

Electronic Palliative Care Co-ordination Systems Progress Report

2017-18



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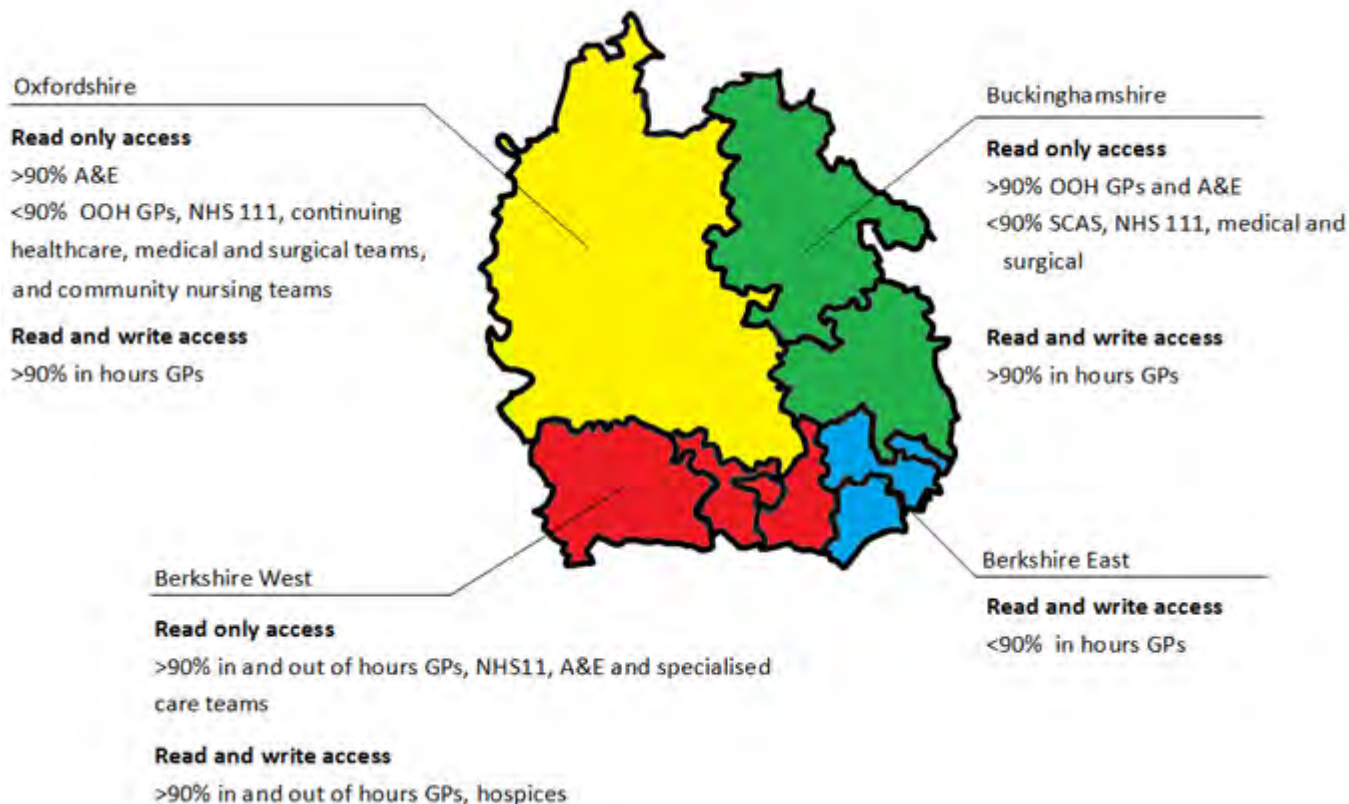
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Executive Summary

This paper reports on the results of an audit of the four Electronic Palliative Care Co-ordination Systems (EPaCCS) used across the Thames Valley region in 2017-18. The audit was based on one undertaken by the South West End of Life (EoL) Regional Network, and adapted for the Thames Valley region.

The map below highlights the level of accessibility by provider group to an EPaCCS in the four localities in the region.



