Healthcare Improvement Scotland is committed to equality and diversity. We have assessed these indicators for likely impact on the nine equality protected characteristics as stated in the Equality Act 2010 and defined by age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. A copy of the impact assessment is available upon request from the Healthcare Improvement Scotland Equality and Diversity Officer.
1 Introduction

Purpose
The purpose of this document is to specify a minimum set of high-level measures or 'indicators' for palliative and end of life care services in Scotland. An indicator is a measure of an outcome which demonstrates delivery of person-centred, safe and effective healthcare, and promotes understanding, comparison and improvement of that care.

Indicators benefit patients and the public because they provide a way of showing that healthcare is person-centred, safe and effective and continuously improving.

Scope
The indicators cover the key themes identified in *Living and Dying Well: a national action plan for palliative and end of life care in Scotland*¹ and *Living and Dying Well: Building on Progress*² including assessment and care planning (including out-of-hours) and last days of life.

The indicators are applicable to:

- all services that support someone in the palliative stage of their illness
- all palliative and end of life services in Scotland, whether directly provided by an NHS board or secured on behalf of an NHS board, and
- all patients using NHS palliative and end of life services in Scotland with regards to protected characteristics under the Equality Act 2010 as defined by age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.

The indicators may have implications for the following national boards and support organisations:

- NHS Education for Scotland
- Scottish Ambulance Service
- NHS 24
- Healthcare Improvement Scotland, and
- NHS National Services Scotland (in particular Information Services Division).

As no new resources are available for data collection, these indicators are based on readily accessible, existing national data sources. The indicators do not address feedback from patient, carer and family experiences and quality of end of life care as no suitable national data sources were available in these areas. However, we recognise that information from these areas is integral to improvement in the quality of palliative and end of life care and we anticipate that methods to collect such data will be developed in Scotland in 2013-2014.
The indicators align with other national palliative and end of life care work which is being taken forward as a result of the Living and Dying Well documents\(^1,2\) and includes the following:

- Healthcare Quality Strategy\(^3\) level one outcome measure relating to the percentage of the last 6 months of life spent in a home or community setting\(^4\)
- Medical Profiles Project\(^5\)
- development and testing of a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) draft indicator to support organisations to implement the national resuscitation policies for adults, children and young people (this work is being undertaken by Healthcare Improvement Scotland)\(^6\)
- palliative and end of life care indicators specific to care homes, included as part of the Care Inspectorate annual returns
- inspection of care of older people in acute hospitals relating to palliative and end of life care
- partnership working to align unscheduled care, including identification of specific primary care out-of-hours indicators (this work is also being undertaken by Healthcare Improvement Scotland)\(^7\)
- inclusion of specific palliative care measures and criteria in a number of Healthcare Improvement Scotland’s condition-specific clinical standards including neurological health services\(^8\), heart disease\(^9\) and chronic obstructive pulmonary disease\(^10\)
- *Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland’s National Dementia Strategy*\(^11\)
- *A Partnership for Better Palliative and End of Life Care: Creating A New Relationship Between Independent Adult Hospices and NHS Boards in Scotland*\(^12\), and
- *A Framework for Delivery of Palliative and End of Life Care for Children and Young People*\(^13\).

**Data reporting**

Data relating to palliative and end of life care services in NHSScotland are collated and held by the Information Services Division (ISD) and the National Records of Scotland (NRS). These national databases will form the source data for the indicators. ISD and NRS will lead on the extraction and generation of data, in consultation with Healthcare Improvement Scotland. Healthcare providers in Scotland will be expected to continue to submit relevant data about their palliative and end of life care services to these national databases.

Data from the indicators will be presented at NHS board level in a format to be interpreted and used locally to stimulate reflection, understand where services are working and identify opportunities for improving patient care. The data will also be reported at a national level to monitor progress of improving palliative and end of life care more generally. We will finalise the frequency of data reporting and how best it can be used to improve patient care following engagement with our stakeholders. We will also engage with our stakeholders to agree a review process for these indicators that will include the use of emerging evidence and data sources.
2 Background

The World Health Organization defined palliative care in 2004 as ‘an approach that improves the quality of life of patients and their families, facing the problems 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’.14

Around 40,000 people with palliative care needs die each year in Scotland. Palliative and end of life care seeks to promote patient involvement in decision-making that supports patients and families across all care settings. For many patients and families this results in care being delivered in the most appropriate place and ensures safe, effective, person-centred care at times of transfer of care. Studies show that most people, given the choice, would prefer to die at home or their usual place of residence15-17. Patients in their last year of life use 30% of all acute hospital bed days. Evidence shows that over 50% of Scotland’s annual deaths take place in hospital18. About 50% of NHS complaints relate to end of life care19.

