SPPC Submission to Scottish Parliament Health and Sport Committee Inquiry into the Future of Social Care

1. How should the public be involved in planning their own and their community’s social care services?

About Scottish Partnership for Palliative Care (SPPC)

The Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people’s experiences of declining health, death, dying and bereavement. We also work to enable communities and individuals to support each other through the hard times which can come with death, dying and bereavement.

SPPC was founded 30 years ago and has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC’s membership includes all the territorial NHS Boards, all IJBs, all Local authorities, the hospices, a range of professional associations, many national charities, social care providers and universities.

What is palliative care and when is it relevant?

Though more specific definitions can be helpful, one way of thinking about “palliative care” is to talk in terms of providing ‘good care’ to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Perhaps what differentiates ‘palliative care’ from ‘just good care’ is the awareness that a person’s mortality has started to influence clinical and/or personal decision-making. However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Most people, including those approaching the end of their lives do not make a clear distinction between health and social care needs. Their needs will be varied and individual and will change over time (often quite quickly and unpredictably).

Annual deaths in Scotland are projected to increase by 15.9% from 56,728 in 2016 (32.8% aged 85+ years) to 65,756 deaths in 2040 (45% aged 85+ years). People will often live with palliative care needs for several years before they die. A recent study in Ireland estimates that “older people living with a serious disease outnumber those in the last year of life by approximately 12:1". A first step in planning social care services is to understand the implications of these trends. The growing number of babies, children and young people living with life limiting illness also to needs to be recognised and planned for.

Q1 is really two questions with different answers. How the public should be involved in service planning and design is one question. How an individual should be involved in planning their own care is a different question.

Thinking about the first question, at an institutional level HSCPs should be proactive in encouraging public representation at strategic planning meetings and support and be involved in local groups in order to understand the day to day issues in specific communities. Members of the public should be encouraged and supported to use technology to express their views, e.g. via videoconferencing, web surveys and email. Care services should routinely seek feedback from the public about their service, either after receipt of a service (satisfaction questionnaire) or to gauge perception and understanding of what is available versus what the public feel they want/need. The health and social care system is often reluctant to admit that people will, inevitably, die. Public health narratives emphasise achieving longer lives, active healthy aging and prevention. All these are important and desirable. However, a narrative which omits death, dying and loss fails to engage and involve the public honestly and effectively in planning of care.

Thinking about the second question everyone should be involved in every step when it comes to planning for their care, ***to the extent that they choose.*** Good planning should be based on effective conversations about what matters to that individual and about how health, care and informal inputs of all types can support the person in achieving their aims. Existing work on Anticipatory Care Planning is a good basis to build on. People need accessible information (and sometimes effective advocacy support) to engage meaningfully.

Self-directed support is the broad approach to all adult social care in Scotland, which is welcome. However, this broad philosophy of approach needs to encompass variety of circumstance. For many people approaching the end life, with poor health and rapidly changing circumstances, self-directed support as currently embodied in slow, unresponsive, bureaucratic systems of direct payments is not an attractive proposition.

1. How should integration authorities commission and procure social care to ensure it is person-centred?

IJBs should procure care services based on intelligence gathered from a variety of sources including Public Health, 3rd and Independent sector providers and members of the public (both those receiving services and those having difficulty in accessing a service). Commissioning teams, when procuring care services, should develop clear service specifications that not only describe the inputs needed but the outcomes required and also stipulate the method via which performance will be measured against those outcomes. Part of the performance measurement should include as a minimum, the requirement to provide an annual report that includes case studies and feedback that shows evidence of a “person-centred” approach and user-led/user-involved outcomes.

Time and task commissioning does not support person-centred relational care. The deficiencies of the current system have been well-rehearsed elsewhere by multiple stakeholders. Part of the solution will be to redesign and refocus commissioning processes. However, where IJBs are under extreme financial pressure it is not surprising if commissioning processes emphasise cost minimisation. Improvement needs both redesign and resources which reflect growing demand driven by demographic and social change.

The Scottish Government’s Health and Social Care Standards provide a good framework. Services should be commissioned to deliver the outcomes set in the standards. IJB commissioning processes should be assessed on how well they embody this approach.

Commissioning processes should encourage, support and require integrated services and partnership working. Alliance commissioning and contracting is one way of encouraging these ways of working.

1. Looking ahead, what are the essential elements in an ideal model of social care (e.g. workforce, technology, housing etc.)?

Looking ahead, an ideal [or even merely adequate] model of social care needs sufficient funding. This requires political leadership and a higher level of public awareness and engagement about what social care is and how it is currently funded.

Looking ahead, an ideal [or even merely adequate] model of social care needs to be able to recruit, retain and develop the requisite workforce. There is a need to equip the social care workforce to support people in the community with much higher levels of need and complexity than used to be the case. NHS Education Scotland and SSSC have developed a good educational framework on palliative and end of life care, but the extent to which this is being used and implemented is unclear. There is scope for more role flexibility. The co-location at local level of health, social care and other relevant workers is a really powerful and important way of supporting the shift to more integrated ways of working.

A common digital platform across services which supports information sharing is a key essential feature of any adequate future system.

At a more detailed and mundane level appropriate equipment must be available and accessible to help people provide good care.   This is particularly important at the end of life when hoists or beds may be required to enable carers to provide appropriate support at home.

Family and other community members provide the vast bulk of social care in Scotland. The rhetoric about treating carers as equal partners in care needs to be turned into more of a reality. Currently most carers have to fight to get even inadequate levels of support and little is often available in advance of the inevitable crises. Eligibility criteria for respite care have become tighter. The impact on carer physical and mental health is well established.

Meeting people’s social care needs requires a systemic approach which goes well beyond what social care services provide. Housing and transport are important.

Aside from formal services there is potential to build individual and community capacity to provide informal care towards the end of life. There are a rapidly growing number of “compassionate community” initiatives across Scotland. Under this umbrella some developments maybe about people undertaking roles as volunteers (for example the “No one Dies Alone” work in Inverclyde, Ayrshire and Lanarkshire or Highland Hospice’s Helping Hands befriending and support service). Other work aims to encourage and support individuals to plan ahead for end of life. A recent development is End of Life Aid Skills for Everyone (EASE) which is a course designed to enable people to be more comfortable and confident supporting family and community members with issues they face during dying, death and bereavement.

1. What needs to happen to ensure the equitable provision of social care across the country?

Equity should be considered in other domains as well as geography. For example, towards the end of life the care and support available varies significantly depending on main diagnosis. Social circumstance and personal characteristics are also associated with inequity.

In terms of geographic variation there’s firstly a need to characterise and understand variation. Commissioning based on the National Care Standards and the development of better metrics would support the reduction of variation.

An infrastructure to share learning from areas achieving above (and below) average would support convergence, alongside other measures.

Locally set and divergent eligibility criteria (for example around access to respite care) is not compatible with achieving greater geographic equity.