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Mr Neil Findlay MSP
Convener
Health & Sport Committee

By Email.

5 December 2016

Dear Neil,

Thank you for your letter of 16 November 2016, which asked for an update on progress with implementing our Strategic Framework for Action on Palliative and End of Life Care. I am grateful for the Committee's interest in this important area of work, and welcome the opportunity to provide an update. For clarity, I have addressed each of the questions set out in your letter in turn, below.

Palliative and End of Life Care Data

What work has been done to improve data collection and analysis as promised in Commitment 9 of the Framework?

When will a complete picture of palliative resource in Scotland be known?

How you will ascertain the palliative care need for Scotland?

How will quality of care be measured, reflecting a person-centred approach?

The National Implementation Advisory Group on Palliative and End of Life Care (NIAG), established to support the implementation of the other commitments, has an information subgroup established to take forward commitment 9 which deals with data. This sub group is taking forward an exercise to identify the gaps in available data, information and analyses that need to be addressed in order to support improvements in palliative and end of life care services. The subgroup will provide recommendations in the spring of 2017, with action to follow during 2017/2018. As this work progresses, I expect it to support a much improved understanding of the spectrum and quality of palliative and end of life care services, and resources, available across Scotland. It will nonetheless continue to be challenging to achieve a complete picture, given that a lot of care at end of life is provided outside specialist settings, and by unpaid carers.

The Committee may wish to note that this work will inform the national review of targets and indicators for health and social care being undertaken by Sir Harry Burns.



The work on commitment 8, which deals with economic and effectiveness evaluation, will require good robust data before it can be meaningfully addressed, and will therefore need to follow progress on work on commitment 9.

Improving Palliative Care for Children and Young People

Professor White noted in oral evidence that the Scottish Government was working in association with the Children's Hospice Association Scotland to test out different models of respite care for young adults. Can you provide details of how the testing is progressing and if any recommendations have been made or any specific respite provisions put in place for young adults?

The Children's Hospice Association Scotland (CHAS) is approaching the end of year two of its three year Transition Project, which focussed on supporting young people to find suitable alternatives to the short planned breaks provided by CHAS. The transition team are currently supporting 52 young people to explore options for their adult lives including respite options. So far, 25 young people have positively moved on from CHAS. The transition team will continue to work with the remaining young people currently using CHAS services to help maximise their opportunities for independence, and identify age appropriate options available to them.

CHAS have also worked with many organisations including Leuchie House, Falkirk Council and Shared Care Scotland to help young people test respite services and be creative around alternatives to traditional respite care. Examples of informal respite models tested have included:

- Parents leaving the family home for a short break and personal assistants moving in to provide round the clock care for a few days.
- Personal assistants being employed to take young people on holiday.
- Young people combining their budgets and sharing breaks away – hiring holiday homes and staff.
- Families taking holidays together, and taking personal assistants with them to create respite break time within the family holiday.
- Supporting young people to try out a range of private and local authority facilities (such as Cornerstone, Community Care Choices, Stanmore Transition Flats, Homelands Trust Properties, March Glen, The Gyle)

Atlas of Palliative Care

A mapping exercise of specialist palliative care services across Scotland carried out by Professor David Clark

The Scottish Atlas of Palliative Care, the first national atlas of specialist palliative care in the world, was published in September. It provides Scotland-specific data on levels, location and types of palliative care services across Scotland, which had previously been subsumed within UK data.

End of Life/Anticipatory Care Planning Conversations

During oral evidence it was advised that NHS National Services Scotland had been commissioned to carry out a piece of work to make sure that the key information summary, in its current state, was being used and accessed. Can you advise if this work has now concluded and if so provide an update on the outcomes?

NHS National Services Scotland (NSS) are investigating current use of the Key Information Summary, Emergency Care Summary and Electronic Palliative Care Summary, and are also considering information requirements for effective Anticipatory Care Planning. NSS will report on this work early in 2017.

Palliative and End of Life Care Educational Framework

You advised that NHS Education for Scotland was recruiting three regional practice education co-ordinators to work across the NHS and social care services on establishing an integrated and collaborative approach to palliative and end-of-life care education provision. Can you advise if these posts have now been filled and how the role is progressing, and also how the new palliative and end-of-life care educational framework, as outlined in Commitment 3, is developing?

Commitment 3 is being taken forward by NHS Education for Scotland (NES) with the Scottish Social Services Council (SSSC). The three practice education co-ordinators have now been appointed, and are working regionally across health and social services in Scotland. Their focus is on ensuring a consistent approach to workforce learning and development, and to sharing practice across Scotland. They are engaging widely, including with the workforce in the statutory and third and independent sectors, and carer organisations, and they recently reported on their work to the Cross Party Group on palliative care.