In its 2007 action plan for health and well being, Better Health, Better Care20, the Scottish Government committed to delivering high quality palliative care to everyone in Scotland who needs it. The action plan noted that this should be based on the established principles of equity, personal dignity and clinical need rather than diagnosis. That commitment led to the publication of the Living and Dying Well documents1,2.

The publication of The Healthcare Quality Strategy for NHSScotland3 in 2010 also outlined the Government’s commitment to drive improvement in the quality of palliative and end of life care.

The Living and Dying Well documents1,2 set out how improvements in palliative and end of life care could be achieved, and formalised the commitment of several organisations, including:

- Care Inspectorate
- Healthcare Improvement Scotland
- NHS Education for Scotland
- Scottish Government, and
- Scottish Partnership for Palliative Care.

Healthcare Improvement Scotland was asked to develop indicators in response to recommendations by the Scottish Parliament Health and Sport Committee21 and the Living and Dying Well National Advisory Group.
3 Methodology

A project group was convened to develop the indicators, with Dr David Oxenham, Medical Director, Marie Curie Hospice-Edinburgh, appointed as Chair. The group met several times between 2011 and 2013. Membership of the project group was drawn from across Scotland (see Appendix 1) to reflect the multidisciplinary nature of palliative and end of life care.

Information and evidence to support indicator development was obtained from a number of sources including:

- a literature review of key themes (undertaken by Healthcare Improvement Scotland’s Knowledge Management Unit)
- actions and recommendations from the Scottish Government's Living and Dying Well documents1,2, policies and other related national initiatives
- anecdotal evidence and expert opinion on the current provision of palliative and end of life care services in Scotland, and
- technical expertise on data sources including Scottish Government guidance on Palliative Care Directed Enhanced Services22 and NHS National Services Scotland (for nationally available palliative care data).

Consultation process

Following the publication of the draft quality indicators in November 2012, a 6-week consultation was undertaken with staff, carers, patients and members of the public involved in palliative and end of life care. Engagement methods included:

- meetings with stakeholders including Palliative Care Managed Clinical Networks within NHS Boards, Scottish Independent Hospitals Association, Scottish Prison Service, hospices, carer and third sector organisations
- direct engagement with service users, carers and staff (focus groups and semi-structured interviews), and
- wide circulation of the draft indicators and feedback form to a range of local, national and UK organisations who deliver health and social care services to people with palliative and end of life care needs.

All responses were anonymised and reviewed to identify themes. The project group considered all feedback and comments and made significant changes to the indicators.

A consultation summary report detailing the group’s responses to each comment will be available in spring 2013 on our website (www.healthcareimprovementscotland.org).
## 4 Format of the indicators for palliative and end of life care

All our indicators follow the same format. Indicators include an evidence-based rationale, details about what we want to measure and data sources. More information about the different parts of an indicator is provided below.

### Indicator 1: Increase in the number of people needs that are identified.

#### Measures

The information required to demonstrate progress against the indicator.

#### Rationale

The reason why this indicator is considered important.

#### Rationale

As more people are living longer, there is a greater risk of dying from chronic conditions such as organ failure, cancer. Evidence suggests that around 75% of people could benefit from palliative care. At present, about 30% of people have been identified at any point before they die.

If patients are identified as having palliative care needs, it is easier to assess and plan to meet those needs. Research has shown that people who have been identified and placed on a palliative care register have their needs and wishes met. For example, they are less likely to die in hospital compared with those not on the register (50%).

This indicator is also included in the National Performance Framework.

### How to measure this indicator

<table>
<thead>
<tr>
<th>Measure 1.1</th>
<th>Proportion of people with cancer needs who are on a palliative care register</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>The number of patients with cancer needs who are on a palliative care register</td>
</tr>
<tr>
<td>Denominator</td>
<td>The number of patients listed with cancer needs</td>
</tr>
<tr>
<td>Data sources</td>
<td>ISD Scotland Quality and Outcomes Data Calculator.</td>
</tr>
<tr>
<td>Exclusions</td>
<td>None.</td>
</tr>
</tbody>
</table>

---

**Note:** The table represents a simplified example of how to measure an indicator. The actual measurement process would involve more detailed analysis and data collection.
5 Indicators for palliative and end of life care

Four palliative and end of life care indicators have been developed.

