Electronic Palliative Care Coordination System (EPaCCS) for Suffolk

Service Description and Process

Version 1.1

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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 the Electronic Palliative Care and Coordination System or EPaCCS used in Suffolk. It describes the SystmOne Unit used as the central database for the system and how both SystmOne and non-SystmOne GPs and other providers access the system to create, view and change patients records.

The document should be read in conjunction with the SystmOne user guides that provide detailed information about the SystmOne implementation and how to create and view EPaCCS records. These documents are referenced at the end of this document.

EPaCCS Clinical Background & 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 (EPaCCS) 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. A list of the data in the standard requires to be held is given in Annex X.

Integration with Yellow Folder Process

The End of Life, patient held, Yellow Folder record system, contains core information for those with a life limiting illness, easily accessible by all agencies.

The folder contains the following documents;

- DNACPR Form
- GSF Thinking Ahead
- Suffolk GSF Patient Passport
- Directory of Key Contacts

The EPaCCS process will run in parallel with the existing yellow folder process. As with the current yellow folder process, patients are identified as being in the final year of life using the GSF coding prognostic indicator guidance. This is reproduced below for reference.
A suitably competent health care professional will facilitate an Advance Care Planning discussion with the patient and will seek consent to enter them onto the Suffolk EPaCCS. The outcome of the advance care planning discussion is recorded using the existing yellow folder process. The initiating clinician will then be required to create an EPaCCS entry and share this record so that other providers of end of life care, such as Acute Hospital, Out of Hours service, Ambulance service can view the information. It is essential that should the patient’s wishes change these are documented in both the yellow folder and EPaCCS. Should the information in the Yellow Folder be different from the information in the EPaCCS record, the Yellow Folder takes precedence.

New Yellow Folder issues will contain a new document that lists the items held in the patients EPaCCS record. This document is included to act as an aide memoir for clinicians to remind them to change or initiate a change to the record when necessary. This document is reproduced in Annex 9 for reference.

Service Description
The Suffolk EPaCCS service is based on a SystmOne Unit hosted by St Elizabeth Hospice. The system holds an EPaCCS record for all patients in Suffolk who are considered to be in the last year of their life, and who have consented for their clinical record to be shared.

The process by which a patient’s EPaCCS record is created and managed, depends on the clinical systems used by the patient’s GP practice and other providers of their care. GPs and other providers who use SystmOne and have ‘write’ access, have direct access to create and maintain a patient’s EPaCCS record, whilst GPs and providers who use other clinical systems, will create and manage the record using the data inputting service provided by St Elizabeth Hospice.

The following paragraphs outline the roles of St Elizabeth Hospice, General Practitioners and other providers in creating, maintaining and using EPaCCS records.

St Elizabeth Hospice
St Elizabeth Hospice plays a key central role in the EPaCCS service, and has the following main responsibilities:

- To host and administer the EPaCCS SystmOne Unit
- To create and maintain EPaCCS records on behalf of GP practices and other providers who do not use SystmOne.
- Quality checking all received data against minimum standards, and chasing providers where data is missing or thought to be in error.
- Checking that a Special Patient Note has been created for new patients
- Notifying all providers when a new EPaCCS record has been created
- Notifying non-SystmOne practices when changes have been made to their patients EPaCCS records.
Publication of performance reports.

The hosting service is operational 365 days of the year during the following times:

- Monday to Friday: 0900 to 1700
- Weekends and Bank holidays: 1000 to 1500

St Elizabeth’s role is fully described in WSCCG specification ‘Hosting Service Specification for the Electronic Palliative Care Coordination System’. This document forms the basis of the contract between the hospice and the CCGs.

It should be noted that St Elizabeth Hospice have a limited SystmOne ‘tree’ that restricts their view of the patient’s record to the following items:

- EPaCCS Template and Views
- Medications
- Last 15 days of the full journal

Creating an EPaCCS Record - SystmOne practices

An EPaCCS record can only be created or initiated by the patients GP. The GP creates the record by entering data into the SystmOne EPaCCS Main template that the system administrator will have loaded on the system. The data to be entered is described in the paragraph, ‘EPaCCS Data Set’ later in the document.

