

# EPaCCS: electronic systems that help improve patient care



*Dr Maureen Baker*

“ These systems benefit patients and healthcare professionals alike. ”

## Better coordination means a better patient experience

I am delighted that RCGP is working in partnership with Marie Curie Cancer Care and that this collaboration is already producing important outputs, such as this paper.

Electronic palliative care coordination systems (EPaCCS) – or key information systems (KIS) in Scotland and Northern Ireland – have been shown to benefit our patients as they approach the end of life, as well as providing reassurance to their loved ones and those who care for them.

The two case studies in this paper demonstrate how these systems – which enable the sharing of information about patients' wishes and care at the end of their lives – benefit patients and healthcare professionals alike.

Both the Cambridgeshire and North East Essex EPaCCS are relatively new schemes. Neither has been running long enough to have registered the 1% of patients likely to be in the last year of life, yet both teams are already hearing anecdotal evidence of patients receiving better care due to improved coordination of services.

I hope you find this paper useful as you plan your own EPaCCS.

We look forward to working with Marie Curie to explore further initiatives to improve the care that our patients receive at the end of their lives.

**Dr Maureen Baker**  
Chair of RCGP Council



*Dr Peter Nightingale*

## The importance of EPaCCS in supporting end of life care

**Dr Peter Nightingale**  
Marie Curie/RCGP National Clinical Lead for End of Life Care

Caring for a patient right through to the end of life can be one of the most satisfying aspects of general practice, but it is also one of the most challenging.

Most people prefer to be cared for at home at the end of their lives, with dignity and their symptoms controlled. Sadly, many fail to achieve this. The current situation of multiple admissions in the last year of life, many of which are unplanned and potentially avoidable, is unsatisfactory for patients and does not make best use of resources.

Many of us have been working hard to find the 1% of patients within our practice likely to be in the last year of life, and take a more proactive approach to their care, but this is not always easy.

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To effectively identify and support patients we need to use both national and locally developed tools to proactively manage care.

#### **Why are we interested in EPaCCS?**

Previously known as locality registers, electronic palliative care coordination systems (EPaCCS or KIS for short) allow GPs and other healthcare professionals to share information about those patients who have been identified as likely to be in the last year of their lives.

EPaCCS enable the recording and sharing of people's care preferences and key details about their care with those delivering care. The systems support coordination of care and the delivery of the right care in the right place, by the right person, at the right time.

Patients benefit from having their care actively managed, and their families also benefit. When patients are managed in this way, they are more likely to be cared for in their place of choice and less likely to experience unnecessary investigations, interventions and hospital admissions.

Drawing attention to the benefits of EPaCCS and their use in everyday practice is a key area of focus for the RCGP/Marie Curie End of Life Care Partnership.

#### **The evidence**

There is strong evidence that EPaCCS support patient choice, shared decision making, individual care planning and integration of care across sectors.

Many areas have already implemented, or are in the process of implementing, EPaCCS across localities. Available data suggests that their use helps people to die in their preferred place of death, decreases the percentage of hospital deaths and increases the percentage of deaths at home and in hospices.

Other key benefits include improvements in communication and information sharing between healthcare professionals and support for making appropriate decisions about patients' care.

While there are some technical challenges in implementing local solutions – such as interoperability of different systems – evidence shows that they can be overcome as the pace of implementation continues. In England, national information standards exist for those wishing to support the development and use of EPaCCS.

There are many benefits to using locally developed tools. They:

- enable the sharing of information regarding patient wishes and key elements of care and planning: this is vital for working with out-of-hours services and Acute Trusts
- reduce the need for patients to tell their story again and again (although they don't replace clinical review and assessments)
- provide a framework for care planning discussions that puts the patient at the centre
- provide a care pathway that enables health professionals to put the patients at the centre of healthcare delivery
- facilitate and strengthen communication across care settings

It is in everyone's interest to use EPaCCS effectively to support people's wishes to be cared for and die where they normally live; as well as reduce unnecessary hospital admissions and costs.

I hope you find the following case studies of interest as you consider how you can embed EPaCCS into everyday practice.

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“ The new service has made such a difference to patients. ”

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## CASE STUDY 1

### Essex hospice leads end-of-life care project

When North East Essex CCG made funding available for an integrated end of life service and an electronic end of life register, St Helena's Hospice in Colchester, Essex, agreed to lead on the new service and to host the register.

