The Strategy Unit.

The Status of Electronic Palliative Care Coordination Systems in the West Midlands

Commissioned by NHS England

October 2018

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NHS
Midlands and Lancashire
Commissioning Support Unit

Document control

Document Title	The Status of Electronic Palliative Care Coordination Systems in the West Midlands
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Date	October 2018

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Executive Summary

As people approach the end of their lives, care arrangements often become complex requiring input from several organisations. Electronic palliative care coordination systems are designed to ensure that all those involved in a patient's care have access to accurate and up-to date information about patients' status and wishes.

Standards for electronic palliative care coordination systems (EPaCCS) were first set out in 2012. Successive audits have demonstrated that NHS organisations have struggled to achieve these standards, but commitment to the standards from clinicians and policy makers remains firm. This report describes the state of electronic palliative care coordination systems in the West Midlands, drawing on a review of the literature, interviews with local NHS staff and responses to information requests.

We hope this report will bridge the gap between the highly technical process of the designing and implementing modern information systems and the clinical and managerial imperative to support frontline staff to deliver joined-up care to patients.

Key Findings and Recommendations

The arrival of **Substantiality and Transformation Partnerships** (STPs) presents a new opportunity to make progress towards the EPaCCS standards. STPs are well placed to negotiate and oversee programmes to put palliative care coordination systems in place. Indeed, the ability to put these systems in place for patients approaching the end of their lives should be regarded as a critical early indicator of an STP's efficacy and value. Success in these programmes could provide STPs with a platform on which to build public support for its wider ambitions.

Several of the STPs in the West Midlands have made good progress towards the EPaCCS standards. Where consent is given, **Birmingham and Solihull's** Your Care Connected system shares patient care records (not just those on palliative care registers) with authorised clinicians and practitioners in a number of agencies. There are firm plans to extend the coverage, content and functionality of this in-house solution. Birmingham and Solihull should be commended for persevering with this ambitious project. It looks set to reap the rewards in the coming years. At present however, very few electronic palliative care records have been created. To maximise the benefits of Your Care Connected for patients approaching the end of their lives, the STP should ensure that all patients on palliative care registers have a comprehensive electronic palliative care record.

Worcestershire CCGs have procured a solution known as Pyrusium from Black Pear Software Ltd. Roll-out has progressed well to date, although plans to extend access to the full range of partner agencies are not well defined. Herefordshire piloted the same system but are now considering adopting an alternative system offered by EMIS. **Herefordshire and Worcestershire STP** should consolidate the gains secured in Worcestershire, firming up plans to complete the roll-out of

Pyrusium. The STP should consider the value of adopting a consistent approach and solution across its patch.

Coventry and Warwickshire STP have also procured the Pyrusium solution. Roll-out is at an earlier stage than in Worcestershire. The STP did not respond to follow up requests for information about system functionality and roll-out plans.

A range of approaches are being pursued in the **Black Country and West Birmingham STP** but it is not clear whether or how these are connected. Sandwell and West Birmingham are involved in the Your Care Connected programme. Wolverhampton has plans to adopt and implement CareCentric, a solution offered by Graphnet and System C. Walsall and Dudley have no system in place and no specific plans to develop or procure a solution, but the CCGs are watching developments in Wolverhampton with interest. The STP should take stock of the various programmes that are underway and establish a clear strategic vision for palliative care coordination systems. If different systems and approaches are to be adopted across the patch, then the STP should ensure that this will not lead to discontinuities and inequities in care.

Staffordshire and Stoke-on-Trent STP do not have an EPaCCs system in place at present but are conducting market testing exercise to inform plans to procure a fully integrated care record solution. Given the lack of progress to date, the STP should consider a staged approach to any future developments, securing early benefits before committing to larger and more ambitious plans. The STP should give adequate consideration to the benefits of adopting the enriched Summary Care Record solution.

Shropshire and Telford STP have made little discernible progress towards the EPaCCS standards and no specific plans appear to be in place. The STP should identify a clinical and managerial lead to take this work forward. These leads should start by meeting their counterparts in the region to learn from their experiences.

Individuals working in this area no longer see **information governance** (IG) regulations and guidelines as presenting an existential threat to palliative care coordination systems. Debates about IG have moved onto more practical matters such as how best to secure patient consent and the production of information sharing agreements. However, the move from the Data Protection Act 1998 to General Data Protection Regulations (GDPR) has the potential to destabilise existing arrangements. Authoritative national guidance on the additional implications of GDPR for palliative care coordination systems would prove helpful.

The **West Midlands Ambulance Services** (WMAS) occupies a unique position in the local network of NHS organisations and it often plays a pivotal role in patient's end of life care. Each STP has taken its own view about the best way to achieve the EPaCCS standards, but this now means that WMAS must interact with multiple, distinct systems. STPs should recognise their collective responsibility to WMAS, supporting the service to access existing systems and considering the implication of any future decisions on the service.

1. Introduction

As people approach the end of their lives, care arrangements often become complex requiring input from several organisations. Effective palliative and end of life care requires excellent coordination and communication between the organisations involved. Electronic palliative care coordination systems are designed to ensure that all those involved in a patient's care have access to accurate and up-to date information about patients' status and wishes.

This report describes the state of electronic palliative care coordination systems in the West Midlands. The report was commissioned by the NHS England, West Midlands Clinical Networks Palliative and End of Life Care Programme and has been produced by the e-Innovations Team in conjunction with the Strategy Unit, hosted by NHS Midlands and Lancashire Commissioning Support Unit.

We hope this report will bridge the gap between the highly technical process of the designing and implementing modern information systems and the clinical and managerial imperative to support frontline staff to deliver joined-up care to patients.

Palliative and End of Life Care in the West Midlands

The World Health Organisation defines palliative care as *"an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."* In 2017, NHS England commissioned a report into the state of palliative and end of life care services in the West Midlands.[1,2] The report explored historical and forecast mortality rates, trends in place of death, the use of primary care palliative care registers, levels of acute healthcare utilisation prior to death, the provision community-based specialist-level palliative care and the results of recent audits of palliative and end of life care services. The report set out the challenges facing palliative and end of life care services and made a series of recommendations for Sustainability and Transformation Partnerships. This report was commissioned in response to one of these recommendations; to review the extent to which electronic palliative care systems have been developed and deployed in the West Midlands.

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[1] http://www.strategyunit.co.uk/index.php/publications/palliative-and-end-life-care-west-midlands

[2] A subsequent report explored the number of children with living limiting or life threatening conditions and the resource use of this group - http://www.strategyunit.co.uk/publications/palliative-and-end-life-care-report-children-and-young-people

National Information Standards for Palliative Care Coordination Systems

In March 2012, the NHS Health and Social Care Information Centre set out the content and functionality of electronic palliative care coordination systems (EPaCCS) in a set of minimum standards (SCCI1580).[3] Public Health England conducted a review of compliance with these standards in 2013 and concluded that most CCGs did not have an operational EPaCCS system in place. A Digital Maturity Assessment conducted by NHS England in 2015 required NHS Trusts to assess their compliance with the EPaCCS information standard. Only 37% of Trusts in the West Midlands confirmed compliance.

