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Executive summary
Executive summary

Background and methodology

The Department of Health (DH) and the National End of Life Care Programme (NCoEoLCP) recently backed a pilot programme to support and encourage the local development of End of Life Care registers in England. The programme comprised eight pilot sites, each following different approaches to the development and implementation of registers. The pilot programme ran from October 2009 to March 2011, though a number of the sites are continuing with the development and implementation beyond this cutoff. The sites are:

- NHS Brighton and Hove
- Camden PCT Provider Services
- Leeds Teaching Hospitals NHS Trust
- NHS Mid Essex
- Royal Marsden NHS Foundation Trust
- Salford PCT with Salford Royal NHS Foundation Trust
- Sandwell PCT
- Weston Area Health Trust and NHS South West

Ipsos MORI were commissioned to undertake an independent evaluation of the pilots. The evaluation deployed a variety of methodologies to gather information on the views and experiences of pilot stakeholders – desk research, in-depth telephone interviews, and a self-completion survey.

The first stage of the research involved gathering all the available documentation and data from each of the pilot sites. The data was then analysed and fed into a framework model in order to develop a picture of how each pilot was progressing against each of the framework objectives.

The next stage was to have semi-structured discussions with pilot leads, to interview them in detail about their experiences of the pilot, what has gone well, what could have gone better, and lessons learned so far. Pilot leads were each asked to provide a list of key stakeholders involved in the pilot in their area. Questionnaires were sent to them to complete and return.
This report covers findings from the undertakings of all sites. Individual sites are considered in case studies which can be found as Chapter 7 of the main body of the report.

This report expresses the views of those involved in the pilot programme and the evaluation team, but does not necessarily reflect DH and NHS policy.

**Implementing an End of Life Care Register: Overview**

The report details key lessons at each stage of development and implementation that other NHS organisations considering developing their own register should consider. The flow chart below brings together these lessons to illustrate what the process of developing and implementing the register looks like, drawn from the experiences of the pilot sites, and what needs to be considered at each stage.

**Key findings**

**Developing the register**

The first stage of register development is necessarily IT-focused. A key finding was that both **clinicians and IT specialists need to work together** from the outset to ensure the system meets the requirements of clinical staff in terms of data and process. Ideally, the clinical lead needs to be sufficiently senior to drive the register forward and secure **high-level buy-in from stakeholders**. A respected clinician may also be more persuasive when communicating the clinical benefits of the register lending credibility to the project when ‘marketing’ the register.

It is also important to ensure that stakeholders are identified and involved early in the development process, with representatives from all of the service groups with an interest in the register. These may include GPs, out-of-hours providers, ambulance services, acute providers, end-users, patients and families, technical delivery and commissioners, although stakeholders will vary locally. Establishing **a stakeholder group which meets regularly** was helpful in smoothing the process of the development and ensuring that the finished product is fit for purpose.
Implementing an EoLC register: key stages and issues to consider

<table>
<thead>
<tr>
<th>Map stakeholders at the outset:</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain dedicated IT and clinical input:</td>
<td>There should be a member of staff from each background who can devote time to register development.</td>
</tr>
<tr>
<td>Register or care plan?:</td>
<td>Although capable of holding more complex information, care planning tools require more complex functionality, consent processes and administration rights.</td>
</tr>
<tr>
<td>Map the systems that are already in-use:</td>
<td>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.</td>
</tr>
<tr>
<td>Select IT platform and approach:</td>
<td>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.</td>
</tr>
<tr>
<td>Establish the data requirements:</td>
<td>Capturing a minimum level of data is necessary in order to fulfill 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.</td>
</tr>
<tr>
<td>Determine administration rights:</td>
<td>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.</td>
</tr>
<tr>
<td>Design the consent process:</td>
<td>Consider the training requirements of staff around obtaining consent. Gaining consent involves some potentially difficult and sensitive conversations with patients. Consider carefully at which points patients should be asked to join the register. Many pilots identified twelve months as the appropriate length of time for patients to be on the register. Anticipate patient’s objections to giving consent. Produce some literature for patients detailing exactly how their information will be safeguarded and used.</td>
</tr>
<tr>
<td>Training:</td>
<td>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.</td>
</tr>
</tbody>
</table>
This initial engagement needs to be maintained throughout the project. This requires a sustained effort until stakeholders can see the benefits of a successfully implemented register. GPs have been noted by pilot sites as a key stakeholder group to engage. They play an important role in early input to the register, and need reassurance about the workload involved from their perspective. Peer to peer support helping to increase understanding of the potential value of the system is also felt to be very important for GPs.

At later stages of register development, hard-to-engage stakeholders should be able to see an improvement in the efficiency and effectiveness of the register. This requires a critical mass of patients on the register and regular feedback on the register’s benefits.

A suitable technology platform is likely to be constrained by the local context and the existing IT infrastructure. A key challenge is to find a platform which can be used across the different local services, such as GPs, acute care and community services. None of the pilot sites developed a platform from scratch, with all choosing to ‘piggyback’ onto pre-existing local or national platforms. The following platforms were used across the pilot sites:

- Advanced Health & Care, formerly Adastra (Royal Marsden; Camden; Mid Essex; South West)
- EMIS, SystmOne and Acute Trust (Leeds)
- SystmOne (Sandwell)
- Summary Care Record (SCR) (Brighton and Hove)
- Local pre-existing bespoke integrated patient record (Salford)

No platform emerged as a perfect solution. Instead it is important to ensure that the selected platform has the functionality, access, reporting, compatibility and ease of use that will be required from the register. Other reasons for selecting particular IT platforms include:

- Choosing a platform with which staff are familiar, in order to decrease the training burden and fit in well with current clinical processes; and
- Using a commercial provider already contracted to provide a service in the area, such as that providing out-of-hours care, although termination of contracts or change in providers can result in unexpected difficulties.
Implementing the register

The **commonly agreed core minimum dataset** used by all pilot sites incorporates a number of items, some of which are set out below:

- Record creation and review dates
- Patient name and address
- Demographic information (date of birth, gender, ethnicity)
- Consent to share/add details to register

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### Key learning points

- Identify and engage stakeholders as early as possible and before you start developing the data specification and collection protocol.
- Maintaining buy-in, once stakeholders have been engaged, depends largely on being able to demonstrate improvements in efficiency as the system ‘beds in’.
- It is often most efficient to build on existing systems rather than develop a new platform from scratch.
- Think about the **functionality** that is required – what do you want the register to be able to do? What type of reporting do you and other stakeholders want?
- Is the register a detailed clinical care record or is it a palliative care summary?
- Which different stakeholders need to access the register and what systems do they have in place already? Will users have to switch between different systems?
- N3 connectivity may need to be arranged for some services that need access to the register.
- Be aware of the potential effect of contractual changes. It can be time-saving to use the same provider to host the register that is already hosting other systems e.g. out-of-hours services. However, if the provider loses that pre-existing contract it can be very disruptive to implementation of the register.
- How will you ensure that different platforms can share data, especially given some commercial providers may be reluctant to fully support this?
- Prepare for unexpected hitches. Build time into the schedule to deal with unforeseen technical problems.
- Name of usual GP and details of practice
- Key worker details
- Carer details
- Hospice details (if applicable)
- Diagnosis and complications
- Secondary diagnoses (if applicable)
- Resuscitation status
- Preferred place of death

Following the pilot it is intended to put this to the Information Standards Board for **approval as a national data set**, which will provide a basis for the development of other registers. Once the basics are agreed, more targeted discussions can be had about any additional information it may be useful to collect. These additional items may contain information for particular groups of patients or within particular localities.

The original intention of the EoLC register was to provide more comprehensive information than that already available on databases such as GP practice palliative care registers, which simply provide a list of names. Whilst there are **some care planning elements** in the current minimum dataset, many pilots have gone beyond this and adapted their dataset to include more substantial care planning elements.

Given this care planning element to the register, who has **access to editing** and inputting patient data, as well as who has **ownership of the record**, are very important issues to resolve. Most pilots have opted for allowing GPs to control the data with rights to edit and the responsibility to ensure accuracy. The GP would therefore also have ultimate say as to whether the patient was added to the register. Allowing palliative care consultants the same rights has also been a common approach as this is another key point where patients are likely to be identified.

**Information governance processes** need to be clearly thought through. Sharing information needs to be done in such a way that it ensures the accuracy, accessibility, consistency, and completeness of the information stored about patients. Information needs to be managed in a way that ensures the attribution of authorship and changes is possible.
An **opt-in approach** for patients to be registered on the EoLC register has been universally adopted by the pilot sites. Gaining consent involves sensitive conversations around patient wishes, often best carried out by the healthcare professional who is most familiar with the patient. It has been found that there is a need for a variety of healthcare professionals to have permission to add patients to the register, although some sites have caveated this with the need for GPs to then sanction all additions.

Conversations need to be broached at an **appropriate time for the patient**. Twelve months has been identified as a suitable time period for patients to be on the register, with a useful guideline for this being the question of whether the healthcare professional would be surprised of the patient were to die within the next twelve months.

Those pilot sites where the register is live have reported a **good uptake from patients** when seeking consent to add them to the register. Any concerns or uncertainties that patients have had about consenting focus on data sharing and data security issues. Those who choose not to consent should be flagged in some way on their medical records to prevent being asked to consent repeatedly. At the time of the evaluation, no pilot sites reported that any patients had refused to consent.

Training requirements for staff to use the register have been identified as straightforward for the IT side of the project. In many cases staff are using a system with which they are already familiar. The key training element identified is to **support clinicians in the development of communication and care planning skills**. Allowing healthcare professionals to feel comfortable having these conversations is vital in order to get them to engage with the project and in order to get a critical mass of patients consented to the register.
Key learning points

- An end of life care dataset is likely to be available nationally.
- Think about what specific local issues and problems there are and what other information might it therefore be useful to collect.
- Will the system hold extensive care planning information? Increasing the complexity has implications for ease of use and the type of training required for users.
- Consider who is best placed to edit the record. This may not always be the GP or consultant.
- Consider developing a data sharing agreement to promote a consistent approach to the sharing of information. Such an agreement can benefit individuals and services whilst protecting the people that information is about. An example of such a data sharing agreement can be found here http://www.protectinginfo.nhs.uk/.
- Specify clearly who the data controller is and who has responsibility for updating the record and ensuring its accuracy. Resolve any conflicts and ensure the register can always be updated promptly.
- Clinical data should be input by the GP as the data controller, or another clinical lead for the patient, and not devolved to an administrative member of staff in the surgery.
- An ‘opt-in’ approach to obtaining consent should be adopted.
- Ensuring relevant health and social care staff are trained and confident in how to have sensitive consent conversations is important in increasing the uptake of the register.
- Consider carefully at what point patients should be asked to join the register. Many pilots identified twelve months as the appropriate length of time for patients to be on the register, which offers a guide for clinicians on when to ask patients if they want to join.
- Consider religious and ethnic diversity.
Interagency and partnership working

Another benefit of the register is to increase interagency and partnership working among services. Increasing interagency working will therefore create a more seamless and patient-centred experience for the patient. In order to encourage successful partnership working, being involved in the register needs to be a positive experience for stakeholders. Public health bodies can also have a role to play here, by focussing public demand for better EoLC from providers. In order to ensure interagency and partnership working, all services must have equity of access to the register. This may mean establishing N3 connectivity for those services that do not currently have this.

It is too early in the life of the pilots to know for certain what the cost benefits will be; however a number of savings and efficiencies are anticipated by pilot sites. Most sites estimate that they will see cost saving as a result of a reduction in unscheduled care, with better communication of patients wishes and more patients dying in their preferred place of care, which is known in many cases to be at home. Early data and anecdotal findings from two of the pilot sites indicates that this is a realistic anticipatory benefit.

Key learning points

- Ensuring benefits to partnership working are communicated to stakeholders can help secure their buy-in.

- Ensuring successful partnership working and entrenching the benefits depends on positive experiences for stakeholders.

- Equity of access to the register (via NHS connectivity) can help agencies involved in a patient’s care to view each other as being equal partners in that care.

- Public health bodies can have a role in uniting EoLC providers by focusing public demand for better EoLC care from providers.
Service users, carers and families

None of the pilot sites are at the point where they have hard evidence that their EoLC registers are improving patient care. Anecdotal findings and early data from the more advanced pilot sites, however, suggest that registers support the delivery of patient choice. The registers’ existence and the activity and conversations that they drive have prompted a positive response from patients who feel reassured that their wishes are being considered. One register was instrumental in ensuring that a patient’s end of life care preferences were met when neither the patient’s family nor GP knew what the patient’s wishes were. As time progresses register sites will seek to measure these outcomes more formally. Some of the things they will be looking to measure include:

- more patients dying in their preferred place
- more seamless care
- fewer hospitals admissions
- fewer hospital bed days
- less family distress

Concerns from patients and families may focus on:

- Data protection
- Sensitivities around the topic of end of life care
- Whether the register is ‘binding’
- Procedure for updating wishes and preferences
- Patient and family conflicts of wishes

**Key learning points**

The two most likely key **benefits** to patients are:

- More patients dying in their place of choice.
- More seamless end of life care.
Introduction
1. Introduction

The End of Life Care Strategy set out several key areas for improving End of Life Care. Overall, it promoted a whole-system approach to ensure consistency and quality of care across the different services that may be involved, and to set out and deliver an End of Life Care pathway.

One of the areas identified for improvement was better co-ordination of services, with locality registers playing a key role. A locality register, broadly speaking, is a facility that enables the key information about, and individuals’ preferences for, care at the end of life to be recorded and accessed by a range of services. The ultimate aim is to improve co-ordination of care so that End of Life Care wishes can be better adhered to and more patients are able to die in the place of their choosing and with their preferred care package.

This report presents the findings from an evaluation of eight locality register pilot sites across England. This incorporates the findings from the interim report, and includes a detailed case study report for each of the sites. They began operating in October 2009 and have been evaluated since September 2010 so that key learning points and good practice from the pilots can be shared.

This report expresses the views of those involved in the pilot programme and the evaluation team, but does not necessarily reflect DH and NHS policy.

1.1 Background and context

The need for action to improve End of Life Care

The Department of Health’s 2010 White Paper Equity and Excellence: Liberating the NHS heralded a greater emphasis on patient choice and focus on patient outcomes and experience, safety, and clinical effectiveness. This change in emphasis has happened at a time when recent evidence has shown that whilst most people would prefer to die at home, many do not achieve this. Between 56 and 74 per cent of people¹ express a preference to die at home. However, statistics show that only 35 per cent of people die either at home or in a care home, with the majority (58 per cent) dying in an acute hospital. The National Audit Office report End of Life Care, which examined large numbers of patient records, found that in one PCT 40 per cent of those who had died in hospital in October 2007 had no medical need to be admitted.

¹ National Audit Office (2008) End of Life Care, p5
In 2008 the Department of Health published an *End of Life Care Strategy* for England aiming to improve the provision of care for people approaching the end of life and for those who care for and support them. Implementation of the strategy is being supported by the National End of Life Care Programme. The Programme is actively supporting the implementation by developing and sharing good practice in collaboration with local, regional and national stakeholders including the public, private and voluntary sectors. The strategy is also being supported through local and regional work established to support delivery of High Quality Care for All.

End of Life Care has also been established as one of the twelve workstreams in the QIPP (Quality, Innovation, Productivity and Prevention) initiative. The purpose of QIPP is to continue to maintain the focus of High Quality Care for All in the current economic climate. Although the NHS is guaranteed increased funding over the new Spending Review period this will happen on a very much smaller scale than the growth up to 2010/11. QIPP aims to help the NHS to save up to £20 billion by 2015 by improving quality, encouraging innovation and efficiencies. Improving patient experiences and outcomes are a key component of QIPP. The End of Life Care workstream is focusing on encouraging the early identification of people approaching the end of life and planning for their care, including advance care planning, which will underpin, and in turn be supported by, the development and roll out of locality registers. However, it needs to be emphasised that, whilst registers may well provide useful performance management data, their principal focus is on supporting improvements to patient care.

**Locality registers**

The potential benefits of locality registers have been set out in Lord Darzi’s report *Healthcare for London: A framework for action* (2007). The End of Life Working Group identified, amongst other things, ‘inconsistent approaches to supporting individuals to state their preferences for End of Life Care’ due to factors such as lack of consistent systems for recording and updating End of Life Care preferences and communicating them to different healthcare professionals, and a lack of designated responsibility for documenting these preferences. The Working Group recommended the development of End of Life Care Registers as a means of providing an opportunity for a structured conversation about preferences, support, and anticipatory care planning.

In Scotland work to develop such a system was taken forward earlier than in England and the electronic Palliative Care Summary (ePCS) is now in place across the country. The

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ePCS contains detailed information on patients’ wishes, past medical history, current diagnosis and DNACPR status and allows GP practices and other health care providers to collect and share information so that Anticipatory Care Plans can be developed and implemented. In Scotland, Anticipatory Care Planning applies to supporting those living with a long term condition to plan for an expected change in their health or social status. It also incorporates health improvement and staying well\(^3\).

Registers offer a mechanism to improve the quality of care through more effective co-ordination both within and between organisations. In short, they are seen to help:

- Fulfil patients’ choice & priorities;
- Reduce unwanted and unnecessary hospital admissions and Accident and Emergency consultations; and
- Streamline notification of palliative care plans to and from GPs.

**Implementation of locality registers**

The Department of Health (DH) and the National End of Life Care Programme backed a pilot programme to support and encourage the local development of these registers in England. The programme comprised eight pilot sites, each following different approaches to the development and implementation of registers. The pilot programme ran from October 2009 to March 2011, though a number of the sites are continuing with the development and implementation. The sites are:

- NHS Brighton and Hove
- Camden PCT Provider Services
- Leeds Teaching Hospitals NHS Trust
- NHS Mid Essex
- Royal Marsden NHS Trusts and Connecting for Health
- Salford PCT with Salford Royal NHS Foundation Trust
- Sandwell PCT
- Weston Area Health Trust and NHS South West

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While other areas are initiating work around registers, these 8 sites were selected as national pilot sites for the registers and received some limited seed funding to aid implementation. It is the evaluation of these sites that this report covers.

1.2 Aims and objectives of the evaluation

The overarching aims of this evaluation are to assess the experience of the pilots and draw out lessons for future sites thinking about setting up a register. The eight pilot sites have implemented locality registers in different ways, reflecting local circumstances and priorities. This has resulted in many lessons learned about the challenges in getting a register up and running, and the key issues that need to be addressed. The objectives for the evaluation were to understand:

- The differences and similarities between approaches;
- Key challenges, how they were overcome and lessons learned;
- The impact of the locality’s existing level of service provision and the IT infrastructure in setting up the registers;
- Communicating with and engaging service users in developing the register, including how to deal with concerns about it and gaining consent;
- The role of wider stakeholder engagement;
- The impact on patients and carers (including differences between a range of demographic groups);
- The quality of the monitoring data being collected in each pilot site and how they have contributed to care quality and patient experience outcomes;
- A review of the potential efficiencies and cost savings compared with current ways of working that implementing a register could bring; and
- A review of costs and benefits.

From this, the evaluation aims to establish some key recommendations and identify best practice.
1.3 Methodology

The evaluation deployed a variety of methodologies to gather information on the views and experiences of pilot stakeholders – desk research, in-depth telephone interviews, and a self-completion survey.

Desk research

The first stage of the research was to gather all the available documentation and data from each of the pilot sites. Project leads were contacted to help them understand what was required from them for the evaluation, and they were encouraged to send relevant documentation and data. Examples of this data include:

- Initial pilot site application submission to DH;
- Project updates (provided to DH on a bi-monthly basis);
- Job descriptions created for specific locality register job roles;
- Any outcome data generated during the life of the pilot; and
- Internal evaluation documents.

The data was then analysed and fed into the framework model in order to develop a picture of how each pilot was progressing against each of the framework objectives.

Interviews with pilot leads

The next stage was to have semi-structured discussions with pilot leads, to interview them in detail about their experiences of the pilot, what has gone well, what could have gone better, and lessons learned so far. The main themes covered in these interviews included:

- Development and implementation of the pilot, looking at the position before the pilot was introduced and what advances have been made as a result of the pilot;
- Technical issues, including the IT platform used, administration rights, patient consent and the functionality of the register;
- Engagement of stakeholders and partners in inter-agency working; and
- Potential benefits or issues for patients, families and their carers.

These interviews were recorded and transcribed for analysis.
Survey of stakeholders

Pilot leads were each asked to provide a list of key stakeholders involved in the pilot in their area. Questionnaires were sent to them to complete and return. The topic areas are similar to those covered in the interviews with pilot leads but provide an opportunity for stakeholders to talk in more depth about their particular area of expertise and what they feel the benefits to patients, carers and families are, or will be.

1.4 This report

When devising the evaluation, certain areas were identified as key elements for the development and delivery of a locality register. These areas provide a framework for the evaluation and for this report. They are:

- technical delivery;
- implementation;
- organisational and inter-agency arrangements; and
- service user/carer/family experience.

This is the final report of the evaluation, following on from the interim report published in February 2011. It incorporates much of the material from the interim report but contains some additional information that has emerged from the survey of stakeholders. It also includes detailed case-study reports for each of the eight pilot sites.

1.5 Presentation and interpretation of data

Two of the key strengths of qualitative research are that it allows issues to be explored in detail and enables researchers to test the strength of people’s opinion. However, it needs to be remembered that qualitative research is designed to be illustrative rather than statistically representative and therefore does not allow conclusions to be drawn about the extent to which views are held. It is also important to bear in mind that we are dealing with perceptions, rather than facts.
1.6 Acknowledgements

We would like to thank all those who helped to develop this research at DH, the National End of Life Care Programme, and the pilots sites, and especially Stephen Lock and Anita Hayes.

We would also like to thank all the pilot leads and stakeholders who gave up their valuable time to take part in the research project.

1.7 Publication of data

Our Standard Terms and Conditions apply to this, as to all studies we carry out. No press release or publication of the findings of this research shall be made without the advance approval of Ipsos MORI. Such approval would only be refused on the grounds of inaccuracy or misrepresentation.

Compliance with the Market Research Society Code of Conduct and our clearing of any copy or data for publication, web-siting or press release which contains any data derived from Ipsos MORI research is necessary. This is to protect our client's reputation and integrity as much as our own. We recognise that it is in no-one's best interests to have research findings published which could be misinterpreted, or could appear to be inaccurately, or misleadingly, presented.
Technical delivery
2. Technical delivery

A locality register combines clinical need with an IT solution and therefore there is a need to ensure that the technological capability of the register is sufficient to meet clinical requirements. Ensuring that the care pathway for individuals approaching the end of life runs seamlessly across different organisations that are or may potentially be involved in their care is essential to meeting their End of Life Care needs. As described in the introduction, Lord Darzi’s 2007 *Healthcare for London* report highlights why this is not always happening, and proposes the introduction of registers as a way of promoting a structured and consistent approach.

This chapter explores the integration of the clinical and technological aspects of the register to cover:

- Who should be involved in developing the register?
- What is the most suitable technology platform?
- What is the minimum data set?

2.1 Involving stakeholders right from the start

Although the initial development of the platform is IT-focused, clinicians and IT specialists need to work together from the outset. Clinicians need to be able to articulate clearly the system requirements in terms of clinical data and process, and IT managers need to establish the technological options on the basis of these requirements.

Also, involving other key stakeholders will help to ensure that the functionality of the register when up and running meets the needs of those who will be involved in implementing and utilising the register.

Identifying stakeholders

The stakeholders that need to be involved will vary locally but are likely to include representatives from all the different groups that have a vested interest in the register – GPs, out-of-hours providers, ambulance services, acute providers, end-users, patients and families, technical delivery and commissioners.

The pilots have highlighted an extensive list of stakeholders, mostly but not exclusively medical and healthcare staff. The following chart lists some of the most relevant.
Possible stakeholders

- Acute Trust and PCT managers
- Allied health professionals
- Ambulance trusts
- Commissioners
- Community matrons
- Consultants in palliative medicine
- Consultant psychiatrists
- Discharge palliative care liaison nurses
- District nurses
- Families/patients
- GPs
- Home managers
- Hospice representatives
- Information Governance staff including Caldicott Guardians
- IT leads in all organisations
- Nurses responsible for triage at A&E
- Out of hours representatives
- Palliative care clinical nurse specialists
- Paramedics
- Pharmacists
- Representatives of IT providers
- Specialist nurses

As the list above shows, the main focus so far has been on health service stakeholders. However, social care is also likely to be important, and pilots will need to engage with stakeholders from this sector as they move forwards.

Getting the right stakeholders involved helps to create a shared ownership of the register, along with a shared responsibility for successful implementation. Evidence from the pilot sites suggests that this can be a crucial factor in generating and maintaining the momentum required to get the register up and running.

Managing expectations

Whilst involving lots of stakeholders is important, it’s worth keeping in mind that they are likely to have very diverse hopes and expectations for what the register can deliver. They may also be starting from different positions: enabling access to the register may be more challenging and time consuming for some stakeholders than others. For example, hospices may not have NHS connectivity and may require the setting up of an N3 connection. These hopes and expectations need to be understood and, where necessary, managed so that stakeholders are not left feeling alienated and not listened to. Differing expectations between stakeholders may focus on the following issues:
There are practical steps that can be taken to manage expectations. As mentioned, a key learning point is the importance of involving stakeholders in planning the register right from the start in order to ensure realistic and shared expectations. In practical terms, this entails:

- **Mapping stakeholders at the outset.** An initial task should be to think through and map all the organisations and types of staff that are likely to be affected by, or have an interest in, the creation of a register. These organisations should be approached and engaged as soon as possible to ensure they have a shared concept of the purpose of the register.

- **Establishing a stakeholder group which meets regularly.** Aligning the development of the register as early as possible with stakeholders' priorities is vital to its success. Establishing a stakeholder group ensures that the lines of communication are kept open throughout the implementation of the register and provides a regular opportunity for any concerns or problems to be raised and discussed. Encouraging the early involvement of stakeholders may also encourage use of the register once it is live. Stakeholders who are offered the opportunity to influence the design or implementation of the register are more likely to feel that it has been tailored to their needs and therefore be more inclined to use it than otherwise.

### 2.2 Selecting the platform

Choosing the most suitable technology platform is likely to be a constrained choice to some extent. Local contexts differ, as do the existing IT infrastructures and the functionality that is required. Most sites will have a wide range of technological 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. A key challenge is to select a platform which can
be used across different services, whilst retaining as much clinical functionality as possible. Consideration will also need to be given to local and regional IT strategies, such as issues around future system compatibility, and roll out of the SCR.

None of the pilot sites developed a platform from scratch, instead choosing to 'piggyback' onto pre-existing platforms. The three main advantages to using an existing platform can be summarised as follows:

- The platform will map to existing clinical processes.
- The training framework may already be in place. This reduces the burden of technical training for staff. The need for minimal training is most important for those who are likely to be most resistant to the development of a new system.
- The existing platform will already be supported by existing Information Governance arrangements which will need to include information sharing protocols.

Overall, choosing a platform that staff are familiar with means that although there may be a need for support in terms of having the End of Life Care discussion with patients, they should already be familiar with the interface they need to access and use. It will fit in with clinical processes they are already used to. This ease of access and use is an important factor when engaging stakeholders in the pilot and building partnerships to encourage use of the register. This will be discussed in more detail later in the report. The majority of pilot sites have chosen to use one IT platform, provided by a single commercial supplier, to support their register. However, it may be the case that all health care providers do not have access to one or other of the commercial suppliers’ platforms, potentially limiting the universal availability of the register.

Rather than compromise this clinical vision by making decisions that limit access to the register, it may be necessary to enter discussions with providers with regard to developing a bespoke solution, involving the integration of data from multiple providers’ platforms. This approach ensures that the register has full functionality across the majority of healthcare providers. Where faced with a similar conflict of interest, future sites may wish to consider this approach. However there are particularly challenging issues surrounding integration of IT platforms which must be carefully considered before embarking on this route. These are discussed in the next chapter, and in some of the case studies.

The platforms that sites have opted for are:
Cost and training implications are key considerations when choosing the platform. Pilot sites have also carefully considered the ease of accessibility and the compatibility of various platforms to ensure that the register can be rolled out across the wider area should it prove to be successful. Whilst no platform emerges as the perfect solution, there are important considerations that may help future sites to choose the right one: functionality, access, reporting, compatibility and ease of use.

- **Functionality.** What will the record be required to do, and what information will it need to hold? One of the key questions to ask at the beginning of the process of developing a locality register is whether it is intended to be a detailed clinical care record that can be used as a tool to help with care planning (including advance care planning), or whether the intention is to simply to have a palliative care summary. A platform like Advanced Health & Care may be more suitable for the former, whilst the SCR may be best for the latter. Envisaging the register as a care planning tool makes the development of the platform potentially much more complex. The more focused the register is on clinical information, as well as simply demographic information, the more complex on the issues of system functionality, administration rights (i.e. who is able to make changes and inputs to the record), and the way in which patients are consented, become. These issues are discussed later.