Indicator 1: Increase in the number of people with palliative and end of life care needs who are identified

Indicator 2: Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan

Indicator 3: Increase in the number of electronic palliative care summaries accessed

Indicator 4: Place of death
Indicator 1: Increase in the number of people with palliative and end of life care needs who are identified

Indicator 1 measures whether people who need palliative and end of life care, regardless of diagnosis, are identified.

1.1 Proportion of people with cancer who are on a palliative care register
1.2 Proportion of people with a long-term condition other than cancer who are on a palliative care register

Rationale
As more people are living longer, there is a greater likelihood that people will die from chronic conditions such as organ failure, cancer, dementia and frailty\textsuperscript{23,24}. It is estimated that about three quarters of all people who die in Scotland could benefit from a palliative care approach\textsuperscript{18}. At present, about 30% of people who need palliative and end of life care are identified before they die\textsuperscript{25}.

If patients are identified as having palliative care needs then it becomes possible to assess and plan to meet those needs. Research indicates that patients who have been identified and placed on a palliative care register are more likely to have their needs and wishes met\textsuperscript{25}.

The indicators presented below are also included in the Palliative Care Directed Enhanced Services\textsuperscript{22} and the Medical Profiles Project\textsuperscript{5}.

How to measure this indicator

<table>
<thead>
<tr>
<th>Indicator 1.1</th>
<th>Proportion of people with cancer who are on a palliative care register</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>The number of people with cancer listed with a general practice and who are on a palliative care register.</td>
</tr>
<tr>
<td>Denominator</td>
<td>The number of people with cancer listed with a general practice.</td>
</tr>
<tr>
<td>Data sources</td>
<td>ISD Scotland Quality and Outcomes Framework (QOF) database calculator, Palliative Care Directed Enhanced Services.</td>
</tr>
<tr>
<td>Exclusions</td>
<td>None.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Indicator 1.2</th>
<th>Proportion of people with a long-term condition other than cancer who are on a palliative care register</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>The number of people with a long-term condition other than cancer listed with a general practice and who are on a palliative care register.</td>
</tr>
<tr>
<td>Denominator</td>
<td>The number of people with a long-term condition other than cancer listed with a general practice.</td>
</tr>
<tr>
<td>Data sources</td>
<td>ISD Scotland Quality and Outcomes Framework (QOF) database calculator, Palliative Care Directed Enhanced Services.</td>
</tr>
<tr>
<td>Exclusions</td>
<td>None.</td>
</tr>
</tbody>
</table>
Indicator 2: Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan

Indicator 2 is a proxy measure of whether people's palliative and end of life care needs are being assessed and have a care plan.

2.1 Proportion of people with cancer who have an electronic palliative care summary

2.2 Proportion of people with a long-term condition other than cancer who have an electronic palliative care summary

Rationale

To ensure safe, effective and person-centred care, it is necessary for those involved in the provision of care across all settings to have access to core information about the patient’s clinical condition, their wishes and any agreed plan of care. Anticipatory care plans (ACPs) are documents used to record discussions between patients and those involved in their care, setting out the patient’s wishes for treatment and care in the event of sudden deterioration in health. In a 2012 study, the use of ACPs in primary care led to a 52% reduction in unplanned hospital admission and a significant reduction in the hospital bed days used in the last 3 months of life.

The content of the ACP should reflect the individual’s circumstances and include:

- medical diagnoses as agreed between GP and patient
- patient and carer understanding of diagnosis and prognosis
- patient wishes on preferred place of care
- resuscitation (DNACPR) status, and
- information on medication and equipment left in the patient's home 'just in case'.