The Information Standard has been updated on a number of occasions, and the most recent version of the standard, published in September 2015 required that providers of adult end of life care services comply with the standard by March 2016.

Petrova et al (2015) identified five key challenges facings organisations attempting to meet the standards which go some way to explain why progress has been limited to date.

The functionality and content standards are set out in Appendix 2.

Five Key Challenges

- Projects need to involve nine key service types and hundreds of individual settings
- EPaCCS teams start a register project and find themselves transforming systems and culture
- The realities of healthcare IT are far from the expectations we have from our daily IT lives
- IG-related decision-making for EPaCCS projects is not backed by a clear framework
- End of life care is an emotive and uncertain domain

Crash course in EPaCCS: 8 years of successes and failures in patient data sharing to learn from, Petrova M, et al. BMJ Supportive & Palliative Care 2016;0:1–9. doi:10.1136/bmjspcare-2015-001059

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[3] https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-inclu9ding-extractions/publications-and-notifications/standards-and-collections/scci1580-palliative-care-co-ordination-core-c10ontent#current-release

The Arguments in favour of Palliative Care Coordination Systems

Whilst these challenges certainly exist, the arguments in favour of palliative care coordination systems are compelling. Organisations that have implemented EPaCCS solutions report increases in the likelihood that a patient will die in their preferred place, reductions in the number of ambulance conveyances and the time patients spend in hospital in the last few months of life.[4] An economic evaluation of EPaCCS pilot sites suggested that expenditure of EPaCCS systems could be recouped over a 4-year period.[5] NHS Right Care's scenarios highlight the role that EPaCCS solutions can play in delivering optimal care pathways for patients at the end of life.[6]

Clinicians too appear to strongly support of the aims that underpin the EPaCCS standards. "*Human kindness combined with high professionalism is the unshakeable foundation that sustains EPaCCS*." Petrova et al (2015).

The concept of EPaCCS has received strong and sustained support from government and national agencies. EPaCCS was a priority in the *End of Life care Strategy for England*, pilots were supported by the *National End of Life Care Programme*, and EPaCCS systems feature highly in the national *Ambitions for Palliative and End of Life Care*. The government reconfirmed its commitment to EPaCCS recently in *Our Commitment to you for end of life care The Government Response to the Review of Choice in End of Life Care*.

The Role of Sustainability and Transformation Partnerships

This report is focused primarily on the role of Sustainability and Transformation Partnerships (STPs) in delivering these standards. Forty-four STPs were established in 2016, six within the West Midlands region: Birmingham and Solihull, the Black Country, Coventry and Warwickshire, Herefordshire and Worcestershire, Staffordshire and Stoke-on-Trent and Shropshire and Telford.

STPs were established to ensure greater integration and coordination of care between NHS and other agencies. This is no easy task. Many of the factors that determine the quality and extent of joint working between NHS providers, local government and third sector agencies are subtle and elusive. It is not clear how STPs might directly influence working culture or the quality or relationship between individual clinicians and practitioners in any systematic fashion or with any confidence. But STPs can create a context in which joint working is more likely to flourish.

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[4] https://spcare.bmj.com/content/bmjspcare/early/2016/09/16/bmjspcare-2015-001059.full.pdf

[5] http://www.thewholesystem.co.uk/wp-content/uploads/2014/07/economic-eval-epaccs.pdf

[6] https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2018/02/katies-story-advanced-colorectal-cancer-full-narrative.pdf ; https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2018/02/sarahs-story-parkinsons-full-narrative.pdf

Contracts can for example reward collaborative behaviours between providers rather than rivalry, competition and mistrust.

We believe however, that one of the most important contributions that an STP can make to facilitate joint working and service integration is to ensure that clinicians and practitioners working with a patient have access to a single shared care record.[7] Individual clinicians and practitioners cannot put these systems in place for themselves and the priorities of organisations within an area rarely align capriciously. So, a supra-organisational entity such as an STP is best placed to negotiate and oversee programmes to put shared care record systems in place.[8]

Many patient groups stand to benefit from more integrated care, but none more so than patients approaching the end of their lives. Every Moment Counts, a narrative for person centred care, emphasises the importance of excellent coordination and integration for people near the end of life.[9]

An STP's ability over the next year or so, to secure and embed a palliative care coordination system for its population will be a critical early indicator of its efficacy and value.[10]

Our Approach

This report's findings and conclusions are based on;

- a review of the information standards, associated documentation and research articles
- a review of each STP's Local Digital Roadmaps
- interviews with LDR leads or suitable substitutes within each STP area
- a survey of those within responsibility for procuring, developing or maintaining palliative care coordination systems in each STP

Electronic Palliative Care Records, Summary Care Records and Integrated Care Records

EPaCCS should be regarded as a set of standards for information systems rather than as information systems per se. The standards are detailed, but in summary they describe the data that should be recorded about a patient as they approach the end of their lives and the functional

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[7] EPaCCS is one of 10 universal capabilities that STPs must address in their local delivery plans.
[8] The national framework for palliative and end of life are, the Ambitions Framework emphasises the need for a system-wide approach.
[9] https://www.nationalvoices.org.uk/sites/default/files/public/publications/every_moment_counts.pdf

requirements for the information systems that hold this data. The required data includes information about the patient's identity and address, demographic characteristics, living arrangements, carers details, medical, functional and communication and needs, the patient's end of life care plans and preferences and their consent or otherwise to share this data to support the coordination of their care. This data makes up the patient's **electronic palliative care record**. Where data sharing consent has been given, the standard requires that a patient's palliative care record should be available to the patient and suitably authorised members of staff and carers who are involved in the patient's care. Furthermore, these individuals should be able to update the record when the patient's status, plans or preferences change. There is no central or standard NHS information system that meets the all of the EPaCCS standards. To meet the standards, CCGs must incur some costs either though purchasing proprietary software or by developing an in-house solution.

There are two other terms that are frequently used to describe shared care records in the NHS. The **Summary Care Record** is automatically uploaded from GP clinical systems to a centralised NHS information system unless patients opt out. The record contains only a small number of data items including the patient's identity and address, medication and allergies. Suitably authorised staff can access the Summary Care Record via a web-portal using a smart card to confirm their identity and authority. The Summary Care Record system does not comply with EPaCCS because it does not contain the requisite information (e.g. about a patient's end of life care plans) and it does not permit the record to be updated.

CCGs can extend the Summary Care Record, to include information set out in the EPaCCS standard but to do this, they must seek explicit consent from the patient. This **enriched Summary Care Record** can be accessed via the same web portal. Whilst this enriched summary care record may contain the required data and can be accessed by staff involved in the patient's care, this is not sufficient to meet all of the EPaCCS standards because the system does not permit patients and their carers to access the record and does not allow the record to be updated.

Many of the GP clinical system suppliers have developed functionality that can allow patient's GP records to be viewed by suitably authorised members of staff outside of the GP practice. EMIS, TPP and Vision each offer their own solution to this problem. These systems however, also fall short the EPaCCs standards because they do not allow the record to be updated by members of staff outside of the general practice.

