About Scottish Partnership for Palliative Care (SPPC)

Ill health, death and bereavement affect everyone deeply and profoundly at some point in their lives. When faced with the reality of deteriorating health and death, people may need many things from the NHS, from social care services, from other formal services, and from their friends, families and communities.

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.

Sometimes our field is described as “palliative care” but depending on what people understand by this term, this language can cause confusion. 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. However, the work of the SPPC 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.

SPPC was founded 26 years ago and has grown to be a collaboration of over 50 organisations involved in providing care towards the end of life. SPPC’s membership includes all the territorial NHS Boards, all the hospices, a range of professional associations, many national charities, local authorities, social care providers and universities.
Addressing the questions posed by the committee:

1. What do you consider have been the main successes of the existing Scottish Government’s eHealth and telecare/telehealth strategies and why?

The ability (and future potential) to link data at patient level from different sources is a key strength of the Scottish system.

2. What do you consider have been the main failures of the existing Scottish Government’s eHealth and telecare/telehealth strategies and why?

Arguably, allowing the procurement of different systems for similar purposes at NHS Board level has hampered sharing of information across boundaries.

3. How well does the Scottish Government’s draft Digital Health and Social Care Vision 2017-2022 address the future requirements of the NHS and social care sector?

The draft vision sets out an ambitious and appropriate direction of travel. One area which might be more clearly emphasised is how technology will facilitate citizen interaction/communication with health and care services. The Vision as it stands tends to emphasise delivery of services and/or the provision of information.

4. Do you think there are any significant omissions in the Scottish Government’s draft Digital Health and Social Care vision 2017-2022.

The vision is very high level. The real scope for significant omissions (and specifying priorities for change) will be in the underpinning strategy.

5. What key opportunities exist for the use of technology in health and social care over the next 10 years?

There are key opportunities for the use of technology in health and social care to:

a) Improve how technology supports Anticipatory Care Planning

Anticipatory care planning is about planning ahead for an expected change in an individual’s condition, and can help the individual be more in control and able to manage any changes in their health and wellbeing.

Many people with long term conditions or chronic health problems can benefit from having an Anticipatory Care Plan (ACP). Anticipatory care planning which encompasses palliative and end of life issues can improve the outcomes experienced by an individual and their family.

The new national ACP resources could be greatly supported by having the right IT systems in place.
b) Improve integration and communication between the statutory, independent and voluntary sectors
There are opportunities to better integrate statutory, independent and voluntary sector eHealth systems. For example, currently there is a particular issue in terms of integrating/linking NHS and hospice systems. Although hospices are the major provider of inpatient specialist palliative care beds in Scotland, they currently have limited access to NHS electronic records, networks and systems. This causes problems and inefficiencies.

c) Support more useful feedback on quality of care and outcomes.
Currently, various data is collected across the health and social care system, and with the right IT systems and governance in place, there is much potential for secondary use of this data for service improvement, planning and research.

Therefore, ICT systems should be developed which expand on the functions of the Key Information Summary (KIS) and have the following characteristics:

- ACPs can be easily and frequently updated to reflect the ongoing and evolving conversations which underpin good anticipatory care planning.
- ACPs can be updated (in real time) by relevant people from different settings which span primary care, secondary, tertiary, social care and potentially education (to enable the appropriate support of children and young people).
- ACPs are accessible to third sector providers such as hospices and independent sector providers such as care homes.
- ACPs are accessible in different settings and by different devices.
- People using services (and their informal carers where appropriate permission has been granted) are able to access their own ACP.
- ACPs are sufficiently flexible in format to support individual preference (both of the patient/client and professionals).
- The system is framed by information governance rules which support secondary use of data for service improvement, planning and research.

6. What actions are needed to improve the accessibility and sharing of the electronic patient record?

There is a need for the right technical architecture. However, just as challenging and important to resolve are issues around information governance – who gets to access and share information with whom, for what purpose and under what circumstances. Extending sharing across health and social care is a major challenge in terms of different working cultures. Introducing patient held/accessible records will also bring significant cultural and practical challenges.

7. What are the barriers to innovation in health and social care?

Some key barriers:

- Service pressures limit the time available to innovate, plan and manage change.
- There are often insufficient resources to manage periods of transition from old ways of doing things to new ways of doing things (eg where there is a time lag between investment required to innovate and eventual payback/saving).
- Cultures which deter risk and punish failure inhibit innovation.
- The sometimes immense complexity of delivering good care and consistently achieving good outcomes.
- Generally the slow adoption/exploitation of telemedicine/telecare technology is related to the challenges of changing wider working practices.