Having entered details into the patient’s record, the record must be shared and referred to St Elizabeth Hospice as follows:

- After gaining the patient’s consent, the patient’s record must be set to be shared both OUT and IN. This ensures that other providers will be able to see the record, and the GP will be able to see any changes made to the record by other providers.
- The GP must also make an electronic referral to St Elizabeth Hospice. St Elizabeth will quality check the patients EPaCCS record and notify all providers that a new patient has been added to the system. This information can be used by providers to flag patients with EPaCCS records on their clinical systems. St Elizabeth will also check that a Special Patient Note has been created for the patient so that information is available to the NHS 111 and Out of Hours services.

Further details are included in process map in Annex 1.

Creating an EPaCCS Record - Non-SystmOne practices and providers

An EPaCCS record can only be created or initiated by the patients GP. As non-SystmOne practices cannot create an EPaCCS record on the SystmOne Unit directly, the record is created by sending the patients EPaCCS data to St Elizabeth Hospice, who will create the record their behalf. The data to be entered is described in the paragraph, ‘EPaCCS Data Set’ later in the document.

The way that the data is entered into the patient’s local clinical record and made available to St Elizabeth Hospice is dependent on the GPs clinical system, and described in the following table. The patients consent to share their record must be obtained and recorded.
<table>
<thead>
<tr>
<th>Clinical System</th>
<th>Data Entry</th>
<th>Extract data and make available to St Elizabeth Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td>EMIS Web</td>
<td>Use template developed by WSCCG IM&amp;T. Available from IM&amp;T, please call Abbey Wallace or Graham Hillson on 01473 770222</td>
<td>Run report to detect patients at end of life. Export EPaCCS data to PDF and send by NHS mail to St Elizabeth Hospice</td>
</tr>
<tr>
<td>EMIS LV</td>
<td>Practices develop their own template. Note 2</td>
<td>Run report to detect patients at end of life. Export EPaCCS data to PDF and send by NHS mail to St Elizabeth Hospice. Note 1</td>
</tr>
<tr>
<td>Other systems</td>
<td>Practices develop their own template. Note 2</td>
<td>Export data to PDF or use EPaCCS Word template below. Note 1</td>
</tr>
</tbody>
</table>

St Elizabeth Hospice will audit the received information and create a SystmOne EPaCCS record for the patient. Initially the data will be marked as ‘private’ so that it cannot be shared. Once the data has been verified by the patients surgery, St Elizabeth remove the private setting, and set the patients record to be shared OUT and shared IN.

St Elizabeth will also notify all providers that a new patient has been registered on EPaCCS and check that a Special Patient Note has been created by the patients GP on the Out of Hours/NHS 111 system, Adastra. Further details are given in the process map in Annex 3.

Note 1. An alternative method to submit patient data to St Elizabeth Hospice, is to use of the Word version of the EPaCCS template below.

![EPaCCS Word Template_v1.docx](http://www.isb.nhs.uk/library/standard/236)

Note 2. Practices developing their own templates should refer to the Information Standards Board specification, End of Life Care Co-ordination: Core Content Standard, ISB1580 version 3. This specification gives the Read codes to be used for the local patient record. The specification can be found at this link: [http://www.isb.nhs.uk/library/standard/236](http://www.isb.nhs.uk/library/standard/236)

### Changing an EPaCCS Record

GPs and other providers who have SystmOne write access can change a patient’s EPaCCS record by opening the EPaCCS template and inputting the changes directly. Non-SystmOne GPs and providers will need to submit changes to St Elizabeth Hospice on a Word or PDF version of the template so that they can enter the change on behalf of the provider. Where changes are entered into the record by St Elizabeth Hospice, verification processes are specified to confirm that the changes have been made correctly before it is shared.

A standard report has been created that enables St Elizabeth Hospice to identify any changes that have been made to the EPaCCS record for patients registered to non-SystmOne practices. St Elizabeth will communicate those changes to the patients practice so that action can be taken if
required. A verification process is specified to ensure that the practice receive the communication correctly.

For SystmOne practices, a further report has been created that enables the practice to detect any changes made to their patients EPaCCS records by other providers, so that appropriate action can be taken.