Key findings

- Access to systems by health and care professionals (in and out of hours) is variable across the region, Berkshire West CCG achieving the highest level of access for Read and Read/Write
- The ability to extra data from the EPaCCS is limited across the four CCG's and difficult to establish whether
- the national information standard SCCI1580 (Palliative Care Co-ordination: Core Content) is being met and essential care planning is being shared across the Multi-Disciplinary Teams
- the number of records are being reviewed and updated to reflect changes are in "date"
- the ability to report on effectiveness and quality of recorded care plans

This report recommends that read/write access to EPaCCS is available to all key providers of care, including emergency services, community care services, and ambulance trusts, including

NHS 111. It also recommends that all CCGs have a fully functioning EPaCCS by 2020 as per national guidance.¹

¹ NHS National Information Board. Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens. A Framework for Action. November 2014, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf

Introduction

Improving the co-ordination and quality of care provided for people at the end of life is a priority for NHS England (NHSE).² EPaCCS offer a process in which essential information and care planning at the end of life can be electronically communicated amongst multi-disciplinary teams, particularly with emergency and out-of-hour services. They allow GPs and other healthcare professionals to share information about patients who have been identified as likely to be in the last year of their lives. EPaCCS enable the recording and sharing of people's preferences and key details about their care with those delivering that care. The systems support the delivery of the right care in the right place, by the right person, at the right time. It also supports NHSE's objective to increase the use of technology to help people manage their health and care.³

Evidence from Co-ordinate my Care (London)⁴, the Airedale model (West Yorkshire),⁵ and papers such as the Marie Curie document *EPaCCS: electronic systems that help improve patient care*⁶ have demonstrated an impact on patients achieving their preferred place of death (79%), and a reduction in the number of people dying in hospital (18%) with more spending their final days in their preferred place.⁷

The South West End of Life Regional Network has developed an EPaCCS standard of best practice to benchmark against what 'good' should look like. This self-assessment tool was produced in collaboration with all CCG EoL and digital leads. The identified three benchmarks of a fully functional EPaCCS are:

- Accessibility
- Compliance with [SCCI1580: Palliative Care Co-ordination: Core Content](#): Information Standard⁸
- Regular review of care plans.

All Clinical Commissioning Groups (CCGs) in the South West region completed the self-assessment tool and the findings illustrated that key healthcare professionals (in and out of hours) did not have full access to an EPaCCS, had difficulties in extracting data, and that records were being reviewed but below compliance.

In 2017-18, Thames Valley Strategic Clinical Network (TVSCN) decided to adapt the South West self-assessment tool and work with the four CCGs within Thames Valley to undertake an appraisal of each of their own EPaCCS. The network worked with each CCG and Commissioning Support

² Commitment for End of Life Care, NHS England, <https://www.england.nhs.uk/personalised-health-and-care/eolc/commitment-for-end-of-life-care/>

³ Transforming Health and Care Through Technology, NHS Digital, <https://digital.nhs.uk/about-nhs-digital/our-work/transforming-health-and-care-through-technology>

⁴ Coordinate My Care, <http://coordinatemycare.co.uk/>

⁵ Palliative care in Airedale and Craven, <http://www.airedale-trust.nhs.uk/services/palliative-care/palliative-care-in-airdale-and-craven/>

⁶ EPaCCS: electronic systems that help improve patient care, Marie Curie Cancer Care, <https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/strategic-partnerships/rcgps/epaccs-electronic-systems-that-help-improve-care.pdf>

⁷ *Ibid.*

⁸ SCCI1580: Palliative Care Co-ordination: Core Content, NHS Digital, <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci1580-palliative-care-co-ordination-core-content>

Unit (CSU) to identify how best to extract data from their systems, highlight the purpose of each standard and what this would demonstrate. From the outset it was clear that accessing the right resource to support the undertaking proved difficult, and the complexity and number of systems in place highlighted a lack of interoperability as well as access for key healthcare professionals.

The figure below provides a high-level view of the number of people at the end of life who were on a GP palliative care register. It highlights the variation across CCGs in the Thames Valley region. It also shows the number of patients who were identified, and had their care plans discussed. As per best practice, this would be followed by a regular EoL multidisciplinary team meeting, where information about patients in the last 6-12 months of life is shared via an EPaCCS. Other professionals involved in their care can then be made aware of any changes or preferences to inform future decision making. These data validate that the number of people on an EoL register should therefore match the number that have an EPaCCS care plan in place. There is an expectation from this study that there should be functioning EPaCCS to support the number of people that are being placed on an EoL Register.

