Scottish
Partnership
for Palliative Care

SPPC Response to the HIS Consultation on Palliative and End of Life Care Indicators

About the SPPC

The Scottish Partnership for Palliative Care (SPPC) is the umbrella body representing the major organisations involved in palliative care in Scotland. Our membership includes all 14 territorial health boards, all 13 of Scotland's voluntary hospices, 17 major national health charities, 7 professional associations and 1 local support organisation. The membership of the Partnership is detailed at www.palliativecarescotland.org.uk. Through a collaborative approach, the Partnership supports and contributes at national level to the development and strategic direction of palliative care in Scotland and the promotion of service improvement at local level. The Partnership's aims are to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis.

About this Submission

This response is based on notes of discussions at SPPC Constituency Group Meetings. The SPPC also invited written comments for consideration and these were received from individuals at the following organisations;- St Columba's Hospice, ACCORD Hospice, Ardgowan Hospice, Association of Palliative Care Social Workers, NHS Ayrshire & Arran, NHS Fife, Parkinsons UK, Strathcarron Hospice, NHS Greater Glasgow & Clyde, NHS Tayside, Ayrshire Hospice, MS Society, NHS Highland, Alzheimers Scotland and NHS Grampian. This submission does not replace any individual submission from these organisations or other member organisations.

This SPPC response is an attempt to synthesise and reflect multiple perspectives.

The Principle of Quality Indicators

The principle of systematically ascertaining the quality of palliative and end of life care experienced by patients and families in Scotland is one which the SPPC enthusiastically supports. Whilst much of this consultation response highlights deficiencies in the proposed draft indicators, the SPPC recognises the constraints imposed on the project group which was required to find meaningful indicators from pre-existing data sources. The SPPC would wish to continue to engage in a further process of development – the proposed indicators represent a starting point but should not be regarded as an adequate end point.

Common Themes

A number of themes were common to many of the respondents and discussions upon which this submission is based. These common themes are also applicable to several or all of the individual indicators and are stated once in this section, rather than repeated for each indicator.

Validity of the indicators as proxies for quality

Most respondents questioned whether these indicators were valid proxies for quality of care. Some responders felt that the indicators might be better than nothing and might act as drivers of policy development. Others observed there was a risk that although inadequate the measures would become accepted as sufficient and hinder further development. Some expressed concern that their use could be harmful by creating perverse incentives.

The Importance of Patient and Family Experience

There was clear overall disappointment that the indicators do not measure the quality of care experienced by patients and families. Whilst this was acknowledged in the preamble to the indicators some responders expressed disappointment that there was no firm commitment to rectify this deficiency through future work.

Scope of services to which the indicators are applicable

Many respondents observed that the indicators had a focus on primary care and that they would provide little or no indication as to the quality care in other settings such as hospitals, care homes, hospices and very sheltered housing. This was in contrast to the preamble to the indicators which asserted that the indicators apply to *"all services that support someone in the palliative stage of their illness"* and *"all palliative and end of life services in Scotland, whether directly provided by an NHS board or secured on behalf of an NHS board".*

There was comment about the absence of indicators for specialist palliative care services. There was also comment that even with primary care the indicators related to GPs activities and not other members of the team. Many respondents highlighted the key role of community pharmacists (as potential data sources and as service providers with whom care plans should be shared).

There was comment about the applicability of the indicators to children and younger people. One respondee highlighted the absence of any indicator relating to the identification and control of symptoms.

Use of the Indicators

Many responders felt there was a lack of clarity as to the purposes to which the indicators would be put. Who was it envisaged that the primary consumers of the indicators were? What would the process of reporting and review be?

Some expressed concerns about:-

- Misunderstanding and misinterpretation by the public and decision-makers
- The drawing of crude and inappropriate comparisons
- Difficulty in interpreting the significance of the data given the complexity of care, the variety of patient preference and variation in populations.

It was suggested that there would be value in producing materials which would support interpretation and use of the data. This should include greater clarity about the type of improvements which the indicators were expected to drive.

A more general point was that there should be access to materials and resources to support improvement activities which might be prompted by consideration of the indicator data.

ePCS

Many respondees highlighted difficulties in using the ePCS as a data source. There were varying levels of implementation in different Boards and settings, and minimal access in many acute settings and other unscheduled services.

Carers

The absence of any indicator relating to the experiences of unpaid carers was highlight by several respondents as a critical deficiency in the scope of the indicators.

Babies, Children and Young People

Some babies, children and young people have palliative care needs and the indicators ought to be capable of measuring the quality of care experienced by these groups. It is important in respect of each indicator to consider how it would function in respect of these groups who may be under-recognised, who may often experience disease trajectories different from adults and who may be cared for in different settings.

Miscellaneous Points

References

Page 2 'Background', paragraph 2, sentence 5 of the preamble states:

"About 50% of NHS complaints relate to end of life care [4]

Reference 4: Living and Dying Well Short Life Working Group 5. Recommendations on Palliative Care in Acute Hospitals. Sept 2010 [cited 2012 30 Aug] states *50% of NHS complaints relate to end of life care* (Audit Scotland 2008)."

