Cabinet Secretary for Health, Wellbeing and Sport

Shona Robison MSP

T: 0300 244 4000

E: scottish.ministers@gov.scot



Neil Findlay MSP Convener Health and Sport Committee Scottish Parliament Edinburgh EH99 1SP

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Thank you for your letter of 19 January 2017, which asked for a further update on progress with implementing our Strategic Framework for Action on Palliative and End of Life Care, particularly in the light of the publication of the Health and Social Care Delivery Plan. I remain grateful for the Committee's continuing interest in this important area of work. For consistency and clarity, I have addressed each of the questions set out in your letter in turn, below.

Milestones and Measurements

Most people receive support at the end of life in non-specialist settings, and data about the quality and quantity of this support is not always flagged as 'palliative'. In endeavouring to make use of the available data and to make this otherwise 'hidden' support visible, the data subgroup of the National Implementation Advisory Group (NIAG) for the Strategic Framework for Action on Palliative and End of Life Care (SFA) are working to produce a report that will detail the existing data sources and data gaps on palliative care. This report, which will be available in Spring 2017, will also make recommendations for a 2017-18 work plan, setting out the required actions to close the data gaps and help ensure that there is appropriate information available to measure the quality of care people with palliative care needs have received and the services they have accessed.

The data group are also working to link palliative care data to the existing individual level data which is aggregated in Source, the linked data resource available to all Integration Authorities from NHS NSS. This will support Integration Authorities in gaining a more detailed picture of palliative and end of life care services and need in their area, for example by age, gender, cause of death, place of death, socioeconomic group and long term condition.

Longer term, access to the electronic Key Information Summary (KIS) and Anticipatory Care Plans (ACPs) will allow progress towards a person centred approach to be assessed and







made available to Integration Authorities to support their strategic commissioning decisions. This will also further support the case for the shift of resource into the community.

On a broader point, as you know the Scottish Government has asked Sir Harry Burns to undertake a review of health and social care targets and indicators. Initial recommendations from the review are expected to be with Ministers in Spring 2017. We expect that the work outlined above will be influenced by the findings of the review and I look forward to sharing more details with you and the Committee on this in due course.

Health and Social Care Delivery Plan

Palliative care is an important component of the Health and Social Care Delivery Plan, and our objective on this is rightly challenging. As reflected in the ethos of the Plan it is essential that improving high quality palliative and end of life care is not considered in an isolated or stand alone manner. Enabling people to live and die well and with dignity at home or in a homely setting will require integrated and coordinated action. This is why Integration Authorities have been given statutory responsibility for meeting this need.

We want to support people to stay in the community (as far as possible) at the end of their lives. By creating the right conditions to enable Integration Authorities to make the changes needed to reduce the use of inappropriate types of care and invest alternatives, we expect to see a reduction in occupied bed days and more people supported to die at home. Much of the work required to support this shift is already addressed by the commitments set out in our SFA. Specific examples of work being taken forward include:

- Supporting Integration Authorities in their strategic commissioning role by developing supplementary commissioning advice on palliative and end of life care, to supplement the statutory guidance for strategic commissioning plans.
- Supporting this commissioning function with appropriate data (as outlined above) covering both specialist and non-specialist palliative care.
- Commissioning Healthcare Improvement Scotland to support six Integration
 Authorities in improving the identification and care coordination of those who could
 benefit from palliative and end of life care. This work is helpfully brigaded alongside
 Anticipatory Care Planning, frailty pathways and falls management and prevention,
 improving links between the housing sector, health and social care elements of
 delayed discharge, and pathways for high-resource users of health and social care
 services in the 'Living Well in Communities' work stream.
- Working with Hospice Chief Executives, to assist in their efforts to increase the capacity and capability of their wider communities in supporting people with palliative care needs.
- Working with primary care colleagues, as they develop cluster continuous quality improvement approaches, to improve the design and delivery of care services across the health and social care system including improvements that support people with end of life care based in the community.
- Focusing on Anticipatory Care Planning, which encompasses both the skills and confidence of staff to have appropriate care planning conversations with people and those that matter to them, and the technology to hold and share the preferences and decisions about how those nearing the end of life wish to be cared for. The Key Information Summary is currently key in supporting this, which is why it has featured in the Health and Social Care Delivery Plan.
- Supporting the health and social care workforce by developing a training framework, which will increase staff confidence and willingness to have conversations about preferences and decisions at the end of life.
- Monitoring through the annual reports produced by Health and Social Care Partnerships, and regular monitoring data will enable progress to be tracked.







 The budget for 2017/18 sets out the financial context for transformation of health and social care services

Strategic Commissioning Guidance

Each Integration Authority is required to publish an annual performance report which sets out how the national health and wellbeing outcomes are being improved.

Although it is for Integration Authorities to decide upon the layout of their own performance reports, on-going engagement with Chief Officers has confirmed their strong interest in improving on palliative and end of life care, and in reporting on improvements in this area.

In addition to a range of indicators which are also relevant there are two specific indicators with explicit connection to palliative and end of life care, which integration authorities are required to report on. Engagement with stakeholders should also be reported on, as this is set out in statute.

The National Health and Wellbeing Framework refers to the PANEL principles, stating that where these are used in planning and delivery, services and support should uphold the rights of everyone, be person-centred, and demonstrate that they aim to ensure good decision-making, improvement in institutional culture and relationships, legal compliance and best practice.

Improving Public Discussion

Conducting a national publicity campaign to change people's attitudes to death dying and bereavement has been considered as an option to help improve public awareness of this issue. However, given the personal nature of established cultural norms, including attitudes to death dying and bereavement, which are not easily susceptible to change, a national awareness campaign would likely have a marginal impact

We are focussed instead on making progress in a number of broader areas:

- Some hospices, working with their local Integration Authorities, are working to create compassionate and resilient communities. One such, 'Compassionate Inverclyde' is a great example of people coming together to support each other at times of stress and challenge. This is of a piece with the vision of Hospice Chief Executives across Scotland. We will highlight this 'public health' approach to palliative care and end of life care in the supplementary commissioning guidance.
- When refreshing our Health Literacy Action Plan, as set out in the Health and Social Care Delivery Plan, we will work collaboratively with the Scottish Partnership for Palliative Care and other key stakeholders to develop actions that best support the skills, confidence knowledge and understanding of people as they seek to discuss, record and share 'What Matters' to them. Each person's needs may vary, but having such care planning conversations may touch upon a wide range of issues including housing arrangements, issues of mental incapacity and establishing Powers of Attorney, 'Do Not Attempt Cardio Pulmonary Resuscitation' decisions and other ceilings of care. They may also include other preferences which aim to support people's desires and dignity at the end of life.
- We are continuing to work with and support the Scottish Partnership for Palliative Care, who established and host Good Life, Good Death, Good Grief which aims to raise public awareness of ways of dealing with death, dying and bereavement, and promotes community involvement in death, dying and bereavement. The Cross Party Group on Palliative and End of Life were recently briefed about this work – and we look forward to further suggestions from this group.







• We are aware of those delivering services responding to the accounts placed on Patient Opinion, and of arrangements to bring aggregated information from those accounts being presented back to Integration Authorities. We have no plans to make this a requirement.

Care in Prisons

As you note in your letter, the measures being undertaken as set out in our previous response to the Committee on 7 December 2016 are preparatory, and as a result outcomes for this work are not yet available. Implementation will be progressed and reported on locally.

I hope that this response, combined with my previous letter of 7 December 2017, provides the Committee with a reasonable overview on the work being taken forward against the commitments set out in the SFA.

SHONA ROBISON