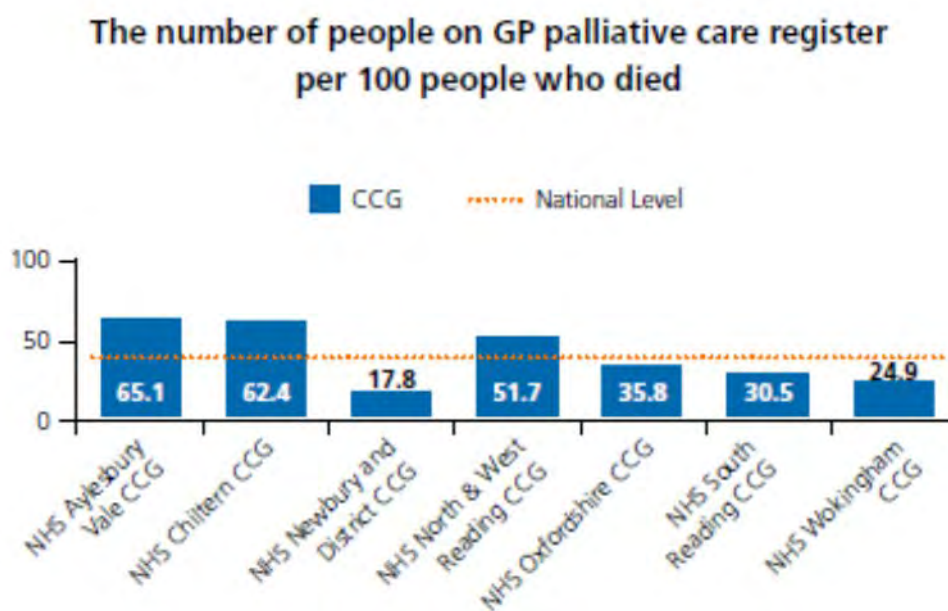


Figure 0.1: The number of people on GP palliative care register per 100 people who died⁹

Each CCG in Thames Valley undertook an in-depth locality self-assessment of their own IT systems to establish the level of functionality of their own EPaCCS. This report reflects the findings of this study and will highlight that there is a need for a systematic approach to ensure consistent best practice for patients, families and carers, to support care and coordination from all professionals involved in their care.

⁹ End of life Care: Sustainability and Transformation Partnership Support Tool: Buckinghamshire, Oxfordshire and Berkshire. Public Health England, 2017

EPaCCS self-assessment results by Clinical Commissioning Group

Buckinghamshire Clinical Commissioning Group

Buckinghamshire Clinical Commissioning Group (BCCG) EPaCCS is via the Summary Care Record: Additional Information (SCR:AI) rather than a dedicated/bespoke EPaCCS module. BCCG are exploring purchasing a dedicated EPaCCS.

A dedicated EPaCCS would provide a bespoke standardised template that lists all the essential care planning information around patient care at the end of life, and has the ability to electronically share with all professionals involved in the pathway. A true EPaCCS system allows all professionals to read and write, so when changes in a patient's care occur, this is immediately recorded so everyone is informed and can respond to changes in needs. A non-EPaCCS holds minimal information eg name, date of birth, address etc, but no related EoL care planning summary or recent history, so is of limited value and does not have the function to electronically share with other professionals, even as read only information.

Standard 1: Structure of EPaCCS accessibility

Service rated as <70% of staff with read access = Red; <90% of staff with read access = Amber; >90% with read access= Green

Table 1.1: Buckinghamshire healthcare professionals with read only* access

READ ONLY	Aylesbury Vale CCG	Chiltern CCG	
GP Out of Hours	Green	Green	Buckinghamshire EoL are held on the national SCR system within the additional dataset that incorporates EoL information. This information is available to organisations with N3 and Smartcard access with appropriate levels of access. Some of these have been marked as amber, not because they don't have access but because the information isn't available to monitor if the EoL information is accessed on a regular basis.
Community Nursing teams OOH	Amber	Amber	
Ambulance services	Amber	Amber	
NHS 111	Amber	Amber	
Emergency Department	Green	Green	
Medical Assessment Unit	Amber	Amber	
Surgical Assessment Unit	Amber	Amber	
Social services/Care Direct	Red	Red	
Continuing Health Care	Red	Red	

* Read only: Staff can view information, but not edit it.

