Marie Curie believes that everyone who needs an anticipatory care plan should have one. This plan should be accessible to all professionals who are involved in care delivery and technology should be in place to support this.

Key points:

1. Anticipatory care planning (ACP) is a vital part of palliative and end of life care and in managing long term conditions.
2. Commitment 7 of the Scottish Government’s Strategic Framework for Action on Palliative and End of Life Care is to ensure that future requirements of eHealth systems support the effective sharing of individual end of life/anticipatory care planning conversations.
3. The Scottish Government Health and Social Care Delivery Plan contains a commitment that by 2021 everyone who would benefit from a Key Information Summary (KIS), the place where these conversations are recorded, will have one.
4. Independent hospices currently do not have the technical support to link their electronic patient records to existing healthcare systems and access someone’s KIS, including the palliative care summary. This is fundamental to the delivery of palliative and end of life care in all settings.
5. Current systems that technically and practically support the existing KIS are not sufficient for what is required. Work needs to be undertaken to maximise access to and use of the KIS.
6. The KIS is not adequate to robustly and flexibly support the requirements for recording and communication of ACP conversations and decisions. These requirements need to be an integral part of the development of a new eHealth system that places patients at the centre of their care.

Someone has a terminal illness when they reach a point where they, or their medical team, carers or loved ones, understand their illness is likely to lead to their death.

Palliative care aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Treatment will involve medicines, therapies, and any other support that specialist teams believe will help their patients. It includes caring for people who are nearing the end of life. This is called end of life care.

**Anticipatory care planning**

Anticipatory care planning (ACP) is a vital part of palliative and end of life care and in managing long term conditions. An ACP is a record that is developed over time through conversations, collaborative working and shared decision-making between people and their practitioners. It is a constantly evolving process, flexible and regularly updated as someone’s condition, wishes or needs change.
ACP can help people make informed choices about how and where they want to be treated and supported in the future. It requires health and care practitioners to work with people and their carers to ensure the right thing is done at the right time by the right person to achieve the best outcome for the person.

The Scottish Government’s existing eHealth strategy 2011-2017 highlights the importance of palliative care, the Palliative Care Summary (ePCS) and the Key Information Summary (KIS) in supporting the sharing of key information from anticipatory care plans.

The vision in that document was to ensure that everyone who needs an ePCS or KIS, has one in place and accessible by the right people at the right time to support a patient’s care wishes. We are still a long way from realising that goal in Scotland. The Health and Social Care Delivery Plan, published in December 2016, is cognisant of that and contains the commitment that by 2021 everyone who would benefit from a KIS will receive one. We fully support that commitment, however, there needs to be wider consideration about how that is managed and supported. Even where people do have a KIS, there are questions around how that information is recorded, accessed and shared with those who need to access it.

Commitment 7 of the Scottish Government’s Strategic Framework for Action on Palliative and End of Life Care, published in December 2015, is to ensure that future requirements of eHealth systems support the effective sharing of individual end of life/anticipatory care planning conversations. There is a real need to ensure that these conversations are effectively recorded and appropriately shared through electronic systems and that everyone who needs access, gets it. It is vital that the new eHealth strategy has a commitment to ensure the right technology is in place to support anticipatory care planning.

**Current and future technology**

The eHealth team in the Scottish Government commissioned NHS National Services Scotland (NSS) to undertake two pieces of work in relation to this:

1. Anticipatory care planning and data-gathering requirements
2. Current KIS technology and its limitations

The first piece of work highlighted that the technology systems that technically support the existing KIS are not sufficient for what is required. The system needs to enable more appropriate information sharing, including greater access for other professionals to contribute to and update the KIS. Due to data-protection limitations, only GPs can currently do this. The second piece of work outlined ways that the current KIS technology could be maximised to support the anticipatory care planning process.

The Scottish Government eHealth team has agreed with the Deputy Chief Medical Officer and the person-centred and quality team that the solution most likely to meet the needs of supporting anticipatory care planning is that of a ‘patient portal’.

We believe that any future system, that effectively manages anticipatory care planning information, needs to include; patient access; read and write access for all professionals who need it including social care, out of hours staff, care homes, hospices and district nurses; and robust data protection and governance safeguards. We believe that this should be a priority in
Scotland, however, there also needs to be immediate measures in the interim to ensure that the KIS is used more effectively to improve information sharing.

Emergency Care and Out of Hours

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is a UK initiative to help guide treatment and interventions in an emergency setting. As ACPs contain preferences and realistic choices over the types of care and interventions an individual wants or doesn’t want, such as Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders, it is vital that there are strong links between ReSPECT and anticipatory care planning process. This will help promote realistic care and treatment options and ensure that a person-centred model of care is followed.

Hospices

Not all Independent Hospices in Scotland currently have access to the ePCS or KIS through their own electronic patient record systems. As major providers of palliative care, hospices provide care and support to people throughout their illness and at the end of life. It is therefore important that clinicians within these settings have access to read information contained within someone’s KIS and have the mechanisms to input to them.

NSS has explored ways of linking hospice systems to the ePCS and KIS, however, there is no ongoing technological support, funding or negotiation with providers of Hospice systems to ensure that these links are made and supported in a sustained way. This is a vital part of ensuring that Commitment 7 of the Scottish Government’s Strategic Framework for Action on Palliative and End of Life Care can be realised.

As part of the next eHealth strategy, we would like to see a requirement to link independent hospices and statutory eHealth systems. As an integral part of care planning and delivery at the end of life, we recommend that this is funded under the Strategic Framework for Action on Palliative and End of Life Care and maintained by NSS.

Conclusion

It is clear that that work is needed to ensure that technology can support realistic and person centred health and social care in Scotland. The systems and processes currently used are not adequate to ensure that people get the care that they need and want, when they need it – particularly in relation to anticipatory care planning.

We recommend three actions need to be taken to ensure that technology supports the Scottish Government’s vision that everyone receives the palliative care they need by 2021:

1. Immediate action: Hospices need to be able to link to existing healthcare systems and access the ePCS and KIS.
2. Interim action: Current technology systems that technically support the existing KIS are not sufficient for what is required. Work needs to be undertaken to maximise access and use of the KIS.
3. Long-term action: An updated or revised version of the KIS which robustly supports the communication of anticipatory care information can be an integral part of a new eHealth system that places patients at the centre of their care.