- **Access to the platform.** Accessibility of the platform, especially to out-of-hours services, and the extent to which it is in use already are key considerations. Advanced Health & Care has been a popular choice for pilot sites because it provides the system for many out-of-hours GP services in England and was already accessed by a wide variety of healthcare professionals prior to the pilot. It is critical that out-of-hours services have access to the register as it is during these hours that EoLC patients are most likely to be seen by a medical professional who is not familiar with their condition. Additionally, this existing familiarity and access means that by selecting Advanced Health & Care to host their register, some pilots have ensured faster implementation and reduced training costs.
Consideration needs to be given to which services are likely to be the most difficult to organise access for. The experience of the pilots shows that hospices and care homes frequently lack access to systems holding patient records. Access to NHS systems via an N3 connection may need to be arranged for them. For remote and lone workers, access via VPN (Virtual Private Network) tokens and mobile technology may need to be considered.

- **Reporting functions.** For some pilot sites, the provision of reporting functionality has been a key factor when deciding which software platform is the most appropriate to support their register. The SCR, for example, has no reporting capabilities and is not easily searchable. This is due to data protection concerns. It was decided nationally during the design phase to limit its reporting and search functions to allay concerns that these functions could encourage people with access to extract and store data in formats that could be more easily lost or misplaced.

  Reporting functionality on other systems can be designed into customised tools. Some simply collect data and flag patients as being on the register, whereas others collect and analyse more detailed data on outcomes and trends.

  Being able to analyse the register’s usage by variables such as the patient’s main diagnosis or ethnicity allows pilot sites to identify groups of patients that are less likely to be added to the register. This means that inequalities in the register’s usage can be monitored and issues addressed. For example, a site may implement additional, targeted training for healthcare professionals or alter the data set of the register to account for the specific concerns of particular patient groups.

- **Compatibility.** What different systems will the selected platform need to interface with? In pilot sites where the register’s host platform is not the same as the majority of out-of-hours services’ host platforms, significant time costs have been incurred. For example, in one pilot site where the platforms differ, the register has to be manually populated with the GP practice data. If the platforms were the same, and/or compatible, this process could be automatic. Although both providers use Advanced Health & Care, the systems are not integrated and cannot ‘talk to each other’.

  Where providers’ system usage is substantially divided between two or more platforms, it may be unclear which platform offers the best compatibility. In these
cases, sites may be forced to decide whether to set up a register which does not necessarily provide the best possible access and ease of use for a large proportion of providers, or to devise a more complex IT solution, using a combination of platforms. When making this decision, sites need to consider the extent to which they are prepared to compromise their clinical vision (will it exclude particular providers from the register?), the long-term sustainability of the register (whether it will need replacing or updating when new IT platforms come into full usage?) and the time constraints within which the register is being implemented (is there time to devise a complex IT solution which will circumvent these negative consequences?).

In some areas there may be a local data-sharing platform in place that allows different services to share generic information about patients. If so, this could have the potential to be developed into a system that holds condition-specific information (including End of Life Care preferences). This approach has been taken in one pilot site with a pre-existing local data sharing platform.

- **Ease of use.** Who will be accessing the register and what is their level of expertise in using similar systems? What administration rights will they have – will they be expected to enter detailed information and run reports, or will they be able only to view the record or request changes? This will have implications for the technical training that is needed for register users, depending on the complexity of the editing they are able to undertake. The SCR in particular can be complex to access and update through the GP systems. The GP requires a smartcard to access the SCR and they need to know how to use their own system to update it.

We have reproduced some examples of data collection templates that have been developed by pilots in the Appendices. Brighton and Hove have developed a palliative care template. The codes and their order within the template are listed in the Appendix. The Sandwell pilot split their minimum data set into three templates covering End of Life Care planning, bereavement details, and details of death. These templates are reproduced in the Appendix.
2.3 Working with commercial providers

There are potential obstacles that may arise from working with commercial providers. They often have different ways of working and priorities that do not necessarily coincide with those wishing to set up the register. It is important to be aware of these from the start. That said, pilots have had generally good experiences working with commercial providers. Working with national public providers also has its own potential pitfalls, discussed at the end of this section.

Contractual changes

Sites may find it beneficial to work with commercial providers that are already contracted to provide a service within the area. For example, choosing the same commercial provider who hosts the local out-of-hours service, to host the register may have significant time-saving

Technical platform: Key learning points

- It is often most efficient to build on existing systems rather than develop a new platform from scratch. This is the approach that all the pilots have taken.

- Think about the functionality that is required – what do you want the register to be able to do? What type of reporting do you and other stakeholders want?

- Is the register a detailed clinical care record or is it a palliative care summary? The specifications and demands on the register increase dramatically if it is intended to be a detailed clinical care record that can be used as a care planning tool.

- Which different stakeholders need to access the register and what systems do they have in place already? Is there a platform already in place that is used by services locally and could this be enhanced to host the register, thus reducing compatibility issues? Will users have to switch between different systems?

- How will accessibility be ensured for all services that need access to the register? N3 connectivity may need to be arranged.

- Consider what expertise users of the register will have and therefore what training will be required. Will they already be users of the platform that is being developed to host the register, or will they be completely new to the system (e.g. care home or hospice staff)?
implications. However, a potential negative consequence of reliance on pre-existing contracts with commercial providers is that there is no guarantee that these contracts will be renewed or that they won’t be unexpectedly terminated.

Where pilot sites have experienced the termination of a provider’s contract it has proved to be very disruptive. Contractual changes often result in a period of instability during which time the new provider may be on a probationary contract or unwilling to enter additional contracts with sites. During this time, any implementation of the register which is reliant on the new provider may have to be postponed until the new provider’s permanence is established. This is necessary to avoid duplication of work in the event that the provider is changed again; however, this can cause significant delays to the technical implementation of the register.

In addition, a new provider’s approach may be very different from that of the previous provider. Goodwill and good working relationships developed with the previous provider will be lost and will have to be developed anew. Work that was previously seen as mutually beneficial to both provider and the register site may now require payment.

**Integration between providers**

The majority of pilot sites have chosen to implement the register using the IT platform already in use by most healthcare providers in their area. However, in many areas there are healthcare providers who use alternative IT platforms. It is therefore important that whichever platform is chosen is able to integrate and interface with other IT platforms so that all the information on the register is accessible to all providers. Enabling this functionality is particularly challenging when different platforms are in use. In these cases, it is essential that the platforms are compatible and that information collected using one platform can easily be shared with healthcare providers who are using the alternative platform. This relies on the different platforms sharing data with one another – a functionality which commercial providers have sometimes been reluctant to provide. This is because providers may view it as against their commercial interests to share data with competitor firms.

To circumvent this concern, some commercial providers have proposed that, rather than full integration between providers’ data, each end-user is provided with an icon on their desktop which links to the register. However, as this solution would not integrate into current clinical processes, there are fears that it could result in lower uptake of the register due to the inconvenience caused to healthcare providers by having to navigate between two systems. Indeed, clinicians have expressed the importance of having the register in plain sight to
encourage use and there is a strong preference among GPs for the register to be located on an additional tab on their usual platform.

It is important for future sites to consider carefully whether data sharing between providers is likely to be an important factor in successfully implementing the register. These needs should be discussed in initial conversations with IT platform providers to ascertain their willingness to supply the necessary functionality. If possible, it is also advisable to stipulate in the contract what is expected of service providers in terms of connectivity and data-sharing.

**Priorities and motivations**

Many pilot sites found that the involvement of commercial IT suppliers complicated the implementation of the register due to their contrasting priorities and motivations. The commercial motivations of IT suppliers were sometimes greater than they had previously encountered with NHS providers and this led to some uncertainty when the implementation of the registers encountered difficulties. It has sometimes been unclear whether a constraint on a register’s functionality is caused by a genuine technical limitation or merely a financial limitation imposed by the IT provider.

In response to these concerns, some sites have tried to reach a compromise whereby they create a register which provides a better service for the patients while meeting the commercial interests of the IT provider. However compromising on some aspects of the clinical vision in order to meet the needs of the provider is less than ideal, particularly in cases where this could jeopardise the long-term viability of the register. If compromises need to be made, it is important that their likely impacts are measured against local and regional IT strategic plans to ensure the IT solution remains aligned with them as much as possible.

Overall, the pilot sites have had good and productive working relationships with the IT providers. These providers tend to already have prior and ongoing experience and understanding of working with the local health sector. Advanced Health & Care, for example, is providing the platform for a number of pilots. It has proved to be flexible and willing to tailor systems to local needs. It has a great deal of experience nationally in providing the IT platform for patient records in GP practices.

**Difficulties working with national public providers**

This has its own potential difficulties. For example, the change of administration over the life of the pilots introduced challenges which could not have been anticipated as the new Government set out its plans and priorities for the health service. They may also not always be as flexible as commercial providers. Some pilots have considered adapting the Summary
Care Record (SCR), developed by NHS Connecting for Health, to host the register. Due to the slow roll out of the SCR, and the review undertaken following concerns raised about the consenting process for the SCR, significant problems and delays were created for these pilots. Additionally, the SCR was not originally intended for use as a register – for example, it has no reporting function. Register priorities need to be ‘retrofitted’ to the SCR rather than being developed into a tailored system.

### Integration and interfacing between IT systems: Key learning points

- Be aware of the potential effect of contractual changes. It can be time-saving to use the same provider to host the register that is already hosting other systems e.g. out-of-hours services. However, if the provider loses that pre-existing contract it can be very disruptive to implementation of the register.

- Integration between providers with different IT platforms. For example, in a number of areas many GP practices will use the same IT platform, but other healthcare providers may not. How will you ensure that different platforms can share data, especially given some commercial providers may be reluctant to fully support this?

- Be aware of commercial sensitivities. The organisation you work with to develop the platform may be an external commercial agency. Think about the priorities of the organisation, how they will work, the kind of relationship you will have with them and, if applicable, what would happen if you needed to switch over to another provider during the project. That said, commercial providers have generally proved to be responsive and flexible.

- Prepare for unexpected hitches. Build time into the schedule to deal with unforeseen technical problems.

#### 2.4 Developing the data set

During the early stages of the pilot programme, it was agreed that a common minimum data set would be adopted by each of the pilots, capturing the minimum level of data that was thought to be necessary to fulfil the objectives of the registers. A level of consistency in data collection was also considered essential to enable effective evaluation of the different approaches adopted by the pilots. The intention is to take this list to the Information Standards Board at a national level to agree a full and proper definition.
A more comprehensive data set was also pulled together with the pilot sites and elements of this, alongside other locally determined data fields, were adopted by some of the pilots. The range of data fields selected reflects the different approaches adopted by the pilots, particularly in relation to the extent to which the register has been utilised as a care planning mechanism.

The core minimum data set
The commonly agreed core minimum data set that all the pilot sites are using incorporates a number of items, some of which are set out below:

- Record creation and review dates.
- Patient name and address.
- Demographic information (date of birth, gender, ethnicity).
- Consent to share/add details to register.
- Name of usual GP and details of practice.
- Key worker details.
- Carer details.
- Hospice details (if applicable).
- Diagnosis and complications.
- Secondary diagnoses (if applicable).
- Resuscitation status.
- Preferred place of death.

As mentioned earlier in this section, the intention following on from the pilots is to put this to the Information Standards Board for approval as a national data set.

Beyond the core minimum data set
Once the basics are agreed, more targeted discussions can be had about any additional information it may be useful to collect. These additional items may contain information for particular groups of patients or within particular localities. Local circumstances may make it useful to collect other information. For example, it is worth asking:

- To what extent is it intended that the register will be a care planning tool? If this is the intention then detailed information on care wishes and advance planning may need to be included.
- Is the local area *ethnically diverse*? If so, recording the patients’ religion may be useful as well as their ethnicity, which is part of the core minimum data set agreed at the outset of the pilot.

- Are there any *staff safety concerns* in relation to any patients or where they live? Recording whether it is safe for healthcare professionals to visit a patient in their home may be useful in areas where personal safety can be a concern.

- Are there any local issues surrounding the *Medical Certificate of Cause of Death (MCCD)*? If so, recording prior to death whether GPs have agreed to sign a MCCD may help to clarify proceedings after death. If this is to be recorded, then the date the GP last saw the patient should also be recorded as the Registrar of Births and Deaths would have a duty to refer to the coroner if the patient had not been seen by a doctor within 14 days of the death or if the doctor did not see the body.

- Has the patient requested *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)*? This is an item in the core minimum data set. However it may be useful for paramedics in particular to know where in the patient’s house the hard copy of the DNACPR form is kept, as, if it cannot be found, they have to attempt resuscitation. There may therefore be a case for including a data item for the patient to specify where they keep their form.

Agreeing what the register’s data set should contain beyond the agreed core minimum requires careful consideration. If too many mandatory data fields are incorporated the time required to complete the register may discourage busy health professionals from using it. Additionally, in emergency situations, excessive data fields will increase the amount of time it takes health professionals to locate the relevant information and this may jeopardise the chance of patients achieving their preferences.

Conversely, if too few data fields are incorporated into the register there is a danger that the register will not be sufficiently comprehensive to allow it to be a reliable and consistent tool to improve end of life patient care. It will be important to explore these issues carefully, and gain agreement, as making changes to the agreed data collection template once it has been implemented could be technically burdensome and could stall the project.
Pilot sites repeatedly emphasised the importance of engaging a large range of stakeholders from the early stages of the register’s implementation as stakeholders’ expectations of the key data set can vary widely. Stakeholders therefore need to be engaged in developing the data specification and data collection protocol along with the IT specialists who can inform them about how the platform could work and manage expectations about what can and cannot be achieved.

Consulting a wide variety of different stakeholders on the register’s design is likely to make it more difficult to reach agreement when prioritising the type of information that should be collected on the register. As it is important to ensure that the register’s data set is not prohibitively large, it is unlikely that it will be possible to accommodate the preferences of all stakeholders. It is therefore essential that stakeholders realise early in development that the data-set is unlikely to cover all aspects of their wishes, and this needs to be handled sensitively but with authority.

**Register or care plan?**
The volume and type of clinical information which has been included in the pilot sites’ data sets has raised questions over the distinction between a register and a care plan. Aside from the information sharing facility, the locality registers were always intended to be more comprehensive than existing registers such as GP palliative care practice registers, which are simply a list of names of those approaching the end of life. The minimum data set, which all the pilots signed up to, has some care planning elements within it. However, the majority of the pilots have adopted systems which contain substantial care planning elements.

This has implications for training and information governance, particularly in relation to the input of data and responsibility for quality control. The more care planning elements are included, the more sensitive and complex the information contained on the register is likely to be. As the GP is ultimately the data controller for the patients’ IT medical records, there are concerns about the dangers associated with authorising non-GP staff, particularly non-clinical staff, to enter sensitive and complex patient information onto the register. The technical and procedural methods that pilot sites have employed to mitigate these concerns are discussed in the Implementation chapter.

There are also implications for naming the register. Through reflecting on their experiences, the pilot sites came to appreciate the importance of finding the right name for the register that accurately described what it was and did not deter patients. The term ‘register’ itself was thought to be misleading, implying simply a list of patients rather than a more sophisticated
tool holding care planning and medical information. ‘End of life’ was felt to be a potentially off-putting term for patients. The pilots collectively preferred a more accurate descriptive phrase such as ‘Electronic Palliative Care Coordination System’ for the projects as a whole, which they might localise. For example one pilot has chosen to call their register ‘Coordinate My Care’.

<table>
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<th>Developing the minimum data set: Key learning points</th>
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<tr>
<td>▪ Identify and engage stakeholders as early as possible and before you start developing the data specification and collection protocol.</td>
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<tr>
<td>▪ Manage stakeholders’ expectations and develop a shared set of expectations about the register. Ensure that they understand what the platform for the register can and cannot support in terms of data collection and functionality.</td>
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<tr>
<td>▪ An agreed minimum dataset is likely to be available nationally. More complex additional requirements need to be discussed and prioritised carefully with stakeholders, ensuring they understand what is feasible and desirable and why.</td>
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<tr>
<td>▪ Think about what specific local issues and problems there are and what other information might it therefore be useful to collect.</td>
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<tr>
<td>▪ Will the system hold extensive care planning information? Increasing the complexity has implications for ease of use and the type of training required for users.</td>
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Implementation
3. Implementation

Once the basis of the register has been designed, the way it is implemented is equally important. This chapter examines key learning points in the areas of administration rights, patient consent and data security. It also highlights the importance of making sure the register has the correct personnel with dedicated time to work on the project and to ensure that buy-in from stakeholders is maintained.

3.1 Maintaining buy-in from stakeholders

Although it is crucial for stakeholders to be involved right from the start, the project leads must also ensure that buy-in from stakeholders is maintained throughout the life of the project. Asking staff to change the way they work to a system which they may initially perceive as cumbersome requires a sustained ‘push’. Once the natural workflow is developed and stakeholders can see an improvement in efficiency, the system should then be able to maintain itself.

Engaging staff groups

Pilot sites have found that certain groups of healthcare professionals are easier to engage than others. GPs in particular are a key stakeholder in ensuring the register is a success, however due to the central role that GPs need to play in the register’s implementation, and the already heavy demands on their time, pilot sites have found full engagement challenging. Whilst many GPs have shown great interest in the register and have been engaged in its development, this has not been consistent. As well as ensuring that GPs are aware of the register’s potential benefits, they must be reassured about the workload involved in implementing and using it. Although registers are likely to offer time-savings in the long term, whilst learning to use the register, GPs may find it less efficient to use than their current system. For this reason peer to peer support would potentially be very valuable in sharing understanding of the system and promoting the potential long term time savings that the register can provide.

Depending on the success of the current system for communicating with out-of-hours, acute and community services, GPs may be reluctant to change their current method of communicating patients’ End of Life Care wishes, whether this is by fax or other means, and can be concerned that the introduction of an electronic end of life register will result in an increased workload with a limited improvement in outcome. There has been a much higher motivation to engage among those who currently find their transfer of information system burdensome. It is important to be able to closely map the new and old systems in each area.
to explain where the advantages of the new system are and when these advantages will become apparent.

One of the most crucial ways to encourage reluctant professionals to support the register and engage in its development is to push forward with enrolling as many patients as possible. The experience of the pilots suggests that hard-to-engage stakeholders can be encouraged to buy into the register when they see that it is working and that it is more efficient and effective than previous processes. This will only be observable, however, once there is a **critical mass of patients** on the register and regular professional feedback from out-of-hours and ambulance services on the register’s benefits.

It is also worth finding out about systems of approval that are required in different organisations for changes to be accepted and integrated. For example, Local Medical Committee (LMC) approval can provide GPs with some assurance that potential areas of concern have been addressed.

### Maintaining buy-in from stakeholders: Key learning points

- Maintaining buy-in, once stakeholders have been engaged, depends largely on being able to demonstrate improvements in efficiency as the system ‘beds in’.
- Maintaining GPs’ engagement in particular is especially dependent on being able to demonstrate efficiency and reduced workload compared with their current methods.
- Persuade difficult-to-engage stakeholders by focusing on enrolling patients. If stakeholders see a ‘critical mass’ of enrolled patients building up, they may be more likely to engage.

### 3.2 Administration rights

The issue of who has access to the patient record to change and update patients' information is one of the more difficult to arise from the pilots. Establishing clear responsibility for updating the register is key, but potentially conflicting considerations need to be resolved. These include:

- Who can add a patient?
- Who has ultimate responsibility for the accuracy of the data?
- Who can alter a record?
• If others can alter the record, how does the person with ultimate responsibility for data accuracy monitor and control changes?

Information governance processes need to be clearly thought through. Sharing information needs to be done in such a way that it ensures the accuracy, accessibility, consistency, and completeness of the information stored about patients. Information needs to be managed in a way that ensures the attribution of authorship and changes is possible. Patient consent should be informed and access to records needs to ensure the security of information. In particular registers will need to take account of:

- The Data Protection Act 1998.
- The common law duty of confidentiality.
- The Confidentiality NHS Code of Practice.
- The NHS Care Record Guarantee for England.
- The Information Security NHS Code of Practice.
- The Records Management NHS Code of Practice.

Control of data

Whilst the data on the register belongs to the patient, someone needs to have responsibility for ensuring accuracy i.e. that the record is an exact reflection of the patient’s circumstances and wishes. The experience of the pilots is that there needs to be agreement on who has ultimate responsibility for the content of the patient record and the accuracy of the End of Life Care information contained in it. Establishing responsibility for a shared record is a difficult issue. The Shared Professional Guidance Project report unpacks this issue and identifies different layers of responsibility at different levels.

A common approach in the pilots is to allow GPs to be the data controller (that is, to have rights to edit the register and ensure its accuracy) as they are often seen as being the clinical leader for the patient in the community. The GP, as the data controller and clinical leader for the patient, should therefore have the ultimate say in what is changed and added to the patient record – and therefore in whether the patient is added to the End of Life Care Register. Many sites have also allowed palliative care consultants editing rights for the register as this is another key point when EoLC patients would be identified.

However GPs and consultants are not always best placed to edit the record, and in some cases (though by no means all) are not always best placed to identify when the patient reaches the point where they should be added to the register. Other healthcare staff – for example, hospice workers, community nurses, or other clinical nurse specialists – may be in a better position to recognise when a patient is eligible. They may have more frequent contact with the patient, spend more time with them, and have built up a trusting relationship with them, better enabling these professionals to have conversations with them about joining the register. Community and hospice-based staff may also be particularly well-placed to identify non-cancer patients who may be eligible to join the register. This can be less straightforward than identifying cancer patients and the in-depth and ongoing nature of the relationship may mean that the member of staff is more attuned to the patient and their condition and better able to identify when they may be approaching the end of life.

The potentially conflicting considerations of responsibility for updating the register and ensuring its accuracy can be resolved and two possible solutions to emerge from the pilots include a technical fix and a procedural fix. Both these fixes depend on, and highlight the importance of, multi-disciplinary team working with the patient at the centre, and the importance of key workers who have an in-depth knowledge of, and relationship with, the patient:

- **Technical fix:** One solution is to allow a variety of clinical staff the ability to ‘initiate’ a patient's entry on the register – in other words to create a record. The GP, however, retains the role of 'sanctioner' – essentially a gatekeeper role – whereby the final decision about whether the patient joins the register and the record goes live lies with the GP. Unless the entry is ‘sanctioned' by the GP, the patient does not join the End of Life Care Register. Thus the GP retains overall ownership but staff from other services involved with the patient also have a access on the register and can initiate inclusion. The ability to implement this fix may depend on the technology platform being used.

- **Procedural fix:** In the absence of a technical solution, the issue can be mitigated by carefully specifying the process for editing the patient record. If only GPs are authorised to add patients to the register, it is important that clinical staff from outside the GP surgery are able to quickly communicate with GPs, whether by fax, email or telephone, to alert them when they come across a patient who is eligible to join the register. This can become quite burdensome on GPs, however.
Access

The other key issue around administration rights lies in deciding which level or type of staff should have the ability to enter or access different types of information. Accuracy of data entry – especially clinical data, including relating to End of Life Care wishes - is a risk area. In order to mitigate this risk, some sites have decided that clinical information should only be entered by clinical staff. This is particularly applicable where the information relates to care planning. Clinical staff can take responsibility for initiating patient entry onto the register and for entering advance care plans and completing after-death information.

Administration rights: Key learning points

- Consider who is best placed to edit the record. This may not always be the GP or consultant. Other healthcare staff such as district nurses, hospice workers or community workers may be in a better position to recognise when a patient is ready to be added to the register, and to update it.

- Consider developing a data sharing agreement to promote a consistent approach to the sharing of information. Such an agreement can benefit individuals and services whilst protecting the people that information is about. An example of such a data sharing agreement can be found here [http://www.protectinginfo.nhs.uk/](http://www.protectinginfo.nhs.uk/).

- Specify clearly who the data controller is and who has responsibility for updating the record and ensuring its accuracy. Resolve any conflicts and ensure the register can always be updated promptly. For a new addition to the register, this could be either by exploring a technical fix that enables healthcare staff other than the GP to ‘initiate’ an entry on the register which the GP then sanctions, or by implementing clear procedures for information to be faxed or emailed to the GP and actioned by surgery staff.

- Clinical data should be input by the GP as the data controller, or another clinical lead for the patient, and not devolved to an administrative member of staff in the surgery.

3.3 Obtaining patient consent
Patient consent for being entered onto the register is a sensitive issue and due consideration needs to be given. The learning points from the pilot sites in this area included:

- **Should an ‘opt-in’ or ‘opt-out’ approach to obtaining consent be adopted?**
  All the pilot sites have chosen to adopt an opt-in approach. Each patient is individually consented onto the register after discussing their preferences with a healthcare professional. The exact form of consent differs between pilot sites. While some ask for consent for the patient’s information to be added to the register, others ask consent only for this information to be shared between healthcare providers.

  There are a number of reasons why an opt-in approach may be preferable. For example:
  - The register is shared with other healthcare professionals potentially over multiple settings.
  - The process of asking for explicit consent helps to build communication, trust and understanding between the patient and the healthcare professional.
  - Discussing consent can be a useful trigger for a conversation with the patient about End of Life Care wishes.
  - Overall, there is a cultural shift occurring in healthcare towards involving patients in decisions about making information about them available to other care providers.

- **Who should ask the patient for their consent?**
  Gaining consent involves initiating sensitive conversations surrounding the patient’s end of life choices. Health and social care professionals are best placed to obtain consent. However staff, particularly those not trained in palliative care, can feel uncomfortable initiating these conversations whereas others such as palliative care nurses are more comfortable discussing end of life choices and are often best placed to consent patients onto the register. This reinforces the importance of allowing a variety of healthcare professions permission to add patients onto the register, even if this has the caveat that each patient’s GP must sanction the record before it is fully uploaded.

**Are there training requirements around obtaining consent?**
There is great variability among clinicians as to how comfortable they feel when speaking to

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5 Commitment 6 of the 2009 *NHS Care Record Guarantee* states that ‘Usually you can choose to limit how we share the information in your care records which identifies you’.
patients about sensitive topics such as End of Life Care. Many pilot sites have emphasised the importance of providing staff with targeted training led by palliative care professionals in order to overcome the challenge of obtaining consent. Although this training may be particularly important for GPs, as they have a key role in identifying people for the register, it is advisable not to assume that any clinician, even those with palliative care training, will feel confident consenting patients to the register. Providing all clinicians with materials, such as communication ‘strap-lines’ to help initiate conversations with patients, before they ask, can help clinicians to feel more comfortable and supported in this role and ensure that all clinicians are well-trained and confident in initiating conversations. This will increase the likelihood of the register’s uptake and will help to make using the register more comfortable for both patient and clinician alike. In most pilot areas, the register is being trialled with practices already familiar with the Gold Standards Framework (GSF) and other palliative care tools. Some thought needs to be given as to how professionals who are less familiar with the current systems are trained.

There is already evidence that providing training for staff on initiating conversations with patients can improve the quality of End of Life Care. In February 2011 the Dying Matters Coalition released the findings of a study whereby a group of GPs were given focused training in how to hold and sustain conversations about dying, supported by tailored materials including leaflets, posters and postcards. The study boosted GP confidence and increased the numbers of patients who communicated openly about their needs and preferences at the end of life. At the start of the study, 60 per cent of the participating GPs said they were worried that patients would reject the conversation or would find it distressing. However the study found that 90 per cent of the patients continued the conversation once it has been initiated by their GP6.

- **At what point is a patient asked if they want to join the register?**
  The point at which patients are consented to the register is significant. If discussion of end of life preferences is broached too early, patients may be unwilling to engage in serious consideration of their options. However, if broached too late, the conversations may prove distressing for patients and/or they may be less able to engage in such a discussion.
  Twelve months has been identified as a suitable time-period for patients to remain on the register and, although impossible to predict, this provides some guidance of the appropriate time to introduce the topic of end of life planning to patients. Health

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6 Further details, a video of GPs talking about dealing with death, and a report of the study can be accessed here: [http://www.dyingmatters.org/news/97](http://www.dyingmatters.org/news/97)
professionals may be advised to ask themselves whether they would be surprised if the patient were to die within the next 12 months. If the answer to this question is “no”, then it would be deemed appropriate to add the patient to the register. However, as it is often difficult to assess when a patient is going to die, the twelve month time-frame is intended as a guide only. It is accepted that patients added to the register may live much longer than twelve months. Indeed, there is a danger that if a specific time frame for remaining on the register is promoted it could discourage health care professionals from consenting non-cancer patients to the register as their prognoses are often less certain than those of cancer patients.

- **What if a patient refuses to consent or changes their mind?**
  Those pilot sites with a live register have reported little or no resistance from patients when seeking consent for their information to be added to the register or shared with other healthcare providers. Many patients welcome the opportunity to discuss their options for end of life and understand the importance of sharing this information between providers. Indeed, some pilot sites have reported that patients are surprised that such information was not already shared across providers involved in their care.