Whenever an EPaCCS record is changed, the clinician should always consider the effect on the Yellow Folder to determine if this also needs to be changed. Similarly, if a Yellow Folder item is changed, this should be reflected back onto the EPaCCS record if necessary.

The change processes are specified in more detail in the following process maps:

- Annex 2: SystmOne practices
- Annex 4: Non-SystmOne practices
- Annex 5: SystmOne providers
- Annex 6: Non-SystmOne providers

**EPaCCS Data Set**

The data set to be captured for a patient’s EPaCCS record is specified by the Information Standards Board specification; End of Life Care: Core Content Standard Specification, ISB1580, version 3. A list of the core data items is given in Annex 9. The list also includes a small number of items that are specific to the Suffolk implementation of the service.

As all of the data may not be available at the time the EPaCCS record is created, Suffolk have specified a minimum data set of the data items that must be present to create a valid EPaCCS record. The minimum data set is defined by the mandatory items in Annex 9. St Elizabeth Hospice will check that minimum data set is present for all new records.

**Consent**

It is essential that the patient’s consent is given before their record is shared out and this decision must be documented in the EPaCCS record. Where at patient does not consent for their record to be shared, this must also be captured in patient record using Read Code XaQVo,’ Refused Consent for Electronic Record Sharing’

Where the patient’s carer or next of kin details are documented in the EPaCCS record, the carers implied consent for their information to be included on the record is assumed. This decision is captured on the EPaCCS Service’s Privacy Impact Assessment.

In addition to a patient deciding that they do not want their record shared, they may also decide that they do not want to be part of any End of Life plan managed by their surgery. GPs will need to manage this situation using their own procedures.

**Process Maps**

The EPaCCS process outlined in the Service Description above is further defined by a series of process maps, given in the appendices to this document. The following processes are defined:
Summary of Roles and Responsibilities

The following table defines the key roles of each of the main providers in the EPaCCS service. Please also refer to the notes below the table.

<table>
<thead>
<tr>
<th>Provider</th>
<th>Yellow Folder</th>
<th>EPaCCS Record</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Create</td>
<td>Change</td>
</tr>
<tr>
<td>GP Practices</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Hospices</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Specialist palliative care teams in Acute Hospitals</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Marie Curie</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Suffolk Community Health</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Ambulance Service</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Acute Hospital Teams</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Out of Hours Service</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Care Homes</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>

- **Note 1.** This is a future requirement for St Nicholas Hospice and is dependent on their project to install SystmOne at the Hospice.
- **Note 2.** This is a future requirement for Harmoni, and is dependent on their project to install SystmOne at their Ransomes Call Centre

**General**

**Viewing an EPaCCS record.** Anyone with a legitimate reason to do so may view the EPaCCS record. For example a Community Nurse who has received a referral in relation to a patient, Doctor at the Hospital who is aware that the patient is an “end of life” patient. (This will be flagged via a regular email generated from the EPaCCS co-ordination centre)

**Changing the contents of the Yellow Folder or EPaCCS record.** It is acknowledged that patients may change their minds in relation to their choices at the end of life. It is essential this is reflected in both the yellow folder and the EPaCCS record.

**Yellow Folder Creation.** A yellow folder may be created under existing processes by a suitable qualified and competent clinician, following a conversation with a patient regarding their choices for
their care at the end of their life. Once a yellow folder has been put into place, if appropriate, a supporting EPaCCS record also needs to be created by the patients GP.

When a Yellow Folder is created, it is essential that the patients GP is notified, and that a Special Patient Note is created on Adastra, so that the Out of Hours and local NHS 111 service are aware that the record exists.

Note that the DNACPR must be reviewed and endorsed by a responsible senior clinician. Please refer to Annex X, DNACPR – Key Messages for GPs

Acute Hospitals. Acute hospitals will be informed of any new EPaCCS patients registered on the system by an NHS mail sent by St Elizabeth Hospice. They will then add a flag to their IT system to highlight that the patient is an identified end of life patient. Should the patient attend the hospital the flag will highlight to the clinician that there is an EPaCCS record that the clinician may then view via the Clinical Record Viewer.

