

Reviewing end of life care indicators in Scotland

A proposal for anticipatory care planning as a new indicator

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Introduction

Ahead of the preliminary recommendations of the review into Scotland's national health and social care integration indicators, Hospice UK, Marie Curie and Sue Ryder propose a new indicator for consideration. The Core Suite of Integration Indicators, first published in 2015, are currently subject to a review led by Sir Harry Burns and provide measures that Scotland's 31 new Health and Social Care Partnerships ('Partnerships') will be expected to report against annually.

Building on the Scottish Government's 2021 vision for palliative care¹ and the significance of anticipatory care planning (via a Key Information Summary) to achieving this,² we propose that anticipatory care planning be adopted as an indicator for improving and widening access to end of life care.

Anticipatory care planning as a new indicator

The two existing indicators under review which relate to death and dying, numbers 15 and 23, measure proportion of last six months of life spent in a home or homely setting; and expenditure on end of life care respectively. While both provide useful data, neither indicator is able to capture quality of care or progress towards widening access to palliative care³ for the 11,000 people who miss out on it every year.

We propose that the review considers a new indicator that will enable Partnerships to more meaningfully measure progress toward widening access to the right care for people living with terminal and life-shortening conditions.⁴

¹ The Strategic Framework for Action on Palliative and End of Life Care states that by 2021 everyone who needs palliative care will have access to it. Scottish Government, 2015.

² The Scottish Government said that, 'By 2021, we aim to: Ensure that everyone who needs palliative care will get hospice, palliative or end of life care. All who would benefit from a "Key Information Summary" will receive one – these summaries bring together important information to support those with complex care needs or long-term conditions, such as future care plans and end of life preferences.' P9, Health and Social Care Delivery Plan, the Scottish Government, 2015.

³ See Appendix for definition of palliative care adopted.

⁴ See Appendix for definition of terminal illness adopted.

We recognise the importance of using data which is easily accessible at the local Partnership level; and analysable across Partnership areas. We therefore propose the following within the context of current recording systems. This indicator is intended to be applicable to any successor anticipatory care preference recording processes which may replace the Key Information Summary (KIS):

MAIN INDICATOR

Of those who died in the last year, upon death how many had an anticipatory care plan such as a KIS?

SUB-INDICATORS

1. Length of time KIS held prior to death
2. Primary diagnosis, as recorded on KIS
3. How many times was KIS accessed/updated in last year (including in acute and out of hospital settings)

Main Indicator

The main indicator will tell us the percentage of people who died, excluding sudden or unexpected deaths, who had an anticipatory care plan (ACP)⁵ such as a KIS in place. This measures how many people had conversations with professionals about death and dying as well as how many people had preferences recorded. By proxy, we can know whether palliative and end of life care needs were formally identified and what progress is being made toward widening access. There are limitations to this, such as whether identification means the right care pathways are being triggered and we recommend further work to ensure that such an indicator is linked to responsive palliative care pathways. There are also issues around ensuring records are updated and accessible to care givers; how KIS can be utilised for babies, children and young people as well as adults; and who creates and updates KIS. However, at present this indicator presents the best opportunity for measuring access to end of life care. It is also suggestive of quality of care in terms of preferences being recorded.

Sub-indicators

The above is a good measure of widening access to responsive palliative care, but alone misses important elements of access to and quality of care. We recommend the inclusion of supporting indicators and have suggested three specific sub-indicators.

1. Sub-indicator: length of time KIS held prior to death.

Data generated: numbers relating to how long before death people have an ACP/KIS created will enable Partnerships to measure progress on people being identified for palliative care early, benefitting from the right care for as long as possible prior to death.

Outcome: widening access to care as early as possible, which will deliver on National Health and Wellbeing Outcomes.⁶

⁵ For more information on the Scottish Government's definition of Anticipatory Care Planning, please see: <http://www.gov.scot/Publications/2010/04/13104128/1>

⁶ The Core Suite of Integration Indicators, Scottish Government, 2015 is to be used in conjunction with the Public Bodies (Joint Working) (National Health and Wellbeing Outcomes) (Scotland) Regulations 2014, which set out Scotland's National Health and Wellbeing Outcomes.

