Making the case for change

Electronic Palliative Care Co-ordination Systems
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Introduction

The End of Life Care Strategy (2008) identified the need to improve co-ordination of care, recognising that people at the end of life frequently received care from a wide variety of teams and organisations. The development of Locality Registers (now Electronic Palliative Care Co-ordination Systems known as EPaCCS) were identified as a mechanism for enabling co-ordination.

By supporting the elicitation, recording and sharing of people’s care preferences, and key details about their care, it is anticipated that EPaCCS will improve the quality of care, with provision meeting people’s expressed wishes and preferences. Early findings from the South West SHA Locality Register pilot showed that the vast majority of people on the register were able to die outside of hospital, and in their preferred place of care.

Why EPaCCS?

EPaCCs will contribute to increases in the quality of end of life care individuals receive by improving co-ordination and communication across sectors, ensuring that all those involved in care will be aware of the individuals wishes and preferences as recorded in Advance Care Plans (ACP) as well as treatment care plans. They contribute to the patient Choice agenda as well as the Quality, Improvement, Productivity and Prevention (QIPP) agenda and improve patient safety by reducing harm through co-ordinated communication in standardised format to reduce the risk of inappropriate interventions. The following briefly underpin why commissioners should make a case for implementing EPaCCS:

- DH End of Life Care (EoLC) strategy 2008 and proof of concept pilots undertaken during 2009/11 (Step 3 EoLC Pathway)
- NICE Quality Standard EoLC 2011, Palliative Care Funding Review 2011, Information Strategy (EPaCCS referenced as case study)
- Need to achieve right information, right care, right place, right time, right resource - delivering person centred care to support a good death
- Support to service transformation and redesign of care outside of the hospital to avoid unnecessary hospital admissions, deaths in hospital and reduced lengths of stay (Key deliverables for the national QIPP EoLC Work stream to which this work is aligned)
- Support to transformation of culture, improving seamless care episodes and benefits driven service improvement
- Supports integrated care across professional and organisational boundaries
- ISB standard for EoLC published March 2012 result of pilots experiences ensuring consistency of data
- Potential for wider utilisation than end of life care.
This resource is intended to support commissioners in developing a business case for establishing EPaCCS. The information contained can fit, or be modified, to a range of business case templates and includes the key drivers and evidence for establishing EPaCCS as well as case studies and additional information to demonstrate where benefits have been achieved. In the appendices, further information on potential savings and efficiencies as well as considerations around key stages and issues for implementation can be found.

**Key Facts**

EPaCCS will contribute to patient safety specifically in relation to:

- Improved communication between professionals – with clarity of staff involved and how to contact them
- Improved access to key information that is not otherwise available e.g. for ambulance staff and out of hours providers
- Improved communication of Advance Decision to Refuse Treatment (ADRT), Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions and advance statements of wishes and preferences
- Improved communication of the issue and location of anticipatory medication
- Clarity of people involved in care – informal carer, Lasting Power of Attorney and others to be involved in decision making
- Impact on avoiding unwanted/unnecessary treatments and interventions.
**EPaCCS benefits dependency network**

The benefits dependency diagram below, gratefully reproduced by kind permission from the Leeds Teaching Hospitals Trust, summarises where and how EPaCCS are expected to improve the quality and efficiency of services and captures succinctly the benefits of EPaCCS both to the service organisations and the individual.

**Leeds EPaCCS benefits dependency network**

<table>
<thead>
<tr>
<th>Key Project Enablers</th>
<th>Key Business Changes</th>
<th>Benefit</th>
<th>Drivers</th>
</tr>
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<tbody>
<tr>
<td>Develop and deliver EPaCCS</td>
<td>Patient’s EOL prognosis is shared</td>
<td>Fewer complaints</td>
<td>Reducing spend in EOL care</td>
</tr>
<tr>
<td>End of Life Care (EoLC) preferences are available and accessed by all clinicians, including in emergency situations</td>
<td>End of Life Care (EoLC) preferences are available and accessed by all clinicians, including in emergency situations</td>
<td>Reduced number of unnecessary hospital admissions</td>
<td>Patient choice and quality of care</td>
</tr>
<tr>
<td>All patients’ preferences are recorded in one place</td>
<td>All patients’ preferences are recorded in one place</td>
<td>Reduced number of unnecessary ambulance journeys</td>
<td>Efficiency savings</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increased numbers of carers identified and supported</td>
<td>No decision about me without me</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Improved clinician productivity</td>
<td>Achieving CQUINS</td>
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<tr>
<td></td>
<td></td>
<td>Reduced number of times a patient has to have a ‘difficult’ conversation with a clinician</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Increased number of patients die in a place of their choice</td>
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Progress to date

