

## **Consultation feedback form: draft quality indicators for palliative and end of life care**

Consultation is a key element of developing our quality indicators. Your views and comments are valuable to us. All the comments and suggestions we receive will remain confidential (and be processed in line with the Data Protection Act 1998) and will only be used to help develop **quality indicators for palliative and end of life care**. All comments received will be treated anonymously. We would be grateful if you could provide feedback on:

- Appropriateness.
- Key points or areas that are not covered.
- Feasibility of data collection.
- Usefulness in prompting and supporting improvement in palliative care.

The consultation closes on Friday **21 December 2012**.

Please return your completed form by email to [hcis.peolc@nhs.net](mailto:hcis.peolc@nhs.net) or alternatively you can return the completed form to Jim Smith, Project Officer, Healthcare Improvement Scotland, Delta House, 50 West Nile Street, Glasgow G1 2NP.

At the end of the consultation period, we will collate all comments and the project group will respond to each comment received on the draft quality indicators. We will publish all comments (which will be anonymised), together with the project group's response on the Healthcare Improvement Scotland website ([www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org))

**Indicator 1: Identifying people with palliative and end of life care needs**

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| Appropriateness   | This aligns with other QOF measures to encourage registration of patients in various therapeutic areas and is a good starting point.  |
| Key points or areas that are not covered                              | It is quantitative and cannot identify whether the listed patients are appropriate or not. Is there a way to breakdown the disease states to confirm the expected proportion of non-cancer patients is included?  |
| Feasibility of data collection  | This is within normal practice in GP surgeries.   |
| Usefulness in prompting and supporting improvement in palliative care | In itself this measure does not actually improve palliative care but provides a starting point for any intervention designed to do that by identifying the correct patient group.   |
| Other comment   | Guidance to GPs will be required to help identify appropriate patients with conditions specified in the Gold Standards Framework Prognostic Indicators.<br>Is there a need for another measure to routinely identify patients in secondary care and care homes? The average stay in care home is now of the order of 15 to 18 months and therefore care home residents should be prioritised to be considered for the palliative care register. This would align with the prioritisation of care home residents in the recently published national polypharmacy guidance. |

**Indicator 2: Assessment and care planning to meet patients' palliative and end of life care needs.**

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| Appropriateness | This is appropriate as all palliative care patients should have an ePCS or its equivalent in future added to their records at the point of joining the register.<br><br>Will the indicators dovetail with the plans for the eKey Information Summary? |
|                 | There is no qualitative measure of the ePCS. The ePCS   |

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| Key points or areas that are not covered                              | <p>data is highly dependent on the updating by GP or other health professionals involved in the patient care.</p> <p>Variance in practice will need to be identified and reduced.</p> <p>Access to ePCS is not universal in all care settings.</p> |
| Feasibility of data collection  | <p>This is easily retrieved in primary care from GP practice systems.</p>  |
| Usefulness in prompting and supporting improvement in palliative care | <p>Usefulness is limited without quality measures that will identify what was done in response to the information in the ePCS including key areas of patient choice and wishes.</p>  |
| Other comment   | <p>Will this be available in care home settings for access appropriately by staff and family to ensure patient's wishes can be accessed at all times to ensure continuity of care?</p>   |

**Indicator 3: Accessing the anticipatory care plan (ACP) in all unscheduled care settings.**

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| Appropriateness   | <p>Limited appropriateness as a quality measure.</p> <p>Outcome that would be achieved is unclear.</p>  |
| Key points or areas that are not covered                              | <p>There is nothing to measure if actions have been taken as a result of access. Evidence that people have responded to the ACP would be more useful.</p>   |
| Feasibility of data collection  | <p>Obtainable from routine sources.</p>   |
| Usefulness in prompting and supporting improvement in palliative care | <p>Only useful as a prompt but does not give any indication of improvements or patient benefits as a result of access therefore of limited usefulness as a quality measure (but is acknowledged as a proxy).</p>  |
| Other comment   | <p>Will the ACP be available in all setting by appropriate professionals to ensure continuity of care and how will we know if patient's wishes have been carried out?</p> <p>This states "number of ePCS reviewed". In out of hours period "Is this intended to mean number of patients seen/</p> |

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|  | <p>reviewed / presenting in the out of hours period?</p> <p>The indicator is measuring access to the ACP but the measure is for access to the ePCS. Is the ePCS included in the ACP in all cases? Some clarity would be helpful in the accompanying text.</p> |
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**Indicator 4: Place of care at end of life.**

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| Appropriateness   | <p>This does not measure patients' preference at all. This measures only time in hospital with no link between times of stay in hospital to time of death.</p>   |
| Key points or areas that are not covered                              | <p>There is no indication of whether or not the patient has spent their last days at their choice of venue. It does not cover at which part of their last six months they were in which setting.</p> <p>It does not allow for those patients who would prefer to die in hospital.</p> <p>It does not measure death in hospital versus preferences on ePCS.</p> |
| Feasibility of data collection  | <p>From routine sources.</p>   |
| Usefulness in prompting and supporting improvement in palliative care | <p>This does not provide any useful information on improvements to care as these could occur in both secondary and primary care.</p>   |
| Other comment   | <p>Would a measure of the percentage of patients dying in hospital not give a better indication of preference as the statistics on preferences are already available for comparison?</p> <p>There is little value in collecting data which has limited usefulness but adds administrative burden.</p>  |

**Any further comments**

We appreciate the constraints regarding data retrieval and cost which have been applied to the measures.

The indicators are a starting point for raising awareness but standing alone have limited usefulness.

There will need to be sharing of data on variation across practices when available to allow practitioners to compare their performance.

Guidance and information will need to be available to everyone involved in the patient journey on the true qualitative measures these indicators are proxy for in order stimulate a raising of awareness of the need for improvement in the breadth of settings and disease states where improvement is required.

In particular the relevance to disease states other than cancer should be strengthened in accompanying documentation. The guidance should include information on the process to be followed once a person is considered for the palliative care register including a polypharmacy medication review.

The data will be incomplete unless a means is found to capture interventions made out with GP surgeries or in the acute setting such as hospices, care homes and community pharmacies.

Thank you.

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