Table 1.2: Buckinghamshire healthcare professionals with read and write* (edit) access

READ AND WRITE (EDIT)	Aylesbury Vale CCG	Chiltern CCG	Comments
GP In hours	Green	Green	
Hospice teams (includes inpatients and Palliative Care Teams)	Red	Red	EoL records for Bucks are held as part of the SCR additional dataset. All organisations with SmartCards and appropriate levels of authority can have READ only access. SCR is write only for GPs. Therefore these have had to be flagged as red as the question is referring to Read/Write access
Hospital Specialist Palliative Care Team (that provide an inpatient service)	Red	Red	
Community Specialist Palliative Care Teams (not employed by a Hospice)	Red	Red	
In hours Community Nursing services	Red	Red	

* Read and write access: Staff can both view and edit information

Buckinghamshire CCG can identify that GP out of hours (OOH) and the emergency department are able to access and read care plans, but is difficult to determine if other out of hours services like the ambulance trust are able to access data, because it is not possible to extract this data from the system. Only in hours GPs can read and edit care plans.

Standard 2: Minimum data set required by clinicians to ensure appropriate care

Table 1.3: Buckinghamshire standard 2 ratings

CRITERION	Aylesbury Vale CCG
Consent status	EoL records for Bucks are held as part of the SCR additional dataset. There is no facility to access the data to audit the last 20 patients added to the system.
The patient/main carer is aware of the prognosis	
Diagnosis	
JIC/Anticipatory prescribing in place	
Advance Statement	
Preferred place of death	
TEP/DNAR in place	
ADRT	
Date of Death	
Place of Death	

Buckinghamshire CCG is unable to extract data from the SCR:AI to assess performance against this standard.

Standard 3: A measurement of % of records 'in date' e.g. Date and time of last amendment within the last four weeks: it is not possible to extract this data from the system.

Buckinghamshire CCG Summary

Primary care is the only service with the functionality to read and edit care plans via the SCR:AI. Services provided with a smartcard, such as the acute and emergency services, can read plans. Specialist palliative care and community (in hours) services have no access at all. It is not possible to extract data from the system, and subsequently it is not possible to understand if the ten key constituents from the Palliative Care Co-ordination Core Content (SCC11580) are being used, or if care plans are being updated and reviewed.

Buckinghamshire CCG feedback

Two of the Buckinghamshire CCGs are above the mean for having dying patients on an EoL register. Probably the majority of those on the register will have an advanced care plan (ACP) and will be visible through Summary Care Record Additional Information (SCR:AI). BCCG primary care EoL scheme stipulates that 95% of patients on an EoL register should have SCR:AI consent and an ACP, so in theory, at least 95% of BCCG EoL patients should be on a SCR:AI.

Discussions with palliative care providers has drawn the conclusion that SCR:AI is not the way forward, because it is read only for anyone outside of primary care, and accessing it outside of a primary care IT system is not straightforward.

In terms of future plans, BCCG are looking at Graphnet,¹⁰ which will enable all the current clinical systems to be seen through one easily accessible portal. In addition to that, BCCG are hoping to have all community providers using EMIS clinical services, which opens up the ability for ACPs to become read-write for all relevant clinicians.

¹⁰ Graphnet, <https://www.graphnethealth.com/>

Oxfordshire Clinical Commissioning Group

Oxfordshire CCG (OCCG) are using bespoke, non-EPaCCS, software.