2. **Sub-indicator: primary diagnosis, as recorded on KIS.**

Data generated: we know that people with terminal and life-shortening non-cancer diagnoses access palliative care in lower numbers and later in their disease progression than those with cancer diagnoses.⁷ This sub-indicator will enable Partnerships to evidence progress toward widening access to care by diagnosis.

Outcome: diagnosis type is not a barrier to care and more people can benefit from the right care. This will support delivery of the National Health and Wellbeing outcomes.

3. **Sub-indicator: how many times was KIS accessed/updated in last year of life (including in acute and out of hospital settings).**

Data generated: there are two sets of data that could be generated by this measure. Firstly, we can know how many times people's recorded preferences have been consulted and updated. Secondly, we can know in which settings records are being consulted and updated. This data will enable Partnerships to meaningfully report on how responsive care is to someone's preferences and illness trajectory across different settings.

Outcome: responsive and respectful care that reflects (changing) choices and preferences seamlessly across care settings, delivering on National Health and Wellbeing outcomes.

While there are a number of other sub-indicators which could be selected to target access inequity,⁸ the three listed here should be more straightforward to establish without creating additional recording mechanisms or requiring complex coordination of different recording processes already in place.

Additional monitoring

We note that the intention is to keep the core suite of indicators under review and refine and update as progress is made. Should an indicator like this be adopted, we recommend further complementary annual reporting to establish correlations between care wishes and actual care experiences including the experiences of family (for example through a similar survey to the 'Voices' survey used for reporting in England and being piloted in Lothian), care providers and most importantly, people directly receiving care (such as via the Scottish Health Council's 'Our Voice' programme).

Contact & further information

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⁷ 'The role of hospice care in Scotland', Hospice UK, 2016; 'How good is primary care at identifying patients who need palliative care? A mixed methods study', Zheng, L *et al*, European Journal of Palliative Care, 2013; 20 (5).

⁸ For example, to measure progress toward widening access by socio-economic group, faith, gender identification, age etc., for more information on palliative care access inequality please see Marie Curie's event report: 'Enough for Everyone? Challenging inequities in palliative care', Marie Curie Scotland, 2016.

Appendix: definitions

Palliative care

In the Strategic Framework for Action on Palliative and End of Life Care, the Scottish Government endorses the 2015 World Health Organisation (WHO) description of palliative care as follows.

‘Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

‘Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

‘Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.’⁹

End of life care

The Strategic Framework for Action also contains a definition of end of life care which it recommends is used as part of the implementation of commitments within the Framework:

‘End of life care addresses the medical, social, emotional, spiritual and accommodation needs of people who have less than one year to live. It includes a range of health and social services and disease specific interventions as well as palliative and hospice care for those with advanced conditions who are nearing the end of life.’¹⁰

Terminal illness

Someone has a terminal illness when they reach a point where they, or their medical team, carers or loved ones, understand their illness is likely to lead to their death.

- Terminal illness includes a wide range of different illnesses and individual needs. People may have a single disease or a number of conditions.
- Depending on their condition and treatment, people may live with a terminal illness for days, weeks, months or even years.
- They are likely to be receiving treatment to help reduce or manage their symptoms, rather than cure their illness. They and their families may find they need different types of care, practical help or emotional support at various points throughout this stage of their illness.¹¹

⁹ WHO Fact Sheet on palliative care, Fact sheet no. 402, July 2015.

¹⁰ The Framework uses an adapted version of a definition used in a 2015 report from the National Institutes of Health in the USA. ‘Dying in America: Improving Quality and Honouring Individual Preferences Near the End of Life. Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine. Washington (DC): National Academies Press (US); 2015.

¹¹ Definition provided by Marie Curie: <https://www.mariecurie.org.uk/who/terminal-illness-definition>