The roll-out of EPaCCS is supported by the Quality, Innovation, Productivity, Prevention (QIPP) agenda, which aims to help the NHS save up to £20bn by 2015. The QIPP work is promoting co-ordination systems as a mechanism to support and complement these areas. Better communication between professionals is expected to reduce the number of unnecessary admissions to hospital, and minimise lengths of stay, freeing up resources that can be invested in community services.

Anecdotal evidence suggests that improving community based care and care co-ordination, and thereby reducing the number of acute admissions, could lead to cost savings, or at worst be cost neutral. Findings from the Marie Curie Delivering Choice Programme suggest delivery of improved community provision, supported by better co-ordination of care can lead to increased numbers of people being supported to die at home, at no extra cost.

EPaCCS projects are well underway across the country, with 14 sites reporting that they have implemented such systems, and a further 10 partially implemented. This covers much wider than solitary PCT geographical areas. This is an impressive leap from the 2010-11 Locality register pilot sites report, which featured eight pilot sites.

The following map shows the latest known position mid-2012.

Map data © 2012 Basarsoft, GIS Innovatsia, GeoBasis-DE-BKG (©2009), Google, Tele-Atlas 2011 Google
CCG geographical data sourced from NHS Commissioning Board, June 2012
The independent Palliative Care Funding Review also supported EPaCCS. The final report (July 2011) advocated the need for local areas to have registers in place to support, with the individual’s consent, the capture, storage and sharing of electronic patient records to support a future funding mechanism. The recommendations in the report are currently being considered, and will inform the ongoing work to develop a per-patient funding system.

Statement 8 of the NICE Quality Standard for end of life care for adults1 published November 2011, also recognises the potential of EPaCCS, highlighting the importance of effective care co-ordination and of standardised documentation. The standard identifies locality registers or other systems as a mechanism for facilitating effective care co-ordination.

Following successful pilots from October 2009 to March 2011, evaluated by Ipsos MORI, the National End of Life Care Programme has led on spreading uptake across England. The evaluation identified key lessons for implementation and confirmed their potential to improve the quality of end of life care. The full report from the pilots can be found at www.endoflifecareforadults.nhs.uk/publications/localities-registers-report

Guidance has been published to support accurate end of life care co-ordination record keeping for EPaCCS and can be accessed via the NEoLCP website www.endoflifecareforadults.nhs.uk/publications/record-keeping-summary and include:

- End of Life Care Co-ordination Implementation Guidance
- End of Life Care Co-ordination Record Keeping Guidance
- End of Life Care Co-ordination Summary of Record Keeping Guidance

**Information Standard**

Building on the learning from the pilots the NEoLCP and the Department developed a national information standard (End of Life Care Co-ordination: core content2), which has been approved by the Information Standards Board for Health and Social Care. The standard was published on the 20th March 2012 and specifies the core record content to be held in end of life care co-ordination systems, facilitating the consistent recording of information by health and social care agencies and, with the consent of the individual, supporting safe and effective management and sharing of information.

Implementation Guidance3 has been published to support commissioners, health and social care organisations and IT systems suppliers in the implementation of the standard and EPaCCS and to inform local decision making. The standard requires all IT systems and software supplier contracts for new EPaCCS issued after 20th March 2012 to specify the requirement for systems to be compliant with the new standard. Where an EPaCCS is already in place, suppliers must ensure systems are compliant by 1 December 2013.

The standard allows for local determination and configuration of the electronic record systems and platforms. Local areas may decide to extend data items beyond the core requirement depending on their own circumstances. A wide range of different implementation approaches are currently being adopted, including Advanced Health and Care (Adastra), SystmOne, McKesson and SCR reflecting the regional differences in systems and size of the locality being covered. Other systems such as EMIS Web and the Medical Interoperability Gateway (MIG) are similarly being considered.

