

## EQUALITY IMPACT ASSESSMENT - RESULTS

<b>Title of Policy</b>	Strategic Framework for Action on Palliative and End of Life Care
<b>Summary of aims and desired outcomes of Policy</b>	<p><b>Palliative and End of Life Care Aims</b></p> <ul style="list-style-type: none"> <li>➤ Access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.</li> <li>➤ People, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this accords with their needs and preferences.</li> <li>➤ Communities, groups and organisations of many kinds understand the importance of good palliative and end of life care to the well-being of society.</li> </ul> <p><b>Palliative and End of Life Care Outcomes</b></p> <ul style="list-style-type: none"> <li>➤ People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.</li> <li>➤ People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.</li> <li>➤ People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.</li> <li>➤ People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.</li> </ul>
<b>Directorate: Division: team</b>	Healthcare Quality and Strategy Directorate Planning and Quality Division Palliative and End of Life Care Team

## Executive summary

The vision for the Strategic Framework for Action on Palliative and End of Life Care (SFA) is that by 2021, everyone in Scotland who needs palliative care will have access to it.

A full Equality Impact Assessment (EQIA) process was undertaken to inform and enhance the SFA.

The EQIA process revealed a focus in research on the following areas across the protected characteristics:

- Improving care to people aged over 85 years who are under-served.
- Improving services for younger people as recommended in the *Children in Scotland requiring Palliative Care: identifying numbers and needs* (The ChiSP Study, 2015).
- More information and research is needed on disabled patients needs including focussing on increasing referrals of disabled patients to specialist care. More joint working, better co-ordination and reasonable adjustments for palliative care provision is also required for people with disabilities.
- Further research required to identify the most effective way of capturing the perspectives of those with learning disability and of enabling people with learning disability to access and engage with palliative care services.
- Further and specific research is required on the population, and the palliative care needs, of patients who are lesbian, gay, bisexual ,transgendered or intersex (LGBTI).
- There is a need for specific and focused education of health and care professionals to enhance their awareness of the concerns of people who are LGBTI about the possibility of discrimination, heterosexist assumptions and recognize the importance of partners in decision making in respect of palliative and end of life care.
- Increase access to end of life care for people from black, Asian and minority ethnic (BAME) groups by ensuring that services understand their differing needs.
- Research required about whether the spiritual needs of all patients are being met by current palliative and end of life care services.

The EQIA process also highlighted that there are other 'non-protected' characteristic groups of the Scottish community who face barriers to accessing palliative and end of life care and will need to be considered and targeted during implementation of the SFA. These groups include the people who are in prisons, people who are homeless, Gypsy and traveller communities, those in geographically isolated regions and low socio-economic circumstances.

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## **Background**

In 2014 the World Health Assembly – the governing body of the World Health Organisation - passed a resolution requiring all governments to recognise palliative care and to make provision for it in their national health policies. The SFA is the Scottish Government's response to that call. It builds on many actions and policies already in place and sets out the goals, challenges and direction for future improvement. It is also informed by the detailed recommendations, suggestions and guidance to be found in the report of the Scottish Parliament's Health and Sport Committee, following its inquiry into palliative care in 2015.

The SFA was developed in a year of unprecedented public discussion about end of life issues – in the Scottish Parliament, in the national media, in expert reports, briefing documents, consultation submissions and in the work of leading researchers.

As a society Scotland is facing a growing need for appropriate care in the face of ageing, life limiting illness and death. We are challenged by the scale and complexity of this but we also have substantial assets and expertise with which to respond. The SFA builds on these, to map out a vision where everyone who can benefit from palliative care in Scotland will receive it – no matter what their circumstances.

To achieve this vision, many people, organisations and agencies will have to work together in a culture of collaboration and with a passion for improvement. Palliative and end of life care are now issues of major public interest. The SFA lays out the elements in the work that must now be done to create a more compassionate Scotland - and to give people the best care possible at the end of their lives.

## **The Scope of the EQIA**

The EQIA has been delivered with input from members of the National Advisory Group and the Health Analytical Services area of the Scottish Government.

## **Key Findings**

The key findings of the equality impact analysis process was that protected characteristics groups including people with disabilities, LGBTI and minority ethnic groups all face additional barriers to accessing palliative and end of life care which meets their needs. To a degree the elderly and young people also do not receive appropriate care for their needs, and for all patients their spiritual needs at the end of life may not be met completely. For women in pregnancy and maternity there are specialist services to care for their unborn and new born babies with palliative care needs but limited UK research on the needs of the very few mothers who have life limiting diseases in pregnancy and maternity. There is a need for more data on all the protected characteristics groups and their use of and need for palliative care.

The 10 commitments for implementation of the SFA to meet the 2012 vision will contribute to better care for people of protected characteristics groups, however, key to this will be capturing data on the use of palliative care by protected characteristic.

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The Scottish Government recognises there is a need to improve data collection and has made two specific commitments. First, to ensure that improvements are made to the way information related to palliative and end of life care is collected, recorded and shared. Second, to ensure that assembled data and evidence is effectively used to inform learning, promote improvement and the spread of high quality care.

The Scottish Government has considerable work underway to improve data for health and social care services broadly, to support integration (the Health and Social Care Integration and Intelligence Project, led by NHS NSS and commissioned by the Scottish Government). This programme of work will help local service commissioners to better understand pathways of care, particularly for people with complex needs and at the end of life.

## **Recommendations and Conclusion**

The SFA was developed with equality of provision and access to palliative care for all Scottish people who could benefit from end of life care as a primary aim. To achieve this aim it is recognised that meeting the needs of protected characteristics groups requires dedicated commitment.

It is recommended that data is identified by the Scottish Government and the NHS Scotland Information Services Division on people with protected characteristics and whether they could benefit from palliative and end of life care. This could serve as a baseline to measure progress of the SFA for people with protected characteristics.

Following on from developing a baseline a National Implementation Advisory Group for the SFA is being formed and will oversee that implementation and improvement plans developed for each of the ten commitments. It is recommended that these plans also ensure that the protected characteristics are considered across all commitments. They should be recognised and barriers to palliative and end of life care by people with protected characteristics addressed. Following on from this work will include the collection of data and the sharing of learning about good, effective, appropriate practice across palliative and end of life care services for all social groups in Scotland.

At the time of publishing the SFA was predicted to have either positive or nil effect on each of the protected characteristics groups. As the SFA is implemented the National Implementation Advisory Group will produce an annual learning and improvement report, this report could be used to inform the Scottish Government and stakeholder groups (including those representing groups of people with protected characteristics and health and social care services) of the impact of the SFA on people with protected characteristics.

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