An **Integrated Care Record** brings together a patient's GP record with information from other providers such as acute hospitals, community services and mental health services. These ambitious projects represent the pinnacle of information sharing for patient care but also present the greatest technical and information governance challenges. Integrated Care Record systems must access data from multiple systems simultaneously and present this in some coherent form to the end user.

Proprietary Integrated Care Record solutions exist, but must be configured to interface with the various local IT systems. In-house solutions must address the same issues. Information Governance arrangements must span all participating organisations.

2. Palliative Care Records

The EPaCCS standard highlights the importance of sharing electronic palliative care records to improve patient care and most attention is therefore given to developing or procuring systems that can hold these records and make them available to clinicians outside the GP practice. But this functionality only has value when electronic palliative care records exist and are rich in content. Electronic palliative care records can be created in all GP clinical system and these records have value even if used solely within the GP practice. Here we report the number of GP registered patients that have an electronic palliative care record as a proportion of the number of patients dying in a given year. Electronic palliative care records contain many data items. We focus here on four of the most commonly recorded data items:

- whether the patient has given consent for the record to be shared
- the patients preferred place of death
- the patient’s cardiopulmonary resuscitation decision
- whether anticipatory medicines were available at the patient’s residence[11]

The charts below, present information on the number of patient records containing this information in five areas, Birmingham and Solihull, Sandwell and West Birmingham, Wolverhampton, Dudley and Worcestershire. This information was supplied specifically for this project by STPs and CCGs in response to an information request from the Strategy Unit. Figures are presented per 1,000 deaths per annum to allow comparisons between areas. Walsall and Herefordshire CCGs and Coventry and Warwickshire, Staffordshire and Stoke-on-Trent and Shropshire and Telford STPs were unable to provide this data.

Across the five areas, approximately 2,000 patient records contained information to confirm whether consent had been given for the palliative care record to be shared. 9,900 records contained information about the patients preferred place of death.

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[11] The use of anticipatory medicines requires careful clinical consideration. We measure here not whether anticipatory medicines have been put in place, but rather whether the patient record contains information about whether (or not) anticipatory medicines are available in the patient’s home. In this context, success is good recording, not high levels of prescribing.

Table 1

STP	**CCG**	**Number of Patient Records** (Rate per 1,000 deaths pa)			
		Consent to Share Record	Preferred Place of Death	CP Resuscitation Decision	Anticipatory Medicines
Birmingham and Solihull		-	**89** (35)	**178** (69)	**53** (21)
Black Country and West Birmingham	Sandwell & West B'ham	**491** (127)	**1077** (279)	**2,135** (553)	**171** (44)
	Wolverhampton	**137** (53)	**231** (89)	**612** (237)	**9** (3)
	Dudley	**27** (9)	**1,126** (361)	**1,583** (508)	**73** (23)
	Walsall	-	-	-	-
Herefordshire and Worcestershire	Worcestershire	**1,380** (236)	**7,332** (1,251)	**9,812** (1,675)	**5,832** (995)
	Herefordshire	-	-	-	-
Coventry & Warwickshire		-	-	-	-
Staffordshire and Stoke-on-Trent		-	-	-	-
Shropshire & Telford		-	-	-	-

Figure 1

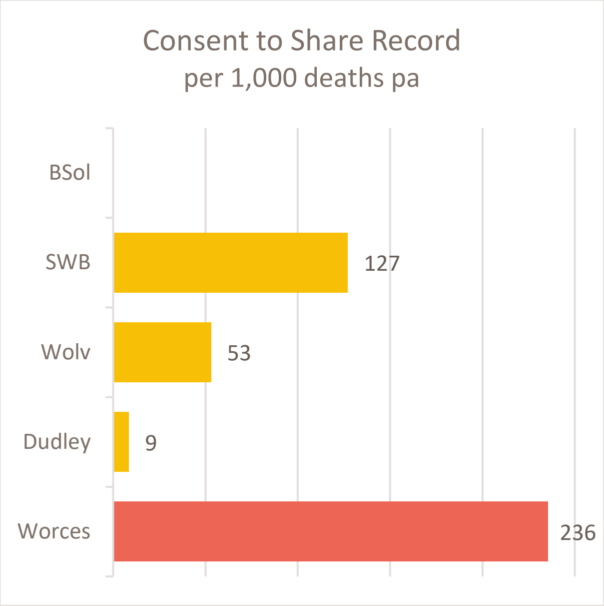
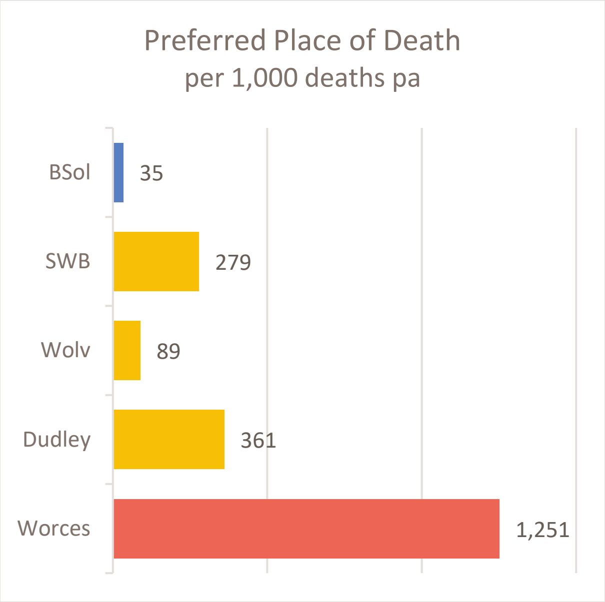


Figure 2



Cardiopulmonary resuscitation decisions were recorded in 14,300 records and 6,100 records contained information about whether anticipatory medicines were available at the patient's residence.