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1 NICE Quality Standard for end of life care for adults. www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp
Interoperability

National implementation has also been supported by specialist technical support from the DH Informatics team. In particular, they have been working on development of ITK\textsuperscript{4} interoperability specifications to enable EPaCCS to be used easily regardless of system supplier. Working in collaboration with the ITK (Interoperability Toolkit) team work is underway to define interoperability specifications that will enable different clinical systems to share data consistently within stringent clinical governance rules. This will ensure that clinical needs are met to support co-ordinated care for people with long term conditions and those approaching the end of life. The work will include defining the requirements for sending an EPaCCS Record and a generic Notification; the technical mechanism for retrieving a clinical document via a Document Request as well as some guidance around enabling Click-Through.

Key Facts

- Organisations contracting for new EPaCCS MUST specify compliance to standard in IT systems and software supplier contracts
- Providers of services for adults at end of life SHOULD review current systems and plan for migration to conform by 1 December 2013
- Suppliers of existing systems to providers of end of life care services MUST demonstrate conformance by 1 December 2013

Drivers for Change

As previously discussed, there are many policy documents, standards and guidance that can be considered as drivers for change but the following three highlighted can provide a good evidence base for a business case:

a) Choice – By supporting more effective co-ordination of care, EPaCCS have the potential to support increased choice at the end of life, which is a commitment in Liberating the NHS: Greater Choice and Control (DH 2010). Individuals’ wishes and preferences will be recorded and known to the multidisciplinary team across sectors resulting in improved quality and experience of care. Surveys such as the recent National Bereavement Survey (VOICES) in 2011 identified that most people would prefer to die at home or in their usual place of residence, however currently over 50% still die in hospitals. Further information can be found at (www.dh.gov.uk/health/2012/07/voices) The right to die at home and the choice agenda is one of the proposed inclusions within the NHS Constitution (www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx)

b) Quality, Improvement, Prevention and Productivity (QIPP) – EPaCCS can support the QIPP agenda to deliver efficiency savings and improvements in the quality of end of life care through changes to delivery. This can be achieved through early identification and recording of people approaching end of life, improved communication and co-ordination of planning for their care to support their wishes, especially in out of hours situations, which can result in reduced avoidable admissions and lengths of stay (where this meets clinical need and the individual’s preferences). The end of life care QIPP work stream has agreed improvement trajectories with the current SHA clusters relating to increasing deaths in usual place of residence (DiUPR) which includes home, extra care housing or care homes.

\textsuperscript{4} Interoperability Toolkit (ITK).

www.connectingforhealth.nhs.uk/systemsandservices/interop
c) **Reducing bed days** – Improved co-ordination of care and better communication through use of EPaCCS can reduce avoidable hospital admissions as well as reduce length of stay. In England people average around 2.1 admissions in the last year of life with an average stay of 30 bed days. 50% will have been in hospital for 8 days or more. The estimated cost of acute admissions ending in death 2010-11 was £520m – a 10% reduction in the number of admissions for people who stay 8 days or more could mean a saving of £57m.

Any savings identified in a reduction of bed days does not equate to net savings, as funding will be required for services to support the individual outside the hospital setting. Marie Curie cancer care suggests an estimated cost for end of life care within the community at £145/day. For further details see ‘What we know now that we didn’t know a year ago? New intelligence on end of life care’ (National end of life care intelligence network (NEoLCIN) and NEoLCP May 2012) [www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx](http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx)

Individual PCTs and LAs can calculate spend in relation to emergency bed days by visiting the National End of Life Care Intelligence Network site ([www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx)).

The profiles also show the average number of bed days per admission ending in death by Primary Care Trust and Local Authority. The national average for PCTs is 12.9. Based on the NICE tariff (11/12) the cost of an unplanned admission is £2506 and the cost per day over 8 days is £231/day.

Number of admissions ending in death over 8 days = X
Average number of days for such admissions = Y
Potential savings are: X * (Y-8) * 231.

If the admission is unplanned, the costs are more. It is important to note that this is not an exact calculation, and in some cases it is entirely appropriate for individuals to stay in hospital over 8 days. However, it does give an indication of the benefits of supporting people to die in their preferred place of death, if that is their choice and outside hospital.
Supporting Care Co-ordination

The following diagram demonstrates how EPaCCS support care co-ordination.
**Summary**

This resource highlights some of the benefits of EPaCCS in improving the quality of care for people at the end of life in terms of supporting individuals to die in their preferred place and streamlining information, in addition to potential cost savings and efficiencies.