  As mentioned, resistance from patients has been minimal and at the time of the evaluation no pilot sites have reported any patients refusing consent. Any concerns that patients may have tend to be about data sharing and security. Healthcare professionals may therefore find it helpful to provide patients with literature explaining exactly how their information would be used and kept safe. If a patient ever chooses not to consent, this decision should be flagged on their medical record to ensure that they are not asked to consent repeatedly by different healthcare professionals.

- **Securing consent from patients from different ethnic or religious backgrounds.**
  In areas with high minority ethnic populations in particular, it may be useful to scope out and approach key figures in these communities in order to engage them in the development of the register. Religious leaders may be able to offer guidance about the key sensitivities that particular religious groups have regarding the end of life. This knowledge should then be fed into training so that they are understood by healthcare professionals using the register and better equality of access to the register can be achieved.
Many areas will have services such as care homes that are specifically designed for particular ethnic and religious groups and these would be key care settings to engage. Staff working in social care settings may also be well placed to identify potentially eligible individuals and initiate conversations about joining the register. Social care providers may become more involved as the pilots progress.

The following flow chart gives a visual summary of the different stages and considerations in developing a process for obtaining consent to join the register.

**Designing the consent process: stages and issues to consider**

- **Choose approach**: ‘Opt-in’ likely to raise fewer concerns than ‘opt-out’.
- **Training needs**: Initiating conversations about joining the register.
- **When to approach patient**: Is patient likely to die within the next 12 months?
- **Patient refuses consent or changes mind**: Reassure on data security and privacy. Concerns most likely to focus on these issues.
- **Patients from minority ethnic or religious backgrounds**: Identify key minority groups locally and any particular sensitivities.
### Patient consent: Key learning points

- An ‘opt-in’ approach to obtaining consent should be adopted.
- Consider the training requirements for staff around obtaining consent. Gaining consent involves some potentially difficult and sensitive conversations with patients. Health and social care staff are often best placed to obtain consent.
- Ensuring relevant health and social care staff are trained and confident in how to have these conversations is important in increasing the uptake of the register.
- Consider carefully at what point patients should be asked to join the register. Many pilots identified twelve months as the appropriate length of time for patients to be on the register, which offers a guide for clinicians on when to ask patients if they want to join.
- Anticipate patients’ objections to giving consent. Produce some literature for patients detailing exactly how their information will be safeguarded and used.
- Consider religious and ethnic diversity.

### 3.4 The Summary Care Record (SCR) and consent

There are two aspects to the patient consent requirements for the SCR:

- Consent to create and edit the SCR; and
- Permission for different healthcare professionals to view the SCR.

#### Consent to create and edit the SCR

Any site wishing to use the enriched SCR as a basis for their register needs to be aware that the consent model for the SCR is already in place and has been evolved nationally. Prior to October 2010 there was an opt-out consent model for both the basic and enriched SCR: there was no requirement for explicit consent to be sought from patients. Following a ministerial review in October 2010 it is now mandatory to ask patients for consent to ‘enrich’ their basic SCR – that is, to add additional information to it, for example relating to EoLC. There is no legal requirement to ask for consent to create a basic SCR. Instead, there is a system of ‘informed implied consent’ supported by a public information programme including:

- Personally addressed letter and information leaflet about the SCR sent to all adults;
- Promotion of the SCR by PCTs via local media;
- Provision of a national information line to support patients and citizens with their queries in relation to the SCR; and
Support from GP practices where staff are trained to answer questions about the SCR.

Permission to view the SCR
Once the SCR is created, any healthcare professional from any organisation that wishes to view the patient’s SCR and use the information it contains needs to ask permission from that patient. In emergency situations where obtaining consent is not possible (e.g. because the patient is unconscious) the healthcare professional can go ahead and access the SCR. Afterwards, the Caldicott Guardian or Information Governance Officer for the healthcare professional's organisation would investigate and confirm whether the incident was indeed an emergency and therefore whether accessing the SCR without consent was justified. This provides a safeguard against unnecessary access.

Permission needs to be asked on every occasion that a healthcare professional wants to access and use information on the SCR. If a patient has given permission to allow a particular healthcare professional to use their information on one occasion, that does not imply consent to access and use the information on future occasions.

The SCR and consent: Key learning points
If the local plan is to develop the register via the SCR, it needs to be borne in mind that the SCR and its consent model has already been evolved nationally. The key points and features of the model are as follows:

- There are two aspects to the consent model: consent to create and edit the SCR, and permission to access and use information from the SCR.
- The model for consent to create and edit the SCR has been evolved nationally.
- Creating the record is governed by a system of ‘informed implied consent’ - that is, an opt-out model backed up by a public information programme. However, be aware that many clinicians may still wish to ask for explicit consent.
- However, explicit consent is required to enrich the SCR, including adding end of life care information.
- Permission needs to be sought from the patient on every occasion a healthcare professional wishes to access their SCR. In an emergency situation where consent cannot be obtained, a healthcare professional can access the SCR. Afterwards, the relevant information governance officer would investigate the incident to ensure that it was a legitimate emergency.
3.5 Leadership

The importance of having a strong **clinical project lead** as well as an IT lead has been clear. Developing the register as an entirely IT-led venture can be difficult as clinical considerations and questions will frequently arise. Having a clinical lead, in particular someone with whom responsibility lies for making decisions, can be useful in gaining consensus from other clinicians. In short, having a clinical lead can promote a quicker and more efficient process.

For the majority of clinicians, however, who may not have IT expertise, implementation of the register presents a very steep learning curve. The pilots have found that it is easy to underestimate the amount of clinical time the project lead (if a clinician) needs to devote to the register. For example, some clinical leads report spending four to eight hours per week for the duration of the registers’ implementation and this is attributed in part to the clinical leads’ lack of expertise in the IT side of the project. In conversations with IT providers, it can be difficult for clinical leads to come to a shared understanding with them and differences in levels of understanding of the IT system and use of IT ‘jargon’ with which the clinical lead may not be familiar can hinder progress.

**Selecting a clinical lead**

Ideally, the clinical lead needs to be sufficiently senior to drive the register forward and secure high-level buy-in from stakeholders. Without strong *clinical* leadership, there is a risk that the process could be seen too much as an exercise in commissioning. This may cause scepticism and suspicion that the register is about meeting targets rather than improving care.

A respected clinician may also be more persuasive when communicating the clinical benefits of the register lending credibility to the project when ‘marketing’ the register. The benefits – especially the clinical benefits to patients who will be supported more effectively – need to be thought through and promoted.

3.6 Additional support

Many of the pilot sites have had to recruit staff specifically to work on implementation. In the current economic climate, making a business case and securing resources in the NHS is increasingly difficult and time-consuming and therefore may present a potential barrier.
**IT support**

Putting in place an IT project manager to work alongside the clinical lead can provide a link between the clinical lead and IT provider, linking an understanding of the clinical vision with technical knowledge. This helps to ensure that relatively expensive and limited clinical hours are used more effectively in implementing the clinical side of the project.

Overall, many pilots have found that their initial estimates of the time and complexity involved have been over-optimistic, and that ring-fenced resources would be useful to drive things forward more quickly. For example, many pilots have experienced unexpected IT issues that have caused long delays, including finding a way to allow the patient to view their record without them seeing their expected date of death, and firewall issues making it difficult for people from different organisations to access the register. Although these difficulties are relatively minor, and platform providers have generally been very forthcoming with their help overcoming them, they can be time-consuming to resolve and in some cases have significantly delayed the implementation of the register. As these technical hitches are inevitable, it is important to ensure that contingency time is built in. Additionally, at the outset project managers need to encourage potential stakeholders to be realistic about the time they can commit.

Advanced Health & Care has proved to be a popular choice of IT provider for the register as in many areas across the country it is the most prevalent software provider for GP and out-of-hours services. NHS connectivity via an N3 connection is required to access most registers and hospices are generally less likely than other providers to have this connectivity so will need to be helped to obtain it. If social care providers are brought into the registers they will also require NHS connectivity.

**Training**

Training may be required, particularly at the start of the project, to get staff and stakeholders familiar with the register and comfortable with talking to patients about End of Life Care wishes. Most pilot sites have initiated some degree of IT training for end-users, depending on their current familiarity with the system on which the register is based. Companies such as Advanced Health & Care and SystmOne are often able to provide training on the tool within the package that they offer. However experience has shown that training requirements for IT are straightforward. The training which is key, underpinning effective use of the register, is for clinicians to support development of communication and care planning skills. Healthcare professionals need to be able to identify patients and feel that they are equipped with the necessary skills to have conversations about a patient’s wishes. In order to get and
maintain a critical mass of patients on the register, it is vital that healthcare professionals feel as comfortable and confident as possible.
Inter-agency partnership and working
4. Inter-agency partnership and working

The primary goal of EoLC Locality Registers is to improve the co-ordination of care for patients at the end of their life. Therefore, improving inter-agency working is vital.

4.1 How can registers improve partnership working?

The potential benefits of the register tend to focus on creating a seamless, patient-centred experience. For example:

- A register available to a range of organisations 24 hours a day should mean that patient care is integrated and patient wishes better adhered to. The range of healthcare providers that may interact with a patient will do so with a shared understanding.

- With hospitals, community teams and GPs able to see the same information about a patient, it becomes easier to develop a better understanding and broader view of the patient's care pathway and where each service fits in.

- A multi-organisational sharing of EoLC information should result in an understanding of patients' EoLC preferences, but perhaps most importantly will act as a flag for patients who are at that stage of life. Flagging these patients as having different care needs will enable the healthcare professional who is treating the patient to make more informed decisions about care. This should lead to fewer inappropriate treatments or hospital admissions.

- A shared register that is accessible by social as well as healthcare providers should help to facilitate holistic assessment and care planning, covering not just physical care needs, but also psychological, social and financial care needs.

- The register should also promote prevention of crises and potential subsequent emergency hospital admissions through proactive planning and symptom management.

In terms of the pilots' experiences, views on the benefits to partnership working depend on how well or otherwise the process of engaging stakeholders and setting up the pilot has gone. As a general rule, securing early buy-in from stakeholders tends to ensure better partnership working.
Implementing the register also involves ensuring that all organisations that may deal with the patient have NHS connectivity in order to view their End of Life Care Register entry. This equity of access should be used to help encourage organisations to view each other as having shared responsibility for the patient’s care, with a duty to work together for their benefit.

**EoLC as a public message**

The uptake from patients for the pilots has been almost universally successful, with patients feeling positive about information and preferences being shared. There was surprise among some patients that such a system did not already exist.

As a multi-agency project requiring the NHS, social care, local authority and third sector organisations to work closely together, there is also a role for public health bodies to play in developing and uniting EoLC across different healthcare provider organisations. Given that so much of the challenge of setting up the registers is in getting stakeholders from across the organisations to fully participate, public health has a role in empowering individuals to be able to access high quality, well co-ordinated EoLC by ensuring they know what they should be able to expect. As well as encouraging stakeholders to embrace the register as a tool for improving patient care, public health messaging has a role to play in letting patients know what service they can expect from their healthcare professional, and promoting greater awareness about death and dying, and encouraging them to think about what a good death would mean to them. This can make the initial conversations that healthcare professionals have with their patients less daunting.
4.2 Cost benefits

It is too early in the life of the pilots to know for certain what the cost benefits will be; however a number of savings and efficiencies are anticipated by pilot sites. The single most important cost saving expected is a reduction in unscheduled care – that is, fewer hospital admissions for patients on the register and a consequent reduction in the numbers of people dying in hospital. The belief is that patients would generally prefer to die at home rather than in hospital. Better sharing of patients’ wishes facilitated by the register should therefore ensure that fewer patients die in hospital.

Other efficiencies 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.

The following diagram gives a breakdown of what the potential savings and efficiencies could be at different stages of the patient journey. This is not meant to be comprehensive at this stage; as the pilots move forward, the actual savings and efficiencies will hopefully become more apparent. In particular, when social care providers join the pathway and the register can be accessed by social care staff, as seems likely to happen, there should be further efficiencies in record keeping.
**Potential savings and efficiencies**

**Patient pathway**

- **Patient joins the register**
- **Patient calls ambulance**
- **Out-of-hours GP visits patient**
- **Patient passes away at home**

**Potential efficiencies**

- 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.
- Ambulance service accesses register and can view EoLC status and patient wishes. Less likely to take patient to A&E unless necessary.
- 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.
- The GP and palliative care nurse know that the patient does not want active treatment. Hospital admission and interventions are avoided.
Service users, carers, and families
5. Service users, carers and families

The EoLC register is intended to improve the service provided to patients, relatives and carers. The register will record and make available patients’ preferences and wishes so that more appropriate treatment decisions can be made. This will allow more patients to experience a ‘good death’, in the place that they wish, with the appropriate intervention.

5.1 Measuring the benefits

None of the pilot sites are at the point where they have hard evidence that their EoLC registers are improving patient care. As time progresses, however, some of the things they will be looking to measure include:

- more patients dying in their preferred place;
- more seamless care;
- fewer hospitals admissions;
- fewer hospital bed days; and
- less family distress.

Early data and anecdotal evidence from two of the pilot sites indicate that the above are realistic anticipatory benefits and likely to be seen where operational registers exist.

5.2 Concerns about the register

It is too early to say for sure what all the concerns of patients, their carers, and their families will be. However, they may include:

- **Data protection (confidentiality and consent):** Patients may be concerned about information being shared between services and who will have access to it. The consent process needs to be transparent and provide reassurance. One example of how it is done is to export the register entry for the patient to Word or similar programme (thinking through which fields should be filtered out – for example expected date of death) and print out hard copes for the patient to sign.

- **Sensitivities around the subject of End of Life Care:** The idea of going on to an ‘end of life register’ may upset some patients and families. This is where the importance of the discussion with the patient about joining the register is crucial. The
healthcare professional having the discussion needs to be well trained and able to clearly and sensitively explain what the objectives of register are and how it will benefit the patient.

Throughout the pilots it has frequently been highlighted that it is very important to choose an appropriate name for the register. The name of the register can have a significant impact on the ease with which the sensitive conversations surrounding the register can be broached. Whereas the term ‘end of life register’ may be upsetting for some patients, a more subtle name can not only soften any negative connotations associated with consenting to the register but also help to communicate the benefits that consenting to the register presents. For example, at the time of writing the pan-London group had provisionally agreed to use the name ‘Co-ordinate my Care’ for their end-of-life care register. This name is not only sensitive to the distress that the register may cause patients but also immediately indicates to patients that the register has a purpose which is directly beneficial to their care.

A sub-set of these concerns is the potential cultural and religious sensitivities around the subject of death and whether any particular cultural groups may have objections to joining the register, and why.

- **The register as ‘binding’ patients:** There is a risk that some patients may be reluctant to join the register because they worry that once they have confirmed their End of Life Care choices and given their consent, they will not be able to change their mind. As part of the initial conversation, therefore, patients need to be reassured that joining the register does not mean they cannot change their preferences at any time and that the register acts as a guideline only. The terms of the Mental Capacity Act will apply to their End of Life Care wishes. It is also vital that healthcare professionals do update the register regularly and promptly when patients change their preferences.

- **Reconfirming choices:** It is also important that patients are offered the opportunity to update the information on the register as their illness and therefore their treatment progresses. It is important that a good balance is found between the difficulty of asking a patient to discuss the circumstances surrounding their death and making sure that what is recorded on the register is up-to-date and accurate.

- **Taking into account the wishes of relatives:** Whilst the register is based on the wishes of patients (and whilst these preferences may often be based on a discussion
with relatives and carers), there will be cases when the wishes of patients and carers are not compatible. For example, a patient may wish to die at home but the relative or carer may not feel able to cope with the death taking place in the home. In these circumstances it is important that staff are able to balance the patient’s wishes as recorded on the register with the relative or carer’s difficulty in coping with the situation as it unfolds. Conversely, relatives and carers who support a patient’s choices may be very disappointed when their preferences are not achieved. It is perhaps prudent to establish ground rules that, in the same way that they do not bind the patient, the preferences on the register do not bind the healthcare professional looking after the patient. The EoLC register is not intended to replace professional judgement on the best way to deal with a medical situation.

**Service users, carers and families: Key learning points**

The two most likely key **benefits** to patients are:

- More patients dying in their place of choice.
- More seamless end of life care.

**Concerns** from patients and families may focus on:

- Data protection.
- Sensitivities around the topic of end of life care.
- Whether the register is ‘binding’.
- Procedure for updating wishes and preferences.
- Patient and family conflicts of wishes.
Conclusions and recommendations
6. Conclusions and recommendations

A number of learning points have emerged from the evaluation. These include:

- **Engage all the relevant stakeholders as early as possible in the process.** Mapping who all the stakeholders are, obtaining their buy-in, and starting to understand and manage their expectations and concerns around the register. Engaging them and anticipating their concerns early on can prevent delays and difficulties later.

- **Developing the register requires dedicated clinical and IT input.** There should be a member of staff on each side who can devote time to register development. These members of staff need to be supported at management board level as engaging some stakeholders may require ‘buy-in’ at that level.

- **Establish what it is you expect from the register.** Before selecting the IT platform, it is important to think through whether you envisage the system as a mechanism with the principal aim of alerting staff to the fact that someone is on the register; or as a care planning tool capable of holding more complex information. If it is to be the latter, then the functionality, consent process, and administration rights become potentially more complex.

- **Establish the data requirements.** A minimum core data set was agreed for the pilots, and the intention is to establish and agree a national minimum core data set which will be available to any other areas developing a register in the future. A list of other potential items that could be included in the local data set at the pilot’s discretion was also drawn up. Additionally, some further items were also identified, and adopted, as part of local discussions in some pilots. At the earliest opportunity there needs to be agreement amongst stakeholders on what the additional data requirements are. Stakeholders need to be aware of what each potential IT system can provide.

- **Think about what to call the register.** The term ‘register’ could be misleading, suggesting simply a list of patients rather than a tool holding detailed care planning and medical information. ‘End of life’ may also be an off-putting phrase for some patients. A more descriptive phrase such as ‘Electronic Palliative Care Co-ordination System’ may be preferable, providing it accurately reflects the intended aims of the pilot.
• **Before selecting an IT platform and approach, think through the needs of different stakeholders.** Bear in mind that the same system will need to be accessible to all partners involved. Pilot sites have generally been slower to include ambulance services due to difficulties with compatibility of systems. Hospices may also need greater support, for example, establishing an N3 connection to enable them to access patient records.

• **Before selecting an IT platform, map out what systems are already in use in your area.** All of the eight pilots have tried to build on a pre-existing platform rather than developing something from scratch. This seems to be the most efficient approach and it is therefore a good idea, prior to selecting a platform, to map exactly what IT systems are in use locally in GP surgeries, hospitals, hospices, and elsewhere. Many pilots have opted to build on the Advanced Health & Care platform as this is already in widespread use in GP surgeries across the country.

• **Establish who has responsibility for accuracy of the patient record.** In line with proposals set out in the NHS Information Revolution, clarifying data controller issues across shared data is a crucial consideration. This is something to be discussed with stakeholders at an early stage as it is potentially sensitive and will have an impact on who has administration rights. It is likely that GPs will want to retain responsibility for the patient record: they may not be happy for healthcare staff from different organisations having the ability to enter and update information. However, non-GP staff may be in a better position than the GP to have a discussion with the patient about joining the register. Therefore, it is important to think about how non-GP staff can liaise quickly and efficiently with GPs.

• **An opt-in model of consent is universally felt to be necessary.** Patients should be consented onto the register. Patients’ and carers’ information needs have to be taken into account and details shared with them where possible. The register also needs to incorporate a mechanism to highlight patients who refuse to be consented onto the register as this will prevent these patients being repeatedly asked whether they want to be registered.

• **Think about how to present the issue of how binding the register is.** It is important that patients who consent to go on the register do not feel that they are removing choice at a later date. It is also crucial that the register is not seen to replace clinical judgement.
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.

Provide staff with evidence of the benefits of the register. This will ensure continued staff engagement and will help to forge links across the organisations.
7. Pilot site case studies
7. Pilot site case studies

Eight pilot sites took part in the evaluation. They are:

- NHS Brighton and Hove
- Camden PCT Provider Services
- Leeds Teaching Hospitals NHS Trust
- NHS Mid Essex
- Royal Marsden NHS Foundation Trust
- Salford PCT with Salford Royal NHS Foundation Trust
- Sandwell PCT
- Weston Area Health Trust and NHS South West

Case study reports have been developed for each pilot site, and are reproduced in this section in the order above. Please note that opinions expressed by individuals in the case study reports do not necessarily reflect policy.
7a) NHS Brighton & Hove

Overview

Summary of development of the pilot

- NHS Brighton and Hove chose to combine their locality register with the launch of the Summary Care Record (SCR). This would work by having the End of Life Care plan enriched onto the SCR, which would then be accessible to staff in those clinical settings which had SCR access.

- Due to the delay in the roll out of the SCR, which followed concerns with regard to the opt-out consent model and the subsequent national review, the pilot was severely delayed as progress could not be made until the issues with the SCR itself had been resolved.

- Consent has been a difficult issue for the SCR as a whole, and therefore for the Brighton pilot. Now that the SCR programme has been reviewed and its continued roll out confirmed, it has been agreed that an opt-out approach for the core data of the SCR together with an opt-in approach for any enrichment of the SCR (including EoLC) will be acceptable to clinicians. The added patient control of providing additional consent for staff to view in all clinical settings will be established also as part of the SCR guidance.

- The functionality of the SCR does not, however, allow reporting. The SCR was designed to be a clinical information tool with strong access controls to increase patient confidence in data confidentiality. The PCT remain keen to find a way to use the data the register will collect to be able to report on EoLC within the PCT, although no steps have been taken yet to begin addressing this.

- Due to the delays encountered in the roll-out of the SCR and the subsequent delays in the Brighton and Hove pilot, stakeholder engagement was postponed. This was in order to align the pilot development appropriately with the SCR rollout, and the necessity of uploading a critical mass of patient records to SCR to create engagement from those clinicians who will be accessing the SCR record.
**Starting point**

At the time of application to become a pilot site, a manual system to share information about palliative care patients was in operation between End of Life Care services, ambulance services and GP practices. The provider of out of hours services for the PCT, South East Health, used an Advanced Health & Care (formally known as Adastra) based IT system. When patients were identified as palliative care patients by the GP the relevant paperwork was faxed through to South East Health, where a physical copy of the information was stored. A flag was added to the patient’s record on the Advanced Health & Care system in order to indicate to out of hours services that palliative care information was available for that patient. This then prompted the member of staff to look for the palliative care copy of the handover form stored by South East Health.

This system only allowed the sharing of faxed information between GPs, district nurses, ambulance and out of hours services. NHS South East Coast had a web-based system to share information between their service and GP practices, but it would still not have given the full electronic transfer and data share capability envisaged by the pilot for the locality register.

**Approach**

NHS Brighton and Hove originally proposed working in partnership to fund the South East Health independent web-based system (Share My Care) which would not be exclusive to a particular IT platform, such as Advanced Health & Care or SystmOne. However, with the launch of the Summary Care Record (SCR) coinciding with the development of the pilot, NHS Brighton and Hove instead planned to incorporate the functionality of their locality register with the SCR. It was decided that an EoLC register linked to the SCR platform would fit best with the strategic objectives of the Trust, especially as it is one of the “fast followers” of the SCR.

Originally, one of the key features of the register was the roll-out of information sharing to a greater number of services, with the plan being for GP practices, district nurses, community specialist palliative care teams, the acute sector, the hospice and the ambulance service all to have access to the data via an electronic solution. The cohort of patients for the pilot was to be those already on local GP practice palliative care registers, with the potential to roll this out further as new EOL patients in the community are identified.

The Brighton and Hove pilot therefore plans to provide an enriched data record on the SCR for those patients identified as palliative care patients. A flagging system would need to be incorporated on the accessing service’s patient administration system to show whether or not
EOL enriched information is available for the patient on the SCR. The SCR does not currently support the inclusion of such a flag, meaning that each patient's SCR record will have to be checked manually for enrichment additions and to confirm the data is stored on the register.

At the time of writing, Brighton and Hove had not yet advanced to a 'live' stage.

Aims and Objectives

The principle aim of the Brighton and Hove EoLC register pilot is to ensure that a record of a patient’s wishes in relation to EoLC and patient medical information is available to all healthcare professionals involved in their care, regardless of the time of day, setting of care or patient diagnosis. The objectives identified by Brighton and Hove in order to achieve this include:

- The availability of palliative care handover information 24 hours a day on an enriched SCR;
- The availability of information into secondary care where patients attend A&E or are admitted to secondary care;
- Sharing of information from GPs and community nurses to a managed register with the appropriate governance checks in place;
- An audit trail to ensure appropriate access and confidentiality; and
- Improved recording of data to inform the commissioning of services for patients at the end of life.

Fitting the locality register in with the broader strategic objectives of the Trust is very important for NHS Brighton and Hove. The Trust decided, with the SCR being rolled out across the SHA, that the register would fit best within that.
Technical and IT developments

Technology platform

The technology platform for the Brighton register is an enriched record stored within the SCR. Because of this there has been little specific development of a technology platform within Brighton and Hove, as this is managed by Connecting for Health.

Data sets

Whereas other pilot sites have had to create only one template data set, because of the overarching nature of the Brighton and Hove technology platform, which sits within different sites with different GP clinical IT systems (such as EMIS, SystmOne, iSoft or Vision) Brighton and Hove have had to create a different template for several of these IT systems.

Each of these templates is designed to collect the same data based on the minimum data set agreed by the Department of Health and the national pilot site steering committee. However, each template itself must be created for each of the GP clinical systems and loaded to the practice with that IT system in place. The pilot’s aspiration is that the templates will in the future be developed for each of the systems and made available by each relevant GP clinical IT provider, as iSoft has already done. This will avoid the need for other PCTs to create their own similar templates and will ensure that they are all compliant with the minimum data set.

In order to assist GP practices to record the required EoLC dataset agreed on within the pilot, templates for each GP IT clinical systems need to be created.

Brighton and Hove Locality register project lead

Development and implementation

Training

As the Brighton and Hove system is based around an IT system that is being rolled out nationally, the training is to be provided by the team responsible for the local launch of the SCR. This includes training to enrich the SCR records, where this function is available, such as for EoLC. There is an aspiration to link this training with specific training around the register, but this has not been addressed as yet.

Using a national system to implement the register reduces ongoing training costs. As clinicians move from one area to another, they should all still be familiar with the SCR and the basic functions.
Clinicians will get used to the Summary Care Record wherever they’re working. Those who have worked in other areas which have rolled out the Summary Care Record, could come into our area and already be familiar with the use of SCR.

Brighton and Hove Locality register project lead

At this stage of the Brighton and Hove pilot there has not yet been a chance to explore the need for GP training in the communications side of using the register (for example having discussions with patients about joining the register). There is currently no evidence of the level of GP uptake of the register and their willingness and ability to have conversations with patients to obtain their consent to join the register.

Administration rights

As the Brighton and Hove pilot has not yet advanced to a ‘live’ stage, there has not been a great deal of discussion so far around the issue of administration rights for the register. These will largely be determined by the national administration rights policy for the SCR, giving the GP sole right to create and edit records on the register.

However the question of administration rights is recognised as an issue within the Trust. GPs are concerned about the extra responsibility for the ownership of the record, particularly for data which will be used by healthcare professionals from outside the practice.

It’s also about data quality, and the extra responsibility of being responsible for data that is being used by other people, rather than just people in the practice. The data enriched onto the patient’s SCR must be accurate and up to date.

Brighton and Hove Locality register project lead

Addressing GPs’ concerns regarding administration rights will be important to ensuring their longer-term buy-in to the register.

Patient consent

Patient consent is an important issue for Brighton and Hove in the development of their register. Issues around consent have now largely been addressed. It has been agreed following the national review and continuation of the SCR that an opt-out approach for core data together with an opt-in approach for enriching the SCR will be acceptable to clinicians. The added patient control of permission to view in all clinical settings is built into the SCR guidance.

Initially, GPs in the Brighton and Hove area were uneasy about the opt-out model of consent for the SCR, with concern being expressed that opt-out consent did not constitute informed consent. The opt-out consent model was supported by a campaign to inform patients.
They were sent letters supported by local information campaigns and a national helpline which includes language translation and text phone services. Those patients who had not or could not read the letter sent to them with information about the SCR and the consent process would be at a disadvantage and unable to decide in an informed way whether or not they wanted an SCR.

Some GPs didn’t believe that all patients had been properly informed, just because they’d received letters

Brighton and Hove Locality register project lead

A member of the Connecting for Health team who has worked closely on the development of the SCR feels that although the burden on the patient should be minimised if they do not want to take part, inclusion on the SCR can be a real benefit to patients, with further benefits being realised for those patients who will be provided with enriched records. Therefore consent to the SCR is also something that GPs may at their discretion choose to discuss with those patients where they think the greatest patient care benefits will be realised.