Figure 3

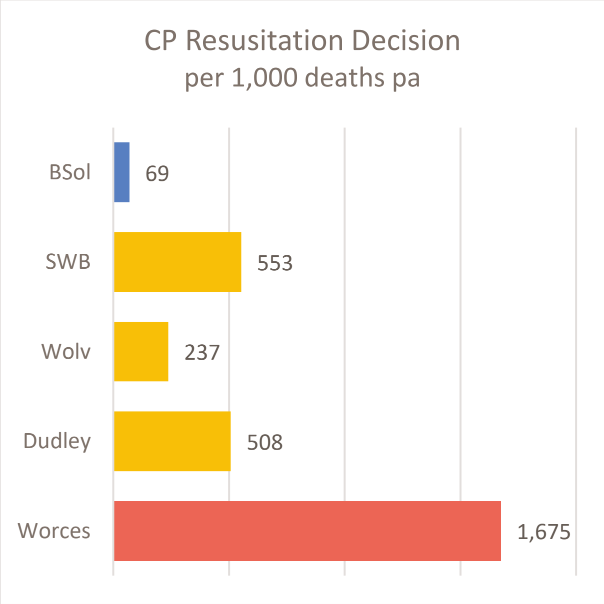
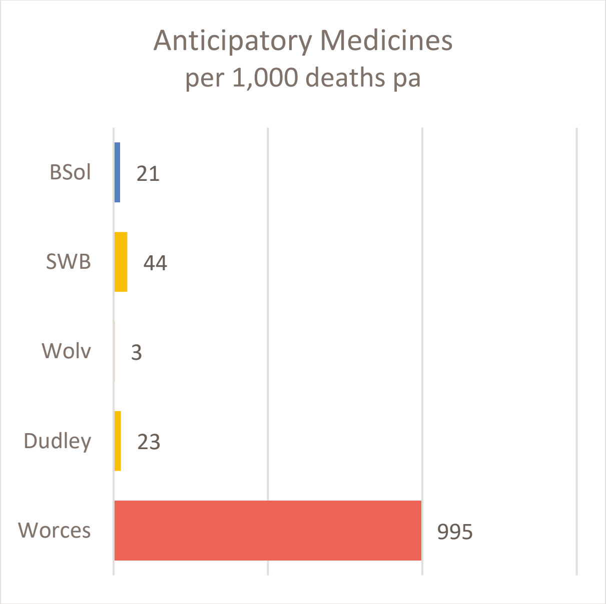


Figure 4



Across the four measures, Worcestershire has made the most progress in creating electronic palliative care records.

Note on figures

1 Birmingham and Solihull STP's figures are based on a sample of 60 practices (rates have been adjusted accordingly) and are derived from the MIG supportive care dataset.

2 Birmingham & Solihull STP's consent model differs from those of other areas. Patients are given the option to opt out of data sharing between care organisations for the purposes of patient care. Those who do not opt out must also give explicit consent for a record to be shared at the point of use.

3 Dudley CCG's identified a number of issues when extracting the data in response to this information request. In particular, the CCG believes that the reported number of electronic records with patient consent and anticipatory medicines is likely to understate the true level.

4 Wolverhampton CCG's figures for place of death include read codes for specific places of death that are not included in SCCI1580_36. For CPR, the additional read code 1R1 (not for resuscitation) has been included.

3. The Status of EPaCCS in Each STP

In this section we summarise the current position in each STP with regard to palliative care coordination systems. These summarises are based on interviews with relevant members of staff in each area and on the responses to a formal information request.

Birmingham & Solihull STP

Birmingham and Solihull STP aims to meet the EPaCCS standards through the delivery of its shared care record programme, *Your Care Connected*. The programme has been running for several years in a planning mode, with investment exceeding £3m to date. In 2017/18, the programme moved into implementation mode and by February 2018, summary GP records, including where appropriate end of life care records, of almost 1 million patients across 148 primary care practices were live on the system and accessible to several local NHS acute trusts and a community trust. Plans are in place to extend the coverage to patients in a further 112 practices and extend access to two out-of-hours primary care providers, a specialist and an ambulance trust. In the medium term there are plans to extend the record to incorporate data from acute, community and mental health trusts. Your Care Connected use the Medical Interoperability Gateway (MIG) and palliative care records presented within this system comply with the EPaCCs record content specification.[12]

Service Type	Service	View record	Update record
Acute hospital services	Uni. of B'ham Hospitals NHS FT	✓ in place	✗ not planned
	Heart of England NHS FT	✓ in place	✗ not planned
	B'ham Women's and Children's NHS FT	✓ in place	✗ not planned
	Sandwell & W. B'ham Hospitals NHS Trust	✗ planned - Aug 18	✗ not planned
	Royal Orthopaedic Hospital NHS FT	✗ planned - no date	✗ not planned
Ambulance service	WM Ambulance Service NHS FT	✗ planned - no date	✗ not planned
Community service	B'ham Community Healthcare NHS Trust	✓ in place	✗ not planned
Mental health service	B'ham & Solihull Mental Health NHS FT	✓ in place	✗ not planned
GP Out of Hours	Badger Group	✗ planned - no date	✗ not planned
	Nestor Primecare Services	✗ not planned	✗ not planned
NHS111	Care UK	✗ planned - no date	✗ not planned
Social care	Birmingham City Council	✗ not planned	✗ not planned
	Solihull Metropolitan Borough Council	✗ not planned	✗ not planned
Hospices	John Taylor Hospice	✗ not planned	✗ not planned
	St Marys Hospice	✗ planned - no date	✗ not planned
	Acorns Hospice (Selly Oak)	✗ not planned	✗ not planned
	Marie Curie Hospice (WM)	✗ not planned	✗ not planned
Patients		✓ in place	✗ not planned
Carers		✓ in place	✗ not planned

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[12] https://healthcaregateway.co.uk/epaccs/

The Black Country & West Birmingham STP

Black Country & West Birmingham STP is made up of four areas; Dudley, Wolverhampton, Walsall and Sandwell and West Birmingham, each with its own acute trust. Whilst representatives of these four areas organisations in these Black Country and West Birmingham STP have held discussions about the potential to converge on a single solution, the areas are at present working on separate solutions.

Wolverhampton have procured an EPaCCs solution from the Graphnet & System C Care Alliance. Short-term funding to trial this solution was obtained from Estates and Technology Transformation Fund (ETTF) and a decision is expected shortly about recurrent funding. The solution supports the creation of fully auditable end of life care plans that can be accessed by health, social care and third sector organisations in Wolverhampton.

Service Type	Service	View record	Update record
Acute hospital services	The Royal Wolverhampton NHS Trust	✗ planned - Aug 18	✗ planned - Aug 18
Ambulance service	WM Ambulance Service NHS FT	✗ planned - Dec 18	✗ planned - Dec 18
Community service	The Royal Wolverhampton NHS Trust	✗ planned - Aug 18	✗ planned - Aug 18
Mental health service	Black Country Partnership NHS FT	✗ planned - Aug 18	✗ planned - Aug 18
GP Out of Hours	Vocare	✗ planned - Aug 18	✗ planned - Aug 18
NHS111	Care UK	✗ planned - Aug 18	✗ planned - Aug 18
Social care	Wolverhampton City Council	✗ planned - Aug 18	✗ planned - Aug 18
Hospices	Compton Hall	✗ planned - Aug 18	✗ planned - Aug 18
Patients		✗ planned - Apr 19	✘ not planned
Carers		✗ planned - Apr 19	✘ not planned

Walsall CCG, working in conjunction with Wolverhampton CCG have also recently adopted and installed the Graphnet & System C solution. The CCGs together are considering extending the solution beyond palliative care to become a more general shared care record system.

Sandwell and West Birmingham CCG are involved in the Your Care Connected programme described above.

