Helping people realise their preferences for where they spend their last days and hours of life and for what care and support they receive at this time is at the heart of England’s National End of Life Care Strategy (Department of Health, 2008). Getting this right can also have a lasting positive impact on carers and families. The purpose of Electronic Palliative Care Coordination Systems (EPaCCS) is to support this, providing an effective approach to improving quality and integration at the end of life by coordinating care so that people’s preferences and choices are respected and achieved wherever possible.

EPaCCS are becoming more commonly recognised in English policy and guidance documents. This paper aims to provide readers with an understanding of EPaCCS, including mandatory requirements for local areas. It also highlights recent developments that may be useful for supporting implementation.

What are EPaCCS?
EPaCCS provide a shared electronic record for health and social care professionals that allows secure access, across care boundaries, to complete and up-to-date information regarding the person’s expressed preferences and needs for care at the end of their life. Person-centred integrated care is high on the agenda for improving care, requiring services to be focused on the needs of individuals and their families (National Collaboration for Integrated Care and Support, 2013). This is particularly relevant to palliative and end-of-life care, where there is commonly a wide range of professionals involved in care, often working across sectors.

Health and social care organisations are increasingly recognising the potential and value of using EPaCCS. The systems provide staff with key information to support care delivery and reduce the likelihood of people being given unwanted or inappropriate care interventions. For example, ambulance staff can be kept informed about do not attempt cardiopulmonary resuscitation (DNACPR) decisions, where people would prefer to receive their end-of-life care, and the contact details of people to be involved in decisions about care.

Working to a standard
To underpin EPaCCS, a national information standard was introduced in 2012 (Information Standards Board for Health and Social Care, 2012). The standard identifies the core data items to be held in EPaCCS and defines the terms and the structures for recording. It provides a mandated, standardised, quality-assured and fit-for-purpose dataset that is ready to be used in local systems. Local areas only have to consider additional data items that they may wish to add to the dataset.

In most areas a range of IT systems are used by the different service providers. Developing an electronic system that links up all providers can feel daunting. Information standards can help as they ensure that data items are recorded consistently across all IT systems and support the development of interoperable systems. There are mandatory elements to the standard that are now in effect and it is important for all involved in planning and developing EPaCCS to understand the requirements:

- IT systems suppliers: provision of EPaCCS must comply with the information standard
- Service providers, commissioners, and planners: there is no mandatory requirement to establish EPaCCS. However, if procuring a system, contracts for IT systems must specify that the EPaCCS will comply with the information standard
- Service providers: data items specified in the information standard that are held in any electronic record must comply with the information standard

The information standard has recently been updated, with new data items added to support the recording of consent and actual place of...
death and with improvements to the data items for carers and disability. These changes must be implemented by 1 June 2014. The supporting guidance has also been updated (National End of Life Care Intelligence Network, 2013).

**Who has access?**

Once agreement has been reached around implementing EPaCCS in a local area, a decision needs to be made about which professional groups should have access. There are no mandatory requirements, but key groups to consider include GPs, key workers, out-of-hours services, and social care. An example is the London-wide EPaCCS approach, called Coordinate My Care. This system uses a shared web interface that the relevant professionals can access, including GP, out-of-hours, ambulance, accident and emergency, community, specialist palliative care, and social care services.

‘Coordinate My Care captures the wishes of patients with life-limiting illnesses and places them at the heart of all care decisions—allowing them to electronically record their wishes for care and treatment. The programme can then communicate them to anyone delivering the patient’s care, in and out of hours, allowing them to live fully according to their wishes.’ Dr Julia Riley, Clinical Lead, Coordinate My Care, and Consultant in Palliative Medicine, Royal Marsden NHS Foundation Trust and Royal Brompton & Harefield NHS Foundation Trust

**Making a difference**

Although EPaCCS are still fairly new, and in many areas implementation is still underway, there are some very encouraging signs that they are making a significant difference to the quality of end-of-life care. An economic analysis of EPaCCS carried out in 2013 for NHS Improving Quality found that benefits included improved coordination of care, improved relationships between professionals and patients, and likely cost savings resulting from fewer deaths in hospital and reduced hospital use. The analysis found evidence that implementing EPaCCS affected the place of death, with an extra 90 deaths per 200000 population occurring in the usual place of residence each year (above the underlying increase in rates experienced across England). Data from a survey carried out by the National End of Life Care Programme in 2012 indicated that, where EPaCCS are implemented, up to 80% of people with an EPaCCS record die in their place of choice.

**Recent developments**

There have been several recent developments of significance for EPaCCS:

- Implementation is being supported by NHS Improving Quality and Public Health England and has been identified as a key lever for supporting improved quality of end-of-life care
- The government’s 2013 Spending Review announced a £3.8 billion Better Care Fund to support integration of health and social care services, of which EPaCCS can be a part
- Fourteen ‘integration pioneer’ sites were announced by NHS England last year. These sites have been appointed to trail-blaze new ways of delivering coordinated care across health and social care services. EPaCCS have an important part to play in this.

**Whole systems**

Implementing EPaCCS is not just about introducing a new IT system. Sharing information to improve care also requires a culture shift in the way health and social care professionals think, work, and interact. It requires recognition that collecting and sharing good information is pivotal to improving the quality, safety, and effectiveness of care. EPaCCS highlight the competencies and confidence that staff need to hold discussions with people and their families about end-of-life care wishes and the way that services are delivered across professional groups, and so they are likely to drive service improvement.

**Conclusions**

Having the right information at the right time can make all the difference to the quality and experience of care for a person reaching the end of their life. We have come a long way already, and EPaCCS now play an important part in supporting people to realise their preferences and choices for care at the end of life. **Although EPaCCS are still fairly new there are some very encouraging signs that they are making a significant difference to the quality of end-of-life care.**

© Crown copyright 2014

**Declaration of interest**

This work had no external sources of funding. The authors have no conflicts of interest to declare.


---