DH has made the process to opt out of the SCR easy and simple for patients. Patients may not understand that there may be benefits to having an SCR and that is why some GPs like to talk to patients where they think there will be a huge benefit to the patient.

NHS Connecting for Health representative

Although it was never intended to include an explicit opt in consent stage for the creation of any enrichment to areas of the SCR above the core dataset, concerns about the consent process for the SCR as a whole were addressed by a Ministerial Review which concluded in October, which impacted implementation of the SCR.

This resulted in severe delays to the Brighton and Hove pilot, which is reliant on the SCR to be able to go live. The consent issue for the SCR has now been resolved with explicit opt-in consent for enriched patient records being standard.

Core information for the Summary Care Record is uploaded following an implied consent model, if patients want their records further enriched, then that will be following patient explicit consent

Brighton and Hove Locality register project lead

As well as consent to have data stored on the register, a further aspect is permission for other healthcare professionals to view the patient record. Where possible, permission should be gained from the patient, relative or carer before each viewing of the data in the SCR. Patients in the Brighton and Hove PCT area have been particularly positive about their
permission for this being sought as it allows them to control who views their record dependent on the service setting or situation. Data is not indiscriminately available and this also obliges clinicians to think carefully about whether they need to view the data, rather than simply looking at all the available data. Control of the data is thus in the hands of the patient to a large extent.

Permission to view doesn’t have to mean ‘yes’ in every care setting, and in Brighton they quite like that control

NHS South East Coast CfH representative

Functionality
One of the benefits of basing the locality register within the SCR is that this reduces duplication of information. When changes are made to the GP system these changes will also be reflected in the core data set. This automatically updates information such as the current medications and dosage taken by a patient. Any information pertaining to the EoLC enriched record can also be transferred through to the SCR section without requiring the GP to re-enter information.

An advantage of the Summary Care Record is that when changes to the medication are made on the GP system it will automatically be available on the Summary Care Record

Brighton and Hove Locality register project lead

However, as the SCR was designed as a clinical data management tool rather than for the specific purpose of hosting an EoLC register, there are some limitations in its functionality.

One of the main drawbacks to using the SCR to provide enriched records such as the EoLC register is that the existence of the register cannot currently be flagged from the core data of the SCR. This means that each patient’s SCR will have to be checked for enrichment additions and to confirm that this data is stored on the register.

The SCR also lacks a reporting function, so each GP practice has to run a search for its own data and then produce a report. As with many of the pilot sites, Brighton and Hove, prior to deciding to link the register to the SCR, hoped to use the data collected in the development of the register to proactively monitor EoLC within the PCT. As mentioned earlier, the SCR does not currently have this functionality.

You can’t pull reports off the Summary Care Record, so that’s another problem … Any data extractions required would need to be run on each of the GP practices’ clinical systems
Brighton and Hove Locality register project lead

The SCR was deliberately designed without a reporting function. It was felt that restricting the ability of individuals outside the practice to extract the data would be reassuring for patients. Given the function of the SCR as a clinical information tool for a basic core data set, the form fits the function of the system in that it aims to encourage maximum buy-in from patients by minimising their concerns about data security.

*The SCR was designed to be a clinical information tool with strong access controls to increase patient confidence in data confidentiality.*

NHS Connecting for Health representative

Brighton and Hove are keen to ensure a way to enable EoLC reporting information to be extracted from the clinical GP IT systems. No steps have been taken yet towards completing this work.

**Impact on inter-agency partnership and working**

Interagency working

Given the stage the Brighton and Hove pilot site are currently at, it is not possible to fully ascertain the affect that the pilot has had on interagency working. However, it is expected that the improvement in data sharing will naturally lead to an increase in, and improvement of, interagency working, with emergency and out of hours in particular benefitting by having access to all of the relevant information for patients from the site of care.

*If the information sharing is improved, we’re not going to get into these situations where an end of life patient gets admitted into hospital and they didn’t want to be.*

Brighton and Hove Locality register project lead

Stakeholder Engagement

Stakeholder engagement has been another key challenge. In part this is because of the concerns that GPs have had about the patient consent model for the SCR and the potential increase in their own workload. The pilot team feels that the amount of work required to ensure the success of the pilot through stakeholder engagement has been underestimated.

*[We] didn’t realise that it was going to be so hard to engage the practices.*

Brighton and Hove Locality register project lead

This was echoed to some extent by the Connecting for Health lead who explained that the slow process with limited immediate benefits could lead to disengagement of GPs. Getting a
'critical mass' of patients onto the SCR so that improvements to the patients' experience and reductions in the administrative burden on GPs can been seen more easily is something that needs to be achieved in the early stages of the project.

If they don't see any benefit you quickly get disengagement … this is why for the Summary Care Record critical mass is very important

NHS Connecting for Health representative

Making sure stakeholders are engaged is felt to be one of the most important lessons learned according to the Brighton and Hove pilot lead. Finding ways to incentivise GPs to enrich the SCR may need to be considered.

One of the lessons we really learnt from it was that you've got to make sure your practices are fully engaged…And it might be that PCTs need to think through how the extra work generated by participating in SCR will be managed by the practice

Brighton and Hove Locality register project lead

Service user, carer and family experience

As the Brighton and Hove register itself has not been launched at this stage, there is currently little information available on how the patient and carer experience is affected. The aspiration is that the register will:

- Reduce inappropriate hospital admissions;
- Assist people to achieve their preferred place of care; and
- Provide patients with a more joined up service, where information is available to all involved in the patient's care.

There are also some issues that the project team have identified, most importantly the need for flexibility in the register to allow patients to update the information held about them. There is recognition that patients do often change their wishes, and is necessary to make sure the system remains flexible enough to allow healthcare professionals to use their judgement to best reflect the wishes of the patient at the time.

They do change their opinions about where they want to die and the effects it has on their families.

Brighton and Hove Locality register project lead

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Conclusions

Key learning points

- Whilst ‘piggybacking’ on a national initiative does have many advantages, the pilot itself is subject to the progress made by the national development. Brighton and Hove did not foresee the delay with the SCR and therefore had trouble maintaining engagement with stakeholders.

- Being tied to a nationally developed product, Brighton and Hove PCT could not influence the functionality of the SCR. They are therefore unable to run reports or create flags indicating the presence of an EoLC enriched record outside of the SCR, so clinicians must check for the record to see if it exists. Locally customised solutions have been able to mould the register to reflect the function that they would find most useful.

- Positively, using a nationally based record system has meant that Brighton and Hove have a system clinicians will be familiar with and will not need specific training to use. This will also help to ensure that clinicians develop a culture of using the SCR both in terms of adding information to it and in terms of seeking information from it.
7b) Camden PCT Provider Services

Overview

Summary of pilot development so far

- In the initial approach, the register was to be built on existing and proven Advanced Health & Care (formerly Adastra) technologies and hosted from a web server situated at Camidoc which, at the outset of the pilot, was providing the out-of-hours services for Camden & Islington PCT. A second phase of the project was to involve the implementation of a pan-London solution, incorporating the learnings from a number of London registers.

- Development of the register suffered a significant set-back with the announcement that Camidoc had its out-of-hours contract terminated and that the new interim provider was Harmoni. After consideration of the various pros and cons, it was agreed that the Camden and Islington pilot would join the Royal Marsden pilot and that Patient 24 (formerly Croydoc, Royal Marsden’s out-of-hours provider) would host both registers, in order to support the London Ambulance Service’s proposal to have one URL across the whole city.

- In the lead up to the date the register was to go ‘live’ the pilot project faced ongoing challenges. Harmoni, the new out-of-hours service, could not directly view the Patient 24-hosted Adastra register or accommodate register information in Special Patient Notes on their server, and the palliative care team could not access the register whilst on call. There was, therefore, no option but to continue using the original paper handover form.

- Despite the insurmountable technical challenges faced by the Camden pilot project, substantial progress was made in many areas, including the development of a data-set and training programme. The learnings from this can be applied to the development of a pan-London solution, to which the team remains fully committed and are actively involved in taking this forward.

Starting point

Prior to the outset of the Camden pilot the local MacMillan GP facilitator, Gold Standards Framework facilitator and Palliative Care Team had worked closely to develop the use of supportive care registers within each GP practice, promote regular multi-professional meetings and develop a palliative care handover form. The palliative care handover form was a one sided A4 template which was completed and faxed by any clinician to out-of-hours...
urgent care providers as appropriate, including out-of-hours GP providers, London Ambulance Service, district nursing and specialist palliative care.

Although this system worked well, access to information out of hours (and using it to improve End of Life Care) was dependent upon the anticipation and identification of patients who were likely to deteriorate as well as actual completion and faxing of the handover form. Prior to the pilot, the proportion of handover forms that were received varied between providers. Some clinicians viewed the handover form as primarily applicable to out-of-hours GPs and London Ambulance Service and therefore only faxed it to these services. However there were other services, for example the on-call palliative care service that operated over the weekend, for which the information on the handover form was very useful. Faxing the form to multiple providers was potentially time-consuming. E-mailing was possible but many providers did not have NHS accounts in order to make this secure.

Additionally, depending on how healthcare professionals complete the handover forms, there were inefficiencies in the system. If handover forms were handwritten and faxed, as the majority were at the outset of the pilot project, any updates also had to be handwritten involving a lot of duplication of demographic information which was avoided by use of the electronic register.

Aims and objectives
NHS Islington has published targets that all End of Life Care providers should aim to achieve. These include the identification of 80% patients in need of End of Life Care, 100% of those patients being offered advance care planning, an increase in non-cancer End of Life Care provision, and a reduction in hospital deaths. The End of Life Care Locality Register had the potential to offer a number of benefits that would enable End of Life Care providers to achieve these targets;

- GPs, community nurses, acute trusts, out-of-hours providers, specialist palliative care and London Ambulance Service crew used different IT service providers. The register was to be accessible to professionals from different organisations and settings using different clinical record systems, therefore improving the co-ordination of care and communication of information.
- The End of Life Care Register was to hold information about all patients identified as being at the end of their life, not simply those whose details have been handed over because they may deteriorate immediately.
The locality register would have enabled the PCT to monitor progress in the aforementioned targets, so that any areas in need of development can be identified and responded to accordingly.

However, the key aim in developing the register was to assess whether the increased availability of information to relevant healthcare professionals translated to the improved provision of EoLC and improved outcomes.

For patients the aims were to:
- Enable them to be more proactively involved with planning and decision-making around their care.
- Enable those choices to be honoured wherever possible – preferred place of care/death, decisions around treatment etc.

 Approach
Camden & Islington proposed a two phase project, initially implementing and evaluating a locality register within Camden & Islington, followed by potential migration to a pan-London register in the second phase.

The proposed Camden & Islington End of Life Register was based on the South West pilot’s model which enables organisations with access to an N3-connected internet browser, as well as those with access to the service provider, the potential to view important End of Life Care information. Built on existing and proven Advanced Health & Care (formerly Adastra) technologies, the register was to be hosted from a web server situated at Camidoc which, at the outset of the pilot, was providing the out-of-hours services for Camden & Islington PCT.

The second phase of the pilot was to migrate to a pan-London model. The project was specifically designed so that it could run in parallel with the Royal Marsden pilot. After one year, both the Camden & Islington and Royal Marsden models were to be compared and contrasted focussing on:

- Efficiency
- Confidentiality
- Consent
- User Experience
Each site was to evaluate those aspects of their register which were successful and those which were not. The best features from both registers were then to be amalgamated before rolling out the register across London. As Advanced Health & Care had been central to the development of both models, it was ensured that transition from one model to the other, including data migration, could easily be achieved.

Technical and IT developments

Technical platform

Initially it was planned that the register itself would be a web-based system, supplied by Advanced Health & Care, hosted by Camidoc, and accessed by any authorised personnel via any computer connected to the NHS N3 spine. Advanced Health & Care was chosen for a number of reasons:

- Advanced Health & Care already supplied the out-of-hours software to 95% of urgent care providers in the UK, including Camidoc.
- Advanced Health & Care offer a 24 hour live web active system, which could be accessed by a healthcare professional regardless of the organisation they worked for
- Camidoc already used Advanced Health & Care’s software to operate their out of hours primary care and nursing services and therefore the technical set up was envisaged to be straightforward.

Advanced Health & Care were very supportive throughout the Camden & Islington project and their system was found to offer excellent functionality. However development of the register suffered a significant set-back with the announcement at the end of July 2010 that Camidoc (who were to host the Advanced Health & Care website) had its out-of-hours contract terminated by the PCT. It was announced that the new, interim out-of-hours provider from 1st September 2010 was to be Harmoni.

Meetings with Harmoni brought to light a number of disadvantages that would be associated with transition from Camidoc to Harmoni hosting the register. Harmoni was initially supportive of the register in principle. However, as Harmoni was in the process of taking over the out-of-hours services in a very short period of time, they were unable to commit to hosting the register within the pilot time frames, which could have led to delays in implementation should Harmoni have been chosen to host the register.

In addition, the relationship with Harmoni was different from that with Camidoc. Good working relationships had been developed with Camidoc over a number of years as local
providers and the implementation of the register was viewed as being mutually beneficial. Harmoni however, were much more rigorous in terms of resource and approached the register from a more commercial stance, with additional considerations for their staff outside the Camden and Islington area. In addition they may have required payment for administration, not factored into the initial costings for the register's implementation.

London Ambulance Service (LAS) had initially specified that they would only access the register via one URL. A difficulty in choosing Harmoni to host the register was that it would have led to two website addresses for LAS to access, both the Royal Marsden register and the Camden & Islington Register. In addition other registers were starting to be implemented across London. The use of Patient 24 (formerly Croydoc, Royal Marsden's out-of-hours provider) to host the register initially mitigated this problem as a single URL would be used to access both the Royal Marsden and Camden & Islington Register.

In light of these considerations it was agreed that the Camden & Islington pilot would join the Royal Marsden pilot and that Patient 24 instead of Harmoni would host the register. The use of Patient 24 offered both advantages and disadvantages over using Harmoni to host the register.

A disadvantage of using Patient 24 over Harmoni was that the register had to be manually populated with Camden and Islington GP practice data information. Usually the out-of-hours provider would have had these details, as would have been the case had Camidoc been able to host the register. However, as Patient 24 are not the provider of Camden & Islington’s out-of-hours services this information was not already present on their system. Consequently, the project facilitator had to contact all 97 practices within Camden & Islington, some of which were more responsive than others, to collate this information before using it to populate the register – a very time consuming exercise. In addition, Harmoni staff needed to log out of their own system in order to log in to the EoLC register hosted by Patient 24, as the two systems could not be integrated, despite both being Adastra systems, which resulted in greater concern from Harmoni in terms of overall efficiency.

Administration rights
It was agreed that selected individuals would be permitted access to log in to the system and view information, including demographic information, diagnoses and End of Life Care preferences. Only a patient’s own GP or a palliative care specialist would be able to consent a patient onto the register. Other health care professionals who had access to the register would have had viewing rights only.
Each GP practice and hospice unit was asked to designate a named practice lead for the end of life register (including a deputy in case of annual leave/sick leave). Usually this would be the palliative care lead for that practice. The individual GPs would have responsibility for completing the EoL register for the patients under their care. Each of these GPs were trained by the project lead, and once it was felt they were competent they were provided with a username and password.

If the patient was living in the community, the GP held the responsibility for patient care and was ultimately responsible for patients' notes being up to date. However, it was not intended that the GP would be the only person who could input data onto the register. It was noted that in some cases patients felt more comfortable having the sensitive conversations surrounding End of Life Care with other members of the multi-professional team, such as a Palliative Care CNS, who would have been able to input data on to the register. Ultimately, therefore, the team looking after the patient and every professional who inputted into the register had a duty to make sure that information was accurate. The initial phase allowed only GPs and palliative care specialists to add/edit information but the plan was to gradually extend those rights to other professionals, e.g. other community nurses and hospital specialists, at a later stage.

Consent

The proposed Camden & Islington register differed from the Royal Marsden register in the method in which consent was gained. The Royal Marsden asked for consent for a patient’s information to be stored and shared electronically, whereas Camden & Islington planned to explicitly ask patients for their permission to have their information added to the register. This consent was to be obtained by the patient’s clinician or GP, usually at a face to face meeting or consultation. After consenting to have their information added to the register each patient would have been sent a copy of the register by post to ensure that they were happy that the register accurately reflected their wishes. The version of the register that was sent to patients was slightly sanitised; omitting fields such as expected date of death.

At consent, it would be explained to patients that the register was live and therefore their preferences and details had the potential to be updated in future consultations. However it was decided that it was unnecessary, and potentially inappropriate, to send patients updated copies of the register after each change, particularly if the patient was very ill. Therefore it was proposed that if a patient would like a copy of the updated register after a significant conversation it would be sent to them on request.
Our feeling was that we didn’t necessarily need to bombard them with updates all the time, because actually if there’s somebody who’s quite sick we might update the register every few days, and to send out a letter every few days in that situation is potentially distressing and unhelpful.

Camden Locality Register project lead

A further difference from the Royal Marsden register was that after being consented to the Camden & Islington register, patients were to be given a card which indicated that they had consented to have their End of Life preferences recorded on the register. The card showed the URL of the register and the patient’s NHS number. This card was intended to provide a fallback mechanism so that, in the event that the register was not accessed by the healthcare provider in question, the patient or relative could present the card prompting the health care professional to access the register.

Prior to the outset of the pilot it was envisaged that the most difficult obstacle in terms of consenting patients to the register would be the challenging issues that surround having the conversations with patients. Health care professionals, particularly those who are not trained in palliative care, can feel uncomfortable initiating the sensitive conversations surrounding End of Life Care. However, if sufficient guidance is given to health care professionals about how to approach these conversations with patients in a sensitive and comfortable way, it is felt that the majority of patients will recognise the benefits of, and be very open towards, the register.

If it’s discussed in the right way with patients, then patients will see the benefits of being on the register. I think patients are more likely to be upset about the conversation itself around resuscitation and preferred place of death if this is not done in a sensitive way, than they will about actually being on the register.

Camden Locality Register project co-ordinator

Functionality

It was intended that the Camden register would have extensive reporting functionality and at the outset of the pilot it was intended that a range of important outcomes and measures would be analysed every four months, including:

- Number of patients who have consented
- Number of patients who declined to consent and reasons for this
- Number of patients on register offered advance care planning
- Number of deaths and place of death
- Percentage of patients achieving preferred place of death
- Reasons for variance if preferred place of death not achieved
- Number of log-ins to view, when and by whom
• Number of log-ins to edit, when and by whom

The pilot was particularly interested in analysing trends in the register's usage to help inform ongoing improvements in the register's implementation. For example, analysis of patient diagnosis may bring to light trends such as a tendency to only add patients with a cancer diagnosis. Alternatively, analysis of the number of log-ins to edit may highlight that only certain groups of clinicians are consenting patients. These tendencies may be greater in certain practices or among certain groups of clinicians, possibly indicating a need for greater training in particular areas.

**Development and Implementation**

**Data-set**

The process of developing the data-set began by evaluating and modifying the original template used in the Weston pilot so that it was more applicable to the local area of Camden and Islington. This was achieved via a series of meetings with stakeholders where they expressed their views as to what should be included in the data-set. The stakeholders were almost at the point of agreeing the specifics of the data-set when the Camidoc contract ended.

As previously discussed, both to accelerate commencement of the register and also to 'standardise' a London format, it was then agreed that Camden would use the Royal Marsden PCT register in its entirety. This caused disappointment for all stakeholders involved as a large amount of time had been spent formulating views and designing the data-set to reflect these. However, in general, stakeholders were supportive of the pragmatic decision making process and understood the need to progress the implementation of the pilot register in order to inform future practice.

The Royal Marsden template differed significantly from the initial Camden & Islington data-set and there were some aspects of the Camden and Islington data-set that stakeholders felt it would have been beneficial to retain. There were hopes that, after the pilot phase, the project could evaluate the data-set and re-introduce the original ideas that stakeholders brought forward. Two important aspects of the original Camden & Islington data-set that differed from the Royal Marsden data-set were:

• Adding ICD-10 coding of common diagnoses in order to evaluate different diagnostic groups of patients and trends
• Whether there were any risks in visiting a patient at home. In the locality there are a significant number of patients that present a risk if visited by a health care
professional alone. Although this information can be typed into the notes section of the Royal Marsden register, it was hoped that this information could be included on a secure tab as this would be simpler for clinicians to navigate to and use.

- Whether there is a doctor who has seen the patient recently and who could potentially sign the death certificate. If the patient has not been seen in the last fortnight by a doctor who could sign the death certificate, the GP practice needs to be informed as soon as possible and this is flagged on the register.

Training
The Camden pilot identified that one of the most important aspects of ensuring their register’s success was that GPs and other health professionals felt comfortable and confident when having conversations with patients about End of Life Care planning and considering which patients were appropriate to consent to the register. The key to achieving this was through an effective training programme for users which was delivered by the project facilitator. This training commenced in November 2010 in anticipation of the register going ‘live’.

The Camden & Islington pilot took a strategic approach to rolling out training. They realised that one of the most effective ways to encourage professionals to support the register in their area was by enrolling a critical mass of patients onto the register and gaining positive professional feedback before approaching more hard-to-engage professionals. Initially, therefore, the focus and priority was to train GPs who were already engaged with palliative care and comfortable having sensitive conversations surrounding End of Life Care planning. Initiating the use of the register using these engaged GPs meant they could be used to demonstrate that the person who consents patients to the register doesn’t necessarily have to be someone with specialist palliative care skills. Having GP ‘champions’ who could also be a resource/support to other GPs was also felt to be of benefit.

The Camden & Islington pilot also recognised potential benefits in encouraging their specialist palliative care team to have End of Life Care planning conversations and consent patients onto the register early in the register’s implementation. This meant that when the project facilitator visited GP practices to train users it would be possible to demonstrate that patients had been consented to the register, encouraging dialogue and reinforcing how the register worked, increasing engagement and uptake of the register.
Out-of-Hours Services

In the lead-up to the register going ‘live, the Camden & Islington pilot project faced ongoing challenges. These related to Harmoni being unable to view patient details on the Register and therefore unable to use the information as part of their out-of-hours service. It became clear that despite Patient 24’s willingness to host the Camden & Islington register, the register could not migrate from the Advanced Health & Care server onto the Harmoni server either electronically or by ‘cut and pasting’ from a report version. Harmoni were also unable to commit to populating their template using a hard copy report formulated from the register due to administrative and time constraints.

In addition, the palliative care team were unable to access the Register Information whilst on-call from home as, at the time that the Register went ‘live’, they were still awaiting VPN links to facilitate this via secure laptops.

As the out-of-hours service could not accommodate register information on their server, and the palliative care team could not access the register whilst on call, there was no option but to continue using the original paper handover form. Therefore, the register was unable to go live in December 2010 as was intended. LAS, who were extremely supportive throughout the register’s development, offered to allow another URL link to the register if Harmoni, instead of Patient 24, hosted the Camden & Islington register. Disappointingly, Harmoni advised they were unable to commence hosting the register immediately due to a planned IT upgrade. Given the lengthy delays the project had already sustained the proposed time frame was considered unfeasible.

The Camden & Islington project encountered challenges throughout the pilot, particularly in relation to integrating their register’s information with their OOH service. Due to these insurmountable challenges, and with regret, they were unable to progress with the pilot to a point where they were able to take their register ‘live’. However, they intend to continue to work collaboratively in the future towards a pan-London solution.

Impact on inter-agency partnership and working

Stakeholder/partners engagement.

Following implementation, it was the Camden & Islington project’s intention that an EoLC Register stakeholder group would meet regularly to monitor progress, discuss issues that had arisen, develop appropriate action plans and anticipate further work that may need to be done. Membership of this group was to include:
As well as training regarding the use of the register, regular updates to local staff were to be made via the EoLC website and targeted emails, including opportunities for queries and comments.

Due to the pan-London ambitions of the Camden & Islington register it was important to engage LAS from the outset of the implementation of the register. Due to concerns about governance and risk management, LAS reacted to the emergence of multiple pilot sites within London by requesting that the register could be accessed via a single URL. The Camden & Islington and Royal Marsden projects therefore worked closely with LAS at every step of the register’s implementation to realise this and to ensure that LAS didn’t have any concerns. In return, LAS have been very supportive and a good working relationship has been formed.

Reactions to the register from GPs were mixed. Whilst some GP practices were very supportive and enthusiastic regarding the Patient 24 hosted register, others expressed frustration and a level of unwillingness to participate. This unwillingness was seen to stem mainly from time constraints upon GPs. Despite the potential benefits that the register holds for patients, GP practices may be unwilling to commit to using the register as using it is seen as a time consuming, yet non-mandatory requirement, for which they receive no additional resources to undertake.

The difficulties engaging GPs may well have been because the EoLC LES (local enhanced service) had been withdrawn after one year due to financial constraints. This had been planned to be a 4 year LES, building on the Gold Standards Framework and developing practice registers. Consequently, there was a feeling that the incentive had been withdrawn but there was still an expectation to implement the electronic register, which ultimately meant...
additional work and a change in practice at least in the short-term. In hindsight if the register had been taken through the LMC there may have been more GP engagement.

GPs’ unwillingness to use the register potentially meant that a large majority of patients’ details would have to be entered onto the register by other healthcare professionals – most likely palliative care CNS. This has implications for palliative care CNS’ workloads and also has the negative consequence that patients not known to palliative care services are less likely to be consented onto the register.

Service user, carer and family experience
Camden and Islington’s key aim in developing the register was to assess whether the increased availability of information to relevant healthcare professionals would translate to the improved provision of EoLC and improved outcomes.

For patients the aims were to:

- Enable them to be more proactively involved with planning and decision-making around their care
- Enable those choices to be honoured wherever possible – preferred place of care/death, decisions around treatment etc.

Had the Camden and Islington register gone live it was envisaged that it would have supported a number of benefits that would have encouraged users to be more proactively involved with their End of Life Care and improved patient experience.

- The act of having to consent patients to add them to the register was likely to be anxiety provoking for both healthcare professionals and patients. However, specifically needing to consent patients to go onto the register would have the potential to open up conversations surrounding End of Life Care, encouraging these to happen earlier rather than in a last minute crisis a few days before death. It was the hope of the Camden & Islington pilot that the benefits of that EoLC planning earlier would outweigh the difficulties with having the sensitive conversations.
- As well as being useful for professionals in order to help patients achieve their wishes, the knowledge that health care professionals have patients’ EoLC information to hand and would act accordingly, would be reassuring for patients and families in a crisis situation.  
  
  *It’s reassuring for the patient and family that actually other people know what’s going on, even though it’s 11 o’clock at night, and that will help the most appropriate*
decisions be made with the patient and family and that’s one of the most important aspects of this.

Camden Locality Register project lead

- In addition, it was noted that many patients assumed that their EoLC information is already shared between the different services, and therefore were sometimes surprised and frustrated when they had to repeat the same information time and time again when they met a doctor nurse or paramedic. By communicating this information between healthcare professionals, the register would have been helpful in terms of saving distress at this point.

It was also hoped that the involvement of religious leaders in the development of the register would improve the patient and family experience. During the register development, there was discussion about whether there were particular religious or cultural groups for whom addition to the register would be unappealing. It was felt that consulting a Rabbi or Imam would be helpful to give different perspectives of the register and to advise whether there is an approach to, or way of explaining, the register that would be more acceptable to any resistant groups. Initially, it was also hoped that the religious leader would be able to help inform the development of the template and to advise whether there are particular questions that need to be included. However, there was difficulty recruiting a Rabbi or Imam. This was because the lack of personal contacts necessitated a generic approach to recruitment, through the local faith forum, which did not gain a response.

Conclusions

Key learning points

- A key consideration from the outset of the pilot project was the potential for a pan-London solution in the longer-term. This necessitated engagement and consultation with a broad range of stakeholders and commercial providers, resulting in a great number of differing opinions and interests which needed balancing against the overall aims of the register. In addition Camden and Islington considered developing a written agreement across all providers to ensure they understood the shared goals and responsibilities they held.

- Camden and Islington considered the longer term equity of the register when making important decisions. Had Camden and Islington chosen to forge ahead using Harmoni to host the register they may have encountered fewer challenges in the initial implementation of the register. However, this solution would not have incorporated LAS’ wish to have access to the register via a single URL and would
have led to a less equitable register in the long-term (as LAS, a crucial stakeholder, would feel that their views had not been taken on board and that the register was not compatible with their systems).

- Adopting Royal Marsden register’s data-set having already developed their own highlighted the value of a data-set that is tailored to the needs of the locality in which it is to be used. When developing the data-set it may be beneficial to consider any local circumstances or concerns which may impact the register’s usage by health care professionals or patients and, where possible, to mitigate these by including additional information in the data-set.
Overview

Summary of pilot development so far

A feasibility study for a citywide electronic Palliative Care Register (PCR) was conducted as part of the Leeds Marie Curie Delivering Choice programme (2006-09). Relevant IT systems that were already in use or in development were scoped, broad support for the register was established across the range of stakeholders, and a proposal made that the PCR be developed using a middleware option, whereby data is drawn from existing clinical records to provide a core data set whilst avoiding duplication.