Standard 1: Structure of EPaCCS accessibility

Service rated as <70% of staff with read access = Red; <90% of staff with read access = Amber; >90% with read access= Green

Table 2.1: Oxfordshire healthcare professionals with read only* access

READ ONLY	Oxfordshire CCG	Notes
GP Out of Hours	Amber	The plans are routinely accessed online by the emergency department; other departments in OUH have online access but may not be aware of it. OOH and SCAS have accessed to scanned documents
Community Nursing teams OOH	Amber	
Ambulance services	Red	
NHS 111	Amber	
Emergency Department	Green	
Medical Assessment Unit	Amber	
Surgical Assessment Unit	Amber	
Social services/Care Direct	Red	
Continuing Health Care	Amber	

* Read only: Staff can view information, but not edit it

Table 2.2: Oxfordshire healthcare professionals with read and write* (edit) access

READ AND WRITE (EDIT)	Oxfordshire CCG	Notes
GP In hours	Green	Plans are created by GPs only at present, but it is hoped that others will be able to contribute during 18/19
Hospice teams (includes inpatients and Palliative Care Teams)	Red	
Hospital Specialist Palliative Care Team (that provide an inpatient service)	Red	
Community Specialist Palliative Care Teams (not employed by a Hospice)	Red	
In hours Community Nursing services	Red	

* Read and write access: Staff can both view and edit information

As seen in table 2.1, all departments in the Oxford University Hospitals NHS Foundation Trust have full access but the emergency department is the only service that is known to be using it regularly to share EPaCCS information. Within out of hours GP and community services, NHS 111, medical and surgical assessment units and continuing healthcare teams have less than 90%. This shows that there is the ability to read care plans but not necessarily edit them (as shown in Table 2.2) as GPs in hours can only read and write EPaCCS care plans. South Central

Ambulance Service (SCAS) are not able to read any care plans. Table 2.3 highlights that key essential data is recordable but clarification is required to ascertain whether this is used by professionals in reference to Table 2.4 feedback.

Standard 2: Minimum data set required by clinicians to ensure appropriate care

Green = information recorded; Red = information not recorded

Table 2.3: Oxfordshire standard 2 ratings

CRITERION	Oxfordshire CCG
Consent status	Green
The patient/main carer is aware of the prognosis	Green
Diagnosis	Green
JIC/Anticipatory prescribing in place	Green
Advance Statement	Green
Preferred place of death	Red
TEP/DNAR in place	Green
ADRT	Green
Date of Death	Red
Place of Death	Red

Standard 3: A measurement of % of records ‘in date’ e.g. Date and time of last amendment within the last four weeks

Table 2.4: Oxfordshire standard 3 ratings

Measurement	Oxfordshire CCG
% of records	It has not been possible to carry out an audit of this information. Information on the OCS system will be as up to date as the last entry in the GP record Information on emailed care plans has not been audited

Oxfordshire CCG summary

Primary care has full access to read and edit, and a majority of the key acute and emergency, including out of hours services, have read access. SCAS does not have any. Seven out of ten of

the ten key constituents from the SCCI1580 are being used; three which are not recorded (in place) are related to preferred, actual and date of death. The system does not allow for data to be extracted regarding whether care plans are being updated and reviewed.

Oxfordshire CCG feedback

1. This survey provides a clear understanding of the gaps in the Oxfordshire EPaCCS system (digital Proactive Care Plan) which need to be addressed in comparison to national standards and other Thames Valley areas.
2. This survey does help us be clearer in the direction we may need to take.
3. The report will inform the development plan of the digital Proactive Care Plan (dPCP) in Oxfordshire.
4. The help needed to go forward will need to be discussed, however, any strategic support to influence and keep this high on the agenda of the Health Information Exchange (Global Digital Exemplar) project in Oxfordshire would be beneficial.
5. A plan to reach a full EPaCCS by 2020 would be a good aim.
6. Monitoring and reviewing the measures of success outlined in this report with regard to EPaCCS will tell us if we have been successful.