The ACP should be available in a transferable electronic format as an electronic palliative care summary. This will ensure it is accessible to all clinical services who may be involved in the patient’s care. The electronic palliative care summary should be regularly updated and be designed with clear governance and accessibility safeguards.
How to measure this indicator

**Indicator 2.1**  
Proportion of people with cancer who have an electronic palliative care summary

| Numerator | Total number of people with cancer on the palliative care register with an electronic palliative care summary across the NHS board area. |
| Denominator | All people with cancer on the palliative care register across the NHS board area. |
| Data sources | Palliative Care Directed Enhanced Services. |
| Exclusions | None. |

**Indicator 2.2**  
Proportion of people with a long-term condition other than cancer who have an electronic palliative care summary

| Numerator | Total number of people with a long-term condition other than cancer on the palliative care register with an electronic palliative care summary across the NHS board area. |
| Denominator | All people with a long-term condition other than cancer on the palliative care register across the NHS board area. |
| Data sources | Palliative Care Directed Enhanced Services. |
| Exclusions | None. |

**Note**

We acknowledge that a variety of end of life care plans and ACPs exist and may be used in different settings. For the purpose of this indicator, the electronic palliative care summary will be used to measure the existence of a care plan.
Indicator 3: Increase in the number of electronic palliative care summaries accessed

Indicator 3 is a measure of how many electronic palliative care summaries are accessed.

3.1 Proportion of people who have had their electronic palliative care summaries accessed

Rationale

The electronic palliative care summary allows, with patient or carer consent, vital information on vulnerable patients to be available in any setting\textsuperscript{22,31}. Ease of access and clarity of information will enable this information to be shared more effectively.

The creation of the electronic palliative care summary is only useful if it is accessed and actively used to inform decision-making\textsuperscript{29}.

How to measure this indicator

<table>
<thead>
<tr>
<th>Indicator 3.1</th>
<th>Proportion of people who have had their electronic palliative care summaries accessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>The number of electronic palliative care summaries accessed in the past 12 months.</td>
</tr>
<tr>
<td>Denominator</td>
<td>The number of electronic palliative care summaries created in the past 12 months.</td>
</tr>
<tr>
<td>Data sources</td>
<td>Electronic Care Summary.</td>
</tr>
<tr>
<td>Exclusions</td>
<td>None.</td>
</tr>
</tbody>
</table>

Note

At present, it is not possible to determine whether an individual’s electronic palliative care summary is accessed by a healthcare professional at the time when the patient presents to the unscheduled healthcare service. Work is ongoing to develop a process to capture, analyse and report on these data. Until specific data are available the indicator will be measured by determining the number of times the electronic palliative care summary is accessed over a 12-month period.
Indicator 4: Place of death

Indicator 4 is a proxy measure of whether people’s preference for place of death is achieved.

4.1 Proportion of people who die in hospital

4.2 Proportion of people who die in their usual place of residence

Rationale

Place of death can be a critical contributor to the quality of death for an individual and their family and friends. It has an impact on their psychological, physical, social and spiritual comfort and may provide the possibility for family and friends to be present during the final days and hours of an individual’s life.\textsuperscript{26,32}

At present, 58\% of all deaths occur in acute hospitals.\textsuperscript{33} Studies report that most people would prefer to die at home or their usual residence.\textsuperscript{15-17} Evidence indicates that more people die in hospital than need or want to, and conversely fewer people die at home or their usual residence than need or want to.\textsuperscript{34-35}

How to measure this indicator

<table>
<thead>
<tr>
<th>Indicator 4.1</th>
<th>Proportion of people who die in hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>The number of people who died in hospital in the past 12 months.</td>
</tr>
<tr>
<td>Denominator</td>
<td>The number of people who died in the past 12 months.</td>
</tr>
<tr>
<td>Data sources</td>
<td>National Records of Scotland (NRS) death records.</td>
</tr>
<tr>
<td>Exclusions</td>
<td>None.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Indicator 4.2</th>
<th>Proportion of people who die in their usual place of residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>The number of people who died in their usual place of residence in the past 12 months.</td>
</tr>
<tr>
<td>Denominator</td>
<td>The number of people who died in the past 12 months.</td>
</tr>
<tr>
<td>Data sources</td>
<td>National Records of Scotland (NRS) death records.</td>
</tr>
<tr>
<td>Exclusions</td>
<td>None.</td>
</tr>
</tbody>
</table>

Notes

It is not currently possible to measure whether preferred place of death and actual place of death match for any individual, but an increase in percentage dying in usual place of residence and a decrease in percentage dying in hospital would suggest people’s preferences are being met more often.