Development of the PCR required attempting to integrate some of the many IT systems in use in the Acute Trust (The Leeds Teaching Hospitals NHS Trust, LTH). It was therefore agreed that commitment to an IT solution for the PCR would be deferred whilst other Acute Trust IT strategic developments, particularly the Ensemble Trust Integration Engine (TIE) and Acute Trust Clinical Portal, were implemented further.

GP colleagues deploy a variety of IT clinical systems and, the pilot entered discussions with LSPs with regard to developing a bespoke solution, involving the integration of data from multiple LSPs.

The bespoke solution requires LSPs and NHS IT platforms to share data – a function that commercial providers do not currently provide. Discussions with commercial providers are ongoing regarding how to overcome the commercial and technical obstacles to such data sharing. It is regrettable that such commitment to data sharing - clearly vital in healthcare - is not addressed at the contract stage with commercial IT providers.

Framing and refining an IT solution for the PCR, in line with the local and regional IT strategic direction, and ‘future-proofed’ as much as possible, has led to technical delays. Meanwhile, the pilot project has made progress in other aspects of the register's development and implementation including GP engagement, and development of a training strategy.
Starting point
As the third largest city in the UK, Leeds offers excellent opportunities for testing models of service delivery in an urban environment. The city has multiple providers of palliative care leading to a pressing need to share information across the city between primary care, acute hospitals, hospices and emergency and out-of-hours services to ensure that patients have End of Life Care in keeping with their wishes, thereby enhancing the patient and carer experience.

In May 2006 Leeds became the third project in the Marie Curie Delivering Choice (MCDC) programme, which aims to improve palliative care services so that all patients with a terminal illness, regardless of diagnosis, have choices over their place of care and death. One of the achievements of the Leeds MCDC project was the completion of a feasibility study, involving all possible local partners and users, for a citywide electronic Palliative Care Register (PCR). The study identified that the concept of a PCR had strong buy-in across Leeds, with clear stakeholder engagement, and an existing infrastructure of information sources and ongoing work streams which could be incorporated into a PCR. The outcome of the feasibility study was to propose that the PCR was developed using a middleware option, whereby data is drawn from existing clinical records to provide a core aggregated data set whilst avoiding duplication. Other recommendations included an opt-in system by patients, and a host-based system with PCR data accessible via a standard Internet browser.

A number of pre-existing systems, either already in use or in development, were identified which related to the aims of the PCR. The oncology database (PPM) in which the LTH Specialist Palliative Care database is housed, was considered as a potential source of detailed data with which to populate the PCR. In addition, the functionality and shared hardware of a Community Cancer Portal (CCP) under development by LTH was considered in the initial design of the PCR. Both PPM and CCP share information across organisational boundaries and there was therefore the possibility of building on existing IT pathways and processes.

Approach
It was this middleware approach suggested by the Marie Curie feasibility study that the pilot initially decided to follow when developing the PCR. At the outset, the objective was that the PCR would be supported, in the first instance, by data from the PPM system, and from primary and community care and hospice clinical systems.
However, the proposal regarding the role of the LTH data systems was reviewed early in the pilot due to a number of potential limitations. Firstly, the close link with cancer services was a potential barrier to the equitable access to the register by all patients regardless of diagnosis and whether or not they were known to Specialist Palliative Care services. Secondly, the CCP project was at an early stage of development and there was the potential that it might not be available to support the PCR. Thirdly, there was the need to consider the implications of emerging local IT strategy for the design of the most coherent, efficient, and equitable development of the PCR. Key considerations in determining the final agreed IT solution were the LSP for out-of-hours providers (SystmOne); the LTH work on the TIE and Clinical Portal; the major commercial IT providers for GPs and District nurses, and developments in the Summary Care Record.

The final IT solution for the PCR was agreed in January 2011. It involves building templates containing the core dataset for the Leeds PCR within the LTH Clinical Portal, EMIS and S1 clinical databases, with the potential to share data directly between these templates on the basis of agreed coding of data items.

By avoiding the implementation of the project in isolation and ensuring that the PCR is embedded within pre-existing clinical systems, the following benefits may be realised:

- The register will form part of systems already in use by clinicians. This will ensure that the PCR will be intuitive for clinicians to use which will, in turn, encourage uptake and use.
- It conforms to the strategic direction of the city, LTH, and all the organisations involved in the PCR. This mitigates the risk of the register becoming obsolete and ensures that the register is sustainable with the ability to offer greater equity in the long term.
- It enables the PCR to find a solution to very complex IT governance issues by using existing IT governance frameworks.

However, the Leeds Pilot have also identified a number of risks associated with the adoption of their chosen approach. Notably, the potential involvement of third party suppliers, particularly in primary care, involves unknown additional costs, and the LTH Clinical Portal is at an early stage of development. Data-sharing issues with one LSP remain unresolved.
Aims and objectives
The principle aims of the Leeds PCR are to utilise effective informatics processes and applications to enable the identification of palliative care patients to all providers who are involved in their care, and the promotion of improved and timely communication between professionals and patients, thereby improving the quality of care and appropriate advanced care planning.

The objectives can be split into organisational objectives and end user objectives. The organisational objectives include;

- identification of patients at the end of life, by patients and providers who are involved in their care, resulting in improved and timely care planning and communication.
- confirmation of an agreed core dataset, with agreement on a citywide approach to the coding of data items which is clear and consistent. The aim of the Leeds PCR is not to provide a clinical record, but to provide a summary of key information to inform End of Life Care provision
- detailed analysis of current processes and other local dependent systems which need to be incorporated within the project, consistent with the required dataset;
- establishing an understanding and approach to issues of patient consent and data protection;
- providing a road-map for the delivery of the benefits of the PCR to other health professionals, including further interfacing requirements.
- Collation of information about service demand and demographics.

End user objectives include;

- encouragement for further discussion with, and documentation of, patients' decisions regarding End of Life Care;
- an increase in patients being cared for and/or dying in the place of their choice;
- empowerment of patients when faced with end of life issues and decisions;
- patients and identified other Health Professionals accessing the PCR as part of the planning and delivery of care;
- healthcare providers made aware of patient choice of place of care/death thus reducing inappropriate admissions.
Technical and IT developments

Technology platform

In 2010 LTH set a strategic direction for IT which includes the integration of approximately fifty IT systems in use across the acute trust. This is to be achieved using the Ensemble Trust Integration Engine (TIE) which is specifically designed for connecting applications in the Trust with applications supplied by commercial organisations to exchange appropriate information. Once integrated, the IT systems will be accessed via the Acute Trust Clinical Portal. Discussions are progressing regarding the integration of the LTH Clinical Portal with TPP SystmOne, and with EMIS systems via the interoperability gateway.

Such integration is necessary for the success of the PCR. It was therefore agreed that commitment to an IT solution for the PCR would be deferred whilst the TIE and Acute Trust Clinical Portal were implemented further. Although leading to a delay in the development and implementation of the register it was felt this would lead to a stronger and more resilient register in the longer term. Meanwhile, work was ongoing on GP engagement with the project, company data sharing, and clear specification of the main IT delivery options.

“It was very much given that the Trust would be very supportive if the PCR project was in line with the strategic direction of the Trust. But if we were wanting to do a small project that then needed managing separately and incorporating and integrating at a later date, no-one was going to stop us but we would also not get the weight of the Trust behind us.”

Project Lead

A detailed system specification was agreed to inform the options appraisal between the main IT LSP options (EMIS, SystmOne, and bespoke) and enhancement of the Summary Care Record (SCR). The Leeds stakeholders formulated an IT solution using the different IT options as building blocks, rather than as stand alone (and competing) solutions.

Within Leeds, approximately 90% of GP practices use one of the two main LSP options; SystmOne or EMIS. However, a significant minority (approximately 10%) of GP colleagues do not use either of these LSP options, limiting universal availability of the PCR. SystmOne is also being deployed widely by district nurses, hospices and out-of-hours providers, in keeping with the Yorkshire and Humber SHA IT strategy. Therefore SystmOne-based services are essential to the successful roll-out of the register.
Consequently, SystmOne needed to be a crucial component of the PCR IT solution. Given this, there were two main options for making the core PCR data available across the different acute and community healthcare settings. Firstly, access to SystmOne via a desktop icon could be made available to LTH, EMIS and other LSP users. The main disadvantage to doing this was reduced intuitiveness of use, as access to the PCR for those on non-S1 clinical databases would be at a distance (more than the ‘one click’) from the main clinical record. The second option is a much more complex bespoke solution, involving the integration of data from multiple LSPs. It involves agreeing a coding set for the core PCR data items across the Primary Care and community LSPs, and building corresponding PCR templates within SystmOne, EMIS and the LTH Clinical Portal. This would permit at least 90% coverage of GP practices, all DN and OOH services, and with access across LTH, with the future option of implementing an enhanced SCR to provide coverage of the remaining 10% of GP practices and to provide patient view via Healthspace. The main advantage to the second approach is that access to the PCR is more in line with existing clinical processes. Within the same region, Bradford have developed and piloted a palliative care register template within SystmOne that they are happy to share and which Leeds could adapt to meet local requirements. However, engagement of SystmOne and EMIS in data-sharing and system development is crucial. This second option is the approach that is being taken.

The timescale for enrichment of the SCR is longer than the timescale for the PCR’s development and therefore it could not be an immediate solution. A disadvantage to the SCR is the lack of a reporting function. However, it does offer a patient view via HealthSpace, and we are keen to explore this to fulfil another aim of the Leeds PCR project that cannot be met elsewhere. An enriched SCR approach does offer the opportunity to link non-EMIS non-S1 GP practices, and to be a back up for connectivity to LTH should either main GP LSPs refuse to data share.

The first priority in Leeds is to implement the PCR across SystmOne users, whilst progressing links with EMIS and the LTH Clinical Portal to support development of the PCR template in these IT systems. The SystmOne work will offer immediate benefits to patients in terms of SystmOne data sharing across community healthcare services, and will provide the focus for the ongoing work on coding, patient consent, training and information governance.

Data sharing
A bespoke solution, involving the integration of data from multiple LSPs, requires that the different LSPs are compatible and that information collected using one platform can easily be shared with healthcare providers who use alternative commercial platforms. This relies on the different platforms sharing data, not just with NHS systems but also with each other – a functionality which commercial providers do not yet provide. This was taken into consideration in the design of the bespoke solution. Discussions with commercial providers are ongoing to overcome any commercial and technical obstacles, but this remains a significant risk.

Clinicians in Leeds have expressed the importance of having the register in plain sight to encourage use and there is a strong preference among GPs for the register to be located on an additional tab on their usual platform, rather than requiring the cumbersome navigation between two systems.

To date this difficulty surrounding data sharing between LSPs has been the Pilot’s greatest obstacle. The government’s aim to move from a ‘replace all’ to a ‘connect all’ approach, as endorsed in the government white paper ‘Equity and Excellence: Liberating the NHS’, is generally supported by the Leeds pilot. However, the problems experienced surrounding data sharing highlight the need for the government to make it clearer to commercial organisations that it is in the nature of healthcare to share information, and for SHAs to stipulate in contracts exactly what they expect of service providers in terms of connectivity and data sharing.

Development and Implementation

Staffing
The initial project plan included the appointment of a part-time Band 7 Lead Nurse. The role of the lead nurse is primarily to consult with patients and clinicians on the acceptability of the register and consent issues, and to consider the training programme in terms of what is required, who would deliver it and what the costings might be.

A job description for the Lead Nurse’s role was submitted to Agenda for Change. However, based on the Agenda for Change evaluation factors, the role was evaluated as a Band 5 admin role. It was identified that the factors comprised in the Lead Nurse's role were so different from those assessed by Agenda for Change that the job description was unlikely to ever meet the Agenda for Change specification for a Band 7 role.
“The job profile is so different from any of the Agenda for Change bandings that there was no way it was ever going to meet band 7. It’s just like square pegs and round holes.”

Project Lead

Therefore, an active recruitment process was taken, leading to the secondment of an existing band 7 Nurse to the project for one day per week, commencing September 2010, nine months after the original job description was submitted to Agenda for Change. This delay inevitably led to delays in work surrounding user and carer involvement in the PCR. The process of attempting to recruit under Agenda for Change was extremely time consuming and in similar cases it would be advisable for future projects to consider alternative solutions to recruitment before taking this route.

A further staffing difficulty has arisen relating to the extreme complexity of the project and the large amount of project management time that is subsequently required. The co-ordination of the huge number of IT and clinical threads and stakeholders involved in the project took the clinical lead at least four to eight hours per week during the first year of the PCR’s development.

“Time wise it takes up a lot more time than we originally anticipated and the project lead certainly spends vast amounts of time on it.”

Lead Nurse

The Leeds PCR Project has an IT Project lead, a Clinical lead, and a Lead Nurse, all of whom have many other demands on their time. It is therefore essential for even the most efficient Project Leads to build time into the project plan and their own job plans to allow for the sheer amount of time and effort it can take to progress the PCR project. There are many stakeholders across multiple settings, and establishing and maintaining engagement with a wide variety of very busy people requires a substantial commitment, and a strategic approach. This said, all those approached have been supportive, encouraging and helpful.

Training

At the time of writing the Leeds project are developing a training strategy for clinicians using the register. The Lead Nurse is scoping the differing clinical settings with regard to what training is required, who is well placed to deliver it, and what the costings will be. It was identified that the clinical time available will be insufficient to provide this support and training, given the resource constraints of the pilot. To mitigate this, early links have been made with the citywide Palliative Care Education group.
Data set

A clinical reference group (CRG) drawn from across the healthcare community has informed the register data-set from the outset. The CRG has contributed to the development of the national DH core PCR dataset, which Leeds has in turn incorporated. As the SHA had expressed a preference for a standardised PCR template across the SHA, the dataset has also been cross-referenced with the Bradford template, and the SHA Senior Clinical lead in End of Life Care has been involved throughout the project.

Data for the Leeds PCR will be drawn from the existing multiple clinical systems used in different services using automatic feeds wherever possible.

The Leeds PCR is designed to act as a summary rather than to be the main clinical record. It is intended that in out-of-hours, emergency situations the register will provide enough timely, up-to-date information to help health care professionals make decisions in accordance with patients' preferences. In hours, however, health care professionals may choose to contact the relevant clinician using the rich source of contact information provided by the data-set to gain a more thorough understanding of patients' end of life choice.

Administration rights

The vision for the Leeds PCR is that the access to the palliative care register will be via the existing clinical system. Either the Acute Trust Clinical Portal if accessing from within the Trust or the usual clinical IT system within primary care (either EMIS or SystmOne in the majority of cases). In both these cases access is governed by username and password.

One of the benefits of the middleware approach to developing the PCR is that it allows the use of existing IT governance frameworks and this has the potential to offer flexibility regarding administration rights. Consequently, each of the PCR’s three main IT providers will use their own existing IT governance frameworks to oversee who has access to the register. Therefore editing rights of different members of the multi professional team will be decided at a relatively low level; in the case of SystmOne either at GP practice level, or the level of the individual GP. It is planned that different members of the healthcare team can propose a person be included on the PCR, with the requirement for GP agreement over inclusion, and to data share.
From the perspective of the Clinical Reference Group it would be ideal if all members of the multi professional team involved in patients’ care have both access to and editing rights of the patients' records. In the majority of cases it is envisaged that GPs will be very happy for district nurses and out-of-hours services to access the register. Indeed, one of the reasons that so much effort has been put into incorporating SystmOne into the Register is because all the district nurses will be using it and it is Leeds’ main out-of-hours provider.

Patient consent
Leeds PCR’s approach to patient consent will follow the opt-in approach. Each patient will be individually consented onto the register after discussing their preferences with a healthcare professional.

It is anticipated that the majority of patients will welcome the opportunity to discuss their options for end of life and understand the importance of sharing this information between providers. It is also recognised, however, that the sensitive nature of the conversations surrounding End of Life decisions may not be welcomed by a small minority of patients who will choose not to consent to the PCR.

“I think that people will agree it’s a good idea that everybody who’s caring for them has got access to their information, particularly because we’re asking them to tell us what they want at the end of life.”

Lead Nurse

Consultation with the Patient Involvement Lead for the Community had highlighted the fact that after the launch of the Summary Care Record there were a significant number of patients who voiced concerns about who would get access to their information. To minimise the potential for these concerns the Patient Involvement Lead for the Community has been involved in the Clinical Reference Group since the outset of the project to input into the design of the register. Patient engagement has now also commenced and the Lead nurse for the project has met with the specialist palliative care team’s bereaved carers group and also the Trust’s cancer user partnership group. The members of both these groups unanimously supported the idea of the PCR and there were no concerns raised around data sharing and the wide number of professionals who would have access to the data on the PCR. Further work is planned with other users groups across the city.

“It will be interesting once I am able to get out to some patients to find out whether there is concern about who will see the details that we’re holding.”

Lead Nurse
**Functionality**

Unlike many of the other pilot projects, the Leeds PCR does not take the form of a clinical record. Rather, it is a set of core data items. As a consequence outcome data directly from the PCR will be limited. Instead reports will be mainly process driven. The project has achieved consensus on the nature of reports to be developed but these will be reviewed once the exact IT solution has been developed. Some of the reporting measures which have been decided upon, or which may be considered in the future, are as follows:

- **Use of the register by members of the multidisciplinary team:** This is useful data to collect and would be important in being able to ensure that all professionals involved in a patient’s care are appropriately entering data into the register and to identify any further training needs. The Leeds project could collect this data on the basis of role based access.

- **Care received in line with preferences:** This is useful data to collect in order to be able to benchmark frequently patients’ wishes are being realised. It would rely on collecting place of death within the register which at present the data-set does not include, due to the proposed ‘patient view’. This is under review.

- **Patient cared for on the Liverpool Care Pathway in final days:** This is a viable piece of information to collect as the register does collect information about whether an end of life pathway is in use.

- **Discussions held with people approaching the end of life:** This data would be viable to collect by the Leeds register but it has been suggested that the outcome ought to be more specific. For example, the percentage of patients who were offered advance care planning, completed advance care planning, and have a documented preferred place of care or death. This would ensure that the key measure is whether patient choice is supported effectively rather than the absolute number of patients with advance care planning.

- **The diagnoses of patients on the register:** This data would help ensure that the PCR is achieving equity of patient access. It is hoped that, where appropriate, all patients will be able to access the register, not just those patients who are receiving specialist palliative care.

**Impact on inter-agency partnership and working**
Improvements

Once implemented the Leeds PCR is likely to provide a number of improvements to inter-agency partnership and working. These benefits are enhanced by the Pilot’s resolve to ensure that the PCR is as equitable as possible in the short term with potential for universal access as soon as possible.

Although it is important to focus on the community IT systems, as this is where the PCR will be mostly used, the Leeds pilot also addresses the importance of IT integration between primary and secondary care. The question of how to get the acute trust and community IT systems to speak to each other is a crucial IT problem which applies to the entire country, and has very rarely been addressed in any aspect of health care. Although it has caused significant delays in the PCR’s implementation, adhering to the SHA’s strategic direction by incorporating the Acute Trust Clinical Portal into the design will ensure that the Leeds PCR is a great asset to inter-agency working by allowing effective communication between health professionals both working in the community and within hospitals in the longer term.

A further aspect of the Leeds PCR which will act to improve inter-agency partnership and working is that the PCR will provide a rich source of information on key contacts. In out-of-hours emergency situations this register will contain enough information for health care professionals to act in a way that adheres to patients’ preferences. In hours, however, health care professionals can choose to use the provided contact information if they wish to gain a more thorough understanding of a patient’s End of Life Care choices. This feature of the Leeds PCR enables, and encourages, one clinician to speak to another regarding what can often be a very complex situation. This can only enhance inter-agency working, as well as acting in the patient’s interests by ensuring that all clinicians involved in their care have a thorough understanding of their preferences.

“It would be much easier if we had a register and peoples’ wishes were on there and the preferences were on there. I think more people will get engaged with advance care planning.”

Lead Nurse

Stakeholder engagement
Leeds is in the fortunate position of having relatively well integrated palliative care services. This has been achieved through close collaboration between services and with commissioners over many years, and a number of successful initiatives have drawn together the different members of the community. The PCR is a further example of how stakeholders are able to work across the city to link with other palliative care initiatives. As a result, and as identified by the Marie Curie feasibility study, there is clear buy in for a PCR across Leeds and all stakeholders involved in the development of the PCR have been very co-operative and worked effectively as a team. In addition, the success of the pilot in attracting DH funding has enhanced the existing interest from key stakeholders which has strengthened the project through active engagement by more senior operational and strategic managers.

“The provision of palliative care reaches out to more areas than imagined and the user group is widespread through the NHS community. It has been a valuable lesson in pulling these people together and learning how to approach them.”

Technical Project Manager

Maintaining regular and widespread engagement with stakeholders has been particularly important for the Leeds pilot due to the middleware nature of the Leeds PCR. The PCR is reliant on the integration of multiple IT systems and the timescale for the integration of local IT integration is not in keeping with the timescale of the PCR project. Therefore, it is vital to the success of the Leeds Register Project that a dialogue is maintained with all key IT stakeholders to ensure continued engagement and productivity.

To ensure this dialogue is maintained an IT Project Group and a Clinical Reference Group were established at the start of the PCR project. The project is being led by the IT Project Steering group, which has appropriate IT representation from the Acute Trust, PCT and Community in Leeds and from the SHA. The Clinical Reference Group is drawn from across the health community and informs the IT Project Group. Both groups meet regularly to discuss any relevant issues, whether IT or clinical.

As the Leeds PCR is yet to be implemented due to the delays in the IT development of the register, engagement with health professionals regarding the use of the PCR has also been delayed pending a firmer idea of the PCR's functionality. Despite this, a number of measures have been taken or planned throughout the development of the register to ensure that health professionals are in agreement with the delivery of the PCR.

Although the design of the register will minimise the amount of clinical time needed to populate the data-set, there were concerns at the outset of the pilot regarding the ease of
engaging GPs, particularly given their key role. A number of initiatives have been introduced to help mitigate this risk. GP colleagues have been consulted throughout the development of the PCR, for example non-SystmOne GPs were consulted as to the acceptability of, and their preferences for, linkage to the PCR. In addition, funding for GP engagement for the PCR project has been identified by the PCT and two GPs have been appointed to represent the two main GP IT systems in use, EMIS and SystmOne. The GP representatives also represent different emerging consortia.

Service user, carer and family experience

One of the criteria for success identified at the outset of the Leeds project was improved patient experience, measured partly using patient surveys. At the time of writing, however, the Leeds PCR is still in the process of development and it is therefore premature to begin implementing these measures of patient experience.

Nonetheless, a number of measures have been taken or planned to ensure patient experience of End of Life Care will benefit from the PCR’s implementation. The Patient Involvement Lead for the Community has been a member of the Clinical Reference Group since the outset of the project to help inform clinical design. A bereaved carers user group formed by the LTHT specialist palliative care team, have already given useful feedback on the project and will continue to provide an interesting insight into the advantages, or disadvantages, they feel they would have experienced had the PCR been in place at the time they lost their relative.

As Leeds is an ethnically diverse city there has been consideration of how opinions relating to End of Life Care planning might differ between different ethnic and religious groups. There are plans to consult patients, via the Black and Ethnic Minority Community Elders Group, about the register and explore what their opinions and concerns are relating to it. The finding from these discussions will not only help to inform the development of the register but may also impact on the training that clinicians receive on holding sensitive conversations surrounding End of Life Care with patients belonging to particular ethnic or religious groups.

The bereaved carers group and also LTH’s cancer user partnership group have also been consulted about potential names for the PCR. The clinical reference group had initially considered names based on an acronym however both of the user groups consulted had strong opinions about not using acronyms and would like to see a name which more reflects the PCR aim of sharing data/co-ordinating care.
Conclusions

Key learning points

- Although it has caused significant delays in the PCR’s implementation, adhering to the SHA’s and Acute Trust’s strategic direction by incorporating the Acute Trust Clinical Portal into its design will ensure that the Leeds PCR is a great asset to inter-agency working by allowing effective communication between health professionals both working in the community and within hospitals and will lead to a stronger and more resilient register in the long term. **Future register sites should consider their Acute Trust’s strategic direction to ensure the Trust’s support of the register, promoting long term viability within the Trust.**

- The difficulty surrounding data sharing between LSPs has been a major challenge. **This highlights the need for any future sites to make it clear to commercial organisations that it is in the nature of healthcare to share information** and for SHAs to stipulate in contracts exactly what they expect of service providers in terms of connectivity and data sharing.

- The process of attempting to recruit a Lead Nurse under Agenda for Change criteria was extremely time consuming, and was ultimately abandoned. Subsequently, an existing band 7 Nurse was seconded. **In similar cases it would be advisable for future projects to consider alternative solutions to recruitment before taking the AfC route to nurse project leadership.**

- The sheer quality and quantity of project management time required, reflecting the complexity of the project.
7d) NHS Mid Essex

Overview

Summary of pilot development so far

- Mid Essex conducted an options appraisal to select the most appropriate IT platform to run the locality register; Advanced Health & Care (formally Advanced Health & Care) was chosen as a result of this appraisal.
- In order to keep running costs down it was decided that the out of hours service provider, Primecare, would host the register, with all other users allocated with individual IP addresses to access the system.
- The pilot has been rolled out initially in four GP practices, chosen because they are geographically spread and are already engaged with End of Life Care.
- GPs have ultimate responsibility for the locality register record, with other staff having the right to edit.
- Reporting is a key function of the register and when the register is more widely rolled out it will enable performance management of practices.

Starting point

In the run-up to the pilot Mid Essex were focussed on driving significant improvements in End of Life Care for the local population. This included the development of a multidisciplinary, multiagency group to work together to ensure that consistent care is delivered across the service. This group is made up of stakeholders from:

- patient links and Service users;
- NHS Mid Essex Commissioning;
- Essex Social Services;
- Farleigh Hospice;
- provider services;
- residential and nursing homes;
- secondary care;
- Macmillan GPs;
- EoLC facilitators; and
- palliative care consultants.
Prior to the implementation of the EoLC locality register, pilot funding had been secured for a Macmillan GP facilitator for three years along with an EoLC facilitator role with funding to support implementation of EoLC tools.

Mid Essex was also moving towards a model of Integrated Community Teams at the time of submission for the pilot, meaning that across the community service different providers were beginning to work more closely together.

Mid Essex themselves acknowledged a starting point of “pockets of excellence, but also some fragmented and uncoordinated approaches to developing End of Life Care”; with few GP practices in Mid Essex currently using EoLC tools such as the Gold Standards Framework (GSF).

Mid Essex had, for some years, been working towards the Connecting for Health “One patient, One record” policy for implementing a joined-up strategy for sharing information across the Trust area. At the start of the pilot 39% of GP practices in the Trust were deploying System One, with plans to roll this out to the Community Hospitals and the Hospice, as well as the new out of hours GP service and walk-in centre. As the Summary Care Record (SCR) is developed the plan is to integrate it with System One and the other clinical applications in use.

Approach

The initial approach favoured by Mid Essex was to utilise the widespread SystmOne coverage and to integrate this with the development of the SCR. Given the well-designed information solution currently in place, and the data sharing protocol that exists to support the current system, it was felt that this would allow the Trust to focus the pilot on the EoLC service, rather than the technology required. However, despite being keen to develop the approach already in place in the Trust, stakeholders wanted to ensure that the correct system was implemented. For this reason the pilot started with an options appraisal of the available information systems.

The pilot site is intended to start with these areas where good practice should already be embedded and to roll out from there, with three of the four chosen sites being those currently working with GSF.

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7 Mid Essex Expression of Interest form for Department of Health & National End of Life Care programme End of Life Care Strategy Locality Registers Call for Test Sites
I think we saw it as a tool really, to start the engagement with the practices, and to improve care

Mid Essex Project Lead

Aims and Objectives

The principle aim of the Mid Essex EoLC register pilot is to embed the identification of EoLC patients as part of everyday practice, and thus to enable the Trust to improve the outcomes and experience for those affected. The pilot aims to improve the PCT’s ability to enable more people to die in the place of their choice, in practice often at home.

The objectives identified by Mid Essex in order to achieve this can be split into organisational and end user objectives. Organisational objectives include:

- Embedding a culture of EoLC providers and commissioners sharing their expertise for patient and carer benefit;
- Driving up the availability and quality of EoLC;
- To enable collation of EoLC information and thus improve services across Mid Essex;
- To reduce fragmented care, crisis situations and inappropriate hospital admissions; and
- To identify gaps in provision in order to implement solutions.

End user objectives include:

- To support patients to achieve their preferred priorities of care;
- To ensure equitable access for users; and
- For the patient and carer to experience a seamless service where all EoLC needs are met.