Service Type	Service	View record	Update record
Acute hospital services	Sandwell & W.B'ham Hospitals NHS Trust	✓ in place	✖ not planned
	University of B'ham Hospitals NHS FT	✓ in place	✖ not planned
	B'ham Women's & Children's NHS FT	✓ in place	✖ not planned
	The Royal Orthopaedic Hospital NHS FT	✖ planned - no date	✖ not planned
Ambulance service	WM Ambulance Service NHS FT	✖ planned - no date	✖ not planned
Community service	Sandwell & W. B'ham Hospitals NHS Trust	✖ not planned	✖ not planned
Mental health service	Black Country Partnership NHS FT	✖ not planned	✖ not planned
	B'ham & Solihull Mental Health NHS FT	✖ not planned	✖ not planned
GP Out of Hours	Nestor Primecare Services	✓ in place	✖ not planned
NHS111	Care UK	✖ planned - no date	✖ not planned
Social care	Sandwell MBC	✖ planned - Dec 18	✖ not planned
	B'ham CC	✖ planned - no date	✖ not planned
Patients		✖ planned - no date	✖ not planned
Carers		✖ planned - no date	✖ not planned

Dudley CCG does not have an EPaCCS solution in place at present.

Herefordshire & Worcestershire STP

Herefordshire and Worcestershire STP brings together the areas covered by the three Worcestershire CCGs (Redditch and Bromsgrove, South Worcestershire and Wyre Forrest) and Herefordshire CCG.

The three **Worcestershire** CCGs have been working collaboratively on a meeting the national EPaCCS information standard as part of a the *Worcestershire Well Connected* programme. The programme procured the Pyrusium solution from Black Pear Software Ltd and implemented it in September 2016. By February 2018, 53 GP practices were using the system and almost 2,000 EPaCCS records had been created.[13]

Service Type	**Service**	**View record**	**Update record**
Acute hospital services	Worces Acute Hospitals NHS Trust	✗ planned - no date	✗ planned - no date
Ambulance service	WM Ambulance Service NHS FT	✓ in place	✗ not planned
Community service	Worces Health & Care NHS Trust	✗ planned - no date	✗ planned - no date
Mental health service	Worces Health & Care NHS Trust	✗ not planned	✗ not planned
GP Out of Hours	Care UK	✓ in place	✗ planned - no date
NHS111	Care UK	✓ in place	✗ planned - no date
Social care	Worcestershire County Council	✗ not planned	✗ not planned
Hospices	Macmillan Unit Evesham	✓ in place	✗ planned - no date
	St Richards	✓ in place	✗ planned - no date
	Acorns Hospice Worcester	✗ planned - no date	✗ planned - no date
Patients		✗ planned - no date	✗ not planned
Carers		✗ planned - no date	✗ not planned

Herefordshire also piloted the Pyrusium solution across five GP practices, a hospice and two care homes, but recurrent funding was not secured to extend these arrangements. The CCG is now exploring a solution centred on the EMIS clinical system. Negotiations are underway to allow palliative care records to be accessed by arrange of acute and community services via this EMIS solution.

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[13] This differs for the numbers provided in Chapter 2 which relates to information in GP clinical systems.

Staffordshire & Stoke-on-Trent STP

Whilst no formal EPaCCS solution is in place in Staffordshire and Stoke-on-Trent STP, work is underway to procure a fully integrated care record solution. By March 2019, it is hoped that a system will be in place which gives acute, community, mental health and hospice services access to an electronic palliative care record, with further services gaining access 12 months later.

Service Type	Service	View record	Update record
Acute hospital services	Uni. Hospitals North Midlands NHS Trust	✘ planned - Mar 19	✘ not planned
	Burton Hospitals NHS FT	✘ planned - Mar 19	✘ not planned
	The Royal Wolverhampton NHS Trust	✘ planned - Mar 20	✘ not planned
Ambulance service	WM Ambulance Service NHS FT	✘ planned - Mar 20	✘ not planned
Community service	Staffordshire & Stoke P'ship NHS Trust	✘ planned - Mar 19	✘ not planned
Mental health service	N. Staffordshire Comb H'care NHS Trust	✘ planned - Mar 19	✘ not planned
	S. Staffordshire & Shropshire HC NHS FT	✘ planned - Mar 19	✘ not planned
GP Out of Hours	Vocare	✘ planned - Mar 20	✘ not planned
	Badger Group	✘ not planned	✘ not planned
NHS111	Care UK	✘ planned - Mar 20	✘ not planned
Social care	Staffordshire County Council	✘ planned - Mar 20	✘ not planned
	Stoke-on-Trent City Council	✘ planned - Mar 20	✘ not planned
Hospices	Douglas Macmillan	✘ planned - Mar 19	✘ not planned
	St Giles	✘ planned - Mar 19	✘ not planned
	Katherine House	✘ planned - Mar 19	✘ not planned
	Tree Tops Donna Louise Trust	✘ planned - Mar 19	✘ not planned
Patients		✘ not planned	✘ not planned
Carers		✘ not planned	✘ not planned

Coventry & Warwickshire STP

Coventry & Warwickshire STP and its three constituent CCGs (South Warwickshire, Warwickshire North and Coventry & Rugby) are working together to deploy the Black Pear Pyrusium solution, under the local name CASTLE, *Care and Support towards Life's End*. 23 early adopter practices have been identified and these are creating palliative care records within the system. Plans are in place to extend coverage to all practices in Coventry and Rugby CCG and North Warwickshire CCG. Funding is being sought to incentivise the participation of GP practices in South Warwickshire CCG. Records created in CASTLE can be viewed by a small number of local healthcare providers. Further work will be required to extend access to the full range of partner organisations.

Shropshire & Telford STP

Shropshire and Telford STP do not have an operational electronic palliative care record system. Whilst stakeholders have expressed an interest in developing or procuring a system to meet with EPaCCS standards, no firm plans exist to take these ambitions forward.

4. Key Themes

This chapter presents the themes that emerged from the interviews and information requests. We hope this chapter will provide useful context for areas that are developing plans to meet the EPaCCS standards.

