1. Contents

2. Introduction

All people approaching the end of life (EoL) need to have their needs assessed, their wishes and preferences discussed, and an agreed set of actions reflecting the choices they make about their care recorded in a care plan. The care plan should be subject to review by the multidisciplinary team in conjunction with the patient and their carers, as and when their condition, or wishes, change.

This document describes how the Electronic Palliative Care and Coordination System (EPaCCS) will be available to Clinicians to help with this process. It describes the principles of the Black Pear EPaCCS system and how GPs and other providers access the system to create; view and update patients register entries.

3. Clinical Background and Objectives

The End of Life Care Strategy (2008) identified the need to improve the co-ordination of care, recognising that people at the end of life frequently receive care from a wide variety of providers. The developments of Electronic Palliative Care Co-Ordination Systems were identified as a mechanism for enabling co-ordination.

By supporting the discussion about, recording and sharing of people’s care preferences it is anticipated that EPaCCS will improve the quality of care, with provision meeting people’s expressed wishes and preferences.

The document, ‘End of Life Care Coordination: Core Content Standard Specification, ISB 1580’ specifies the core content to be held in end of life care co-ordination systems. This facilitates the consistent recording of information by health and social care agencies and, with the consent of the individual, supports safe and effective management and sharing of information.

4. Service Description

The Worcestershire EPaCCS software has been developed by Black Pear and is hosted by an NHS Digital accredited company (AIMES). Part of the software developed by Black Pear has the brand name Pyrusium. The system works on the principles of Interoperability where the repository for data is held in a central EPaCCS database with a complete record also held on the GP clinical system.

The system will hold an EPaCCS record for all patients in Worcestershire who are considered to be in the last year of their life, and who have consented to have an EPaCCS record created for them and for this to be shared with clinical staff. Once an EPaCCS record has been created it is then available to:

- Worcestershire Acute Hospital
- Worcester Health Care Trust
- St Richards Hospice
- Hospice Day Centres
- CareUK Out of Hours Service
- 111 Service
- West Midlands Ambulance Service (999 Service) - Initially via auto email.
The process by which a patient’s EPaCCS record is created and managed depends on the location where this is undertaken. GPs and Practice based staff will create the record using a Black Pear application running in Pyrusium, which integrates with EMIS to auto-populate the EPaCCS record and write back information to the EMIS record. Outside of general practice (Hospices, Acute and Community settings) the EPaCCS record will be created and managed using a web link to the Black Pear application.

5. Patient Consent and Information Leaflet

Prior to an EPaCCS record being created, the patient must give their consent for this to happen. The principles of the EPaCCS should be explained to the patient and this can include their family and other carers. Any conversation should cover the sharing of the EPaCCS record with health agencies covering the county and the advantages this brings to help prevent clinical intervention which might be contrary to a patient’s wishes.

A leaflet for patients and their relatives has been produced and is attached as appendix 16.4. This leaflet will also be available to download from the EPaCCS system.

6. Ownership of Data and responsibility for updating records

With the technology employed for providing the EPaCCS, the Black Pear application provides a central repository of data items together with a complete record also held on the patient’s notes at their Practice. For an EPaCCS created in a Practice, the data owner will be the Practice. For an EPaCCS created in a Hospice or other Secondary Care setting, those staff and their employing organisations will be responsible for data items that they have entered. Any data pulled from the GP system (e.g. demographics) to prime the EPaCCS, the data owner for that data is the supplying Practice.

There is no write back from Black Pear direct into the GP system; all externally generated EPaCCS/amendments are highlighted and available for review from within the Pyrusium dashboard. An email is sent to the nominated email address to notify you that a record has been changed. Once the GP views and accepts the amendments, it will generate a new PDF for entry into the patient record.

Should a clinician at a practice not be in agreement with any updates/changes to the EPaCCS record, it is suggested that they discuss this direct with the clinician who made the amendments to obtain the background to them.

Updating of an EPaCCS record can be undertaken by any Clinician who is party to a patient altering their previously declared wishes or aware of other changes e.g. change of carer, etc.

It should be noted that there are already in place across Worcestershire, Data Sharing Agreements between the various providers of Palliative and related healthcare.

7. Who should create a Register Record

The Register record should be created by the Clinician who has the ‘conversation’ with the patient (including their relatives) as to their wishes as regards an end of life care plan. This can take place in a variety of settings depending on the patient’s on-going clinical management. Typically this may be in General Practice – in the surgery or domiciliary visit, Hospices – in-patient or day care, Acute Care or with the Community Health Services. EMIS anywhere can also be used to create/access the EPaCCS Register.

The EPaCCS record could be best completed using the paper template – Appendix 16.1 and entered afterwards, in which case this could be undertaken by support staff.
8. **Creating a Register Record**

The below is a summary only, user guides are in Appendix 16.2. (There will be a full PDF User Guide and Quick Reference Guides available when the system is live, and these will be able to be downloaded from within the support section of the system).