The development of the register is closely tied to the board’s objectives both in terms of improving the current position of the Trust and in terms of setting targets to move the Trust forwards. Whilst there is currently a performance target within the Trust to improve the proportion of deaths at home from 20% to 30%, the Trust itself has also set a ‘stretch’ target (an ideal aim) for 40% of Mid Essex patients to achieve their preferred place of death.

There has also been a keen interest from neighbouring Trusts who are looking to implement something similar, but are keen to share learning from the Mid Essex pilot. Mid Essex is
keen to be able to share experiences with other areas, and make recommendations for the national roll out of the scheme

**Technical and IT developments**

**Technology platform**

Although Mid Essex is moving towards the “One patient one record” objective, there are still several different IT systems in place across different GP practices. With the planned introduction of the Summary Care Record (SCR), and the aim to integrate the SCR with the other information systems in place, it was decided to conduct an appraisal of all of the major IT system providers in use.

> Some of this is probably a bit political. At the very beginning of the project I think we, and I know other Trusts, tried to drive forward the idea that it was the Summary Care Record that would form the basis of the register. And that’s probably why we had to do the options appraisal [to look at options over and above the SCR].

**Mid Essex Project Lead**

Although the SCR has been considered, there is concern about its lack of reporting functionality. The pilot lead would like to have the data gathered for the minimum dataset available to use to improve outcome measures, identify gaps and work with practices and clinicians to support and improve EoLC within practices. The Summary Care Record does not offer this function in its current form.

It was recognised early on in the process of setting up the register that one of its key benefits would be to enable communications across different healthcare professionals. The SCR was also felt to prevent this level of communication amongst non-clinical staff.

> The basis of our register is actually trying to communicate people’s wishes … Part of that requires that people sometimes viewing the register are not always clinicians. It might be a call handler in the ambulance service or administrative support from the out of hours provider. And the summary care record didn’t have that flexibility.

**Mid Essex Project Lead**

The key *technical* features required of the register are felt to be:

- ease of use; and
- the ability for all stakeholders to be able to access the register regardless of location or organisation.
Advanced Health & Care has been chosen as being the only solution that offers functionality in both these areas. It has the ability to interface with all the different clinical IT systems in use in practices across the pilot area. This would allow joined-up working with the same system for all of those using the system. Although only a small number of practices are taking part in the pilot, it has also been considered how easily the system would be able to roll out across the whole Mid Essex area, both in terms of function and of cost.

We’ve got about three of four different clinical systems within practices, a different one with our provider, and none of the other solutions could address this, because none of the other solutions currently had the ability to interface with each other… It was just ease of use and ease of access, and that it would be able to be hosted and viewed by a range of people without too much of a problem.

Mid Essex Project Lead

Technical issues
The main technical problem encountered by Mid Essex was the difficulty in enabling access to the Advanced Health & Care platform for all staff. Ideally it should be possible to host the register from within the Trust itself. However due to cost limitations it has been decided that Primecare, the out of hours service provider, will host the register rather than the PCT.

This has necessitated the provision of individual internet protocol (IP) addresses for users of the register, which has caused some technical difficulties. Any computer or network used to access the internet needs an IP address to be able to send and receive information from other networks. It is the equivalent to a house address or telephone number. IT staff from the PCT created unique IP addresses for each of the users outside the PCT IT systems. Whilst this has been resolved in conjunction with Advanced Health & Care, it has caused some delay in enabling access to the register for some users. Although the Mid Essex locality register went live in August 2010 across all of the pilot GP practices there are still some community based organisations where the register cannot be viewed from the work base as it has not yet been possible to provide an IP address.

It is not clear at this stage whether a permanent fix can be found for this when the pilot is rolled out further or whether hosting the register from within the Trust may become a more cost effective option.

We weren’t able to set it up just with ease of access. What we’ve had to do is, all of the people who need to be able to view and edit the register, we’ve had to provide individual IP ranges … Rather than it going live with everybody being able to access, the IT people in Advanced Health & Care and our own organisation, have had to get individual IP ranges.

Mid Essex Project Lead
Alongside the pilot, Mid Essex has also been trialling access to patient information via iPhone connection for District Nurses. It is too early to say whether this has proved a success.

**Development and implementation**

**Staffing issues**
The Mid Essex pilot has been implemented without taking on any additional staff. The role of pilot lead has been taken on by a member of commissioning staff with a clinical background who has a lead role for End of Life Care Commissioning, supported by an existing member of the IT team. It was felt that the pilot would have benefited from more ring-fenced time dedicated to the development of the End of Life Care Register. The pilot has been run in addition to, rather than embedded in, the core work of these members of staff.

Having both clinical and IT input throughout the project is viewed as essential. Setting up the IT side of the project took longer than anticipated as there was initially no PCT IT lead for the project and a number of initial technical decisions were taken on choosing and designing an IT platform and hosting service for the register. The clinical lead feels that the evaluation of these options would be better undertaken by an IT expert.

> *My view would be you've absolutely got to have IT commitment. Because I am a clinician and can't evaluate or understand some of the things that I'm being told or asked to make a judgement on. In my perspective, for this to run successfully elsewhere, you need a strong clinical lead, but equally you've got to have absolute IT commitment to the project*

**Mid Essex Project Lead**

The support of the PCTs Chief Executive (CE) has been one of the key foundations for the pilot in Mid Essex. The CE has enabled the project to move forwards with commitment from the organisation and prioritised input from IT.

However it is not just representatives from the clinical and IT side who are of importance. Mid Essex are finding that having a GP to liaise with other GPs in participating practices was invaluable. GPs and other professionals find it easier to engage with the programme when someone working with the same systems as them explains the benefits of the change.

> *We have a fantastic McMillan GP who's very credible within our organisation, and so I think the medical champion, the doctor champion has been important to this as well.*
Because I think it brings it credibility with that group of staff. So I think you need a doctor lead.

Mid Essex Project Lead

Training
Training has been found to be fundamental to the success of the pilot. Whilst basic training in the use of the Advanced Health & Care system and dataset was provided by Advanced Health & Care, the pilot highlighted further training needs in the way that advance care planning is currently being carried out within the practices.

I think the things that it really should be the driver to do, like advance care planning and preferred priorities of care, it’s highlighting that they are not being done. And I think that’s the training requirement, and the support requirement within the practices.

Mid Essex Project Lead

With the practices being picked on the basis of being the most engaged with End of Life Care, and the majority already operating with the Gold Standards Framework, the use of the register has been surprisingly inconsistent and unpredictable, partly due to a lack of knowledge amongst users.

I suppose the other thing that I’m surprised about, coming from a clinical background myself, is the lack of knowledge and people just not doing what you would expect them to do with the registers.

Mid Essex Project Lead

One of the key learning points from the pilot is the realisation that the generalist training of many staff who deal with EoLC and palliative patients does not necessarily equip them with the tools to have the conversations required to maintain an EoLC register. This has been identified as a key area of training and support need.

Really it’s just lack of confidence and fear. Maybe some of that comes with experience, but more structure around supporting generalist staff who are dealing with palliative and End of Life Care patients, as the bulk of contact is probably going to be with them if somebody’s in a community setting.

Mid Essex Project Lead

This training gap has been addressed by appointing a facilitator to work between GP practice staff, and staff in the community and the PCT.

Local ‘Champions’ have also been established across the area to act as support when the pilot is rolled out to other practices. The pilot has highlighted that skills gaps exist even in areas where perhaps it was assumed staff would feel confident. The development of a small
pilot area of practices within Mid Essex has been designed partly to address this training need. Practices already engaged with EoLC were deliberately picked from different geographic regions across Mid Essex in order to provide ‘Champions’ to a greater extent.

_We felt if we had champions already established within their patch they would be more able to provide some support to their neighbours when we try and expand off of this._

Mid Essex Project Lead

As champions, the pilot practices would be familiar with the use of the locality register systems and thus able to offer practical support to neighbouring practices. They would also be able to act as advocates for the system, as well as hopefully providing an example of how the system can work when it is up and running. Given that one of the key challenges of getting buy-in to the locality registers has been to convince those who will be end users of the benefits both to themselves, and, ultimately, to patient care, the opportunity to see the benefits in action will be vital in convincing stakeholders to use the register. As discussed previously, having strong advocacy from a clinician is effective in getting other clinicians on board with the project. Growing the pilot from sites that are already up and running will provide a natural advocacy base within vital stakeholder groups.

Achieving the cultural and clinical behaviour shift is viewed by the lead as the biggest task facing the pilot. Whereas the technical aspect can be easily accommodated, the clinical behaviour requires a more fundamental change and has thrown up organisational lessons for rolling out the register following the pilot.

_The learning is also that it’s not just the technical bit, the big bit is the culture and clinical behaviour._

Mid Essex Project Lead

**Administration rights**

There are two main issues to be considered under administration rights:

- Creation of the record; and
- ‘Ownership’ of the record and editing rights.

Looking first at creation of the record, the pilot team accepts that there may be a range of healthcare professionals (other than GPs) who are well placed to initiate the conversation with regard to preferences with a patient, dependent on circumstance. Mid Essex are keen to ensure that their pilot includes non-cancer patients, such as those with long term
conditions (e.g. Congestive Cardiac Failure). These patients may have a more developed relationship with community staff who have been attending them for some time. In these cases it may be appropriate for the main healthcare professional to have the conversation about consent with the patient, with GP having ultimate approval of the record. It is intended that cases would be identified at practice-wide palliative care meetings, thus the decision to add a patient to the register would be a multi-disciplinary one rather than a unilateral decision by the GP.

Sometimes it may not be the GP who has this very well established relationship. It might be the community matron or somebody who’s been going in for a long time.

Mid Essex Project Lead

Ultimate responsibility for and ‘ownership’ of the record lies with the patient’s home practice or GP. However, the Mid Essex pilot has allowed other staff groups to have rights to edit the record. This will be tested in the pilot to see whether having editing rights to the register will increase clinical engagement and foster a sense of ownership and responsibility for the record amongst clinical staff.

As across other pilot sites there is a requirement to notify the home practice or GP, where ultimate responsibility lies, of any changes made to a record. Currently there is no automatic flag generated by the system to do this. Mid Essex would like to be able to add such an automated flag in order to emphasise that ‘ownership’ of the record lies with the GP.

The consensus was that for the purpose of the pilot everybody has viewing and editing rights, because it was felt that would support greater clinical engagement. So, anybody can input into the register but that they are also supposed to notify the practice that they’ve done that. Because the practice really is the initial generator or holder of the register. Other staff are able to edit or add.

Mid Essex Project Lead

Patient consent

As with many sites, particularly following the concern surrounding the SCR consent process, it was decided that an opt-in approach to the EoLC register would be the most appropriate. In Mid Essex, the form of this consent has been left very much up to the individual practices. Most practices have settled on a verbal opt-in where the patient is consented onto the register by the healthcare professional most responsible for their care. It is explained to the patient the purpose of the register and the information that will be stored about them. It is then recorded on the register that consent has been obtained from the patient.
However, one member of clinical staff feels that the issue of consent is not something that needs to be tackled only with patients. Whilst patients are often happy to consent once the process of data sharing has been explained to them, the healthcare professionals are not always comfortable with the idea of sharing data themselves.

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\text{Patient consent is quite easy, getting professionals to believe that they can share data is more difficult} \\
\text{Mid Essex Hospice Manager}
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Although verbal consent is standard amongst the majority of the Mid Essex practices involved in the pilot, there is one pilot practice that has opted to use a written consent method. This will ensure that there is a hard copy document of consent.

**Functionality**

The Mid Essex locality register has been designed as a useful tool for communication and information sharing, but beyond that the PCT hope that it will enforce good clinical behaviour in terms of advanced care planning for EoLC, as well as create a culture of more open communication.

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\text{At the end of the day it’s just a tool. The big thing is about clinical behaviour and culture within clinical teams.} \\
\text{Mid Essex Project Lead}
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To help in developing this the PCT are also hoping to be able to use the reporting measures of the register to understand gaps in practice in relation to EoLC and therefore to target support and education. In terms of outcome measures the locality registers will allow the PCT to measure the numbers of patients achieving their preferred priorities of care, as well as being able to see where the register has been used as a tool for advanced care planning.

As has previously been discussed, the register has already been a very effective tool for highlighting where practices are falling short in terms of care planning. It is hoped that when rolled out more widely across the PCT the register will be able to be used as a tool to educate practices in good EoLC planning also.

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\text{[It provides] support for practices and some really focussed work around this [EoLC]. So it should have a huge advantage in terms of being able to give us an accurate picture of what percentage of patients actually achieve their preferred priorities of care, and whether the tools had been used in the planning of care prior to the patient’s death.} \\
\text{Mid Essex Project Lead}
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Impact on inter-agency partnership and working

Interagency working
Although there is not yet any empirical evidence available to show the effect of the register on interagency working, there is a feeling that this will certainly be improved by using the EoLC register. The hospice is particularly keen to engage with the programme, and was one of the stakeholders who proposed Mid Essex becoming involved in the pilot. As an organisation not previously equipped with an N3 connection they have therefore had less direct access than other organisations to records stored by the PCT. In the course of the pilot, hospice services have been provided with an N3 enabled computer connection. Non-NHS organisations such as hospices are likely to benefit the most from data sharing such as this, as they are relatively independent and thus have little access to electronic data currently. Because of the nature of the institution the EoLC register is also likely to affect many, if not all, of the patients at the hospice and will therefore ease communications between the GPs, community matrons and nurses, whose work often overlaps.

One of the key benefits, in relation to interagency working, of having the register is that it allows all the healthcare professionals involved in a patient’s care to see which other healthcare professionals they have had contact with. This enables staff to start up a dialogue about the patient’s care directly with the others who are involved in caring for the patient.

_I would love to see more of a team approach rather than individuals working, not knowing what other people are doing. So instantly if you’re looking at a patient’s data you can see who else is involved … I think it will drive team involvement._

Mid Essex Project Lead

Stakeholder engagement
Prior to the pilot Mid Essex already had an EoLC stakeholder group which was itself part of the driving force behind implementing the pilot. However the pilot has highlighted how different stakeholders tend to work in parallel with each other rather than together. The pilot aims to change that culture and way of working.
As well as highlighting gaps in stakeholder engagement, there is also evidence that the pilot is beginning also to improve it, with stakeholder meetings providing a forum for discussion of EoLC within practices.

*Bringing the stakeholders together has generated some of the clinical discussions that also should help to drive change. Often they don’t have a forum where they can get together and discuss how they manage things at a practice level.*

Mid Essex Project Lead

Engagement of GPs was felt by other healthcare professionals to be a difficulty, with some seeing GPs as very focussed on the patient in front of them, but having difficulty in broadening this focus to proactively provide care for those patients under the umbrella of their service who may not currently require treatment.

*It is endemic in the GP system that there isn’t much proactive service. It’s very patient led; they wait for the patient to contact them.*

Mid Essex Hospice Manager

**Service user, carer and family experience**

One of the main objectives from the outset of the Mid Essex pilot has been to improve outcomes and experience for EoLC patients. One strand of this focuses on stretching targets for preferred place of death, with an eventual aim to have 40% of patients dying in their own homes (based on the current preferences for death at home expressed by up to 74 per cent of the population*). As Mid Essex is still in the process of developing the pilot and does not yet have results from the end-to-end process of patients on the register it is too early to see any outcome measures or influence on patient and carer experience.

Once of the key improvements noted by clinical staff at this stage is that the register is drawing attention to EoLC and to the decisions that may have been made by the patient around this. It has been noted that services are now proactively discussing the existence of documented wishes around their preferred priorities for care with patients.

*What this has done is get the ambulance service and others asking “Have you got preferred priorities for care?”*

Mid Essex Hospice Manager

However, there is hope that the register will smooth the process of death and dying for EoLC patients beyond just the preferred place of death. The development of a new hospital and consequent reduction in the number of available acute beds in the area has emphasised the

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need to reduce inappropriate hospital admissions. There is also hope that making the journey through care less difficult for patients will also have long term benefits for relatives and carers in terms of the help and support they require in the immediate aftermath and beyond.

There have been risks identified with the patient and carer experience of the register, not least the difficulty in explaining to patients that they are on the register.

*People don’t necessarily want to know they’re on an End of Life Care Register. We’ve called it Palliative and Supportive Care register. There’s some sensitivity in how that’s discussed with patients. The focus of the register is about being able to share the relevant information to enable support of that person’s care.*

Mid Essex Project Lead

The need for generalist staff to have the ‘difficult conversation’ with regards to preferences for death and EoLC with patients has been indentified as a key gap in learning locally, and the pilot has highlighted the need for this to be addressed. Improvement in this area will also contribute to the overall aim to improve the experience and outcome for service users.

Conclusions

- The main technical difficulty in Mid Essex has been enabling access to the Advanced Health & Care platform. This has been overcome by creating separate IP addresses for all users, but has taken a significant investment in time. However, encountering this problem in the pilot has allowed the team to prepare IP addresses in advance for any users joining the register from this point forwards.
- A mixture of clinical and IT input was felt to be essential for the project’s success, with a number of IT and clinical decisions needing to be made by a lead within the project. Having a named lead with final responsibility for making decisions, rather than making decisions through committee, is felt to be preferable.
- The pilot highlighted the lack of tools that those clinicians with generalist training have to deal with having the difficult End of Life Care conversation. This has been identified as the key area of training and support when rolling out the pilot.
- The geographic spread of the participating GPs in the pilot provide a network of champions to spread the usage of the register amongst other local practices. It is hoped that this will increase engagement among other GPs who can see the benefit already achieved in the pilot practices.
- The name End of Life Care Register has been identified as something that can make discussing the register with patients more difficult.
7e) Royal Marsden NHS Foundation Trust

Overview

Summary of pilot development

- Before the pilot started, Royal Marsden had spent almost 2 years developing an agreed data-set for their EoLC locality register in consultation with clinical staff in order to ensure uniformity and standardisation. Having reached an agreed data-set, the form was completed in hard copy and faxed between providers.

- A part time Band 7 Nurse was appointed to lead facilitation of the project. Throughout the implementation of the register the role of the facilitator has expanded to include ongoing support of trained users, attending GSF meetings in practices and liaising with other sites wishing to introduce registers.

- To ensure the register was scalable across all 31 PCTs, to support a pan-London approach, it was important to identify and engage all those who were going to be part of the pilot at an early stage. To achieve this, core implementation group meetings have been ongoing since the outset of the project. By meeting regularly, the pilot has developed very good working relationships with all stakeholders enabling all stakeholders to work through any issues constructively and effectively.

- Prior to the implementation of the electronic register, a pre-register audit was carried out on the forms that were filled in manually and faxed to the ambulance service and the out-of-hours team. By completing further audits after implementation of the electronic register the pilot will be able to compare the number of forms that were completed, the quality of the data and outcomes.

Starting point

Prior to the outset of the pilot project Royal Marsden had already made significant progress in the implementation of their End of Life register. They had identified the importance of creating a standard data-set to mitigate the difficulties that were caused across London resulting from the use of different palliative care forms in each trust.

The main problem is getting professionals to use standard forms. If you ask ten palliative care clinicians what the key data sets are there will be ten different datasets.

Royal Marsden Locality Register project lead

Consequently by the initiation of the pilot projects, in order to ensure uniformity and standardisation of forms, Royal Marsden had spent almost 2 years developing the data-set for their EoLC locality register. To achieve this they had consulted, and reached agreement...
with all clinical staff – namely GP Practices, Out-of-hours GPs, London Ambulance Service and Palliative Care consultants. Achieving consensus on the data-set for the PCR was one of the most difficult, and time consuming activities associated with the implementation of the Royal Marsden register.

Having reached an agreed data-set, the form was completed in hard copy and faxed between providers. However, as palliative care services are one of the few services that cross between acute Trust, community Trust and into the home, it remained very difficult to maintain the register across all the different healthcare providers or to know whether the information contained on a hard copy of the form was current. Therefore, as well as standardisation of the EoL data-set, Royal Marsden wanted to develop a contemporaneous electronic record so that if any changes were made to a patient’s preferences they could be automatically accessed by health care professionals, wherever they were in the community.

A seamless, standardised communication document that would be accessible 24/7 by all legitimate care providers, across all sectors of health and social care.

Royal Marsden Locality Register project lead

Aims and objectives
The over-riding aim of the Royal Marsden register is to improve identification and communication of information between health care providers in all settings to enable End of Life Care patients’ preferences to be achieved.

The more specific aims of the register, through which this over-riding aim will be achieved, are:

- to identify more patients approaching the end of life across all diagnoses;
- to discuss preferences and wishes with a higher proportion of these patients and record the outcome of discussions in a sharable format;
- to have a mechanism with which all out of hours services are alerted to end of life patients and have access to up to date information;
- to reduce hospital admissions and length of stay for end of life patients;
- to increase the number of patients at the end of life with a community do not resuscitate order in place appropriately;
- to increase the number of patients who have a preferred place of care and death documented; and
- to increase the number of patients who achieve their preferred place of care and death.
Approach

Initially, the pilot project aimed to use the Summary Care Record (SCR), once implemented, to hold the EoLC register. As an IT system in the process of being implemented, using the SCR to hold the register offered a number of benefits. Firstly, it was hoped that the register would have minimal financial implications for the Trust and secondly, as it is generated from processes which are already in place, it was anticipated that it would avoid duplication of work for health professionals completing the register's data-set.

In the interim, whilst waiting for the SCR to be rolled-out, the pilot planned to use a secure nhs.net e-mail based register. During this phase of implementation it was envisaged that each GP practice would have a secure central nhs.net email account as their nominated end of life register email address, and a key professional responsible for monitoring and updating records from this email address.

A number of risks and disadvantages of using the SCR to host the register were identified early in the pilot. Implementing the register through the SCR relied on a national roll-out, and the register was therefore at risk if the national roll-out did not occur. Additionally, it became apparent that the SCR was not deliverable within the time frame of the pilot and that reliance on it would significantly delay the implementation of the register. A further consideration was that the SCR did not support the reporting functionality that the pilot desired which could consequently jeopardize the aims of the project.

For these reasons, the pilot decided to explore alternative options. They consulted Advanced Health & Care (formerly Adastra) and designed a bespoke template for the electronic register based on the hard copy of the register that was already in use within the network (acute, and community services including the LAS and OOH GPs). The Advanced Health & Care register was to be hosted by Patient 24 (formerly Croydoc), Royal Marsden’s out-of-hours provider. However, even having developed an interim solution, the pilot intends that when the SCR comes online, if possible, it will integrate the register with the SCR. Advanced Health & Care has worked with Connecting for Health to achieve spine compliance and access to the SCR. Therefore, it may be possible to achieve integration with the SCR at a later date, whilst still using the current Advance health & Care system.
Development and Implementation

The affect of wider issues on the pilot

The register has been designed to ensure that it fulfils a number of Quality Markers developed to support implementation of the Department of Health’s End of Life Care Strategy across all health care providers, including some of the top ten quality markers for providers. However, the decision to incorporate these quality markers into the register’s data-set has required the register to undergo a paradigm shift. Due to the level of detailed and complex information that the Quality Markers require, the nature of the register has altered from that of a simple register to that of a managed care program. The impact of this shift is vast and is highly problematic in terms of clinical governance. It necessitates additional consideration of the roles and responsibilities in relation to the register, in particular whether administration staff should be authorized to enter complex clinical data onto the register and whether GPs, as they hold legal responsibility for patients in the community, should be responsible for entering, or at least verifying, all information entered onto the register by other clinical staff. These concerns have been partially mitigated by the implementation of closely controlled, high-quality training for everyone that uses the register.

As the implementation of an End of Life Care Locality Register is in itself a Quality Marker, other PCTs are keen to start developing their own solutions. This is problematic because as the London Ambulance Service is the only provider that covers all PCTs in London, there is a real risk that each PCT will request LAS staff to view their individual electronic register for their patients. Hence there could potentially be numerous web-links (i.e. one for every PCT) for LAS to view with each register having different formats for them to train and familiarise themselves with. This presents a clinical risk to patients if information is missed because LAS view the wrong register or are not familiar with it or if patients are on more than one register (hospice and GP are in different PCTs so might potentially have different registers) and the information on the two registers is not identical.

There is also concern that some potential register sites may view the process of setting up a register as relatively straight forward. This view is corroborated by system providers who are very accommodating and offer reassurances that they can meet any needs in terms of data-set. This approach to the register, however, views it as a data collection tool rather than a managed care tool which will result in a change in service provision. To prompt a change in service provision requires not only development of a data-set, but also years of designing the register and developing training modules to address some difficult issues such as the approach to consenting patients to the register. New register sites must be prepared for this involved process if they wish to achieve real improvements in patients’ End of Life Care.
Staffing
From the outset of the PCR project it was planned to appoint a part time band 7 Nurse to lead Facilitation of the project. The role of the lead facilitator was initially to implement the use of an e-mail based register, by visiting clinicians across the PCT, developing training materials and training dedicated key staff members at each location in accurate completion of the email registration form. However, throughout the implementation of the register the role of the facilitator has expanded to include ongoing support of trained users by attending practice GSF meetings to help identify appropriate patients to be entered onto the register, addressing numerous requests from other localities to present the register template and assist with their developments, as well as liaising with other sites wishing to introduce registers.

In the initial project plan appointment of the lead facilitator was due in September-November 2009. As has been the case in other pilot sites, however this appointment was delayed whilst waiting for approval of the job description by agenda for change and the appointment did not take place until April 2010. The role of facilitator has been critical to the successful implementation of the register. Future sites should not under-estimate the importance of facilitators’ experience of End of Life Care, communication skills, ability to persuade clinicians and resilience in coping with close scrutiny of the register. Due to the importance of the role it is essential that future sites employ a full time facilitator or establish a strong team who are able to commit dedicated time to implementing the register. It is not sufficient that the demanding responsibility of facilitating the register should be appended to an existing job role without the facilitator being given the resources to fulfil it.

The project needs a skilled facilitator to be able to communicate with all agencies, acknowledge their concerns and frustrations but still be able to present the benefits of the register to both them and to their patients.

Royal Marsden Locality Register lead facilitator

Training
It is important that future sites do not underestimate the potential risks that the register could pose to patients, both concerning data protection and clinical governance, if not implemented with due consideration. These considerations are particularly important if, as in Royal Marsden, the register holds relatively complex care planning information. To ensure that patients’ End of Life Care is safely managed it is the view of the pilot that the quality of training cannot be compromised.

The key to the success of entering patients onto the register is training. The training needs to include how to write a comprehensive care plan with current problems and
anticipated problems. Any other problem should be dealt with according to normal good clinical practice. Otherwise you might, for example, have a patient who has cancer of his prostate and is relatively well. Then he has a heart attack and because he is on the register no active treatment is given to him for his heart attack.

Royal Marsden Locality Register project lead

The Royal Marsden project's approach to training has been carefully developed and a number of training measures have been implemented to ensure that users are competent and confident in using the register, both immediately after training and over the longer term:

- Each care setting identifies a number of individuals who will have, via username and password, the authorisation to edit the register. These individuals are not provided with a username and password until they have been trained and the Lead facilitator is certain that they have attained the correct level of understanding and competency.
- Knowledge and interest in End of Life Care varies across different professionals and care settings. Training is therefore adapted to the audience in each care setting in order to address any specific concerns or frustrations that that particular group of clinicians may hold.
- After training, a site file is available at all GP practices and hospices. This includes a process map to using the register, an entry criteria checklist for the register and contact details (including central NHS email address) of the End of Life register team.
- Extra sessions are offered to cover annual and sick leave for GP practice and hospice staff expected to use the register.
- After training, the Lead Facilitator continues to provide ongoing training and support to users. This includes attending GSF meetings to help identify appropriate patients to be entered onto the register.

*Be prepared to put time, effort and money into training your users and supporting them once trained.*

Royal Marsden Locality Register lead facilitator

Impact on inter-agency partnership and working

Improvements

The Royal Marsden register has provided a number of improvements to inter-agency partnership and working within the PCT:

- The register will reduce duplication of work for health care professionals through improved communication. For example, if a health care professional based in the Acute trust begins to fill in a form that feeds into the register’s data-set, other health
care practitioners in the community will be able to see this information and the whole process will not be duplicated.

- It is the intention of the Royal Marsden project that after the pilot an amended register will be rolled out across London. This will improve inter-agency efficiency as, in circumstances where a patient is accessing health care services in more than one PCT, clinicians will not have to spend time identifying, and completing, the appropriate form because a single form will be used across all areas.

- In the same way that implementing the register has brought agencies together, the process of sharing information through the use of the register provides more opportunity and reason for interagency communication, not only about register-related matters but also in wider areas.

- Possibly the most important improvement in inter-agency communication that the register provides is the enhanced quality of the information that is accessible to clinicians across providers. Clinicians can be confident that the information that is provided by the register is accurate, contemporary and reliable. This high quality information is due not only to the ‘live’ nature of the register but also to the high quality of training and support that users receive.