Suffolk Community Health. Identify End of Life care patients using the Gold Standards Framework (GSF) Needs Based Coding. All identified patients will need to be discussed at the relevant practices next GSF meeting and be entered on the GSF register by the practice. Yellow Folders are to be initiated with ALL patients when coded ‘GREEN’ and ‘flagged’ onto the practices’ IT system. Once the process is initiated, the practice will supply the Yellow Folder

Out of Hours Service. The hosting service will ensure there is a Special Patient Note in place for all patients with an EPaCCS record. The out of hours service will be able to view these notes when seeing patients. Should the patients yellow folder require a change following contact with the service the OOH GP will amend the folder and make a note in Adastra for the patient’s GP to update the EPaCCS record. Adastra will message the patients GP with the visit report and an instruction to change the EPaCCS record.

Ambulance Service
Ambulance Service. The ambulance service has the ability to read EPaCCS information at the control centre. It is expected, but not confirmed, that this information will be used to inform the dispatcher and the ambulance crew of the patient’s situation. For information, when an ambulance is dispatched from the NHS 111 service in Suffolk, any

Special Patient Notes held on the local 111 systems Adastra control system, are made available to the ambulance service.

Care Homes. Yellow folders will be initiated as currently and the GP will create the EPaCCS entry. Care home staff will not be able to view or amend the EPaCCS record, this will have to be done via the GP.

When a patient dies. Health care professionals are asked to update the After Death tab of the EPaCCS record with details of where the patient died, whether they achieved their preferred place of death and, if they did not, the reason why this did not occur. It is important that this information is captured as it will help in the planning of end of life services going forward.
Marie Curie – will be able to view the EPaCCS record for the patients that they are involved with?? We also want them to be able to write eventually??

**SystmOne Design**

**Templates**
The SystmOne design is based on a standard Community unit adapted for EPaCCS use. Records are created by entering information into a specially designed EPaCCS template which has four tabs that segregate the data into logical sections:

- Medical
- Personal
- Relationships
- Choices
- After Death

The template has been designed with drop down menus and check boxes to simplify data entry wherever possible. There are two versions of the template:

- EPaCCS Main Template. This version of the template is used only by GPs to create the patient’s EPaCCS record. It includes fields to enter the QOF code and diagnosis code.
- EPaCCS Change Template. This version of the template is identical to the Main template other than it does not have fields for the QOF code or diagnosis code. It is used by providers who have write access to enter or change information in the patients EPaCCS record.

**Views**
There are 5 EPaCCS Views available; a full view that shows the entire record and 4 partial views that reflect the 4 tabulated sections of the template.

**Status Markers**
The template automatically creates the following Status Markers in the demographics area of the patient’s record. These provide a quick visual indication about key elements of the record. The following are provided:

- Orange circle: Patient is EPaCCS registered
- Triangle: The triangle will be Red, Amber or Green according to the patients GSF status
- Triangle with red border and exclamation mark: Not for attempted CPR
- Scroll: Yellow Folder exists

**Reports**
The system automatically creates a number of reports to manage changes and inform performance reporting. The following are provided:

- EPaCCS Unit. EPaCCS Daily Update Non-SystmOne GP Report. This report identified changes that have been made to the EPaCCS records of patients who are registered at GP
practices that do not use SystmOne. St Elizabeth Hospice will use this report to notify the patients GP that changes have been made.

- **EPaCCS Unit. Place of Death.** This report lists all patients who have died against their preferred and actual places of death. Analysis of this report will be used as the basis for the performance report created by St Elizabeth Hospice.

- **GP Unit. EPaCCS Daily Update Report GP.** This report identifies all patients whose EPaCCS record has been changed by another provider in the previous (not the current) 24 hour period.

- **All Units. EPaCCS New Patients.** This report can be run by any SystmOne provider to identify new patients registered on EPaCCS.

**St Elizabeth Hospice Contact Details**

- Email: suffolkEPaCCS@nhs.net. Note that Patient Confidential Data must only be sent to St Elizabeth Hospice by NHS Mail.
- EPaCCS team number: 01473 707990

**Performance reporting**

EPaCCS will have the ability to generate information in relation to the number of patients who achieved their preferred place of care and, in incidents where this was not achieved, capture the reasons as to why this was so. This information can be used to plan end of life services to ensure more patients are supported to achieve their wishes at the end of their life. These reports will be anonymised and seen by commissioners of end of life care and can also be shared with providers.

