

## **We need to talk about Palliative Care**

### **Healthcare Improvement Scotland**

Thank you for the opportunity to provide evidence in relation to the inquiry into palliative care. Rather than address the specific questions raised in the call for evidence, we would like to make three main points to the Committee:

1. As members will be aware from our evidence to the Committee on this subject on 2 June, Healthcare Improvement Scotland does not currently have a specific workstream on palliative care. However, we touch on palliative care as a theme in our inspections of services for older people in acute hospitals, joint strategic inspections of adult services with the Care Inspectorate and inspection of independent palliative care hospices. We are also responsible for maintaining key guidelines on palliative care and a number of our improvement activities going forward are linked to palliative and end-of-life care. Appendix 1 provides a summary of Healthcare Improvement Scotland activities relevant to palliative care provision in Scotland, for information.
2. Healthcare Improvement Scotland is represented on the Palliative and End of Life Care National Advisory Group, which is currently developing a Strategic Framework for Action. It is anticipated that the Strategic Framework will include for adults and children high level aims and ambitions within which all health and care providers will have the scope to work together to develop local plans in order to deliver improvements and to meet the palliative and end of life care needs of local populations. We would expect that this will address a number of the issues raised by the Committee's inquiry.
3. As noted above, we have chosen not to answer the specific questions contained in the call for evidence. A number of the questions, particularly question 4, focus on the timing, nature and location of discussions on palliative care. We feel that it is not possible to come up with definitive answers to these questions, which highlights that ultimately this issue is about providing consistently high-quality, person-centred care. This will depend on individual patients, their carers and families, and what matters to them. This should be at the core of all healthcare services of which palliative care is just one specific aspect; it is ultimately about continuing to develop a culture with the person at the centre, which can be supported by education and training across the service.

It is also worth noting that complaints, feedback and adverse events – as well as examples of good practice - relating to palliative and end of life care can provide useful learning and intelligence from a service user or carer perspective about what works well or does not.

**Healthcare Improvement Scotland**

## **Appendix:**

### **Overview of Healthcare Improvement Scotland activities relating to palliative and end of life care**

- **Standards and inspections for the care of older people in hospital**

We published revised [standards for the care of older people in hospital](#) in June 2015. While there is not a specific standard on palliative and end of life care, key issues are threaded throughout the standards. For example, the standard on maintaining patient privacy and dignity is relevant to discussions on options for palliative care, and the standard on assessment on admission to hospital supports the identification of palliative or end of life care needs.

We are scoping the extension of these inspections into community settings, and the inclusion of the inspection of dementia services within the wider programme.

- **Joint strategic inspections of adult services**

Our joint inspections, with the Care Inspectorate, of older people's services, look at how well health and social work services are delivering good outcomes for older people and their carers. This includes looking at palliative and end of life services where appropriate. In particular, we look at how partnerships are progressing with the implementation of anticipatory care plans. We plan to ask for a sample in the forthcoming inspections so we can also look at the quality of the plans.

- **Regulation of independent healthcare services**

There are currently 15 (plus one registration pending) palliative care hospices in Scotland that are regulated by Healthcare Improvement Scotland. As a part of the inspections we have been looking at:

- the arrangements the service have in place to record the care delivered in the last days and hours of life
- how the service records the discussions staff have with patients about end of life care and the important decisions to be made
- that a patients preferences about places of care and place of death are sought, noted and that there are plans in place so every effort can be made to honour them, and
- that Scottish guidance is being followed in respect of DNACPR.

We have inspected all of the hospices recently and the inspection reports are published on our website. These reports will hold a lot of intelligence about the quality of palliative care delivered in hospices.

An assessment of the safe delivery of systemic anti cancer therapies in independent healthcare services in Scotland has also been undertaken.

- **Scottish Patient Safety Programme**

Specific aspects of the acute workstream of the Scottish Patient Safety Programme are relevant to palliative and end of life care, as noted in several NHS Board responses to the Committee's recent annual budget questionnaire.

### **Deteriorating patients**

The acute adult programme has ongoing work to improve the recognition and management of deteriorating patients in acute hospitals. This work aims to reduce cardiac arrests by improving reliability of response and review of patients with physiological deterioration who trigger the Early Warning Score.

The change package associated with this work includes interventions such as

- Structured ward rounds: reviewing patients for potential deterioration and forming management plans that may include referral to palliative care
- Treatment Escalation plans that may range from ICU transfer to referral to palliative care
- Prompting access to electronic Key Information Summary (EKIS) which may include Anticipatory Care Plans

This national approach to care of adult deteriorating patients is underpinned by [SIGN 139: Care of deteriorating patients – consensus recommendations](#) (May 2014).

### **DNACPR**

There is ongoing work with three NHS boards to develop a framework of measures that will provide information to support improved delivery of DNACPR guidelines in line with recent legal changes.

- **Living Well in Communities**

Healthcare Improvement Scotland, in collaboration with the Joint Improvement Team and the Quality and Efficiency Support team, has recently undertaken a scoping and design phase for a new portfolio of improvement support. The Living Well in Communities portfolio is designed to enable individuals to live at home or in a homely setting and avoid unnecessary hospital admissions. The portfolio is under development and one area of focus is anticipatory care planning, which aims to facilitate NHS boards and partnerships to better understand individual pathways, including those for end of life, and as a result, identify opportunities for implementing anticipatory and advance care planning and increase the update and access to Key Information Summary.

- **Standards and indicators**

Healthcare Improvement Scotland published [Palliative and end of life care](#) and [DNACPR](#) (Do not attempt cardiopulmonary resuscitation) indicators in 2013.

As noted above, palliative and end of life care issues are threaded through the recent standards for the care of older people in hospital. We are currently developing standards for [complex nutritional care](#) which are also likely to address relevant issues. The requirement for standards or indicators for palliative care will be considered in the light of the forthcoming Strategic Framework for Action.

- **NHSScotland Palliative Care guidelines**

Supported by Healthcare Improvement Scotland and the Scottish Partnership for Palliative Care, the updated [guidelines](#) (published November 2014) reflect consensus of opinion about good practice in the management of adult patients at the end of life. Healthcare Improvement Scotland is responsible for maintenance of these living guidelines, through a multidisciplinary governance group.

### **Other relevant activities**

- **Person Centred Health and Care Programme**

While this area of work is not specifically connected to palliative care, the importance of person-centred care to this issue is central, as emphasised in point 3 of our response. The programme takes a human rights-based approach to health and care that respects the personal experiences of the individual. We promote and support systems for listening to the experiences of people who use services and use their feedback to drive improvement and make care more person-centred.

Practical improvements to person-centred care are promoted and supported through five key 'Must Do With Me' areas. These help to ensure that all of the interactions between people using services and the staff delivering them are characterised by **listening, dignity, compassion and respect**, which we would maintain are central to high quality palliative care.