Berkshire West Clinical Commissioning Group

Berkshire West CCGs (BWCCG) main EPaCCS system is Adastra.¹¹

Standard 1: Structure of EPaCCS accessibility

<70% of staff with read access = Red; <90% of staff with read access = Amber; >90% with read access= Green

Table 3.1: Berkshire West healthcare professionals with read only* access

READ ONLY	Berkshire West CCG	Notes
GP Out of Hours	Green	Full access
Community Nursing teams OOH	Amber	Read only
Ambulance services	Amber	Read only
NHS 111	Amber	Read only
Emergency Department	Amber	Read only
Medical Assessment Unit	Red	No
Surgical Assessment Unit	Red	No
Social services/Care Direct	Red	No
Continuing Health Care	Red	No

* Read only: Staff can view information, but not edit it

Table 3.2: Berkshire West healthcare professionals with read and write* (edit) access

READ AND WRITE (EDIT)	Berkshire West CCG	Notes
GP In hours	Green	Full access
Hospice teams (includes inpatients and Palliative Care Teams)	Green	Full access
Hospital Specialist Palliative Care Team (that provide an inpatient service)	Amber	Have read only in A&E
Community Specialist Palliative Care Teams (not employed by a Hospice)	Amber	Have read only in A&E
In hours Community Nursing services	Red	Using RIO

* Read and write access: Staff can both view and edit information

Table 3.1 highlights that BWCCG out of hour community services have read only access, with GPs out of hours being able to read and edit. Emergency services do have read access within the

¹¹ Adastra clinical patient management system, <https://www.oneadvanced.com/solutions/adastra/>

EPaCCS. Hospice teams that include community and inpatient services have the ability to read and edit, as do GP practices. However hospital palliative care teams have read access in A&E but no direct access and are unable to edit care plans. Community specialist teams have read access. Community nursing services use a different system (RIO) and that is not linked to Adastra and gain information via another system: Connected Care.¹²

Standard 2: Minimum data set required by clinicians to ensure appropriate care: it is not possible to extract data from the system to address this standard.

Standard 3: A measurement of % of records clinicians to ensure appropriate care e.g. Date and time of last amendment within the last four weeks: it is not possible to extract data from the system to address this standard.

Berkshire West CCG summary

Primary care (both in and out of hours) and hospices have full read and edit access. Read access can be obtained by acute and emergency, specialist palliative care and community (in and out of hours) services. Data cannot be extracted from the system to address whether the ten key constituents from the SCCI1580 are being used and whether care plans are being updated and reviewed.

Berkshire West CCG feedback

1. This survey highlights the limitations of it in terms of access by all providers and ongoing challenges re connectivity. Disappointingly apparent low rates of usage in three out of four CCGs in Berks West
2. This survey helps BW CCG be clearer in the direction it may need to take.
3. We will use these findings to take back to our Locality Steering Group and disseminate findings at next meeting. Develop Action plan as a result with key areas to work on. Share finding with locality councils of GP practices as well, identify variance and reasons for this and offer support to improve identification and communication at end of life. We are planning some education workshops later this year as part of our role out of ReSPECT tool.
4. We are uncertain to what help we need until the above actions have been achieved.
5. Yes - We have a plan to reach a full EPaCCS by 2020
6. We will develop metrics to give us assurance re process and improved outcomes for patients and carers /families to know if we have been successful.

¹² Share Your Care, Berkshire West, <https://www.shareyourcareberkshire.org/>

Berkshire East Clinical Commissioning Group

Two systems, Aداstra and the Summary Care Record Additional Information (SCR:AI) are concurrently being used to populate patient information. The Future Planning template¹³ is used to populate into the SCR:AI.

Standard 1: Structure of EPaCCS accessibility

<70% of staff with read access = Red; <90% of staff with read access = Amber; >90% with read access= Green

Table 4.1: Berkshire East healthcare professionals with read only* access

READ ONLY	Bracknell & Ascot CCG	Slough CCG	Windsor, Ascot & Maidenhead CCG	Notes
GP Out of Hours	Red	Red	Red	GPs are being advised to continue to update Aداstra (OOHs patient record system) in order to ensure the service is kept up to date.
Community Nursing teams OOH	Red	Red	Red	The Community nurses use RIO as their main clinical record. They can review SCR via Connected Care but not input and the info they get from Connected Care is very basic. They can't access the additional info from SCR. They used to access (view only) Aداstra but that has ceased as accessing multiple data bases is complex. Whilst access to Aداstra is possible this would require retraining and new passwords. Can only access SCR and Connected Care via Rio.
Ambulance services				GPs are being advised to continue to update SCAS (not via SCR)
NHS 111				
Emergency Department				
Medical Assessment Unit				
Surgical Assessment Unit				
Social services/Care Direct	Red	Red	Red	
Continuing Health Care	Red	Red	Red	