**How to report problems with the EPaCCS Service and process**

The EPaCCS service is jointly owned by the West Suffolk and Ipswich and East CCGs who will conduct regular reviews with St Elizabeth Hospice. Problems with the service should in the first instance be raised with St Elizabeth Hospice, who will escalate to the CCGs as necessary. Please contact St Elizabeth Hospice on 01473 707990.

**References**

Further information on the use of SystmOne for EPaCCS and EDSM is available from the following sources:

- **SystmOne GP EPaCCS User Guide.** Available from IT
- **Provider View and Update User Guide.** Available from IT
- **View Only User Guide.** Available from IT
## Configuration Management

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<td>DNACPR GP advice and process maps added. Many minor changes to text and structure</td>
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<td>1.1</td>
<td>21/1/14</td>
<td>Graham Hillson</td>
<td>Para, Creating EPaCCS record by non-SystmOne practices updated. Document changed to reflect core data changes specified in ISB1580 version 3. Typos fixed and other minor changes</td>
</tr>
</tbody>
</table>
Annex 1: Create EPaCCS Record – SystmOne GP Practices

1. GP/practice identifies new patient at end of life

2. Does patient have a Yellow Folder?
   - Yes: Create EPaCCs record
   - No: Create Yellow Folder under existing processes

3. Request to create EPaCCs record from another provider

4. Create EPaCCs record

5. Gain patient’s consent to share record. See note 1 Enable Sharing Out. Make Direct Electronic Referral to St Elizabeth Hospice

6. SEH accept referral and quality check data against minimum reqts

7. Data OK

8. Log into Adastra, has SPN been created?
   - Yes: SEH Notify all providers that a new patient has been added to EPaCCS
   - No: Remind GP to create SPN

9. Verified EPaCCs record shared on SystmOne

10. SEH Notify all providers that a new patient has been added to EPaCCS
Annex 2: View or Change EPaCCS Record – SystmOne GP Practices

GP/practice needs to view or change patients EPaCCs record

View or change?

Open full or partial views

Is Yellow Folder impacted?

Arrange to change Yellow Folder contents

Open EPaCCs template and enter changes

Changed EPPaCCs record on SystmOne
Annex 3: Create EPaCCS Record – Non SystmOne Practice

1. GP/Practice identifies new patient at the end of their life
2. Does patient have a Yellow Folder?
   - Yes: Complete EPaCCs Word Template and send by NHS mail to St Elizabeth hospice.
   - No: Create Special Patient Note
3. SEH quality check data against minimum reqts
   - Data OK: SEH create EPaCCs record and mark as PRIVATE. Copy returned to GP for verification
   - Data errors: Request to create EPaCCs record from another provider
4. GP/practice verifies data is complete and correct
   - Data OK: SEH uncheck PRIVATE setting in patients record. Enable record to be shared out
   - Data errors: SEH quality check data against minimum reqts
5. Log into Adastra, has SPN been created?
   - Yes: SEH Notify all providers that a new patient has been added to EPaCCs
   - No: Remind GP to create SPN
6. Verified EPaCCs record shared on SystmOne
Annex 4: View or Change EPaCCS record – Non-SystmOne Practice

1. View or Change patients EPaCCs record
   - Enter changes required on EPaCCS Word template and send by NHS Mail to St Elizabeth Hospice
   - Is Yellow Folder impacted?
     - Yes: Arrange to change Yellow Folder
     - No: SEH quality check data against minimum reqts
       - Data errors: Data OK
         - Data OK: GP/practice verifies data is complete and correct
           - Data OK: SEH uncheck PRIVATE setting in patients record
             - Changed EPaCCS record on SystmOne
               - Electronic viewing not possible, contact St Elizabeth Hospice on 01473 707990

2. Data OK: SEH make changes to EPaCCS record and mark as PRIVATE. Copy returned to GP for verification
   - Data errors: Data OK
     - Data OK: SEH uncheck PRIVATE setting in patients record
       - Changed EPaCCS record on SystmOne
Annex 5: View or Change EPaCCS Record – SystmOne Providers

View or change patients EPaCCs record

View or change?