System Scope

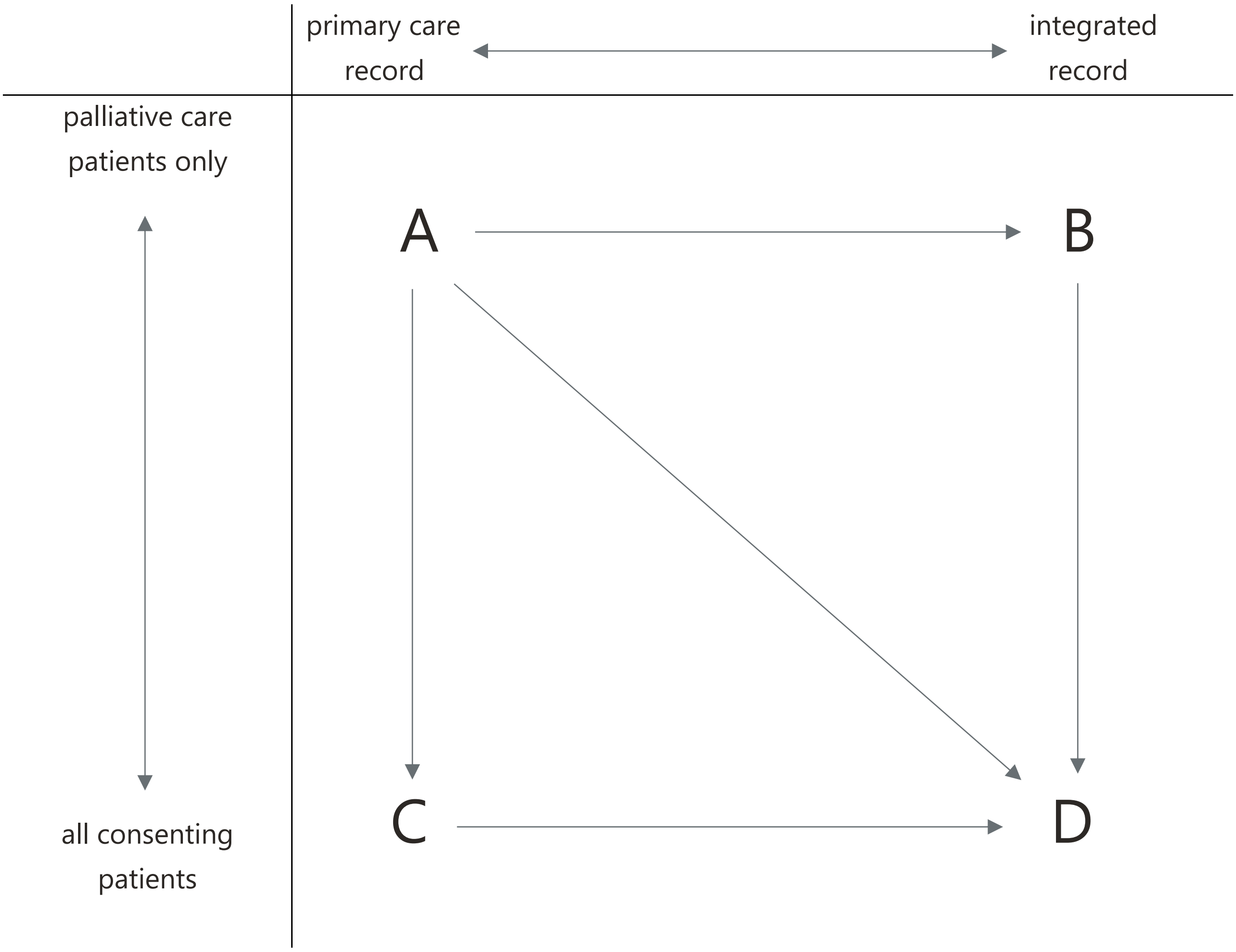
Many of the interviewees talked about the importance of determining the scope of any planned system to share palliative care records and highlighted some critical early design decisions. These decisions operate on two dimensions:

- whether the system should aim to share the records of palliative care patients, or of a wider group, or indeed of all patients
- whether the system should share the patient's primary care record (from the GP clinical system) or an integrated record from primary care, secondary care, community services, mental health services etc.

Interviewees spoke about the value and importance of narrowing the scope of the system in early phases of a project to make implementation easier or to allow time for the case for wider roll-out to be made. In some cases however, these early design decisions can preclude later ambitions to extend the system scope.

The figure 1 below, represents the domain of design choices that are available to health economies. Worcestershire, Wolverhampton, and Coventry and Warwickshire have decided to start their journey in zone A, initially sharing the primary care record for patients with palliative care needs. Birmingham and Solihull on the other hand have started in zone C, sharing primary care records for all consenting patients and have clear plans to move to zone D where the shared record will integrate information from several sectors. Whilst the design decision that Birmingham and Solihull have taken appear to place it well for the future, considerable investment and time was required to realise these plans. Plans as ambitious as these are not without risk

Figure 5: System Scope design decisions and trajectories



The Extent of Record Sharing

A further design decision relates to the extent to which palliative care records are shared. Most areas expect in the long run, to share records with local acute hospitals, community service providers, the ambulance service, mental health services, GP Out-of-Hours services, NHS111, hospices and local authority social services teams. However, systems must be individually configured, and bespoke Information Governance arrangements must be negotiated before record sharing can begin with each agency. It is inevitable therefore that some ordering of agencies emerges as health economies prepare and implement roll-out plans. There was no clear consensus from the interviews about the best order with which to share records with these agencies. Rather decisions seem to be taken with reference to a number of often competing criteria: technical ease of implementation, quality of relationships the appetite for record sharing and the scale and nature of potential benefit.

STPs also varied in terms of their ability and plans to share records directly with patients and their authorised carers. This functionality exists in the Birmingham and Solihull STP solution and Wolverhampton have plans to build this functionality into their solution. Plans were less clear in Worcestershire and in Coventry and Warwickshire STPs.

Viewing and Updating records

EPaCCS standard sets out the expectation that palliative care records should not only be accessible by those delivering care to patients, but that these individuals should also be able to update the record as the patient's circumstances, health status and preferences change. Most systems are able to offer a 'view' of the patient record to clinicians and practitioners, but allowing changes in that record to be 'written back' to the underlying clinical systems presents a more substantial technical and governance challenge.

This feature represents a key limitation of one of the cheapest and simplest solutions, the enriched Shared Care Record. It is notable that no STP or CCG in the West Midlands is intending to adopt this system and the lack of 'record updating' capability might explain this. However, many of the solutions selected by STPs also do not appear to have a clear and well-tested solution to this problem.

Systems & System Suppliers – Make or Buy

Whilst Birmingham & Solihull STP have chosen to develop an in-house system, most STPs have or are planning to procure a solution from one of a small number of system suppliers. Black Pear's Pyrusium solution has been adopted by Worcestershire, Coventry and Warwickshire. Herefordshire piloted the same system but are now exploring a solution offered by EMIS.   Wolverhampton have chosen to deploy the CareCentric solution offered by Graphnet & System C. The GP System-of-Choice (GP SoC) contractual framework contains other potential solutions offered by a range of suppliers. Interviewees did not report that a lack of credible IT solutions were holding back their ambitions to share patient records.

Information Governance

Interviewees were asked about the extent to which information governance issues were disrupting or holding up plans to share patient records. Whilst many of the interviewees spoke about Information Governance, the issues they raised were of a practical nature. There was a broad acknowledgement that Information Governments requirements were clear and that Information Governance did not represent an fundamental barrier to sharing electronic palliative care records. Issues focused more on the time, capacity & expertise to draw up & negotiating appropriate data sharing agreements and patient consent forms. This new perspective demonstrates the progress that has been made in understanding the legal risks associated with record sharing. However, the move from the Data Protection Act 1998 to General Data Protection Regulations (GDPR) has the potential to introduce fresh uncertainty. Some interviewees were planning to review arrangements in light of GDPR.

Resources

Lack of financial resources to purchase proprietary software and human resources to develop in-house solutions were commonly quoted as the cause of failures to meet the EPaCCS standards to date. Whilst the initial system costs are not substantial, the resources required to deploy, test and maintain these systems can be considerable. Many interviewees talked of the difficulties of delivering EPACCS projects as an 'add-on' to their substantive role (the 'day job'). Where projects were being overseen by STPs, there was a concern that the gap between responsibility and authority in these new quasi-NHS bodies and the lack of formal budgetary responsibility resulted in delays in securing resources to deliver solutions.