This indicator promotes individual choice at end of life and does not preclude hospital admission when appropriate.
6 References


Further reading


## Appendix 1: Project group membership

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>David Oxenham (Chair)</td>
<td>Medical Director</td>
<td>Marie Curie Hospice-Edinburgh/NHS Lothian</td>
</tr>
<tr>
<td>Derek Blues</td>
<td>Policy Manager</td>
<td>Scottish Partnership for Palliative Care</td>
</tr>
<tr>
<td>David Carroll</td>
<td>Chair of RCGP Scotland palliative and end of life care working group</td>
<td>NHS Grampian</td>
</tr>
<tr>
<td>Keith Farrer</td>
<td>Consultant Nurse and Clinical Lead for Long-Term Conditions</td>
<td>NHS Orkney</td>
</tr>
<tr>
<td>Joyce Gillespie</td>
<td>Patient Representative</td>
<td></td>
</tr>
<tr>
<td>Mark Hazelwood</td>
<td>Director</td>
<td>Scottish Partnership for Palliative Care</td>
</tr>
<tr>
<td>Susan Kinsey</td>
<td>Patient Representative</td>
<td></td>
</tr>
<tr>
<td>Elaine MacLean</td>
<td>Professional Adviser, Palliative Care</td>
<td>Care Inspectorate</td>
</tr>
<tr>
<td>Lindsay Martin</td>
<td>Palliative Care Consultant</td>
<td>NHS Dumfries &amp; Galloway</td>
</tr>
</tbody>
</table>
## Appendix 2: Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>electronic palliative care summary</strong></td>
<td>Provides up-to-date information about palliative care needs to out-of-hours services.</td>
</tr>
<tr>
<td><strong>emergency care summary</strong></td>
<td>Provides up-to-date information about allergies and GP prescribed medications for out-of-hours services.</td>
</tr>
<tr>
<td><strong>Palliative Care Directed Enhanced Services</strong></td>
<td>A directive, from the Scottish Government to NHS boards, to ensure appropriate patients are identified for the palliative care register and that electronic palliative care summaries are completed and available to out-of-hours services.</td>
</tr>
<tr>
<td><strong>palliative care register</strong></td>
<td>A register of patients identified as having palliative care needs.</td>
</tr>
<tr>
<td><strong>place of residence</strong></td>
<td>The usual residence of the patient which may include home, care home, hospice or prison.</td>
</tr>
<tr>
<td><strong>proxy measure</strong></td>
<td>A method of determining an outcome when it is not possible to measure the exact value, for example, when data are not available.</td>
</tr>
<tr>
<td><strong>unscheduled care</strong></td>
<td>Treatment given to patients presenting in an emergency setting.</td>
</tr>
</tbody>
</table>
Appendix 3: About Healthcare Improvement Scotland

Healthcare Improvement Scotland was launched on 1 April 2011. This health body was created by the Public Services Reform (Scotland) Act 2010 and marks a change in the way the quality of health care across Scotland will be supported nationally.

Our vision
Our vision is to deliver excellence in improving the quality of the care and experience of every person in Scotland every time they access health care.

Our purpose
Our organisation has key responsibility to help NHSScotland and independent healthcare providers to:

- deliver high quality, evidence-based, safe, effective and person-centred care, and
- scrutinise services to provide public assurance about the quality and safety of that care.

What we do
We are building on work previously done by NHS Quality Improvement Scotland and the Care Commission, and our organisation includes:

- Healthcare Environment Inspectorate
- Scottish Health Council
- Scottish Health Technologies Group, and
- Scottish Intercollegiate Guidelines Network (SIGN).

Our work programme supports Scottish Government priorities, in particular those arising from The Healthcare Quality Strategy for NHSScotland. Our work encompasses all three areas of the integrated cycle of improvement (see Figure 1) with patient focus and public involvement at the heart of all that we do.

The integrated cycle of improvement involves:

- developing evidence-based advice, guidance and standards for effective clinical practice
- driving and supporting improvement of healthcare practice, and
- providing assurance about the quality and safety of health care through scrutiny and reporting on performance.
Figure 1: Integrated cycle of improvement

Visit our website: www.healthcareimprovementscotland.org for more information.
The Healthcare Environment Inspectorate, the Scottish Health Council, the Scottish Health Technologies Group and the Scottish Intercollegiate Guidelines Network (SIGN) are key components of our organisation.