View or change patients EPaCCs record

Is Yellow Folder impacted?

No

Open EPaCCs template and enter changes

SEH run daily report to identify changes to EPaCCs records for patients of Non-SystmOne practices.

Is patients GP SystmOne

No

SEH notify patients GP of the change and confirm receipt

Yes

Changed EPaCCs record on SystmOne

Open full or partial views

Arrange to change Yellow Folder

Yes

View
Annex 6: View or Change EPaCCS Record – Non-SystmOne Providers

View or Change patients EPaCCs record

Electronic viewing not possible, contact St Elizabeth Hospice on 01473 707990

View or Change?

View

Change

Is Yellow Folder impacted?

No

Yes

Arrange to change Yellow Folder

Enter changes required on EPaCCS Word template and send by NHS Mail to St Elizabeth Hospice

SEH quality check data against minimum reqts

Data OK

Data errors

SEH change data in EPaCCS record and mark as PRIVATE. Copy returned to provider for verification

Provider verifies data is complete and correct

Data OK

Data errors

SEH uncheck PRIVATE setting in patients record

Is Patients GP SystmOne

No

SEH notify changes to GP and confirm receipt

Yes

Changed record available on SystmOne
Annex 7: View or Change EPaCCS Record – Harmoni Out of Hours

OOH GP Visits patient

Does patient have an EoL SPN?
- Yes: Clinical intervention as required
- No: Continue under existing processes

Does Yellow Folder need to be changed?
- Yes: Arrange to change Yellow Folder
- No: Continue under existing processes

Does patients EPaCCs record need to be changed?
- Yes: Make note in Adastra for patients GP to update EPaCCs record
- No: Continue under existing processes

Adastra messages patients GP with visit report and instruction to change EPaCCs record

GP updates patients EPaCCs record
Annex 8: View or Change EPaCCS Record – Ipswich Hospital Trust

1. Patient arrives at IHT and is registered on PAS
   - Check for EPaCCs record using CRV

2. Does patient have Yellow Folder or is flagged on Evolve as End of Life?
   - Yes: Continue under existing IHT processes
   - No: Continue under existing IHT processes

3. Is there a clinical suspicion that patient is at end of life?
   - Yes: Create Yellow Folder under existing processes
   - No: Continue under existing IHT processes

4. Does patient need a Yellow Folder?
   - Yes: Create Yellow Folder under existing processes
   - No: Continue under existing IHT processes

5. Does patient need an EPaCCs record?
   - Yes: Send request and Word template to patients GP by NHS Mail
   - No: Continue under existing IHT processes

6. Does existing EPaCCs record need to be changed?
   - Yes: Enter changes required on EPaCCs Word template and send by NHS mail to St Elizabeth Hospice
   - No: Continue under existing IHT processes

7. Does existing Yellow Folder need to be changed?
   - Yes: Arrange changes to Yellow Folder
     - Data OK: Update Evolve if required
     - Data errors: End
   - No: Continue under existing IHT processes

8. ADT: Discharge summary/Outpatient letter to GP as required

9. End

-Verified EPaCCs record shared on SystmOne
Annex 9. Data Items on EPaCCS Record

This annex summarises the core data items held in the patients EPaCCs record. There are two groups of data items; those required by the specification, End of Life Coordination: Core Content, ISB 1580 version 3, and those required by the Suffolk implementation of EPaCCS. The Mandatory Item column indicates the data items that comprise the minimum data set specified by Suffolk CCGs, and must be present to create a valid EPaCCS record.

A copy of this list will be given on a new form to be included in the patients Yellow Folder. Clinicians caring for the patient should check if any of the items have changed, and if so, ensure that the changes are reflected in the patients EPaCCS record. If the clinician has write access to the patients EPaCCS record, they should make any changes themselves. If they do not have write access, they should note any changes on the Word version of the template, and send by NHS Mail to St Elizabeth with the changes clearly marked and initialled. St Elizabeth will enter the changes into the patient’s record and verify that they have been made correctly with the provider of the change.