A number of the interviewees described software that was in place or due to be implemented as an interim solutions or pilot project. In some cases, this was because funding had only been confirmed on a short-term basis and no recurrent funding sources had been identified.

Clinical and Managerial Leadership

Interviewees from STPs that had successfully implemented EPaCCS systems spoke clearly about the importance of consistent clinical and managerial leadership. Similarly, interviewees from areas that had not yet put systems in place, talked of the disruptive effect of changes in management responsibility.

The development and deployment of an EPaCCS solution is unlikely in itself to change clinical practice. STPs must also seek cultural change, encouraging joint working between agencies. These changes are best lead by senior clinicians.

West Midlands Ambulance Service

West Midlands Ambulance Services (WMAS) is often the first point of contact for patients and their carers when urgent and unexpected difficulties arise in end of life care. The service routinely plays a pivotal role in determining the pathways that patients follow.

WMAS occupies a unique position in the local network of NHS organisations requiring good working relationships with CCGs, acute, mental health and community trusts and many more NHS and non-NHS organisations. Each area has developed plans to put a coherent solution in place to support the coordination palliative care within their area, but these solutions were by no means consistent between areas. Little consideration seems to have been given to the implications of the plurality of these decisions on WMAS nor has there been any concerted effort to coordinate or constrain local decisions to minimise the impact of WMAS. It now appears impractical or at least problematic to create links between WMAS's clinical information system, CLERIC and each of the local EPaCCS solutions, leaving only low-tech manual solutions available to WMAS staff.

Conclusions

Electronic Palliative Care Coordination Systems have the potential to improve the quality of care for patients approaching the end of their lives whilst reducing demand on hospital and ambulance care services. The standards for EPaCCS systems are clear, long-standing and are strongly supported by patients, clinicians and politicians. Some parts of the West Midlands are making good progress towards these standards.

Developing and implementing EPaCCS systems is not straightforward, but STPs are well placed to take on this challenge. The ability to put EPaCCS systems in place for patients approaching the end of their lives should be regarded as a critical early indicator of an STP's efficacy and value. Success in these programmes could provide STPs with a platform on which to build public support for its wider ambitions. We encourage STPs to prioritise this issue for attention.

Appendix 1 - Interviews and Information Requests

The following individuals were interviewed during the course of this project:
Ciaron Hoye, Head of Digital, NHS Birmingham and Solihull CCG
Steve McIlraith, Local Digital Roadmap Programme Manager, NHS Birmingham and Solihull CCG
Tim Berry, Associate Director ICT Programme Delivery, South Warwickshire Hospitals NHS FT
Roma Holland, Information Sharing Manager & Clinical Safety Officer, NHS Coventry & Rugby CCG
Maria Hardy, Programme Manager Urgent and Emergency Care, NHS Herefordshire CCG
Dr Stephen James, General Practitioner &Clinical Director for Primary Care, NHS Shropshire CCG
Andy Hadley, CCG Digital Lead and Staffordshire GPFV Digital Lead, NHS Staffordshire CCGs
Tony Gallagher, Director of Finance & Local Digital Roadmap Programme Lead, NHS Walsall CCG
Dave Dolton, Interim Project Manager (ISCR Project), NHS Walsall CCG
Graham Westgate, Interim Strategic IT Lead, NHS Walsall CCG
Stephen Cook, IM & T Lead, NHS Wolverhampton CCG
Dr Maggie Keeble, General Practitioner, NHS South Worcestershire CCG
Mark Docherty, Director of Nursing, Quality & Commissioning, West Midlands Ambulance Service

Responses to information requests were received from:
Dr Maggie Keeble, General Practitioner, NHS South Worcestershire CCG
Stephen Cook, IM & T Lead, NHS Wolverhampton CCG
Manoj Behal, IT Lead, NHS Sandwell and West Birmingham CCG
Ciaron Hoye, Head of Digital, NHS Birmingham and Solihull CCG
Richard Corner, Head of IT, NHS Dudley CCG

Partial responses to information requests were received from:
Andy Hadley, CCG Digital Lead and Staffordshire GPFV Digital Lead, NHS Staffordshire CCGs

No response to information request has been received to date from:
Maria Hardy, Programme Manager Urgent and Emergency Care, NHS Herefordshire CCG
Dave Dolton, Interim Project Manager (ISCR Project), NHS Walsall CCG
Dr Stephen James, General Practitioner &Clinical Director for Primary Care, NHS Shropshire CCG
Tim Berry, Associate Director ICT Programme Delivery, South Warwickshire Hospitals NHS FT

Appendix 2 - EPaCCS Standards

The following tables are drawn from the National Information Standard (SCCI1580) Palliative care co-ordination: core content - Requirements specification.[14]

Requirements for IT System Suppliers

Ref	Requirement
1	Suppliers of existing systems to providers of end of life care services MUST demonstrate conformance with the information standard and with Amd 11/2015 by 1 March 2016. All data items captured, held or displayed in the system MUST do so in compliance with SCCI1580.
2	Suppliers MUST comply with user interface standards for input and display of patient demographic data (ISB 1500 to 1507). Other design guidance developed by the HSCIC common user interface programme [6] SHOULD be considered.
3	Entry, display and printing of data MUST be assessed as clinically safe.
4	Information shared MUST be kept up-to-date. The solution MUST include controls to ensure that (as far as reasonably possible) discrepancies cannot occur between the Palliative care co-ordination: core content record and other systems or databases holding this information.
5	The system MUST include functionality to notify staff caring for people approaching the end of their life that an EPaCCS record has been created or updated. This MUST be communicated securely in line with information governance requirements. Note: This SHOULD use the national interoperability toolkit (ITK) notifications specification where possible.
6	It SHOULD be possible to send notifications of record creation/update to staff or individuals (including the patient's family and carers) not registered as users of the system.
7	The system MAY use the national Personal Demographics Service (PDS) service to trace patients, retrieve and manage updates to their demographic information.
8	The system MAY use the national Summary Care Record (SCR) service to retrieve medication, allergy and adverse reaction information for a patient where this is available.
9	All integration with other systems (other than Spine services such as PDS or SCR) MUST be built using national ITK specifications unless agreed otherwise with the local NHS organisation.
10	Local systems may hold more information than is shared with other systems using ITK messaging. The sending system MUST make it clear to the sender exactly what information will be sent to other systems and what will be held locally and not shared.
11	Users who ‘click-through’ into a record from another system MUST be able to view and update the record, subject to role-based access controls, and having a legitimate relationship with the patient.
12	Any additional data capture requirements beyond the data items specified in SCCI1580 SHOULD be agreed with the local organisations and care providers using the system.
13	The system MUST allow users to update and logically delete records (in-line with retention policies for clinical data and role-based access controls). This (as with all changes to a record) must be fully auditable.