A national consultation exercise is underway to gather views from the workforce on the content and structure of this new framework. The consultation is informed by evidence from relevant literature, focus group discussions, a survey, and consultation and feedback events at a national and local level.

Strategic Commissioning Guidance

Can you confirm that this guidance has been provided to the partnerships? How will the Scottish Government monitor the implementation and use of the guidance?

We published statutory guidance on Strategic Commissioning Plans in early 2015. Work is underway to produce additional advice on the strategic commissioning of palliative and end of life care to augment the statutory guidance, with a small task group, made up of a range of key stakeholders, providing input.

We are also working with Health and Social Care Partnerships to review progress on strategic commissioning of new services, and to share good practice and lessons learned. Healthcare Improvement Scotland are providing direct support to partnerships as integration beds in, and also to share learning. In addition, each Health and Social Care Partnership is required to publish an annual performance report using the national indicators, as well as any locally derived indicators, to show progress against the national health and wellbeing outcomes.

Review of Hospice Funding

A review of hospice funding to address the disparity between adult and children's hospices and specifically the review of the funding agreement between NHS Tayside and Children's Hospice Association Scotland.

The broader issue of commissioning guidance is dealt with above. We have addressed the specific issue of support for children and young people's palliative and end of life care needs by committing £30 million over the next five years, which has been welcomed by CHAS.

Given this progress, I am due to meet with officials shortly to discuss how best to progress a review of hospice funding, and to decide whether a separate process is now required.

Improving Public Discussion of Bereavement, Death, Dying and End of Life Care

The Committee highlighted the need for greater public and personal discussions of death and dying whilst also acknowledging the success of previous campaigns in this area. Commitment 6 agrees to support this need partly through commissioning of work. Can you advise if any work has been commissioned to support this goal and if there are any further campaigns to be run on this topic?

The previous Minister for Sport, Health Improvement and Mental Health and yourself advised that you were looking at ways of extending VOICES so that it was Scotland wide. Can you advise if any progress has been made on achieving this and if any other options have been explored for including families and service users in the feedback process?

I am very thoughtful about how best to support public and personal comfort in discussions about death and dying. I am particularly mindful of the importance of supporting local developments that, by working with care givers and professionals, Health and Social Care Partnerships and hospices, encourage and sustain compassionate communities. At this time, I do not plan to run a national campaign in relation to death and dying as such, but there are important potential links to be explored with, for example, public awareness of the importance of planning for later life – in relation for example to Anticipatory Care Planning and Power of Attorney arrangements.

Feedback on the quality of palliative and end of life care from service users and families is particularly important to assuring and improving services, and we are working with NHS Lothian to test the potential effectiveness of extending the VOICES approach. VOICES previously suffered from a low response rate when we used it in Scotland, we think in part because of the challenges of running a retrospective survey with people who have been bereaved.

In addition, the Patient Opinion website continues to provide an online route for people to share their experiences of care services, including palliative and end of life care, directly with service providers. We are also developing "Our Voice", with the Scottish Health Council, Healthcare Improvement Scotland public partners, COSLA, the Scottish Government, the ALLIANCE and other third sector partners, to enable people who use health and care services, carers and the public to engage with service providers across health and social care to help improve and transform services.

National Implementation Advisory Group

The Framework also advises that a national implementation support group will provide an annual learning and improvement report. It would be helpful to know when this report will be published each year and I would be grateful if you would advise.

We will publish this in Spring 2017.

Palliative and end of life care for prisoners in all settings

One of the areas covered in the previous committee's inquiry report was the range of different settings that palliative care could be provided in. One setting not covered in that report was prisons. We are aware that the responsibility for the health care of the prison population now falls with health boards and it would be helpful if you could advise what steps have been taken to ensure that all prisoners who need palliative care receive it; whether within the prison or on release to a hospital or hospice

Palliative care is an increasingly challenging area of healthcare for those working in prisons, given the increasing age of the prisoner population. A number of strands of work are addressing these challenges.

Healthcare Improvement Scotland developed palliative and end of life care indicators for NHS Boards to support their delivery of palliative and end of life care in March 2013. The National Prisoner Healthcare Network professional leads made contact with HIS as part of the consultation process, to suggest that these indicators should also be useful in the context of a prison healthcare setting; this led to HIS colleagues making visits to prison establishments to establish the nature of the environment and how these indicators could be used to measure the impact of their work.

There has been close collaboration between NHS and the Scottish Prison Service teams to drive improvements in palliative care. This has also included forming strong links with community partners such as Macmillan Cancer to enhance knowledge and understanding of palliative care, and to support prisoner healthcare teams to gain access to appropriate resources. This aligns closely with an objective within the strategic framework to recognise the wider sources of support within communities that enable people to live and die well.