EPaCCS provide a valuable resource for capturing *all* individuals who are approaching the end of their life, supporting delivery of person centred end of life care for all and inclusive of all diagnosis. When considering cause of death, it is helpful to remember that a third of all deaths are accounted for by those within a diagnosis of cancer. The inclusion of those living with long term conditions (who are potentially within the last year of life) will have both individual and economic benefits to support more individuals dying within their preferred place, reducing emergency admissions. This in turn will generate potential cost savings from these avoidable emergency admissions to invest in alternative services to support more individuals to die in the preferred place of care.
Appendix 1

Potential savings and efficiencies

<table>
<thead>
<tr>
<th>Patient pathway</th>
<th>Potential efficiencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient consents to join the register</td>
<td>All agencies with access to register aware of patient’s wishes re. end of life care. No need for multiple agencies to ask patient the same questions routinely.</td>
</tr>
<tr>
<td>Patient calls ambulance</td>
<td>Ambulance service accesses register and can view EoLC status and patient wishes. Less likely to take patient to A&amp;E unless necessary.</td>
</tr>
<tr>
<td>Out-of-hours GP visits patient</td>
<td>GP knows via register what patient’s wishes are, what medication they have, what palliative care they are receiving, end of life care wishes etc.</td>
</tr>
<tr>
<td>Patient passes away at home</td>
<td>The GP and palliative care nurse know that the patient does not want active treatment. Hospital admission and interventions are avoided.</td>
</tr>
</tbody>
</table>

(www.endoflifecareforadults.nhs.uk/publications/localities-registers-report page 44)

National Audit Office

The National Audit Office report End of Life Care (2008) highlights an analysis that was undertaken within Sheffield. It identifies that from a snap shot of 200 individuals who died in hospital that 40% had no medical need to be there. Additionally over the course of a year Sheffield could potentially have saved 4.5 million in the cost of hospital care for those at the end of life that could be reinvested to support people in the community.

Appendix 2

Implementing an EoLC register: key stages and issues to consider

Map stakeholders at the outset: Who is likely to be affected by, or have an interest in, the creation of a register? These stakeholders should be engaged as soon as possible to ensure they share the same vision of the register’s purpose.

Obtain dedicated IT and clinical input: There should be a member of staff from each background who can devote time to register development.

Register or care plan?: Although capable of holding more complex information, care planning tools require complex functionality, consent processes and administration rights.

Map the systems that are already in use: Most areas will have a wide range of IT platforms already in use in GP surgeries and out-of-hours services, with separate networks for acute care, community services and the local ambulance service.

Select an IT platform and approach: A key challenge is to select a platform which can be used across all different services, whilst retaining as much clinical functionality as possible. Having mapped the pre-existing systems in the area, an approach can be decided upon based on the functionality, equality of access, compatibility and ease of use offered by each system.

Establish the data requirements: Capturing a minimum level of data is necessary in order to fulfil the objectives of a register. The intention is to establish through the Information Standards Board a national data set which will be available to any other areas developing a register in the future. Once these basics are agreed, more targeted discussions can be had locally about any additional information it would be useful to collect.

Determine the administration rights: Consider who is best placed to edit the record. Healthcare staff other than GPs, such as district nurses, hospice workers or community workers may be in a good position to recognise when a patient is ready to be added to the register and to update it. Specify clearly who the data controller is and who has responsibility for maintaining the record and ensuring its accuracy.

Design the consent process: Consider the training requirements of staff around obtaining consent. Gaining consent involves some potentially difficult and sensitive conversations with patients. Consider carefully at which point patients should be asked to join the register. Many pilots identified 12 months as the appropriate length of time for patients to be on the register. Anticipate patients objections to giving consent. Produce some literature for patients detailing exactly their information will be safeguarded and used.

Training: It is vital that end-users are trained in both the IT and the clinical skills required to use the register. Users need to be able to add patients and record their preferences, but they also need the confidence and skills to approach the EoLC conversation with their patients. Feeling unable to have or uncomfortable with having this conversation may result in it not happening.
Additionally the costs implications for EPaCCS in terms of start-up and maintenance costs are an essential consideration and need to be cross-referenced with local data, projections regarding admission avoidance with the focus remaining around choice and quality of care.

