to asking for profiles to provide more information about care homes generally, delegates made specific recommendations for care home indicators they felt would be useful, particularly:

- discharges and admissions to and from care homes from and to hospitals
- differences for long term and temporary-residents

The need for a special category for end of life in learning disability homes and supported living environments was raised. Stakeholders would like to be able to get more data about the end of life care offered within care homes, (and private residences), by other care providers.

4. Minorities and 'hard to hear' groups

A recurrent request in most workshops was a need for much more data and detail specifically about mortality for children and young people, including indicators which would help in transition to and prediction of need for adult end of life care services, incorporating indicators and data from National Child and Maternal Health Intelligence Network (CHIMAT) for comparison. Delegates also asked for indicators to be presented by ethnic group and deprivation. The absence of sufficient mortality and end of life care data for people with learning disabilities and other ‘hard to hear’ groups such as prisoners and people offered treatment for drugs and substance misuse was also noted.

5. Developing skills and understanding of data

Many delegates felt ill-equipped to analyse and present data and would appreciate training and resources describing best practice. Delegates highlighted the need for data workshops targeted to support:

- commissioning decisions, and service planning
- improvements in the accuracy and detail of death certificate completion especially cause of death
- improvements in consistent application of clearer definitions for the current minimum data set collected by the National Council for Palliative Care (NCPC), such as perceived. irregularities in 'hospital at home'

Some delegates asked for additional detail in the metadata guidance, for example providing more information about what counts as an emergency admission in the local authority end of life care profiles, and to clarify the official boundaries used to define reporting areas.

6. Timeliness

Delegates presented most responses from the point of view of someone requiring data at the point of care, and their comments reflected the need for relevant data that is accurate and timely (ideally in real time), and up-to-date, in order to make well-informed decisions.

Some delegates also addressed the issue from the point of view of strategic reporting (reflective planning information), and highlighted the need for data to be presented as trends, and projections to help them plan ahead for services. These comments expressed a need for:

> ‘more sense of demography and how this can support the long term agenda’.

Requests for increased frequency of reporting ranged from daily and fortnightly updates to quarterly and others highlighted a need to enable comparison of seasonal factors.

7. Hospital data - indicator detail

Some specific suggestions were made for more hospital activity indicators to include (often with additional detail):

- hospital admissions in the last year of life
- hospital admissions in the last three months (90 days) of life
- discharges from hospital in the last two days of life, by whether that place of discharge was home, a care home in which the person had previously been a resident or another care home which had not been the person's place of residence
- hospital admissions in the last year of life split by whether or not they were for planned or unplanned interventions
- the percentage of those who died, (by cause of death or diagnosis [ICD-10 code]) who
    - were admitted in the last year of life
    - were admitted in last two weeks of life
    - were discharged in last two weeks of life

It was also suggested that hospital indicators be presented separately for acute or community based hospital activity, in addition to providing an overview (all hospital activity), especially when reporting to CCGs. Similarly some delegates requested comparative indicators for hospital activity according to whether care received was from Specialist palliative care (SPC) team or generalist alone.

There were several requests from for reports to help compare how long people who were in the last year of life, stayed in hospital:

- for the same procedures
- with the same underlying cause
- depending on whether they were temporary or long-term care home residents when they died
- depending on place of death

Delegates wanted to be able to compare outcomes across these groups with the national average, NICE guidelines or other measures of best practice).

Requests were made to resolve long-standing issues with ONS place of death coding, particularly as it affects hospices. Some asked for indicators regarding other sorts of hospital activity than inpatient, such as deaths in accident and emergency (emergency medicine) departments.There was some concern about HES coding for deaths within 48 hours of admission to hospital.

Publication of a standardised approach on analysing hospital admissions for end of life care was also suggested, and action to improve access to organisation level data such as Hospital Episode Statistics (HES) more quickly and easily than is currently the case was also raised.

8. Presentation format/information context

In order to assist discussion, delegates were provided with copies of local authority end of life care profiles (published 2012). These were selected because they show a wide range of indicators (and because they are due to be updated). Participants frequently suggested that the format would improve by inclusion of more narrative intelligence, perhaps identifying three key highlights, and three challenges at top of each EoLC profile in negotiation with the relevant leads. It was also suggested that a good model for producing these might be to co-operate with local contacts, such as Directors of Public Health, to provide interpretation relevant to the local context, prior to publication.

Another recurrent theme regarding presentation was that it would be useful to have trend data for the indicators, rather than just snapshot reports. Several asked for data to be presented in a way that would allow them to benchmark or make comparisons between relevant (smaller) localities, geographies, or organisational groupings and national averages or agreed best practice or aspirational attainment levels.

Some delegates from CCGs wanted profiles which showed the overall picture and then breakdowns for each type of care provider within their area (acute or community hospitals, care homes, hospices, primary and community care). Other delegates suggested that local authority reports would be more useful if they included breakdowns for lower tier geographies such as district local authorities. The ability to cross-reference profiles for the same time periods for care homes or, say, primary care, and hospitals as well as CCGs was highlighted.

9. Social care data

Variation in access to social care was suggested as a key factor in end of life care. Delegates wanted to be able to see reports, including trend data, for social care indicators for people who were in the last year of life, and people thought to be near the end of life. (national data currently does not provide this, although it is known that some local authority systems are capable of generating it.)

10. Cause of death

The causes of death groups reported on the workshop resource were cardiovascular disease, cancer, respiratory disease, alzheimer's, dementia, and senility and ’other’. Some delegates requested more detail, ranging from subdividing the current groups into significant subtypes of each disease, to providing breakdowns by specific cause of death via an interactive data portal to national data. Delegates also suggested developing indicators which measure the complexity of cases and compare outcomes for people with particular types or levels of co-morbidity.

11. Funding data

There is a desire for access to intelligence about how allocation of NHS continuing healthcare funding and other funding streams, varies by geography, administrative area, type of care provider and key characteristics of the dying person. Stakeholders also asked for national comparative data about funds are being invested in end of life care, (suggesting it might be available through the Care Quality Commission).