NHS healthcare teams and the Scottish Prison Service have also recently collaborated on an estate wide social care needs assessment. This looked primarily at people's need for support with the activities of daily living, but thereby gives indication of the growing issue of palliative care needs, and where those needs could be better met.

In addition, there are specific examples of work that is being delivered by NHS Boards to provide palliative and end of life care across the prisons estate:

- In HMP Glenochil - an establishment which houses a significant number of ageing prisoners - the multi-agency Primary Care Team were recently recognised at the Scottish Health Awards for their work on Integrated Care for Older People. This work has led to the development of an advanced model of nursing practice for those in prisons across NHS Forth Valley. The board has also appointed a Palliative Care Coordinator, who will commence in January 2017.
- NHS Board staff at HMP Dumfries have created detailed plans and enhanced their own skills to support prisoners in need of end of life care. The Healthcare Manager has spent time working in a palliative unit and shadowed the Lead Nurse for Cancer Services, who has visited the prison to give guidance on the accommodation and its suitability for end of life care.
- HMP Greenock and Low Moss support nursing services by making use of the SPS contract to engage with Social Care agencies. The latter used this to provide care for a prisoner at the end of his life.
- Within HMP Barlinnie a named nurse, working in liaison with Marie Curie Nursing Services and the Beatson Hospital, is assigned when someone needs end of life care.
- HMP Barlinnie have made use of 'release on compassionate grounds' arrangements, and in two recent cases beds at the Beatson and St Margaret's Hospice were accessed for prisoner in need of end of life care. In a further example a prisoner was released to die at home with his family, who were very grateful for the support.

Scottish Research Forum for Palliative and End of Life Care

Whilst I have mentioned specific commitments and strands of work within this letter I would be grateful if you could update us in relation to all work that has been undertaken to implement the commitments in the strategic framework

The Research Forum has so far met twice and will meet again in February 2017. Details can be found here: <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/Implementation-SFA-peolc/researchforum>.

The most relevant Scottish research to inform the Strategic Framework has been presented, among researchers, and to relevant managers, trainers and clinicians, with a focus so far on:

- Identifying more people for palliative care
- Communicating and planning better with patients and carers
- Encouraging the general public to be able to talk more openly about death and dying

Request to Healthcare Improvement Scotland to submit a report describing how its existing work could support the commitments to palliative and end-of-life care and how that links in with on-going work on the national care standards and the inspection process.

Agreement from three health and social care partnerships – Glasgow, East Ayrshire and Western Isles- to test out how the Commitments can be implemented

Healthcare Improvement Scotland's ihub (the new improvement resource for health and social care) has been commissioned to deliver commitment 1 of the Strategic Framework for Action on Palliative and End of Life Care, which is being taken forward as part of our 'Living Well in Communities' work.

'Living Well in Communities' has worked on anticipatory care planning with a range of health and social care providers to create documentation for use at the end of life. This documentation has been designed to improve the quality and co-ordination of care, and it aligns to fields within the Key Information Summary. This will improve the quality of anticipatory care planning information shared with out of hours, emergency, hospice and acute care services. A range of supportive learning materials, which include end of life scenarios, are also being developed, with specific focus on:

- Increasing the number of people identified who could benefit from palliative and end of life care
- Improving the co-ordination of palliative and end of life care
- Testing Alzheimer Scotland's Advanced Model to support people with dementia at the end of their lives

Five Health and Social Care Partnerships – Glasgow City, East Ayrshire, Fife, Western Isles, and Perth and Kinross – are testing implementation of the commitments with support from the ihub as follows:

- Funding and training locally-based staff to deliver palliative and end of life care improvement activity within the partnership.
- Providing expertise to analyse current systems to identify the key areas for improvement within the context of their local system.
- Undertaking evidence searches to provide local test sites with knowledge to make evidence-based decisions to inform local improvements.
- Providing expertise on testing different mechanisms to identifying who would benefit from palliative and end of life care and improve co-ordination of care. This includes designing, implementing and evaluating tests of change. Evaluation support includes access to health economists.
- Acting as a knowledge conduit to bring learning from other SFA commitment-owners, and the wider palliative care community, to the benefit of local test sites.
- Sharing learning from local test sites with the NIAG, other commitment-owners, other health and social care partnerships and the wider palliative and end of life community.

In Conclusion

Progress on achieving our vision for palliative and end of life care will be achieved by delivering on the commitments in the strategic framework over the next five years. Some parts of our work, especially those on data and training, lay the foundation for progress on the other commitments.

I hope that the Committee finds this update helpful.

Best wishes,
Shona

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