**Stakeholder/partners engagement.**

*Use your stakeholders wisely - they can be your biggest allies if you have them on your side.*

**Royal Marsden Locality Register lead facilitator**

As the register is aiming to reduce duplication of work across the 31 London PCTs, it has been necessary to consider scalability very carefully when designing the register. To ensure the register is scalable it is important to identify and engage all those who are going to be part of the pilot at an early stage.

To achieve this, core implementation group meetings have been ongoing since the outset of the project. Initially the purpose of these meetings was to clearly define the information flow within the sector, for example, to map the process that LAS or out-of-hours services employed when they received a faxed handover form. This insight into the working practices of providers helped to ensure that the design of the register not only met the needs of all users, but also offered an improvement over the old system. These considerations make it more likely that the register will be used by these stakeholders and therefore more effective.
By meeting regularly, the pilot has developed very good working relationships with all stakeholders. Every time there has been a problem, these good working relationships have enabled the relevant agencies to work through the issues constructively and effectively. Regular meetings with stakeholders have also created a shared understanding of the aims of the register. Every agency that is involved in the pilot understands that the patient is at the centre of the pilot and that the whole idea is to improve the quality of patient care and the delivery of patient preferences. Those priorities are unarguable and this understanding makes it easier to sit down with stakeholders and to work through any issues.

Although engaging stakeholders in the development of the project has been successful, early in the pilot there was concern that engaging professional users who are not trained in palliative care would present the main barrier to implementation. It was noted that the uptake of the register could be affected if GPs, community health professionals and acute specialist doctors felt concerned about the sensitive conversations that surround asking a patient if they would like their information shared through the register. This concern was addressed in the register training programme. However, after the first workshop and demonstration of the register to a wider health care community in Sutton and Merton (which included GPs, users, acute hospital trust palliative care team and hospice representatives) this has not appeared to be a major problem.

Initially I was concerned at yet another form to complete but in fact it only takes a small amount of time to do and I believe it is an effective tool for all involved to understand the patient's preferences and needs.

CNS

There is a significant minority of professionals that will only buy into the register once they see that it is working, is more efficient than former processes, and is improving patient care. However, this will only be appreciated once there is a reasonable number of patients on the register and access by LAS and out-of-hours is regular. The need to achieve this ‘critical mass’ of patients on the register is paramount but has caused a delay in rolling out the training to professionals in other areas. This has been because facilitators have expanded their role to spend more time encouraging the addition of patients onto the register by attending GSF meetings and advising on patients who should be uploaded to the register.

Technical and IT developments

Technology platform
As discussed earlier, the pilot project initially aimed to use the Summary Care Record (SCR), once implemented, to hold the EoLC register. Using the SCR to hold the register offers a
number of benefits, including the minimisation of financial implications for the Trust and the avoidence of duplication of work for health professionals completing the register’s data-set.

However, a number of risks and disadvantages of using the SCR to host the register were identified early in the pilot, in particular, that the SCR was not deliverable within the time frame of the pilot and that reliance on it would significantly delay the implementation of the register. For these reasons, the pilot decided to explore alternative options.

The project lead looked at a range of different systems including EMIS, SystmOne and Advanced Health & Care. Advanced Health & Care was chosen because Advanced Health & Care covers 95 per cent of out-of-hours services across the country. That out-of-hours services have access to the electronic register is particularly critical as the majority of problematic deaths occur out-of-hours. The commonality of Advanced Health & Care in out-of-hours services means that, run on Advanced Health & Care, the EoLC register was easy to hybridise and “bolt-on” to the care provider’s Advanced Health & Care system. Consequently it enables End of Life Care information to be easily shared with the OOH service directly within the Advanced Health & Care call handling application. It also means that many system maintenance functions are already performed by the host service, reducing the administrative burden on EoL care teams.

**Technical issues**

The pilot has faced many small technical issues which were both difficult to anticipate and relatively time consuming to overcome. For example, when patients are consented to the register they are provided with a print out. There were certain fields which appeared on the register, for example expected date of death, which are not appropriate to appear on the hand out which is provided to the patient. In order to resolve this issue, filters had to be applied to the template. Many relatively minor technical details such as this have taken weeks and months, after the data-set was finalised, to resolve. It is therefore essential that sufficient leeway is built into the project plan to allow for these unanticipated issues and the amount of time and effort that can be required to overcome them.

*The amount of ongoing tweaking that has been necessary is actually very time-consuming. You need to have a good relationship with your IT provider.*

Royal Marsden Locality Register lead facilitator

**Administration rights**

Each person that gets trained is granted either viewing rights or editing rights. GPs and special palliative care teams have got the right to edit the register. Each practice identifies
GPs who will edit the register; they are trained, and once it is felt that they are competent they are given a username and password.

Each GP practice and hospice unit is asked to designate a named practice lead for the end of life register (including a deputy in case of annual leave/sick leave). The individual GPs will have responsibility for completing the EoL register for the patients under their care. However, in consultation with the users, it became evident that GPs would want or need their Gold Standard Framework admin supporters to be able to assist them with inputting data onto the register. This has been incorporated, whilst maintaining that the clinical information on the register is decided by the clinician.

The consensus from the wider health community in Sutton and Merton is that some GP practices may want to enter information directly onto the register themselves (by nominating an individual in the practice) while others may prefer sending the records to the register team via e-mail to do this for them. To minimise the risk relating to this, (potentially having more than one person entering information onto the register about a patient) training and information packs are being adapted and each person entering or viewing data will have their own individual PIN so that data entry is auditable. There is an audit trail of who’s been in and who has edited it.

**Patient consent**

GPs were generally very concerned about the way that patients are consented onto the register. This concern stems from GPs’ discomfort with the opt-out method by which the Summary Care Record was consented. The pilot has overcome this consenting issue by employing an opt-in approach whereby each patient is asked individually for explicit consent to be stored and share their information electronically. This consent is obtained by their clinician, GP or Clinical Nurse Specialist, usually at a face to face meeting or consultation. After the first question on the register which asks whether the patient consents, a second question is asked to override consent in the event that the clinician feels that doing so was in the best interests of the patient and/or the patient is deemed to have insufficient mental capacity to grant consent.

If patients consent to having their information on the register then it is added immediately. If they refuse, they are not entered. From the patients’ perspective, at the time of writing there have been no problems consenting patients to the register - all patients who have been asked have consented to join the register. Once the register is competed it automatically
generates a Microsoft Word document, excluding the filtered fields. Each patient is given a hard copy of this document to check if they wish to have one.

The most difficult obstacles in terms of consenting patients to the register have been the challenging issues surrounding identifying patients, as health care professionals, particularly those who are not trained in palliative care, can feel uncomfortable initiating the sensitive conversations surrounding End of Life Care. As the information required for the register's data set is very sensitive the patient may be upset or unwilling to discuss the issues and it is crucial that the clinician obtaining consent is supported and trained in these situations. Indeed, the pilot has shown that where clinicians were comfortable having these conversations, patients have welcomed the opportunity to be on the register.

**Reporting**

Extensive reporting functions have been developed which will enable continuous monitoring of outcome data including preferred place of death, actual place of death, variants and admissions to hospital. It will also be possible to monitor all patient demographics, and to assess whether these have any effect on outcomes.

Prior to the implementation of the electronic register, a pre-register audit was carried out on the forms that were filled in manually and faxed to the ambulance service and the out-of-hours team. By completing further audits after implementation of the electronic register, month by month the pilot will be able to compare the number of forms that were completed, the quality of the data and outcomes, such as whether more people will die at home, or fewer at hospital.

Prior to the implementation of the electronic register there was also an After Death Analysis (ADA) audit of Sutton and Merton. This measured the number of deaths in hospital and the number of deaths in homes and care homes. This data from before the implementation of the electronic register can be compared to how many people are choosing to die in each of the locations after the register was implemented.

**Service user, carer and family experience**

The Royal Marsden pilot site has identified a number of different areas in which patients and carers will benefit from the implementation of the register.
• Patients will get the right care that they've chosen, at the right time, delivered by the right person and they will be centre to making that decision. So it will decrease inappropriate crisis intervention.

• Families will be part of making those choices. Therefore, if their relative has a crisis, as long as their preferences are respected, the family will be prepared and know what to expect. It has been shown that this is very good for the patient's relatives in terms of their bereavement.

• It might be less burdensome for a carer because if they know the information has been shared correctly, they won't feel like they have to worry about speaking up for their loved ones when they are in a crisis situation. It helps carers communicate with health care professionals.

There are already some very positive anecdotal examples of how the register can help ensure that patients attain their end of life preferences.

_A daughter phoned LAS for an ambulance with a GP in attendance. Clinical support in LAS checked the register and said “did you know?” The phone was passed to the GP who didn’t know and concluded that the register details must have been entered by a colleague. Instead of an ambulance being called out, a district nurse was called out to manage pain and the patient died peacefully at home._

_Stakeholder_

To help support this anecdotal evidence of the register’s benefits and to inform the findings from the pre- and post-register audits, qualitative research will be undertaken in addition to the register audits. This research will be undertaken with health professionals who have consented patients onto the register, health professionals who have used the register in the out-of-hours setting and with patients and carers.

Conclusions

Key learning points

The key to the success of the register is a culture change. Changing a culture requires a major investment into training and feedback of clinical scenarios. In order to change the culture, plans have to be made and crises have to be avoided. In order to do this the project must be clinically driven. Every register needs a clinical champion. The technology is the easiest part of the managed care program. Simply put, the IT should be seen only as the enabler to the culture change of clinical care for End of Life Care patients.
The role the facilitator has been critical to the successful implementation of the register. Future sites should not under-estimate the importance of facilitators’ experience of End of Life Care, communication skills, ability to persuade clinicians and resilience in coping with close scrutiny of the register. Due to the importance of the role it is essential that future sites employ a full time facilitator or establish a strong team who are able to commit dedicated time to implementing the register.

The Royal Marsden pilot project made efforts to clearly define the information flow within and across the different services which used the paper version of the register. For example, the process that LAS or out-of-hours services employed when they received a faxed handover form was mapped. This insight into the working practices of providers helped to ensure that the design of the register, not only met the needs of all users, but also offered an improvement over the old system. These considerations make it more likely that the register will be used by these stakeholders and will therefore be more effective.

The pilot has faced many small technical issues which were both difficult to anticipate and relatively time-consuming to overcome. These issues took months to resolve after the data-set was finalised. Sufficient leeway must be built into project plans to allow for these unanticipated issues and the amount of time and effort that can be required to overcome them.

In order to ensure that the register would provide real improvements in patients’ End of Life Care, the Royal Marsden pilot project approached the development of the register as a managed care tool rather than merely a data collection tool. To prompt this change in service provision requires not only development of a data-set, but also long term input into designing the protocols surrounding the register’s usage and developing training modules to address some difficult issues such as the approach to consenting patients to the register. New register sites must be prepared for this involved process if they wish to achieve real improvements in patients’ End of Life Care.
7f) Salford PCT with Salford Royal NHS Foundation Trust

Summary of pilot development
The key points in the development of the pilot so far can be summarised as follows:

- Salford chose to base their locality register on a local bespoke electronic patient record, the Salford Integrated Record (SIR). This is primarily used to share information between GPs and acute care.
- All End of Life Care patients were to be added by GPs and other senior clinicians, with the acute services focussing on end stage Chronic Obstructive Pulmonary Disease patients in the early stages of implementation.
- A Business Information Analyst in order to map the information system processes in order to understand how the SIR can be extended to cover all services.
- As the SIR is unable to provide the required functionality at this point, Salford is currently implementing an electronic End of Life Care handover form, that links a number of district nursing teams and St. Ann’s Hospice with the respective GPs, GP End of Life Care and North West Ambulance Service.

Overview
Starting point
When NHS Salford submitted their Expression of Interest to be a pilot site for the End of Life Care Locality Register (June 2009), there was an existing central electronic patient record: the Salford Integrated Record (SIR). The SIR provides a shared access point to electronic patient data from GP and acute systems.

The SIR was designed to share information quickly between GPs and A&E, such as diabetes care. The SIR was not developed with any function for recording EoLC details.

However, NHS Salford felt that advance care planning in End of Life Care was increasing across the city, with all GP practices and around a third of nursing care homes already implementing the Gold Standards Framework (GSF) for EoLC and the use of GSF was developing well in the acute sector.
Approach

The roll out of the SIR was seen by NHS Salford as a potential platform to launch an EoLC locality register. With the data sharing and IT protocols already in place, the idea was to link the register directly with the SIR. This would be achieved by providing a specific module to sit within the wider data sharing framework. It was intended that the register would be rolled out across the entire Salford area for the pilot and would link all of the services involved in EoLC (acute care, community care, Hospices, out of hours services, the ambulance service and social care).

NHS Salford made the decision that all appropriate (palliative) patients in the community and hospice settings would be asked to consent to join the register. However, it was felt that this issue would be more complex within a large teaching hospital. The PCT, therefore, focussed the locality register on end stage Chronic Obstructive Pulmonary Disease (COPD) patients within the hospital. This patient group is perceived to have “a range of co-morbidities and unmet need, traditionally having had reduced access to high quality palliative and End of Life Care compared to cancer patients”.

We’re going to start it off with the COPD population to develop an effective model and see how we can get it working for them to start with. Within the community and the Hospice it will be all patients, particularly cancer patients in the early stages.

Salford Project Lead

Following the pilot the intention will be to roll out access to the register to all patients with “a life-limiting illness”, across all settings.

Part of the reason for focusing on this group of patients is the existence of a working group looking at EoLC for COPD patients with a particular emphasis on how to improve working relationships and develop cross-over between the services. This working group has become the basis for the locality register steering group. By utilising an existing forum Salford were able to ensure that they had a group of stakeholders with buy-in and committed time to sit as a clinical steering group for the locality register pilot. Whilst the clinical side of the project was driven by this group, the IT side of the project was progressed by a Business Information Analyst, appointed particularly for this role.

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8 NHS Salford Expression of Interest form for Department of Health & National End of Life Care programme End of Life Care Strategy Locality Registers Call for Test Sites
9 Ibid
Aims and Objectives

The principle aim of the Salford EoLC register pilot is to ensure patient choice in EoLC by providing up-to-date shared clinical and care information. The objectives identified by NHS Salford in order to achieve this can be split into organisational and end user objectives. Organisational objectives include:

- Supporting the NHS Salford and Salford Royal NHS Foundation Trust in ensuring delivery of best practice, and local, efficient and cost effective services to produce best outcomes;
- Ensuring that all services have a mechanism for recording patients’ preferences and choices, maintain this register and provide access to all relevant healthcare personnel; and
- Enabling collation of EoLC information for audit and evaluation purposes.

The key end user objective is to identify and engage key stakeholders as end users of the register. Key stakeholders include:

- GP practices
- Salford GP End of Life Care service
- District nurses (including evening/overnight service social workers included within the Integrated Care Teams)
- Community matrons
- Salford Care Homes Practice
- Chronic Obstructive Pulmonary Disease Assessment and Support Team (CAST)
- Hospital palliative care team
- Emergency medicine staff
- Community palliative care team
- North West Ambulance Service
- Social care

Strategically, linking with the SIR was useful, as senior buy-in had been secured for the roll-out of the SIR and could therefore be capitalised on.
Because our local integrated record has already got a well established board for the integrated record that currently exists, it has already got a board that has senior buy-in

Salford Project Lead

Technical and IT developments

Technology platform

NHS Salford originally planned to ‘piggy back’ the EoLC register onto the existing Salford Integrated Record. SIR is a local precursor to the SCR, allowing GPs and acute care to share information. There is hope that the locality register will be able to increase the scope of the SIR to share information between all the EoLC services (acute care, community care, Hospices, out of hours services, the ambulance service and social care) as opposed to simply between acute care (primarily A&E) and GP practices. No decision has been made on exactly how this will be achieved at the current time.

There is an awareness that specialist IT input is needed in order to map the full functionality of the local SIR. Whereas in other pilot sites the IT platform is managed externally, the Salford system is managed from within the PCT. That has meant that there is not enough understanding of the internal IT systems within the pilot team. It was identified at an early stage in the process that the capabilities of the current system needed to be mapped in order to assess the feasibility of developing the pilot model as intended. The mapping of the IT system involved looking at the ways in which each bit of the system was designed and interacted with other systems, looking at both the technical IT interfaces as well as how the system could work within the Information Governance policies of the Trust. The mapping process was also to assess the opportunity to extend the scope of the SIR, looking at possibilities for rolling this out to other services, such as the ambulance service.

I had very limited knowledge of how the IT systems work across boundaries from acute to primary care. So somebody needs to spend the time mapping that process

Salford Project Lead

Clinical staff hope that the functionality achieved in running the register alongside the SIR may indicate the possibility to do this with the SCR post full roll out also.

Technical issues

Due to the recognition of the need for specialist IT input for the mapping process, a Business Information Analyst has been appointed to work specifically on development of the EoLC locality register. The primary function of this role is to look at mapping the functions of the current systems in use and look at how these can support the locality register. A key aim is
to develop the reach of the SIR so that the community, hospice staff and social care staff can also have access to the register.

_We want the electronic record to be shared by people in the community, not just primary care, and we want it shared by the Hospice. We’re realising it’s not going to be as straightforward as we thought and there’s a lot of work the analyst has been doing over the last month or so, looking at the potential of SIR as a system itself, but realising it’s got its limitations_

Salford Project Lead

The process mapping of the SIR and other Trust IT systems has taken much longer than anticipated by the pilot team. The original plan was to capture all the data automatically in a master patient record, with the GP having a role as a ‘sanctioner’, with responsibility for approving information added or patients uploaded to the register. However, the system currently in place for the SIR is not able to support this function.

The temporary solution to this problem has been to reinstate a system whereby requests for changes and additions to the register are sent by NHS Mail to GPs, thus requiring them to be the focus for all of the data entry to the locality register. This places the majority of the administrative burden on GPs, with the success of the register relying on GPs promptly updating the database with any new information received. Although this process does result in the electronic storing of the EoLC database information, the system of sending information to the patient’s GP does not represent a significant change to the current information sharing procedure.

Salford are currently continuing to populate the EoLC register manually and are searching for an automated process solution.

**Development and implementation**

**Staffing issues**

As mentioned in the previous section, NHS Salford have taken on a Business Information Analyst to assess the feasibility of the proposed approach and to project manage the IT elements of the project. This was primarily due to the decision to develop a platform for the EoLC register within the Trust. It was decided early in the project that this would be a critical role and would require someone with ring-fenced time dedicated to working on the project.

Initially there were attempts to find an internal IT secondee to the project, as this would ensure that the candidate had relevant knowledge of NHS computer systems in general and
NHS Salford computer systems specifically. However, there was no resource available to be seconded to the project, and a job advertisement within the NHS did not draw any suitable applicants. It was suggested that this may have been partly because the post offered was part-time, but required a skilled individual with knowledge of NHS IT systems.

In order to comply with NHS and Trust recruitment policies it was necessary to fully explore the internal and secondment routes before approaching an agency to locate a suitable candidate. Although this approach did prove to be successful, with a Business Information Analyst with NHS experience being recruited for the role, the lengthy recruitment process delayed the ability of NHS Salford to start working on the register by approximately nine months.

*Because it took us a long time to recruit an analyst, I think that it [the project] was losing a little bit of steam.*

**Salford Project Lead**

Training

As in other pilot sites, the key training issue has been identified as communication and advance care planning, rather than training in the processes and IT systems introduced for the pilot. This is particularly the case in Salford, where the IT element of the project has been based on a system already in use.

Training in advance care planning and communication has been in place in Salford for some time with a combined acute and community End of Life Care training programme.

*Salford has had a cross boundary training programme for End of Life Care for a couple of years now, so the hospital, community, and hospice have a shared education programme where people come and learn all aspects of End of Life Care, including communications and advance care planning*

**Salford Project Lead**

The pilot is seen as another way to enhance the dissemination of advance care planning and patient communication around EoLC. By focusing the pilot on a cohort of patients other than traditionally well-provided-for cancer patients, Salford is hoping to increase the contact between generalist healthcare professionals responsible for the care of these patients (such as GPs) and specialist healthcare professionals, such as palliative care consultants.

*We are encouraging our providers to do a lot of work around communication skills with non-cancer healthcare professionals to try and engage them in advance care planning, and it’s one of the reasons why we chose the COPD cohort of patients … I think we’re going to learn a lot from working with specialists in long term conditions.*
We're trying to develop a model to extend it to other conditions such as heart failure and renal failure

Salford Project Lead

Administration rights
The discussion around administration rights revolved, as for other pilots, around the right to view and edit the record versus the ‘ownership’ of the record. Viewing and inputting data is seen as a function that should be able to be performed by any healthcare professional involved in the care of the patient, acknowledging that not only the GP can have an in-depth knowledge of them. The ownership or ultimate responsibility for the record, however, does still lie with the patient’s GP.

In order to ensure that the GP is confident in the record that they own, it was decided initially that a GP ‘sanction’ would be added to the system. This would entail any patient or data added to the record by someone other than the GP being available to view to other users but with a flag to indicate that this information had not yet been validated by the GP. This would allow healthcare professionals to see information soon after it has been added, and also to see whether or not it has been approved by the GP. In order for the information to be approved, a warning would be sent to the GP flagging the addition of a patient or patient data to the register.

There is a list of people who are on the register and a list of people who are pending, but that information is still stored and seen, but obviously there’s a wait until the GP accepts it

Salford Project Lead

However, due to the changes in data process necessitated by the SIR not being able to provide the functionality and interface that the register requires, all data must currently be entered by GPs themselves. Should this issue be resolved and automated the intention is to add a GP sanction flag to the record which will work as described above.

Patient consent
Using an existing system within the Trust on which to base the register meant that most consent and information governance structures were already in place.

If it’s completely linked into the SIR then those issues have already been covered. But we’re not sure if it is going to link in completely

Salford Project Lead

However consent is still an important feature of the register. Opt-in consent is seen as an approach that will encourage healthcare professionals to have a conversation with patients
about joining the register which should lead to discussions around advance care planning. This is felt in itself to be an important part of encouraging a cultural shift that will result in GPs feeling more confident in having the difficult conversation with their patients.

_We want [consent] to be very much a feature of it because we want more people to talk to patients when they're thinking about things such as advance care planning and that they are in the last 6 to 12 months of life, we feel that conversation should, as far as possible, be had with patients._

_Salford Project Lead_

**Functionality**

A key function of the EoLC register is to alert healthcare professionals to the fact that the patient is thought to be in the last year of life and consequently to signpost healthcare professionals to their advance care plan. It is envisaged that anyone who comes into contact with patients on the register will be be able to access details about care, treatment and preferences/choices made by the patient.

_ I think a feature of the register would be shared access to the fact that somebody has got an advance care plan._

_Salford Project Lead_

Although the register has not yet been implemented to the stage where reporting can take place, reporting is another important potential function of the Salford register. It was initially hoped that using the SIR would allow dashboard-style reporting of EoLC records, with the ability to drill down to different levels of disaggregation, thus being able to look at the performance of individual GP practices as well as PCT-wide data.

_What I'm hoping for is that the locality register for Salford will allow the extraction of data and reports … we know the numbers who go on the registers within individual GP practices is far too low. Compared to the number of people who die, it is miniscule, so we want to monitor the number of people going on the register compared with the number of monthly deaths_.

_Salford Project Lead_

Although this would be useful in terms of monitoring outputs from the register, currently the analysis of read codes used in patient records from the SIR does not allow the reporting function to drill down to EoLC patients only.

However, there is hope that the register will be of help in positively influencing and measuring the impact on:
• Hospital admission rates of those who die within a few days of admission to hospital;
• Number of hospital or A&E attendances of those from care homes; and
• Number of patients who are placed on the Liverpool Care Pathway, either in hospital or in the community.

The locality register does have a function in its own right as an electronic database for healthcare professionals to share up-to-date information about their EoLC patients. However, it is also a tool within a proposed NHS Salford business case for trying to reduce the burden on unscheduled care.

_The Register will be linked into a potential business case, separate from [the pilot], with the aim to reduce the spend on unscheduled care in the last year of life … We see the locality register as being as a key instrument in making it work._

_Salford Project Lead_

**Impact on inter-agency partnership and working**

_Interagency working_

Alongside the SIR, which improves communication between Salford acute care and GP practices, the hospital and community trust were also moving towards vertical integration by April 2010. With this being planned for the middle of the pilot period, interagency working was already a focus for the Trust, allowing the locality register pilot to sit well within this.

_Hospital and community trusts are merging, with vertical integration in April, so they're increasingly working together in all aspects of care provision._

_Salford Project Lead_

The pilot is felt to be positive for interagency working because its success relies on all the services working together to develop it. The pilot lead comments that with no single service dominating the multi-service field of EoLC, it is an ideal opportunity to develop a scheme that links all the services together. One of the primary reasons is that all services will benefit from the creation of the register, as well as seeing a benefit to their own patients.

_Because we're facing the issue together, at the same time, our working relationships can only improve … We all want it to work for the benefit of the patient._

_Salford Project Lead_

The pilot team feels it is particularly important that the ambulance service is engaged with the project, as issues go well beyond the boundaries of the PCT. Having the ambulance service involved at this early stage bodes well for the potential future roll out of the register.
Service user, carer and family experience

It is too early currently to be able to see any direct patient experience benefit from the Salford locality register. However clinicians are hopeful that the register will reduce the burden on patients at a difficult time by allowing information to be shared. Recording and sharing this information will prevent the patient from having to undergo a potentially difficult conversation on more than one occasion and will allow healthcare professionals to ensure that their wishes are met wherever possible.

*We hope the benefits will be that patient information is used sensitively to help them get what they want and to try and make sure their choices are listened to*

Salford Project Lead

Although there are currently no opinions or outcome measures available from those who have used the register the idea of the register itself has been discussed with a patient user group at the Trust and has met with a positive reception.

*We have an effective local patient/user group. We’ve shared with them the idea of a locality register and they all think it’s a good idea*

Salford Project Lead

Although the register is not currently in a position to be assessed by measuring patient experience there is an awareness that this is something that needs to be considered. The Salford pilot lead is keen to ensure that as well as recording outcome measures from the locality register, patient views are also sought.

*We need to give more thought to measuring [patient experience]. It’s a complicated area, because you are working with a vulnerable group of people who are in the last phase of life, but it is something we want to do*

Salford Project Lead

Key learnings

- The process of exploring the feasibility of a bespoke local system can take a lot longer than expected. Both the hiring of qualified staff and the information mapping process were lengthy stages of the pilot for which Salford had not factored in the degree of time required.
- Linking the pilot to other PCT activities, such as the development of integrated working teams, ongoing development of SIR and established EoLC
community training programmes, has enabled Salford to keep a degree of momentum with the project, despite delays to the IT side of the project.
7g) Sandwell PCT

Overview

Summary of pilot development so far

The key points in the development of the pilot so far can be summarised as follows:

- Sandwell chose to extend an existing project and launch their register using SystmOne.
- The register has been rolled out to palliative care services and community services using the SystmOne template and the agreed minimum data set;
- Roll out to SystmOne GP Practices in Sandwell PCT commences in April 2011;
- The SystmOne implementation allows a status marker on the home page of a patient record and has a full reporting function for read code inputs;
- There is no evidence thus far as to the impact on patient and relative care, however in the future Sandwell plan to introduce an evaluation of patient care to monitor the progress of the pilot when fully implemented.

Starting point

At the time of application to become a pilot site, Sandwell PCT had already committed to an approach to create an integrated working system within palliative care. These initiatives already in place in Sandwell were:

- implementation of the Gold Standards Framework (GSF) across primary care;
- development and implementation of a supportive care pathway;
- establishment of a primary care liaison team working at the primary, community and acute services interface;
- Sandwell PCT and Sandwell Community Healthcare Service (SCHS) to all be signed up to SystmOne;
- piloting of active case management of a cohort of patients living with a long term condition by one of the Practice Based Commissioning Clusters (PBCCs); and
- implementation of a supportive care pathway by the local acute Trust including an electronic record of patient history.
Given the commitment in the Trust to working towards an electronic and integrated system of End of Life Care, the pilot opportunity was timely. Some of the projects described above were taking place in ‘silos’ and it was felt that the pilot would be a useful vehicle for rectifying this. The locality register pilot was a good opportunity to formalise all of the current objectives under one project umbrella and improve communication between services.

Approach

As mentioned, Sandwell already had a defined IT solution that they were working towards as a Trust, to implement SystmOne to provide integration across GP, out of hours, community, palliative care and child health. The acute trust would then be linked in via the national roll out of the Lorenzo system in 2011. This system enables electronic record management across all locations of care through the creation of secure virtual health networks offering secure connection between different professionals. The intention was to employ the dedicated palliative care module within SystmOne with an agreed cohort of patients for the pilot study.

Prior to the pilot, four Darzi care practices and four other GP practices had already migrated to SystmOne, along with child health services, and community services. There was also an anticipation that more GPs would migrate over during the course of the pilot if the benefits of an integrated system could be demonstrated.