In fact there is no such reference in the audit Scotland Review. This could be replaced with

"Dying for Change (DEMOS 2010) Charles Leadbeater and Jake Garber, Chapter 4 - How well do we do? (pg 40)

Dissatisfaction with how hospitals care for those dying is widespread: about 50 per cent of the most serious complaints about acute hospitals relate to the conditions in which someone dies [58]

Reference 58: Almost half of complaints about NHS services related to acute hospitals. Of these 54 per cent related to care given at the end of life. See Department of Health, End of Life Care Strategy, 2008; I Higginson, *Priorities for End of Life Care in England, Wales and Scotland*, London: National Council for Palliative Care, 2003; YouGov survey, ‘Patients wanting home death fear they won’t get care they need’, 2008. See also National Audit.”

CYPADM

This should be mentioned on page 5 where other pieces of relevant work are listed.

Pilot Data

Some respondees suggested it would be useful to see some pilot data.

Social care

The sharing of plans across sectors was important and should encompass social care where appropriate. Links between primary care and care homes were an important example of this.

Indicator 1

The importance of identifying people with palliative care needs was recognised and some respondents felt that this indicator might encourage the use of registers.

Respondents highlighted the need to understand practice demographics in order to be able to interpret resultant data.

A concern was expressed that overall increases in identification might mask continued inequities for some groups. For example people with neurological conditions might continue to be under-represented on registers as might the very frail elderly. Sub-analysis could be valuable and informative. To mitigate against this risk it was suggested that additional wording might be included to prompt consideration/identification of groups known to be currently under-identified e.g. people with dementia, neurological conditions, children etc.

The need to prompt early identification in dementia was highlighted since the window for planning future care whilst the patient still had capacity might be short.

The measure ignores the importance of identification of people with palliative care needs in other settings.

One respondent felt that under or over registration was a risk without clear definitions, and that more research was needed in this area.

The indicator is a useful way of measuring potentially unmet needs.

Indicator 2

Many respondents questioned whether an ACP could be equated with an ePCS record. An ACP ought to be updatable by multiple professionals and by patient and family. Some respondents highlighted that some patients did not want to engage in anticipatory/advance care planning and that this choice should be respected (and the indicator should not drive service-centric rather than patient centred care).

It would be important to ensure that the replacement of ePCS by KIS did not prevent the measurement of this indicator.

Many noted that the quality of the ePCS was very important but that this indicator could not measure this (and the listed bullet points could not be ascertained).

One respondent questioned the simple assumptions about the impact of ACP on reducing unscheduled hospital activity, highlighting NHS Highland LTC's work on ACPAs.

The ePCS is not used in NHS Borders.

For this measure there would be a need to identify ePCS records created within a period (not just the cumulative total to date, as is currently commonly presented).

Indicator 3

Concerns about the equation of an ACP with ePCS applied here too, as did concerns regarding access to ePCS. The indicator assumed patient consent, up to date and dynamic information, but the system did not currently deliver this consistently. If content of the ePCS is poor/out of date, then encouraging its consideration would not lead to better care.

Some felt that for the record to be accessed once was a low aspiration. In addition if there was no differentiation between the record being accessed by different unscheduled services (GP OOH, NHS24, acute settings) then the value would be greatly reduced. One respondent questioned whether sequential repeated access to the ePCS was allowed.

One respondee suggested extending data collection to include the outcome of the contact with unscheduled care services (e.g. emergency admission).

Incorrect terminology was used “Trak” not “Track”.

Would emergency admissions to hospices be counted as unscheduled care?

Questions were raised about some of the technicalities of the measure, as one respondent wrote:

“Concern was raised about how the numerator for indicator 3 would be collected. From a technical point of view, will someone have to match up admissions via trakcare with whether the patient has an ePCS? How will it be possible to avoid people being counted twice? What about patients who have hand held ACPs or who change their minds and relay this verbally – their needs may still be being met but not counted.

Regarding the denominator: Does ‘**review** in an unscheduled care setting’ refer for example to review in A&E, then review in acute receiving ward etc hence allowing for the number of opportunities for acting on the ePCS per admission, or does it refer to a single admission? Is each episode of unscheduled care counted for a patient with an ePCS, or is each patient with an ePCS who has had an episode of unscheduled care counted once regardless of whether they have had 1 or 5 episodes of unscheduled care? This indicator will be meaningless if it does not accurately record all of the potential opportunities for accessing the ePCS for each patient in each episode of unscheduled care.”

This indicator had potential but it was likely to be some time before it was fully realised.

Indicator 4

Most respondents questioned the basic assumption of the indicator that it was a proxy for preferred place of care. It was highlighted that preferred place of care often changes nearer death. There was also evidence that some groups were less likely to prefer to be cared for at home towards the end of life. Hospital may be the right setting clinically and reflect patient preference. Patient circumstances, goals and choices needed to be reflected. This area needed further research.

There was comment that place of care does not provide information about the quality of care in any setting. More people may be cared for in the community but this indicator does not provide information about the adequacy of community support.

The figure used in the denominator is wrong. It should be 182.5 not 187.5.

A respondent questioned whether the referenced oncology study was entirely relevant or convincing evidence.

Some wished to understand the rationale for measuring the last 6 months of life as opposed to some other period of time.

Some wondered whether since the current data showed high percentages and little variation how useful this indicator would be.

Would the indicator count all deaths?

There were a range of queries raised about the definitions to be used, particularly in respect of the position of community hospitals.

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Dec 21st 2012