8.1 **GP Surgery**

Within Worcestershire where all practices use EMIS. The basic workflow will be:

1) Open patient in EMIS Web  
2) Pyrusium can then retrieve the open patient  
3) For that patient, select the EPaCCS care plan as opposed to the *special note* for non-palliative care patients  
4) EPaCCS form will pre-populate itself with as much info as it can from the patient record e.g. demographics, practice details, clinical summary  
5) Clinician completes the form as required – (some fields are mandatory and as an EPaCCS can be an iterative process, the register could well be developed over a period of time)  
6) On saving, this will post a PDF and a selection of readcodes back to the EMIS Web (and also made available for the Adastra palliative care special note.). It will also save to the central EPaCCS database which will trigger the WMAS notification.

This system can also be used to raise a Special Note (demographics and free text only) for non-palliative care patients.

8.2 **Special Care Notes**

The system gives you the option of creating a special note for the patient – this can be created in addition to the EPaCCS form or instead of. The special note can be created for *any* patient not just those at end of life. This note will be shared with the OOH and 111 in the same way as the EPaCCS record and will mean administrators will not have to notify OOH and 111 separately, as they do now.

8.3 **Other locations – Hospice – Acute Hospital - other N3 connected sites**

1) Retrieve a patient by entering name/NHS no and selecting the patient's practice.  
2) For that patient, select the EPaCCS care plan as opposed to the special note for non-palliative care patients which has been requested for further down the line  
3) EPaCCS form will pre-populate itself with as much info as it can from the patient record e.g. demographics, practice details, clinical summary  
4) Clinician completes the form as required  
5) On saving, this will save to the central EPaCCS database which will trigger a series of notifications: to ambulance service, GP and Adastra.  
6) The notification to the GP will indicate whether a new record has been created or amended. The GP must accept these before they will post to the record.

9. **Updating/amending a Record**

A patient’s EPaCCS record should be updated whenever there is a change in circumstances/wishes. The update should be undertaken by the clinician who is recording the changes and may well be a different to the originator of the EPaCCS record.

The system records all transactions by user and date/time.

10. **Patients copy**
Should a patient request a copy of the EPaCCs form it is acceptable to print it off provided the patient understands that it is for their use and not for clinical staff who visit them, *they also need to be aware* that there is a risk that the printed copy may not be the most up to date copy.

11. When a patient dies/ceases to require an EPaCCS

Any clinician who is aware of the death of a patient, who had an EPaCCS record, can update the record to this effect. Recording the death of a patient does not lock the EPaCCS record and it is still possible for any data to be entered e.g. at a Practice.

12. Unscheduled Care Providers

12.1 West Midlands Ambulance Service

West Midlands Ambulance Service (999) will initially receive an automated email providing details of the EPaCCS record. This will then be transcribed onto their Cleric dispatch system. They will also be notified about any changes to the EPaCCS record which result in changes to the original ambulance form or when a patient’s dies/ceases to require an EPaCCS record. In the longer term the plans are for WMAS to receive a notification which then integrates into their software system and removes the manual process.

12.2 CareUK OOH Provider

The Out of Hours Services use the Advanced HealthCare Adastra Unscheduled Care software. This system is enabled to provide interoperability with the Worcestershire EPaCCS Database. This means that when a call handler or clinician accesses a patient’s record on the Adastra system, they are advised if that patient has an EPaCCS record. They can should they wish to then view a reduced dataset of the relevant sections of the record.

12.3 111 Service (Vocare)

As with the OOH service above, the 111 Service also uses the Adastra Unscheduled Care software and as such system access will be exactly as for the Out of Hours service providers.

13. Viewing of an EPaCCS Register Record

Providing a Clinician has user access rights to the EPaCCS system and if they have a legitimate clinical relationship with a patient, they can view a patient’s register record. As with all IT systems, a full audit trail of users, their access and records viewed/transacted is recorded.

14. User Access/setting up users on the Register

System Management to enable users to be set up on the EPaCCS system will be on a devolved basis. This means that within each organisation (GP Practice, Hospice, Acute and Community Trusts) there will designated Managers who can set users up/suspend accounts, etc. These Managers will have the responsibility to ensure that only ‘bona fide’ users are set up and they have the correct level of access.

15. How to report problems/issues with the EPaCCS Register

Any problems with the EPaCCS Software should be reported to support@blackpear.com Please include your Practice ODS code and a contact telephone number with a brief description of the problem.
16. Appendices

16.1 Clinical Template

Clinical Template
WWC EPaCCS.docx

16.2 User Guide – see links below:

Relevant movie clips:

- Pyrusium installation: https://www.youtube.com/watch?v=84h8KFARo0I
- EPaCCS form: https://www.youtube.com/watch?v=67iU_vQeo08
- EPaCCS integration with Adastra: https://www.youtube.com/watch?v=vhsVQ56ofzl
- Non Palliative Care SPN integration with Adastra: https://www.youtube.com/watch?v=vl4-P4Vem4

16.3 System User Roles

The service user roles would be as follows:

- **read/write/create**
  This will allow users to read and amend existing records and create new records.

- **read/write**
  This will allow users to read and amend existing records.

- **read only**
  This will allow users to read existing records only.

16.4 Patient Information Leaflet

EPaCCS - Patient GuideFINAL.pdf

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