As there were already many different initiatives in place in Sandwell, one of the key features of the pilot was to be able to join all of these work streams together. As such the pilot approach involved establishing a formal agreement between the main parties involved (the PCT, PBCCs, SCHS and the local acute trust), identifying and developing links between all of the existing work streams and setting up a project steering group to include the leads for each of the identified work streams.

Aims and Objectives

The principle aim of the Sandwell EoLC register pilot was to ensure the availability of an electronic register that is accessible to all relevant professionals and staff providing care and support to patients, their carers and families at the end stage of life. The objectives identified by Sandwell in order to achieve this include:

10 Sandwell Expression of Interest form for Department of Health & National End of Life Care programme End of Life Care Strategy Locality Registers Call for Test Sites
• the development of a real-time information system to share information between staff across primary, acute and community settings, including out of hours services and ambulance services;
• to support the delivery of high quality and equitable access to services; and
• to support the increase in the number of home deaths and the decrease in the number of inappropriate hospital admissions, with an increase in the number of patients who are able to exercise a choice in their preferred place of care and death.

Technical and IT developments

Technology platform
As SystmOne was already in the process of being set up across Sandwell, the decision to use this system for the register was based on the current IT direction the Trust was taking. The initial pilot encompasses SystmOne community staff, palliative care staff and PCT staff.

The acute Trust is not to be introduced until a later date, when the national Lorenzo interface has been rolled out and the IT interface will be able to take place more smoothly. However due to the current changes in the structure of PCTs this part of the project has temporarily been put on hold.

At the start of the pilot the technical infrastructure was already in place, with PCs with an N3 connection already installed in all the services in which the pilot was to run.

As the IT platform is hosted by SystmOne, community and palliative care staff can be provided with a laptop and 3G ‘dongle’, thus enabling them to have real time access to clinical records whilst completing patient visits.

Technology issues
The roll out of the IT infrastructure has been very smooth in Sandwell. This is largely because Sandwell chose to use an adapted platform that they had already begun to roll out prior to the start of the pilot. The main challenge encountered was to ensure that network service coverage was available for palliative care and community staff connecting to the server using 3G ‘dongles’. Coverage and connectivity for wireless connections is obviously not something the PCT is able to resolve. Rather it is something that community and palliative care staff need to be aware of and work around.
Data sets
Sandwell have used the SystmOne palliative care template and combined this with the minimum dataset agreed among the pilot sites. The data set records details such as the patient’s carer, next of kin, preferred place of death, medication and primary and secondary diagnosis. This information can also be linked to the patient’s ethnicity and religious beliefs.

The data set has been divided into three separate sections, with templates created for each. These templates are:

- End of Life details
- Details of death
- Bereavement template

Development and implementation

Staffing
The Sandwell pilot lead has been appointed specifically as the lead for the implementation of the palliative care module. Sandwell is the only pilot to run with an IT lead rather than someone from a clinical, commissioning or governance background. Although this works well from an IT systems and project management point of view, it was also noted that clinical involvement would add value. In light of this, a palliative care consultant was taken on for 2 days a week to work for Sandwell PCT and to link into the project. Although this was not felt to be enough time it helped to ensure clinical engagement and provided a bridge between clinical staff wanting a solution adaptable for all situations they would encounter and the need to fit this within the strictures of the IT system and the processes and procedures of information governance.

Training
Ten days of training on the use of the IT system has been provided for community staff by the SystmOne contractor. No other training has taken place at this stage.

Administration rights
Administration rights have been divided with different staff taking on responsibilities for different services. Nurse prescribers have administrative rights for all nursing staff, with two specialist nurses having administrative rights for all services. This will be reviewed as the pilot is rolled out to further services.
Patient consent
An opt-in approach to patient consent has been agreed. This is recorded by the provision of a tick box on the patient record to log that patient consent has been obtained.

Functionality
The Sandwell register will be able to provide real time information to staff in the care setting in which they work. Patient records within the SystmOne system display status markers on the front page of the record – represented by a pair of scales – indicating to staff that an EoLC record is stored for that patient.

SystmOne also offers a reporting function. Only the read codes entered can be reported on and not the free text field, although this still encompasses around 75-80% of the record. This will allow Sandwell PCT to monitor preferred place of care or death and actual place of care or death – along with being able to gather details of care and death to monitor changes in outcomes following the introduction of the pilot.

Impact on inter-agency partnership and working

Interagency working
The Sandwell pilot was designed to aid and develop interagency working. One of the specific aims was to use the pilot to draw together several independent work streams, all of which have contributed to the way that the pilot is running. Even at an early operational stage there is anecdotal evidence that the register is improving the relationship between GPs and palliative care staff by improving communication and creating a shared vision. GPs are now also aware at a much earlier stage that patients have been referred to palliative care. Previously it could take up to two weeks for the information to be transferred and the quicker update of information is helping the teams work together much more effectively.

Stakeholder Engagement
There was a lot of work upfront to show stakeholders how the pilot would work and why it could be successful. This investment was crucial and has helped to get stakeholders onboard, engaged and supportive of the pilot. The only issue has been trying to get busy clinical stakeholders to input and buy-in to the project. This difficulty is attributed to the fact that the pilot site was initially launched with an IT lead rather than a clinical lead. The pilot lead needs authority to implement changes, which was to come from the clinical steering group. However, clinicians have many and varied ideas about how the pilot and register
should function, and the pilot lead found that it is difficult to get the clinicians to all meet and talk through their ideas in a timely manner.

Despite some initial difficulties stakeholders are generally engaged with the project, particularly as it advances other projects already underway and which they were already invested in working on.

**Service user, carer and family experience**

There is little data with regard to patient experience from the Sandwell pilot at this stage. However there is hope that having patient information recorded will reduce the number of incidences where patients are asked about their EoLC preferences as the information will be recorded and shared. It is also felt that the register will set expectations that preferences for EoLC are recorded routinely, thus increasing the number of healthcare professionals who raise the issue.

Sandwell plan to conduct a patient survey to measure the experience that patients have with palliative care teams. They will track this information to measure patient experience throughout and after the life of the pilot.

**Conclusions**

- Sandwell is the only pilot to take an IT-led approach. Their experience has highlighted the importance of having clinical input as it has proved difficult for a non-clinical lead to engage the clinical stakeholders in decision making in a timely manner aligned with the timescales of the project.
- The Sandwell pilot has improved partnership working between GPs and palliative care staff. The register allows information about patients to be shared smoothly, in real-time.
- By choosing to adapt a pre-existing platform the IT development has been fairly unproblematic.
- Community and palliative care staff can use wireless technology to access the register when they are out in the field. However, there are localities where connectivity is poor or non-existent. This is beyond the control of the PCT. It is therefore important that community staff are aware of this and if possible anticipate connectivity issues.
7h) Weston Area Health Trust and NHS South West

Overview

Summary of pilot development

- The South West register is designed to capture information about the end of life care needs and wishes of individual patients that healthcare professionals can access on a 24 hour basis.

- The Advanced Health & Care system was selected to host the register as it was already being used for management of out of hours services within the NHS which meant that it had existing widespread accessibility and it had already undergone assurance in relation to clinical governance requirements.

- As part of the governance protocol developed for the roll-out of the project, designated levels of access to the register were agreed depending on health care professional group. In some localities GP practices have agreed to view only the records of patients from their own practice; in other areas all practice view the whole register. Out of hours GP services, and Ambulance control centres have access to the whole register and the information gives them access to a number of potential alerts.

- The extensive reporting functions which the South West register supports provide numbers and proportions of patients who achieve their end of life preferences in the locality. As of March 2011, of the 153 patients on the South West register who had died, in the Weston catchment, 116 were recorded as having achieved their preferred place of death and 32 had not. Of the 153 patients on the register who had died as of March 2011, 24% died in a care home, 42% at home, 21% in the hospice and 8% in hospital. Implementation of the End of Life Care Strategy, in particular advance care planning, is thought to be having an impact on the proportion of people dying in the community. However the majority of patients recorded on the register in the early stages are those known to the hospice and may be less likely to die in hospital than other groups.
Starting point

The End of Life Pathway Group which was formed as part of the Next Stage Review process in the South West set as one of their ambitions ‘the identification of the number of people with a plan for their death, and the proportion where preferred place of death was delivered’. The development of locality registers was felt to be the best way of achieving this. An End of Life Care Leads Group, facilitated by the clinical leads for End of Life Care and the Strategic Health Authority and including a membership of Primary Care Trust commissioners and local lead clinicians, was formed to take forward the end of life care agenda. The group agreed in February 2009 that a register should be developed and implemented on a region-wide basis. At the outset of the pilot the specification and data-set for the register had already been developed and shared with the End of Life Care Leads Group. The data-set consists of patient demographics, Advance Care Planning information, contact details and other relevant information including:

- Consent to share
- Key worker details
- Advance Care Planning document status
- Diagnosis and complications
- Secondary diagnoses
- Resuscitation status (and whether this has been discussed with the patient)
- Preferred place of death
- Actual place of death
- Variance reason (if applicable)

Having established the data-set, the aim of the pilot project was to implement the electronic end of life register across the South West.

Approach

The End of Life Care Register was due to be piloted and implemented across the South West during 2009/10. Advanced Health & Care (formerly Adastra) was chosen to support the register to enable organisations to implement and monitor End of Life Care objectives quickly.

However the pilot project and Advance Health & Care were also concerned to ensure that, if and when the SCR reached a suitable level of functionality, data transfer links would allow effective integration, or data transfer, between the two systems.
The implementation programme followed a staged approach. The register was initially
developed in Somerset and North Somerset, and was trialled in sample hospitals, GP
practices, Ambulance centres and hospices in this locality.

In the second phase of implementation, once the dataset and software had been revised
following feedback from the test sites, a phased pilot roll out was initiated across the South
West. Sharing of local experience and practice was crucial to the implementation, with
feedback learning from the early sites contributing to the implementation in subsequent
localities.

Aims and objectives

The Register is central to the delivery of the End of Life Care Strategy in the South West.
The aim of the project was to implement a system, across the region, which would:

- Be accessible to all professionals involved in End of Life Care on a 24 hour basis;
- Allow recording of advance care plans, including preferred place of death, resuscitation wishes and medication requirements;
- Ensure all key information was ‘live’ and available to be use in emergencies, in and out of hours;
- Record details including key-worker and use of the Liverpool Care Pathway;
- Form the basis for Gold Standards Framework meetings in primary care;
- Allow continuous audit of all of the above, demonstrating whether ambitions round
the place of death, care planning, and other strategic objectives have been met for all
patients approaching the end of life in the south west.

Three questions are being tested in the full pilot to ensure that the register is suitably
designed to meet the above aims:

- Has the register been designed to fulfil its function?
- Is the register practical and fully usable by all organisations?
- How does the register affect and improve clinical practice and outcomes?
Technical and IT developments

Technology platform

The Advanced Health & Care system was selected to host the register as it offered a number of distinct advantages:

- It was already embedded within the NHS and had widespread accessibility. It was easy to use and, as health care professionals were already familiar with it, there was potential for reduced training requirements and speedier implementation;
- The system was a clinical one, and has already undergone scrutiny in the context of the Data Protection Act and Caldicott guidelines.
- Patient demographics were already part of the existing Advanced Health & Care System, which allowed some time-savings for clinicians using the register where patients were already known to out of hours services.

Advanced Health & Care is accessible via N3 or ADSL connection to ambulance services, out of hours GP services, GP practices, hospitals including A&E departments, and community nursing teams. A programme of NHS connectivity for hospices is being developed. Some hospices already have an N3 connection and are therefore already able to access the Advanced Health & Care system. Where this is not available, the plan is to develop an ADSL connection to the NHS.

All Primary Care Trusts except for Dorset/Bournemouth & Poole are currently using or implementing the Advanced Health and Care register. The register has been loaded on to the five out-of-hours hubs that cover the whole of NHS South West. Individual service configuration is the responsibility of local Primary Care Trusts, but joint protocols and purchasing arrangements are being shared across the region.

An IT Project Manager was seconded into the project to support implementation and this role has been crucial in supporting and enabling the full implementation of the programme.

Technical issues

It is particularly critical that out-of-hours services have access to the electronic register. To ensure this, all stakeholders worked together to ensure a direct route via one username and password from the desktop so that all users could access the End of Life Care Register via N3.
The Ambulance Services can access the system but do not currently have a direct automatic link. A workflow process has been agreed between Great Western Ambulance Service and Advanced Health & Care to enable all GWAS staff to identify patients on the End of Life Care Register. Clinical alerts can be added to the Ambulance Service internal IT system so that any advance care planning decisions can be recorded. When a 999 call is made from a patient’s address their wishes, or the fact that there is an end of life care plan in place, is shared with the attending crew so that their wishes can be identified and respected. This information must currently be sent or faxed to the Ambulance Service. Work to develop automatic links between the register and both Great Western Ambulance Service NHS Trust and South Western Ambulance Service NHS Foundation Trust systems is underway.

**Development and Implementation**

**Training**

The electronic end of life register needs to be accessible and usable to ensure uptake among clinicians, which is crucial to the success of the system. Therefore care has been taken to ensure that the electronic end of life register is a simple, intuitive system which is easy to use. While use of the system is self explanatory, the South West pilot identifies two components necessary for successful implementation. These are (i) establishing it as part of the normal patient management and review process, and (ii) integration of training in the use of the register with dedicated training around advance care planning, and the sensitive conversations with patients approaching the end of life and their families and carers. The register is simply a system which will enable people to carry out their existing role more effectively; the organisational development change required is often around the way in which people approaching the end of life are identified and managed.

The roll out of the register has been supported by educational initiatives across the South West for all health care users. This has been an integral part of the project planning and each Primary Care Trust has identified an element of the multi-professional education and training budget for End of Life Care to support implementation and roll out of the register. Training typically consists of awareness training sessions for all practices and community nurses, followed by practice based training in the use of the system. Specialist Palliative Care Nurses and matrons are also a key audience.

*Do not be disillusioned by how long this all takes and the amount of teaching and support required for the introduction and continuing support.*

**Lead Nurse**
Administration rights
Access to the South West End of Life Care Register is via Advanced Health & Care, which in most cases is the health care professional's existing clinical system. In circumstances where the health care professional cannot access the Advanced Health & Care system, access to the register may be via an N3 connection. In both these cases access is governed by username and password. Using these access routes, a large variety of health care professionals can access and update the register:

- GPs and GP surgeries;
- District nurses, community matrons, specialist nurses;
- Hospitals – especially A&E departments;
- Hospices who have access to N3 – either directly or via Citrix software;
- Ambulance services;
- End of Life Care co-ordination centres.

This list may be expanded in future phases of the implementation.

One of the biggest challenges in End of Life Care is ensuring that non-cancer patients with terminal disease have access to the same level of services as cancer patients, with the choice to die at home if they wish. It is therefore important that it is possible for community matrons to enter patients on the register. The greater proportion of their caseload is non-cancer patients, and use of the register will therefore help to widen the scope of the register. In addition, specialist non-cancer nurses in hospital and community settings, particularly for heart failure and chronic respiratory disease, are important in promoting the use of the register, as are End of Life Care co-ordination centres where these exist.

As part of the governance protocol developed for the roll-out of the project, designated levels of access to the register are agreed depending on health care professional group and their needs.

Information accuracy is part of ensuring the successful roll out of the register. The register has been designed so that the key worker, who is identified as the health care professional who has the prime relationship with the patient, is responsible for advance care planning. This person is also responsible for entering the advance care plans onto the register and
completing the after death information for their patients. It is also the responsibility of the patient’s key worker to ensure that the patient’s details are as accurate and as up to date as possible. However it is also recognised that the key-worker can change over time, and that they are part of a multi-disciplinary team, and that the whole team has a responsibility at different times to view and ensure that the record is accurate and up to date.

Where a patient changes their preferences at the end of life, or there is a significant change in their circumstances, it is important to ensure that this is reflected in the patient’s advance care planning documentation, patient held paper record of their advance care planning preferences and the electronic End of Life Care Register. Although the electronic end of life register is very important in enabling the communication of key information between professions and organisations, and prompt consideration of the patient’s expressed wishes, it does not replace the patient’s individual advance care planning document. Therefore it is essential that in the absence of the patient’s verbal decision, the patient held paper record of their advance care planning preferences, and other advance care planning documentation, is the overriding record of the patient’s wishes. Health professionals should always ensure that the patient held record is checked and that any action is a reflection of the decisions made in this document.

Patient consent
Patient consent is an important issue which has been carefully considered as part of the project as it was identified early on as an area of concern. The project has tackled this issue by including consent for information sharing in advance planning documentation. Each patient is asked if they consent to their advance wishes being shared with appropriate health care professionals. Patient consent must be gained before they can be added to the electronic End of Life Care Register. This consent is given verbally, after which patients are provided with a patient information leaflet. No written consent is necessary from the patient.

It has been found that the vast majority of patients welcome the opportunity to discuss their options for end of life care and understand the importance of sharing this information between providers. Indeed, at the time of writing there had been no reported problems consenting patients to the register.

Patient consent is always obtained. Nobody has refused so far as far as I am aware. They all think it is a good thing for out-of-hours staff to know about their condition and to have the information so they can be treated more quickly and effectively.

District Nurse
Where a patient does not give their consent to be added to the electronic register, it is important that the consequences of this are communicated to them. A further safeguard is that, once the patient demographics have been entered, the Register will not allow any further information to be entered if the patient has not given consent. One challenge related to consent is the need to increase the number of non-cancer patients that are consented to onto the register. In March 2011, 23% (96) of the 411 patients on the North Somerset register were non-cancer patients, an increase of 5% on December 2010. The majority of non-cancer patients had chronic lung disease, dementia or heart disease. As discussed above, it is important to encourage community matrons to consent patients onto the register as the greater proportion of their caseload is non cancer patients. In addition, specialist non-cancer nurses in hospital and community settings, particularly for heart failure and chronic respiratory disease should be encouraged in their use of the register.

**Reporting**

Extensive reporting functions have been developed which allow users to interrogate the system to provide a range of important information. The key measures include:

- The number of people on the register;
- The number of people who have completed advanced care planning;
- The number of people who achieve their plan;

Secondary outcomes include:

- The reasons for advance care plan/preferred place of death not being achieved;
- The number of people who were not on the register (diagnosis is recorded on the register- if disease specific number of deaths are compared to population figures it is expected to be possible to calculate how many people die who are not recorded on the register);
- Use of the register in GP surgeries and as part of palliative care meetings.

Since the register has been in use it has been possible to run reports to monitor activity. Figures are planned to be produced quarterly. These reporting functions make an excellent audit tool. The South West pilot is able to feed back to individual PCTs how well the register is being used. This information is likely to be of great use to commissioners to inform improvements to local palliative care services. If, for example, people do not achieve their
preference because of a lack of community care, the commissioner will know where they can act to improve matters. In addition to this kind of reporting the South West pilot is hoping to explore further aspects of the register’s usage including how many people with chronic diseases die who are not on the register.

**Impact on inter-agency partnership and working**

**Stakeholder engagement**

Prior to the implementation of the register, palliative care services across the South West were well established. By implementing the register in consultation with clinicians, the project has secured enthusiasm from specialist palliative care teams.

* [A key milestone has been] the gradual knowledge and acceptance of the register and its aims by health professionals and an increased awareness of the principles of advanced care planning.*

**Lead Nurse**

Each PCT within the South West signs up to the EoLC register individually. This means that the responsibility for each register sits with the PCT and the project is answerable to the PCT board. The pilot project has aimed to be as helpful as possible to support full implementation. At the time of writing, 12 of the 14 PCTs within the South West SHA were signed up to use the EoLC register, covering approximately 4.2 million population. This growing usage of the register across the SHA has further enhanced the communication benefits, ensuring co-ordination around the development, implementation, and audit of advance care plans.

Regional and local stakeholders review progress and future direction of the implementation, discuss concerns and keep all stakeholders abreast of developments. The regional End of Life Care leads group includes End of Life Care commissioning leads and the lead clinician for each PCT. It meets quarterly and is used to share news of progress and how successfully each area is using the register. IT leads and, where applicable, project leads from the PCTs are also linked. A dedicated website, hosted by the Strategic Health Authority, has been set up to support implementation.

The SHA seconded an IT specialist to the project and they have been crucial to supporting the implementation across the South West. After the initial trial, the IT project manager met with stakeholders in all localities to demonstrate the revised EoL Care Register. She has worked with all major stakeholders and project teams across the 14 PCTs, facilitating
implementation, producing guidance documentation, liaising with Advanced Health and Care, and in particular with the Ambulance Services, and resolving issues – both general and technical – as they arose. This role has been a strong driver for the implementation and success of the project.

**Service user, carer and family experience**
The extensive reporting functions which the South West register supports will provide a good overview of success in supporting patients to achieve their end of life preferences. There are a large variety of reasons for patients not achieving their preferred place of death but the most common reasons recorded in the data produced so far were admission to hospital with an acute problem (e.g. fit, fractured hip, dyspnoea), the patient becoming too ill to move, or the patient’s register entry not stating a preferred place of death.

**Conclusions**
**Key findings**
It is important to note that the implementation of the register is still at a relatively early stage, even in the first phase localities. It has been live for just over a year in these areas, and it will take time and continued effort to gain full coverage, commitment and regular use of the register across primary, secondary and community sectors. Some key findings and learning points from the use of the register so far include:

- **The electronic end of life register needs to be accessible and usable to ensure that uptake among clinicians is optimal.** The pilot identified two components necessary for the successful implementation of the register: (i) establishing it as part of the normal patient management and review process, and (ii) **integration of training in the use of the register with dedicated training around advance care planning.** There is a need for dedicated time for the essential underpinning training around the sensitive conversations relating to advance care planning.

- One of the biggest challenges in End of Life Care is ensuring that non-cancer patients with terminal disease have access to the same level of services as cancer patients, with the choice to die at home if they wish. The South West pilot project has made efforts to encourage health care professionals to consent non-cancer patients to the register. For example, specialist non-cancer nurses in hospital and community settings were approached to promote their participation in End of Life Care planning, including the use of the register. **In order to ensure patient equity, future sites should consider ways of encouraging health care professionals to consider consenting non-cancer patients to the register.**
• There is a need for dedicated project management to support implementation.
• The South West has made good use of the reporting functions that their register supports and will be producing figures quarterly. Through the SHA end of life leads forum and individually, the South West pilot is able to feed back these figures to the participating PCTs to give them some idea of how well the register is being used and to help them identify any need for additional training. **Future sites may also benefit from careful use of reporting functions and this should be a consideration when selecting the platform for their register.**
Appendices
Appendix 1: Palliative care templates

The template below lists the codes and order within the EMIS LV specialist palliative care template designed by the Brighton & Hove pilot site.

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Classification Code</th>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excep report: pal car qual ind</td>
<td></td>
<td>(9hB)</td>
<td>Prompt Age &amp; Sex Coded Subsets</td>
</tr>
<tr>
<td>ind: Pat uns</td>
<td></td>
<td>0-140</td>
<td>Exc pal care qual</td>
</tr>
<tr>
<td>ind: Inf dis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnic category - 2001 census</td>
<td></td>
<td>(9i)</td>
<td>British/mixed</td>
</tr>
<tr>
<td>British 2001cens)</td>
<td></td>
<td>(9i0)</td>
<td>Irish - ethn cat</td>
</tr>
<tr>
<td>2001 census)</td>
<td></td>
<td>(9i1)</td>
<td>Other White - eth</td>
</tr>
<tr>
<td>cat 2001cens)</td>
<td></td>
<td>(9i2)</td>
<td>White &amp;</td>
</tr>
<tr>
<td>BlackCaribbean 2001cens)</td>
<td></td>
<td>(9i3)</td>
<td>White &amp; Black</td>
</tr>
<tr>
<td>African 2001cens)</td>
<td></td>
<td>(9i4)</td>
<td>White &amp; Asian eth</td>
</tr>
<tr>
<td>cat 2001cens)</td>
<td></td>
<td>(9i5)</td>
<td>Other Mixed - eth</td>
</tr>
<tr>
<td>cat 2001cens)</td>
<td></td>
<td>(9i6)</td>
<td>Indian/Brit</td>
</tr>
<tr>
<td>Indian 2001cens)</td>
<td></td>
<td>(9i7)</td>
<td>Pakistani/Brit</td>
</tr>
<tr>
<td>Pakist 2001cens)</td>
<td></td>
<td>(9i8)</td>
<td>Bangladeshi/Brit</td>
</tr>
<tr>
<td>Bangl 2001cen)</td>
<td></td>
<td>(9i9)</td>
<td>Other Asian - eth</td>
</tr>
<tr>
<td>cat 2001cens)</td>
<td></td>
<td>(9iA)</td>
<td>Caribbean - eth cat</td>
</tr>
<tr>
<td>2001census)</td>
<td></td>
<td>(9iB)</td>
<td>African - ethn cat</td>
</tr>
<tr>
<td>2001 census)</td>
<td></td>
<td>(9iC)</td>
<td>Other Black - eth</td>
</tr>
</tbody>
</table>
(9iD) Chinese - ethn cat
(9iE) Other - ethn categ
(9iF) Ethn cat not stated

Form DS1500 completed (9EB5) 0-140
On gold stand pall care frame (8CM1) 0-140
Liverpool care pathway dying (8CM4) 0-140
Palliative care plan review (8CM3) 0-140
Specialist palliative care (8BAP) 0-140

Terminal care (8BA2) Specialist
(8BAP) Sp palltiv care
(8BAS) Sp palltiv care
(8BAT) Anticipatory
(8BAe)

Palliative treatment (8BJ1) 0-140
[V]Palliative care (ZV57C) 0-140
Terminal illness (1Z0) 0-140

Early stage

Patient aware of diagnosis (1H0) 0-140

Diagnosis

Patient not aware (1H0)

Family aware of diagnosis (1H2) 0-140

Diagnosis

Family not aware of (1H2)

Pref place death disc patient (8CN1) 0-140
Preferred place of death (94Z0) 0-140
| Preferred place of death: home | (94Z1) |
| Preferred place of death: hospice | (94Z2) |
| Pref pl of death: commty hosp | (94Z3) |
| Pref pl of death: hospital | (94Z4) |
| Pref pl of death: nursing home | (94Z5) |

| For resuscitation (1R0) | 0-140 |
| resuscitation (1R0) | |
| resuscitation (1R1) | Informing patient of diagnosis (67D0) | 0-140 |
| Informing relative of prognosis (67F1) | 0-140 |
| Issu palli care antici med box (8BMM) | 0-140 |
| LPA personal welfare (9W5) | 0-140 |
| Under care of team (9Nh) | 0-140 |

| Care team | |
| healthcare MDT | |
| resp team | |
| Under care of person (9NN) | 0-140 |
| attends (13G1) | |
| practice nurse | |
| Macmillan nurse | |
| Carer's details (9180) | 0-140 |
| Ref to palliative care service (8H7g) | 0-140 |

| care consult | |
| care (8H6A) | Refer for terminal |
| care (8H7L) | |
| care service | Ref to palliative |
| palliative care tm | Ref com spec |
Appendix 2: Core data set
<table>
<thead>
<tr>
<th>Record creation date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review date</td>
</tr>
<tr>
<td>Patient surname</td>
</tr>
<tr>
<td>Patient forenames</td>
</tr>
<tr>
<td>Date of Birth</td>
</tr>
<tr>
<td>NHS number</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>Disability</td>
</tr>
<tr>
<td>Patient address &amp; Tel no.</td>
</tr>
<tr>
<td>Carer details</td>
</tr>
<tr>
<td>Usual GP name</td>
</tr>
<tr>
<td>Practice details including phone &amp; fax</td>
</tr>
<tr>
<td>Key worker / contact details [containing details of all professionals involved]</td>
</tr>
<tr>
<td>Primary and secondary diagnoses</td>
</tr>
<tr>
<td>Is the carer and family aware of the above?</td>
</tr>
<tr>
<td>Other relevant issues</td>
</tr>
<tr>
<td>Allergies / adverse drug reactions</td>
</tr>
<tr>
<td>Current medications and doses</td>
</tr>
<tr>
<td>Anticipatory medicines / Just in case box completed and in patient's house / hospice</td>
</tr>
<tr>
<td>EoLC tool in use? (e.g. GSF, LCP, PPC, Kite etc)</td>
</tr>
<tr>
<td>Preferences for place of death</td>
</tr>
<tr>
<td>Has a DNACPR request been made?</td>
</tr>
<tr>
<td>Patient has Legal Advance Decision treatment refusal document</td>
</tr>
<tr>
<td>Has someone been given a lasting power of Attorney?</td>
</tr>
<tr>
<td>Contact number(s) concerning advance care planning and Lasting Power of Attorney</td>
</tr>
<tr>
<td>Who else would patient like involved in decisions (1)</td>
</tr>
<tr>
<td>Who else would patient like involved in decisions (2)</td>
</tr>
</tbody>
</table>