When developing a business case for EPaCCS, robust data will be essential to provide a baseline for current provision and identify expected benefits. In particular, it will be valuable to gather data on numbers of people who die in their usual place of residence and the rate of unplanned admissions within the last year of life with concurrent total numbers of bed days. To assist with the collation of the data required useful information is available at the NEoLCIN site regarding PCT profiles [www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx)

Additionally information can be gathered through Office for National Statistics (ONS), primary care mortality data from local PCTs and the Joint Strategic Needs Assessment (JSNA).
Appendix 3

Further data and useful resources

To gain a more in-depth understanding visit the NEoLCIN website which provides local data in relation to end of life care profiles [www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx).


The APHO has data at GP, CCG and PCT level on age profile. Taken with the QOF data above, it is possible to show those areas with high numbers of an ageing population, but with low numbers on registers. This should warrant further investigation to determine the facts. [www.apho.org.uk/PracProf](http://www.apho.org.uk/PracProf)

It is important to note the following from the NEoLCIN re the data profiles: “These profiles [from which place of death is derived] use Office for National Statistics (ONS) data for place of death. The ONS categorises place of death by address. As a result, it is not possible to distinguish between hospital deaths and deaths in specialist palliative care units / hospices that are based in hospitals. This means that, in many areas, the indicator showing hospital deaths will be an over-count and hospice deaths an under-count. This is a known limitation of the data. We would be most grateful for feedback from PCTs about whether this is the case in your local area. For full descriptions of the indicators, including definitions and limitations, please see [www.endoflifecare-intelligence.org.uk/view.aspx?rid=300](http://www.endoflifecare-intelligence.org.uk/view.aspx?rid=300)

The NHS Institute has a useful ROI calculator available from their website which calculates the return on investment (ROI) of quality improvement initiatives such as EPaCCS. The calculator applies the financial benefits and costs associated with the project. The tool can be used at the start of a project to provide an estimate of the costs for upfront justification and again towards the end of a project as a measure for the success of the improvement project (not only by confirming initial costing validity but also by validating any on-going project maintenance and sustainability costs). ROI can be used throughout the life of a project to continually see if benefits are being realised [www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/Return_on_Investment_(ROI)_calculator.html](http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/Return_on_Investment_(ROI)_calculator.html)

Support for EPaCCS has also been expressed by the independent Palliative Care Funding Review final report, which was commissioned by the Secretary of State for Health. The review, published in July 2011, includes a recommendation for every Clinical Commissioning Group to maintain an end of life care locality register ([http://palliativecarefunding.org.uk/wp-content/uploads/2011/06/PCFRFinal%20Report.pdf](http://palliativecarefunding.org.uk/wp-content/uploads/2011/06/PCFRFinal%20Report.pdf))

The quality standard for end of life care for adults, developed by the National Institute for Health and Clinical Excellence (NICE), also recognised the potential of EPaCCS. Statement 8 of the standard, which was published in November 2011, states:

‘People approaching the end of life receive consistent care at all times of day and night, that is co-ordinated effectively across all relevant health and social care organisations, and which is delivered by practitioners who are aware of the person’s current medical condition, care plan and preferences’ ([www.nice.org.uk/media/EE7/57/EoLCFinalQS.pdf](http://www.nice.org.uk/media/EE7/57/EoLCFinalQS.pdf))

The definition for this statement identifies EPaCCS (locality registers) and standardised documents as mechanisms for facilitating effective care co-ordination.
The Health and Social Care Act 2012 is clear about promoting the integration of health and care services. The national information standard will support integration of end of life care services across health, social care, voluntary and independent sectors.

Other efficiencies, as identified in the Ipsos MORI report (2011), are likely to centre on the streamlining of information sharing (the register may reduce the need for emailing and faxing information about the patient between healthcare professionals) and reducing the likelihood that the patient will be asked the same questions each time they are in contact with a new agency.

www.endoflifecareforadults.nhs.uk/assets/downloads/Ipsos_MORI_EoLC_Locality_Register_FINAL_REPORT_sent210611.pdf
Appendix 4

Initial results from pilot sites

EPaCCS are still in the formative stages; early findings are encouraging about the potential to improve patient care and choice. The case examples below illustrate this:

London
NHS London has been using EPaCCS since August 2010, starting as a locality register pilot in two PCTs, and now covering four such patches across the capital. The statistics show that there could be a significant impact on achieving place of death.