* Read only: Staff can view information, but not edit it

Table 4.2: Berkshire East healthcare professionals with read and write* (edit) access

READ AND WRITE (EDIT)	Bracknell & Ascot CCG	Slough CCG	Windsor, Ascot & Maidenhead CCG	Notes
GP In hours	Amber	Amber	Amber	Most practices input to the Future Planning template that populates SCR-AI. Some practices use other care plans (audit to be undertaken) and it has yet to be ascertained whether all of the codes and associated freetext from these plans populate the SCR-AI. GPs cannot view data inputted to other systems. EMIS Enterprise (being procured) will allow data to be shared between EMIS and Vision (GP records systems). Practice staff can write to Aداstra.
Hospice teams (includes inpatients and Palliative Care Teams)	Red	Red	Red	Can only access SCR and Connected Care via Rio
Hospital Specialist Palliative Care Team (that provide an inpatient service)	Red	Red	Red	
Community Specialist Palliative Care Teams (not employed by a Hospice)	Red	Red	Red	Can only access SCR and Connected Care via Rio
In hours Community Nursing services	Red	Red	Red	The Community nurses use RIO as their main clinical record. They can review SCR via Connected Care but not input and the info they get from Connected Care is very basic. They can't access the additional info from SCR. They used to access (view only) Aداstra but that has ceased as accessing multiple data bases is complex. Whilst access to Aداstra is possible this would require retraining and new passwords.

* Read and write access: Staff can both view and edit information

Connected Care is used by the community services to extract data from RIO and the SCR (but not the Additional Information template). Aداstra appears to have provided more access for GP and community nursing services but SCR:AI is overall used.

¹³ Future Planning Project, <https://www.futureplanning.org.uk/for-general-practice.html#>

SCR:AI has limitations as to who has read and edit access (GP practices only) and appears to be problematic via Connected Care as to what data (no SCR:AI) can be extracted for community nurses in and out of hours who have read access only. No out of hours or emergency services have access to the SCR:AI and SCAS is dependent on the Adastral being updated by GP practices.

Standard 2: Minimum data set required by clinicians to ensure appropriate care: it is not possible to extract data from the system to address this standard.

Standard 3: A measurement of % of records clinicians to ensure appropriate care e.g. Date and time of last amendment within the last four weeks: it is not possible to extract data from the system to address this standard.

Berkshire East CCG summary of results

Primary care have limited read and write access to two systems that do not link together. Other services, including acute and emergency, specialist palliative care and community (in and out of hours) have no access to either system. It is not possible to extract data to analyse whether the ten key constituents from the SCCI1580 are being used and if care plans are being updated and reviewed.

Berkshire East CCG feedback

1. In and out of hours community nursing teams cannot access SCR via Connected Care. Information from Connected Care is a range of clinical data about a patient, but it not currently an EPaCCS system.¹⁴
2. We don't believe that the GP in hours section stating that practice staff can write into Adastral is correct, would advise that this is checked. GPs can see some from other systems in CC.¹⁵

Berkshire East CCG, in response to the findings, will map the functional requirements of an EPaCCS, by mapping what is required from local or national guidance and create a comparison with their current system. This would identify what the current system provides, what is missing, and what work needs to be completed to produce an effective EPaCCS.

¹⁴ During the audit the team had said they could access SCR through CC so this might be a misunderstanding on the CN team's part.

¹⁵ It transpires that, while many practices CAN write to Adastral, they aren't doing so due to time constraints.

Conclusion

The results provided by the audit have indicated issues in the following areas:

1. It is difficult to share care information effectively

The range and difference in functionality of the various systems makes it difficult to provide joined up, effective access to patient information and patient care plans. There are five different IT systems in use in the region (Summary Care Record: Additional Information, AdastrA, Connected Care, RIO, and EMIS), and not all of these systems are EPaCCS. There is little to no interconnectivity across the different programs, which makes information sharing in localities that use two systems particularly difficult. Sharing key data is vital to enable clinicians to provide appropriate care.

