Case study database – Electronic Palliative Care Coordination Systems (EPaCCS)	
Title of case study	**EPaCCS Leeds**
The issue	Leeds had no consistent way of recording and sharing an individual's end of life care preferences, decisions and plans both within and across organisations. Most practices kept a folder of hand written forms for patients who were palliative (usually in the last few weeks of life). The forms were not shared and the majority would have been cancer patients. Our aim was to improve recognition of and shared decision-making with patients with palliative care needs and share those plans to enable them to achieve their care preferences.

Intervention chosen	EPaCCS templates have been developed within the clinical systems in use by key services providing palliative and end of life care across Leeds, primarily:
	• SystmOne
	• EMIS
	• PPM +
	
	Participating organisations:
	• Leeds Community Healthcare NHS Trust (LCHT)
	• Primary care
	  ○ Leeds South and East Clinical Commissioning Group
	  ○ Leeds North Clinical commissioning Group
	  ○ Leeds West Clinical Commissioning Group
	• Local care direct (out of hours GP service)
	• Leeds Teaching Hospitals NHS Trust (LTHT)
	• St Gemma's Hospice
	• Wheatfields Hospice, Sue Ryder
	
	The long term aim is to share end of life care information between clinical systems as part of a citywide Leeds Care Record project to integrate all electronic patient records (EPRs) and which adopts an implied consent model of sharing.
	
	EPaCCS information is shared across organisations using a single clinical system and shared electronic patient record (EPR) and EPaCCS template i.e. all SystmOne users**.** SystmOne users make up the majority of community and primary care providers in and out of hours. Clinicians involved in the patient's care can create an EPaCCS record, view a shared summary of end of life care information and write in the shared EPR. Clinicians with access to SystmOne EPaCCS include all community nursing and therapy teams, two Leeds hospice in-patient units and community teams, over 80% of GP practices and out of hours GP services.
	
	Primary care staff using EMIS have their own EPaCCS template so clinicians can create an EPaCCS record, view a summary and write in the

	record. However at present this information cannot be shared between clinical systems. As PPM+ underpins the citywide Leeds Care Record and is used in Leeds Teaching Hospitals. All users can potentially view EPaCCS information created within PPM+. EPaCCS within PPM+ is currently used by the hospital palliative care and oncology teams. All clinicians with write access to PPM+ can create an EPaCCS record; write access is granted on a role basis and includes clinical nurse specialists in addition to medical staff. There are plans for rollout across all hospital services in 2018 in tandem with the implementation of the Respect process (https://resus.org.uk/respect) Currently LTHT hospitals teams cannot view EPaCCS information recorded in SystmOne or EMIS and potentially there could be up to three EPaCCS records per patient. However options are being tested to enable wider sharing. Use in community settings: Currently EPaCCS is widely used and embedded in community settings and Leeds hospices. The EPaCCS templates include core content that meets the EPaCCS Information Standard SCCI 1580. An EPaCCS template can be initiated in a patient's record and updated by either the general practitioner (GP), a community nurse or therapist, or a member of a community/hospice inpatient palliative care team (medical and clinical nurse specialists). The record is then designed to be continually updated following any Advance Care Planning discussions with patients to ensure that wishes expressed on the system are relevant and up to date for a patient. Completion within community settings triggers inclusion of patients and review of their needs at GP palliative care multidisciplinary meetings. Across Leeds in 2016-17 approximately 33% of all patients who died had an EPaCCS record in place. System Reports: Quarterly reports are generated from SystmOne and EMIS on a GP practice, CCG and citywide level. Key information includes: • number of patients with palliative care needs identified • place of death • whether preferred place of death was achieved Data quality issues reflect the challenges of reporting from multiple templates and systems. They are however, in the process of being resolved to ensure information recorded by all SystmOne users is included and patients with EPaCCS records in both SystmOne and EMIS are not double counted. This is expected to be resolved by the end of 2017-18. The current data we have is thought to be under-reporting EPaCCS use. Leeds Community Healthcare NHS Trust uses information recorded within SystmOne EPaCCS to report monthly to commissioners how many patients known to integrated neighbourhood teams achieved their preferred place of death. In 2016-17: • 91% of patients had both place of death and preferred place of death recorded, and • 86% of these patients achieved their preferred place of death.

	In 2016-17 one CCG introduced an end of life care (EoLC) quality enhancement scheme. The EoLC lead is utilising the EoLC reports generated from EPaCCS to drive improvements within primary care, and has seen the most significant increase in identification of patients with palliative care needs.
How it was implemented	<u>Implementation</u> The EPaCCS project in Leeds was initiated as part of a Department of Health funded pilot in 2009– 2011 to support implementation within GP practices. This funding was approximately £40,000 and commissioners provided an additional £100,000. Initially, EPaCCS was trialled in four SystmOne GP practices and two hospices from 2011. A dedicated local team, representing relevant organisations, subsequently continued with the rollout of EPaCCS across Leeds with the additional support of project management from the Yorkshire and Humber Commissioning Support (YHCS) from August 2013. EPaCCS development was completed by 31 March 2015. From 2012 onwards EPaCCS was rolled out by an EPaCCS project team to the remaining SystmOne practices and GP out of hours services, followed by implementation in the city's EMIS Web practices. EPaCCS was implemented concurrently within community and hospices services by Leeds Community Healthcare NHS Trust and Leeds hospices, following implementation of SystmOne from 2010. The EPaCCS template was revised in line with changes to the Information Standard SCCI 1580 in 2015-2016 by a city-wide group consisting of hospital, hospice, community and primary care professionals, with CCG funded informatics support. Between 2011 and 2015 the rollout of EPaCCS to GP practices was led by a dedicated local project team with community, GP and hospital clinical representation and dedicated IT support, with additional project management support from August 2013. Implementation of EPaCCS was supported by GP practice based training across the city, delivered by the project team. At its peak in 2012-14 the EPaCCS project team comprised of: • GP lead 1 day/week • Community nursing lead 1-2 days/week • Acute nursing lead 1 day/week • IT CCG lead 3 days/week (ended October 2014) • Specialist Palliative Care consultant support • CCG project lead /admin from summer 2013 onwards <u>Maintenance</u> A city-wide palliative care informatics task and finish group was established in 2015 to provide an ongoing forum for reviewing EPaCCS and progressing wider sharing of information via the Leeds Care Record. The group reports to the newly established Leeds Palliative and End of Life Care Managed Clinical Network.