*Please note that for the list to be included in the Yellow Folder, items 48 and 49 have been deliberately omitted because of their sensitive nature.*

### Summary of Data Items to be held on patient’s EPaCCS Record

<table>
<thead>
<tr>
<th>ISB 1580 v3 Reference</th>
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<tr>
<td>3</td>
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<td>Date and Time of Last Amendment</td>
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<td>Yes</td>
<td>Person Family Name</td>
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<td>5</td>
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<td>6</td>
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<td>Is Main Informal Carer Aware of Persons Diagnosis</td>
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<td>Practice Details including Fax and Phone Numbers</td>
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<td>Yes</td>
<td>Primary End of Life Diagnosis</td>
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<td>Yes</td>
<td>Other Relevant End of Life Care Diagnosis and Clinical Issues</td>
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<td>Allergies/Adverse Drug Reactions</td>
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<td>Yes</td>
<td>Anticipatory Medicines/Just in Case Box Issued</td>
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<td>Yes</td>
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<td>30</td>
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<td>EoLC Tool in Use? (e.g. GSF, ICP PPC, other)</td>
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<td>31</td>
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<td>Advance Statement Requests and Preferences</td>
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<tr>
<td>32b</td>
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<tr>
<td>32c</td>
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<td>Preferred Place of Death, 1st Choice is Usual Place of Residence</td>
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<td>Preferred Place of Death, 2nd Choice, Organisation Name</td>
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<td>33b</td>
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<td>33c</td>
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<td>34</td>
<td>Yes</td>
<td>DNACPR Decision Made</td>
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<tr>
<td>35</td>
<td>Yes</td>
<td>Date of DNACPR Decision</td>
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<tr>
<td>36</td>
<td>Yes</td>
<td>Date of Review of DNACPR Decision</td>
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<td>37</td>
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<td>Location of DNACPR Documentation</td>
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<td>38</td>
<td>Yes</td>
<td>Person has made an Advance Decision to Refuse Treatment</td>
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<td>Location of Advance Decision to Refuse Treatment</td>
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<td>Name of Lasting Power of Attorney for Personal Welfare</td>
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<td>41</td>
<td>Yes</td>
<td>Authority of LPA</td>
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<td>42</td>
<td>Yes</td>
<td>Telephone Numbers Concerning Lasting Power of Attorney</td>
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<td>Yes</td>
<td>Name of Additional Person to be Involved in Decisions (1)</td>
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<tr>
<td>44</td>
<td>Yes</td>
<td>Telephone Number of Person to be Involved in Decisions (1)</td>
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<tr>
<td>45</td>
<td>Yes</td>
<td>Name of Additional Person to be Involved in Decisions (2)</td>
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<td>46</td>
<td>Yes</td>
<td>Telephone Number of Person to be Involved in Decisions (2)</td>
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<td>47</td>
<td>Yes</td>
<td>Other Relevant Issues or Preferences about Provision of Care</td>
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<td>48</td>
<td>Yes</td>
<td>Actual Place of Death</td>
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<td>49</td>
<td>Yes</td>
<td>Date of Death</td>
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</tbody>
</table>

**Additional Data Items for Suffolk EPaCCS Implementation**

A. Yes  Is Patient Aware of Diagnosis
B. Gold Standard Framework Status: Green, Amber or Red
C. Yellow Folder: Confirmation that patient has a Yellow Folder and the Date issued
D. Yellow Folder: Confirmation that the following documents are included in the Yellow Folder and are live:
   - Directory of Key contacts
   - Thinking Ahead – Advance care Planning Discussion
   - End of Life Plan
   - DNACPR

The embedded document below is the form to be included in the Yellow Folder:
Annex 10 - Do Not Attempt Cardiopulmonary Resuscitation [DNACPR] Key Messages for GPs

Do Not Attempt Cardiopulmonary Resuscitation [DNACPR]

East of England regional DNACPR documentation has been rolled out to all sectors and care settings across the region to enable a DNACPR order once completed to follow the patient and be readily transferable and recognisable between care settings including Hospital Trusts, Community Trusts, GP Practices, Hospices and Care Homes.

Why a regional DNACPR form?

Patients with end of life care needs are now encouraged to develop advance care plans which include the consideration of a DNACPR order.