2. Access to EPaCCS is limited

It is clear that having an EPaCCS in place does not guarantee even a minimal level of read access for appropriate staff. Whilst in hours primary care has a good level of read and write access, out of hours GPs, community services (in and out of hours), emergency services, and ambulance trusts have low levels of read access. This causes significant issues with the recording, editing, and acting upon information, and subsequently drives an increase in email and telephone communications.

3. The ability to extract data from systems is very limited

All of the systems in use have significant limitations with regards to data extraction, which makes analysing system and information usage very difficult. Data needs to be clear, accessible and appropriate, but currently it is not possible to determine levels of system access, the quality of recorded care plans, or use of recorded care plans. Whilst it stands to reason that everyone on the GP palliative care register will have a care plan recorded on EPaCCS, it is not possible to verify if this is the case.

4. Measuring against the information standards is difficult

All EPaCCS should be measurable against the national information standard SCCI1580 (Palliative Care Coordination: Core Content). With the difficulties in extracting data from each system, we have been able to establish that three out of four CCGs are only meeting standard 1 (structure of EPaCCS accessibility), and only one CCG is meeting standard 2 as well (minimum dataset required by clinicians to ensure appropriate care), and no CCGs are meeting standard 3 (percentage of records 'in date'). Without meeting these three standards, no CCG is meeting the benchmarks for an effective EPaCCS.

It is clear that further work is required to improve on the various components of a fully functioning EPaCCS, including access by all members of multidisciplinary teams, especially emergency services and out of hours, and the extraction of data to demonstrate that care plans are being recorded and shared effectively, which is a crucial part of quality end of life care.

Next steps and questions for consideration

Next steps for commissioners

1. What does this survey of the EPaCCS systems in your locality tell you?
2. Does the survey help understand the direction you may need to take?
3. What are you going to do with these findings?
4. What help do you need going forward?
5. Do you have a plan to reach a full EPaCCS by 2020?
6. How will you know if you have been successful?
7. How do measure the quality of the care plans?

Considerations for commissioners

Further exploration from the commissioners to identify:

- What CCG current systems can be used to electronically share information?
 - Are they compatible with the national information standard (SCCI1580: Palliative Care Co-ordination: Core Content)?
 - Does the system have the ability to widen access for providers?
 - Read only
 - Read and write (edit)
- What other key stakeholders can read and edit e.g. emergency departments, ambulance trusts?
- Whether the Palliative Care Register used by practices to identify patients in the last one year of life highlighted:
 - A care plan in place?
 - An advance care plan in place?

Next steps for Thames Valley SCN

Further investigation from the network to the commissioners to identify:

- A benchmark of “what does good look like?” (linked to the UEC pathway and NHS 111 pilot)
- Presentation and findings to the U&EC STP Board
- Measurement of quality, impact and progress (quality improvement methodology and tools)
- Joint collaborative working with NHS Digital on national solutions to provide direction and guidance for commissioners.

References

Adastra clinical patient management system, <https://www.oneadvanced.com/solutions/adastra/>

Commitment for End of Life Care, NHS England, <https://www.england.nhs.uk/personalised-health-and-care/eolc/commitment-for-end-of-life-care/>

Coordinate My Care, <http://coordinatemycare.co.uk/>

End of life Care: Sustainability and Transformation Partnership Support Tool: Buckinghamshire, Oxfordshire and Berkshire. Public Health England, 2017

EPaCCS: electronic systems that help improve patient care, Marie Curie Cancer Care, <https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/strategic-partnerships/rcgps/epaccs-electronic-systems-that-help-improve-care.pdf>

Future Planning Project, <https://www.futureplanning.org.uk/for-general-practice.html#>

Graphnet, <https://www.graphnethealth.com/>

Palliative care in Airedale and Craven, <http://www.airedale-trust.nhs.uk/services/palliative-care/palliative-care-in-airdale-and-craven/>

SCCI1580: Palliative Care Co-ordination: Core Content, NHS Digital, <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci1580-palliative-care-co-ordination-core-content>

Share Your Care, Berkshire West, <https://www.shareyourcareberkshire.org/>

Transforming Health and Care Through Technology, NHS Digital, <https://digital.nhs.uk/about-nhs-digital/our-work/transforming-health-and-care-through-technology>