Prior to the introduction of Co-ordinate my care (CMC) the data for 2008-10* showed that, on an annual average for the four PCTs using EPaCCS, hospital was the place of death for 60% of people. Now, the data show that if a patient is put onto an EPaCCS, called CMC, less than half of that proportion is dying in hospital.

In August 2012, 2198 patients had a CMC record. 429 of them have died.

Of those that have died, 20% died in a care home, 31% died in their own home, 12% died in a hospice, 24% died in hospital, with 13% in other locations.

For those who have died, preferred place of death was recorded in 80% of cases. This was achieved in 84% of cases for those who said they wanted to die in a care home, 66% in their own home, 41% in a hospice, and 69% - 9 from 13 – in a hospital.

Additionally around half of the people on the register had a non-cancer diagnosis. It should be noted that the register is part of a wider local work programme on end of life care, which includes advance care planning; an essential and effective part of the process of care. This comprehensive approach is thought to have been particularly important in achieving these results.

Medway
Medway’s End of Life Register is called My Wishes, and covers the local CCG. The system went live in July 2011 using Adastra, and is hosted by the out of hours provider.

Since launch, 12% of all deaths in the area have been entered on the register. A study of two month’s data showed that 70% of patients that stated their intentions achieved their preferred place of death.

Bedfordshire
Bedfordshire has tied its end of life care information register into a central co-ordination centre called Partnership for Excellence in Palliative Support (PEPS), At the end of July 2012, of 330 deaths using the service and register, 65% have been at home (including residential and nursing homes), 12% have been in hospital and 22% in a hospice.
Appendix 5

1. EPaCCS case study: NHS Somerset

EPaCCS has been implemented throughout the South West area, covering 14 PCT areas across the region. One of these is Somerset, where the Somerset Electronic Palliative Care Co-ordination System ensures patients’ expressed choices are communicated across the local health community, their wishes are respected, their dignity preserved, and unnecessary and unwanted admissions to hospital avoided whenever possible.

Built on Adastra and hosted by the out of hours service, GPs, out of hours, A&E, community health providers, social care and specialist palliative care access the record via a shared web interface. N3 access has had to be arranged in some instances. The ambulance trust receives daily alerts.

Somerset has developed a simple reporting template to get more insight into the performance of the system. Data entered can have a negative impact on what you can report; for example, if actual place of death is not recorded, then it is impossible to know whether patients have achieved their stated preference.

Key lessons learned include:

- Engage clinicians and commissioners to see the benefits of EPaCCS and wider collaboration to support better end of life care
- Build on existing systems rather than develop a new platform
- Regularly demonstrate improvements to stakeholders as the system beds in; a user group has helped to support this process
- Define your functionality requirements
- Understand the systems in use for those who you want to use the register
- Encourage IT leads to take responsibility
- N3 connectivity will be required for some services
- Be aware of the impact of any contractual changes, i.e. change in out of hours provider
- Prepare for the unexpected

It is understood that the Somerset CCG will continue to commission the use of the Somerset EPaCCS.

Progress to date

1706 patients on register
Of the 1168 who have died,

63% achieved PPD
47% died at home
6% died in hospital

(September 2012)
2. EPaCCS case study: Impact in Practice (Somerset)

An elderly gentleman with lung cancer was admitted to hospital when he developed a chest infection. He was treated and discharged home.

After this, he decided he didn’t want to go into hospital to pass his last days. He wanted to die at home. His details were added to the EPaCCS by his GP. A Just in Case box was organised, containing pain-relieving medications and supporting information. The multi-disciplinary team discussed his on-going care at one of their monthly Gold Standards Framework meetings, which look at the needs of patients expected to die.

The time did come. The local out of hours service could see his preferences on the EPaCCS. They contacted his GP and District Nurses, who worked together to enable him to die peacefully at home. Through shared access to this information, a person achieved a dying wish. Another hospital admission, potentially ending in death, was avoided.