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Having EPaCCS in place enables clinicians to gather data about the population such as identification of people dying in their preferred place. In 2014-2015, the proportion of patients achieving their preferred place of death varied. When preferred place of death was to die:

at home, 65% of patients (431/664), died in their place of choice
in a hospice, 83% of patients (253/305) died in their place of choice
in a care and residential home, 92% of patients (207/225) died in their place of choice
in a hospital, 83% of patients (5/6) died in their place of choice

Additional data from EPaCCS records, were recorded, included:

when carer assessments were completed; this was identified as being completed at a median of 47 days prior to death (n = 61; range: 5–348 days)
when a key worker was assigned; this was identified as happening at a median of 25 days prior to death (n = 47; range: 1–754 days).

Since EPaCCS has been implemented there has been:

A significant increase in the numbers of patients identified as having palliative care needs (who have subsequently been included on EPaCCS) of 10-15%.
More patients have out of hours and DNACPR (do not attempt CPR) forms completed as a result.

A formal evaluation into of the use and impact of EPaCCS across the city (see ‘link to useful resources’) concluded that:

Sharing of patient information improves co-ordination of care, planning of care and anticipation of crises.
Palliative care meetings are more streamlined and effective, as a result of increased knowledge of patients needs and preferences.
GP practices are able to access evidence to satisfy QOF reporting requirements more easily.
Hospice and community services are able to report end of life care outcomes such as preferred place of death being achieved for patients known to their services.

In a comparison of annual CCG data from 2015-16 and 2016-17:
<table>
<tr><th>% of patients who</th><th>2015-16</th><th>2016-17</th></tr>
<tr><td>Had an EPaCCS record at time of death</td><td>27%</td><td>33%</td></tr>
<tr><td>Of these, had a preferred place of death recorded</td><td>65%</td><td>71%</td></tr>
<tr><td>And of these, died in their preferred place of death</td><td>78%</td><td>81%</td></tr>
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<td>Conditions for success</td>
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Technical and clinical involvement in EPaCCS development and reporting outcomes
City-wide approach to implementation of clinical systems and information sharing
Collaborative approach, supported by commissioners, to improving

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	palliative and end of life care
Learning from key challenges	The approach in Leeds represents a pragmatic and adaptive approach to sharing end of life care plans. The creation and sharing of EPaCCS records between organisations using SystmOne is well established. The city is now taking a new approach via the Leeds Care Record to further improve sharing of EPaCCS whilst avoiding the procurement of another IT system for professionals to use. <u>Key lessons learned</u> • Include informatics and clinical representation to support successful implementation • Support and funding from commissioners was key to early implementation of EPaCCS in Leeds • Align to other IT developments, such as the implementation of new clinical systems and ways of working • Implement across providers, working collaboratively to deliver care • Seek clinician feedback and include clinically useful information within EPaCCS, such as links and commonly used documents, to maximise use • Explore reporting improvements e.g. electronic GP palliative care registers linked to EPaCCS • Establish a forum for ongoing review and improvements <u>Challenges</u> • A number of barriers arose during implementation and expanding the use of EPaCCS. • Organisational changes and priorities could have impacted on EPaCCS implementation, however consistency and continuity within the project team and subsequent informatics group mitigated this to some extent. • The ability to share information between clinical systems is still not realised in practice, however early involvement with the Leeds Care Record project team has enabled end of life care to be prioritised within future developments and the testing of technical options. • The local city-wide approach to information sharing was an implied consent model, whereas the EPaCCS Information Standard SCCI 1580 advocated an explicit consent model that presented both information governance, clinical practice and technical challenges. Advice was sought from the citywide information governance group and an implied consent model adopted. The recording of patient involvement was strengthened in the revised 2016 version of EPaCCS. • Reporting from multiple organisations and clinical systems has proved challenging. However, this is in the process of being resolved through local data sharing agreements. <u>Future plans</u> To further develop EPaCCS in Leeds there are plans to reduce the number of different EPaCCS forms and records on different systems. This will be combined with the development of further data sharing via the Medical Interoperability Gateway (MIG) on the Leeds Care Record. The sharing of information between systems on the scale of the Leeds Care Record is envisaged to be a pioneering approach across the UK. The city is now moving towards integrated patient records through the Leeds Care

	Record which will facilitate links between providers with different platforms. EPaCCS records will be a part of this. A formative evaluation was carried out after implementation, helping to detect problems and inform the re-design of the EPaCCS programme in Leeds.
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Link to useful resources	• The Leeds Care Record: https://www.leedscarerecord.org/ • Allsop, Matthew J et al, Electronic palliative care coordination systems: Devising and testing a methodology for evaluating documentation, Palliative Medicine, (2017) Vol. 31(5) 475–482 available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5405823/pdf/10.1177_0269216316663881.pdf