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[14] https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-inclu9ding-extractions/publications-and-notifications/standards-and-collections/scci1580-palliative-care-co-ordination-core-c10ontent#current-release

Ref	Requirement
14	It MUST be possible to create a record for a person with a minimum set of data fields: Demographic fields, GP details (as per the definitions in SCCI1580). All mandatory items MUST be included, along with any relevant items marked as 'required' in the standard.
15	The system MUST ensure that any changes to the person's preferences are updated and made available in a timely fashion. The specific timescale required should be agreed with the local lead organisation.
16	The system MAY include controls or a user prompt to ensure that any advanced decision to refuse treatment is only recorded for a person who is over 18 and who has mental capacity. There is no requirement to capture anything in the record relating to this.
17	When recording advanced decisions to refuse life sustaining treatment, the system MAY prompt the user that such statements must be made in writing, signed and witnessed as well as being recorded in the system.
18	General record keeping principles stipulated by GMC (2006), NMC (2010), HPC (2008), AoMRC (2008) and AoMRC and the NHS (2008) MUST be adhered to, including all entries and amendments being dated and timed, confidentiality, accuracy and timeliness of content.
19	The system SHOULD prompt for a review date to be set when a record is created, and also at each review. The review date should not be more than three months from the date of creation or review.
20	The system SHOULD allow for reminders to users when a planned review date is approaching or has been reached.
21	The system SHOULD allow any of the carers involved in the care of the person to contribute to the record (subject to relevant IG controls).
22	The system SHOULD prompt users that DNACPR decisions should only be recorded by the senior responsible clinician. Note: The choice of who the senior responsible clinician is will be made by the user and there is no requirement for the system to verify this.
23	The solution MUST allow a copy of a person's record to be printed.
24	Local organisations will make decisions about any data fields not to be reproduced on the person's copy and any fields to be filtered out depending on how they have been answered. The system MUST support this. This should be in line with the principles established under Section 7 of the Data Protection Act which gives individuals a right of access to personal data about them.
25	The system MAY allow the person to access their own record electronically, and to have editing rights for specific fields. The requirements for this must be agreed with the local lead organisation.
26	The system MUST include reporting capabilities as agreed with the local NHS organisation.
27	The system MUST allow for the creation of data quality and validation reports as agreed with the local NHS organisation.
28	The solution SHOULD provide capabilities allow reporting of equality information to support organisations in ensuring equitable provision of services, where such information has been recorded in the record.
29	It MUST be possible to extract effectively anonymised or pseudonymised data from the system to support secondary analysis.
30	Data extracted for secondary uses MUST be effectively anonymised or pseudonymised unless explicit consent has been gained from the person for this use of their data.

Ref	Requirement
31	It MUST be possible to extract all user-entered and necessary reference data from the system in patient-identifiable form in a standard format (eg CSV or XML) to allow for local analysis.
32	PI data extracts should be limited to records ‘owned’ by the organisation of the user running the extract (ie for whom they are the data controller) unless data sharing agreements are in place that allow for other organisations data to be included.
33	The solution MUST conform to safety risk management standards ISB 0129 and ISB 0160.
37	Where SNOMED CT codes are supported, the system MUST be updated with the latest releases of SNOMED CT codes in a timely fashion (SLA to be agreed with local NHS organisation).
38	The system MUST use the NHS number as the primary unique identifier for a person.
39	The system MUST allow electronic copies of documents to be attached to a person’s record. It should be possible to enable or disable this functionality for any given organisation.
40	The system MUST allow for changes to the data set over time, including any changes to the locally defined additional information that is captured.
41	The system MUST be highly available – in line with service levels agreed with the local organisation.
42	The system MUST be accessible to authorised users on the N3 network (or its successor).
43	The system SHOULD be accessible to authorised users who are not on the N3 network. Appropriate security and information governance controls must be in place and agreed by the Health and Social Care Information Centre (or its successor).
44	Users SHOULD be able to access records without a network connection (eg on a mobile device).
45	It SHOULD be possible to capture information using an offline digital capture mechanism such as a digital pen or scanning solution.
46	Common user interface standards: ISB standards (1500 to 1507) MUST be followed for input and display of demographic data. This applies to devices capable of operating at 1024x768 which have a keyboard and pointing device, but can also be applied to smaller devices.
47	The solution SHOULD comply with guidance developed by the Common User Interface programme within the Health and Social Care Information Centre.
48	Common user interface guidance relating to navigation and clinical noting SHOULD be followed.
49	Information about a person’s end of life care and preferences should appear as a single record which is updated whenever/if ever the person wishes to change it.
50	The system SHOULD be accessible for those with disabilities, and SHOULD comply with guidance set out in the Government service design manual for accessibility. Specific accessibility needs of the users within a local organisation using the system should be taken into account.
51	All web interfaces for general users or patients MUST meet level AA success criteria of WCAG 2.0 (Web content accessibility guidelines 2.0).
52	The system MAY provide online help and/or training facilities to help users understand how to use the system.
53	Systems MUST adhere to user interface standards and to National Patient Safety Agency (NPSA) guidelines for safe on-screen display of medication information.
54	Systems MUST alert users when data item: preferred place of death 1st choice has not been completed.

Record Core Content

Ref	**Summary core data items**
1	**Consent** Consent status*
2	**Record creation* date AND record amendment* dates**
3	**Plan** and requested actions Planned review date Cardiopulmonary resuscitation decision – whether a decision has been made, the decision, date of decision, location of the documentation and date for review
4	**Person demographics** Person name* including preferred name Date of birth* Person address* NHS number* and NHS number status indicator code* Person telephone number Gender Relevant contacts Main carer name and contact details Availability of carer support*
5	**Special requirements** Need for interpreter Preferred spoken language Functional status Disability End of life care tools in use eg Gold Standards Framework
6	**Information and advice given** Is main carer aware of person's prognosis? Is person aware of the cardiopulmonary resuscitation clinical decision? Family member/carer informed of cardiopulmonary resuscitation clinical decision?
7	**GP Practice** GP name* GP practice details*
8	**Key worker** Name Telephone number
9	**Services** and care Names of health and social care staff and professionals involved in care Professional group Telephone number
10	**Diagnoses** Primary end of life care diagnosis* Other relevant end of life care diagnoses and clinical issues Likely prognosis
11	**Allergies or adverse reactions**
12	**Medications** and medical devices Whether a 'just in case box' or anticipatory medicines have been prescribed Where these medicines are kept

Ref	**Summary core data items**
13	**Legal** information **Advance statement** Requests or preferences that have been stated **Advance decision to refuse treatment (ADRT)** Whether a decision has been made, the decision, date of decision and the location of the documentation **Lasting Power of Attorney** or similar Name and contact details of person appointed with Lasting Power of Attorney (LPA) for personal welfare - without authority to make life-sustaining decisions - with authority to make life-sustaining decisions
14	**Person** and carers' concerns, expectations and wishes Preferred place of death 1st and 2nd choices if made Names and contact details of others (one and two) that the person wants to be involved in decisions about their care Other relevant issues or preferences around provision of care?
15	**Actual place of death**
16	**Date of death**

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