The result is the SinglePoint service and the My Care Choices Register, which launched together in September 2013.

“One GP told me the new service has made such a difference to patients,” says Stella Fletcher, Director of Business Transformation at the hospice.

“When she gets a call late on a Friday afternoon about a patient, she finds it much more straightforward now to get arrangements in place for the weekend. She knows she can ring SinglePoint and that someone will visit that patient.”

After securing consent, GPs add details of those patients considered to be in the last year of their lives to the register. This includes the patient's wishes, along with details of the teams involved with their care. Other services such as community nurses and the ambulance service can then access that information.

Once on the register, patients can access SinglePoint: a dedicated service offering 24-hour telephone support every day of the week. It can also arrange routine, urgent and rapid-response visits from nurses, depending on the situation.

The team had four months to launch the register, so chose an off-the-shelf product, Adastra, which all services with an N3 connection and an NHS smartcard can use.

Initially, the CCG wasn't sure what sort of data reports it would need, so the hospice team worked with it to produce a set of requirements. It became clear later on that the initial set did not meet all the CCG's

requirements. GPs were having to do three types of reporting.

The hospice team have now renegotiated with the CCG, identified exactly what is needed and reconfigured the system accordingly. Now, if GPs enter the required data on to the register, the team can report to the CCG on their behalf. The hospice has also introduced a grant, part-funded by them, part by the CCG, as a financial incentive.

It's been just over a year since launch, and all but a handful of GP surgeries have signed up to the My Care Choices Register and are using the SinglePoint service: the project team are working with those that have not.

In north east Essex, around 3,000 people die each year and 2,500 of those are people at the end of their lives, rather than those who die unexpectedly. There are currently 850 people on My Care Choices.

Stella says: “That's not a bad starting point, considering the register has only been up and running since September last year.”

## CASE STUDY 2

### Cambridgeshire and Peterborough's data sharing scheme

It's been more than a year since the launch of Cambridgeshire and Peterborough CCG's EPaCCS. Ian Merrick, Project Manager for the Data Sharing in End of Life project, says that the initiative is gaining support.

The CCG based its EPaCCS on SystmOne hosted clinical software, as almost 80% of its 108 GP practices use it, as do many nursing staff within Cambridge Community Services NHS Trust, the local 111 and GP Out of Hours service and all the palliative care teams. In the future all three acute hospitals expect to have SystmOne clinical records viewers.

“ It's a definite selling point that it takes less than five minutes for a GP to complete. ”

The system, which launched in July 2013, enables GPs to create an end of life care summary for those patients considered to be in the last year of their lives. GPs record patient information in a template within SystmOne and obtain the patient's consent for their record to be shared with other professionals involved in their care.

Staff in any service providing care for the patient can then access the patient's record with their consent. After seeing the patient, health professionals can enter their notes and share these with the GP practice or other nominated services.

One key benefit of the system is it makes completing the template fast and part of routine record keeping.

Ian says: "It's a definite selling point that it takes less than five minutes for a GP to complete a first version of the template, and updates will normally be even less work."

The template acts as a prompt for issues to be considered and contains a number of embedded documents such as a DNACPR form, prescribing guidance and a directory of bereavement services.

Reaching the 20% of practices that don't have SystmOne was a challenge the project team overcame by developing templates in those IT systems (EMIS and Vision) that those surgeries can turn into a Word document. Surgeries then send these to multi disciplinary team coordinators in Cambridge Community Services for attaching to the patient's SystmOne record.

The team are currently developing an end of life care reporting dashboard that will present summary data back to practices and aggregated anonymised data at practice level for use by LCGs and the CCG.

While Ian admits that there's plenty of work still to do, he believes that "it's absolutely right that everyone should be working together as a united and joined-up NHS to ask patients where they'd prefer to die and to make that happen".

#### For further information, please contact:

##### Ian Merrick

Project Manager  
ianmerrick@nhs.net

##### Dr Stephen Barclay

Project Clinical Lead  
sigb2@medschl.cam.ac.uk

#### Next steps

- For more information on EPaCCs, contact your CCG.
- To find out about the Marie Curie/RCGP partnership, visit: [mariecurie.org.uk/rcgp](http://mariecurie.org.uk/rcgp)
- For recent NHS guidance on setting up EPaCCs, visit: [tiny.cc/lessonslearned](http://tiny.cc/lessonslearned)

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