Senior Responsible Officers [SROs] are also encouraged to assess proactively each individual patient with end of life care needs [as appropriate] in relation to DNACPR. This planned approach aims to reduce inappropriate resuscitation attempts irrespective of where the cardiac arrest takes place.

If a patient requires resuscitation and has a DNACPR order in place immediate information sharing is vital. However at critical points in the patient pathway incompatible systems can lead to DNACPR orders not being followed through and an inappropriate resuscitation being attempted. This can lead to the patient having a painful and undignified death which is also distressing for their loved ones.

Who can make a DNACPR decision?

The decision to complete a DNACPR order is a medical decision and the form must be signed by the original Senior Responsible Officer [SRO]. The SRO is the most senior clinician usually the Consultant or GP in charge of the patient’s care at the time the DNACPR order is made. The patient’s signature [or that of their LPA if the patient lacks capacity] is NOT required but the reason for the DNACPR decision and record of discussion regarding the decision must be clearly recorded on the DNACPR form.

The British Medical Association [BMA] guidance stresses that these decisions should not be made in isolation, but where appropriate, should involve the patient (or those close to the patient if s/he lacks capacity) and others involved in the clinical care of the patient and be clearly recorded on the DNACPR form. Teamwork and good communication are of paramount importance.

The DNACPR form, to be valid, must either state it is an indefinite order or in date [if date set for review] and contain the original Senior Responsible Officer [SRO] signature. The original patient copy signed DNACPR form must stay with the patient and follow the patient when they change care settings for the DNACPR order to remain active.

The patient’s GP Practice should notify the ambulance service as well as the out of hours service that a DNACPR order, once completed is in place. This will then be logged on the local ambulance/out of hours systems so they are aware, if requested to visit, to look for a DNACPR form on arrival.

A DNACPR nurse competency training package has been developed nationally which will enable senior nurses, on completion of this training, to have the option to take on full SRO responsibility for DNACPR decision making. This is being set up across the East of England and the decision to train senior nurses in this extended role will lie with their employing organisation.
Which DNACPR forms can be accepted?

The DNACPR form is available in a triplicate carbonated format or, for GPs, as a single page form to leave with the patient [as the record for clinical notes in GP Practices is held electronically and can be retrieved electronically for audit]. Further forms can either be ordered at cost or printed off for completion. The DNACPR form is also available in Word format for GP Practices to adapt to their GP electronic templates.

Ideally the regional DNACPR form should retain the red border. This is to allow it to be recognised easily at all times and located rapidly in a patient’s health record in case of the patient’s arrest.

Original black and white regional DNACPR forms, whilst not encouraged, are acceptable from GP Practices if fully endorsed with the original SRO signature and stated as indefinite or in date [if date set for review].

There are 2 signature boxes on the DNACPR form as in hospital often a doctor junior to the Consultant initiates and signs the form which the Consultant as SRO must countersign within 72 hours. In the community the GP as SRO only has to sign the form once for it to be valid. However it is recommended the GP signs both boxes for completeness to avoid any ambulance crews who are attending an arrest unnecessarily querying the DNACPR form’s validity where one signature box is empty.

NB: There are ongoing DNACPR information sessions with East of England ambulance crews to reinforce what constitutes a valid DNACPR form.

Photocopied completed regional patient copy DNACPR forms are NOT acceptable.

To reduce the likelihood of inappropriate resuscitation events taking place the completed DNACPR form, which is retained by the patient, should be readily accessible for ambulance crews if a patient arrests.

Where can I access more DNACPR information and resources?

The following DNACPR documents are available:

- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy - electronically
- DNACPR form – electronically or by ordering paper copies [at cost]
- DNACPR Patient information leaflet - electronically
- Frequently Asked Questions - electronically

An e-learning package has also been developed by local clinicians to support all healthcare and care home staff who may be involved in a DNACPR decision. To access the e-learning package, please visit: www.dnacprlearning.co.uk .

For further information about DNACPR in the East of England including ordering DNACPR forms please contact:

Sara Bradley, DNACPR Project Manager, NHS Health Education East of England

Email: sara.bradley@enableeast.org.uk

Tel: 07733 111348