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How can the outcomes of Advance care planning be recorded and made accessible?

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NHS Improving Quality

South East Coast Clinical Senate Meeting - Monday 12th May 2014

Understanding Advance care planning and how best to record and share information

- Consider the context
- Consider the outcomes
- What are the current examples for information sharing?
- Considerations for individuals, providers and commissioners.

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Context

- Advance care planning works best as an aspect of whole systems change needed to provide better ongoing end of life care to people living with serious illness and an uncertain prognosis
- The evidence about advance care planning is mixed but suggest that advance care planning can improve end of life care
- Not every person will wish to engage in advance care planning
- Some people may experience negative outcomes from the process since it may challenge their coping style or bring to mind issues about their illness and their future which they are not ready to think about
- This may be especially true in some social and cultural contexts.

Advance care planning: what does it mean?

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- A **process** of discussion involving an individual receiving care and their care-givers, usually where loss of future capacity is expected
- A means of **setting on record** views, values and specific treatment choices
- Can be done at any time, but is often promoted as particularly important for someone who has a serious and progressive illness
- Based on ideas about the value of **'open awareness'** and **'autonomy'.**

Possible outcomes of ACP

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- The setting out of general values and views about care treatment: non legally binding
- An 'instructional' directive (or 'living will'): advance refusals of treatment can have legal force
- The nomination of a 'proxy' or 'attorney'.

Dunbrack, J. Advance care planning: the Glossary project. Health Canada

English example 1

1. Henry C and Seymour JE (2011) Capacity, care planning and advance Care planning in life limiting illness: a guide for Health and Social Care Staff. NHS Improving Quality

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Specific outcomes in the context of the Mental Capacity Act (2005)

Advance Statement

Advance decisions to refuse treatment

Lasting power of attorney

Current methods

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Ask
+ Document
+ Share
+ Evaluate
= Advance care planning:
It all ADSE up

Click here
to start

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National End of Life
Care Programme
Improving end of life care

Commissioning person centred
end of life care
A toolkit for health
and social care professionals

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to start

The care of all dying patients must improve to the level of the best

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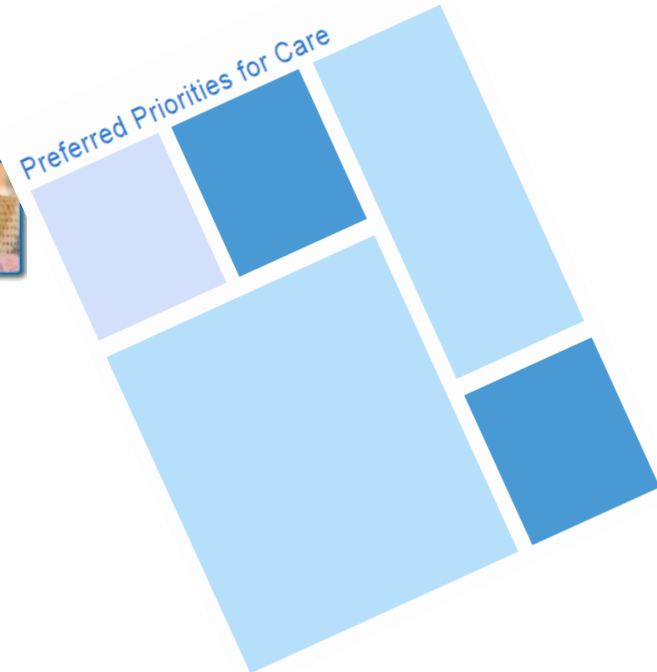
Capacity, care planning
and advance care planning
in life limiting illness
*A Guide for Health
and Social Care Staff*



Preferred priorities for care

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Preferred Priorities for Care (PPC) NOTIFICATION/AUDIT FORM

Dear Colleague
Our patient:
NHS Number:
DOB:

Address:
Telephone No:

Diagnosis:
GP:

Practice Address:

Has completed the above document and has stated a preference to be cared for at:

HOME/ CARE HOME/ HOSPICE/ HOSPITAL (Acute/Community)
(circle as applicable)

Other priorities/preferences for care are:

I give consent for the information contained above to be shared with the professionals identified below YES/NO *(please circle as appropriate)*
If NO has been circled I have had the possible impact of this explained to me YES/NO

I give consent for the information in this document to be used for audit purposes anonymously YES/NO *(please circle as appropriate)*

I confirm that the information contained within the PPC is a true record of my wishes at this time.

Signed...*(please print and sign)*
Date ....

Name of person initiating the document:
Designation:
Place of Work:
Date:
Contact No:

Notification to:	*Please tick*	*Fax Number*	*Date*
General Practitioner			
District Nurses			
District Nurses Out of Hours			
Specialist Nurse			
Community Macmillan Nurses			
Out of Hours GP service			
Hospice			
Hospital *(name)*			
Ambulance Service			
Social Care Worker			
Other relevant professional(name)			

Preferred Priorities for Care (PPC) NOTIFICATION/AUDIT FORM

Dear Colleague
Our patient:
NHS number;
DOB;

Address:
Telephone No:

Diagnosis:
GP:

Practice Address:

PPC Review:
Please note our patient recorded the following changes to preferences and priorities which you need to be aware of:
(please date any review)

Outcome:
Place of death:
Date of death:

Were preferences and priorities stated in PPC achieved YES/NO
If no please state reasons why.
(E.g. problems associated with equipment, OOH, communication, medication, service availability etc.)

Notification to:	*Please tick*	*Fax Number*	*Date*
General Practitioner			
District Nurses			
District Nurses Out of Hours			
Specialist Nurse			
Community Macmillan Nurses			
Out of Hours GP service			
Hospice			
Hospital *(name)*			
Ambulance Service			
Social Care Worker			
Other relevant professional(name)			

Electronic Palliative Care Coordination Systems (EPaCCS) Supporting Care Coordination

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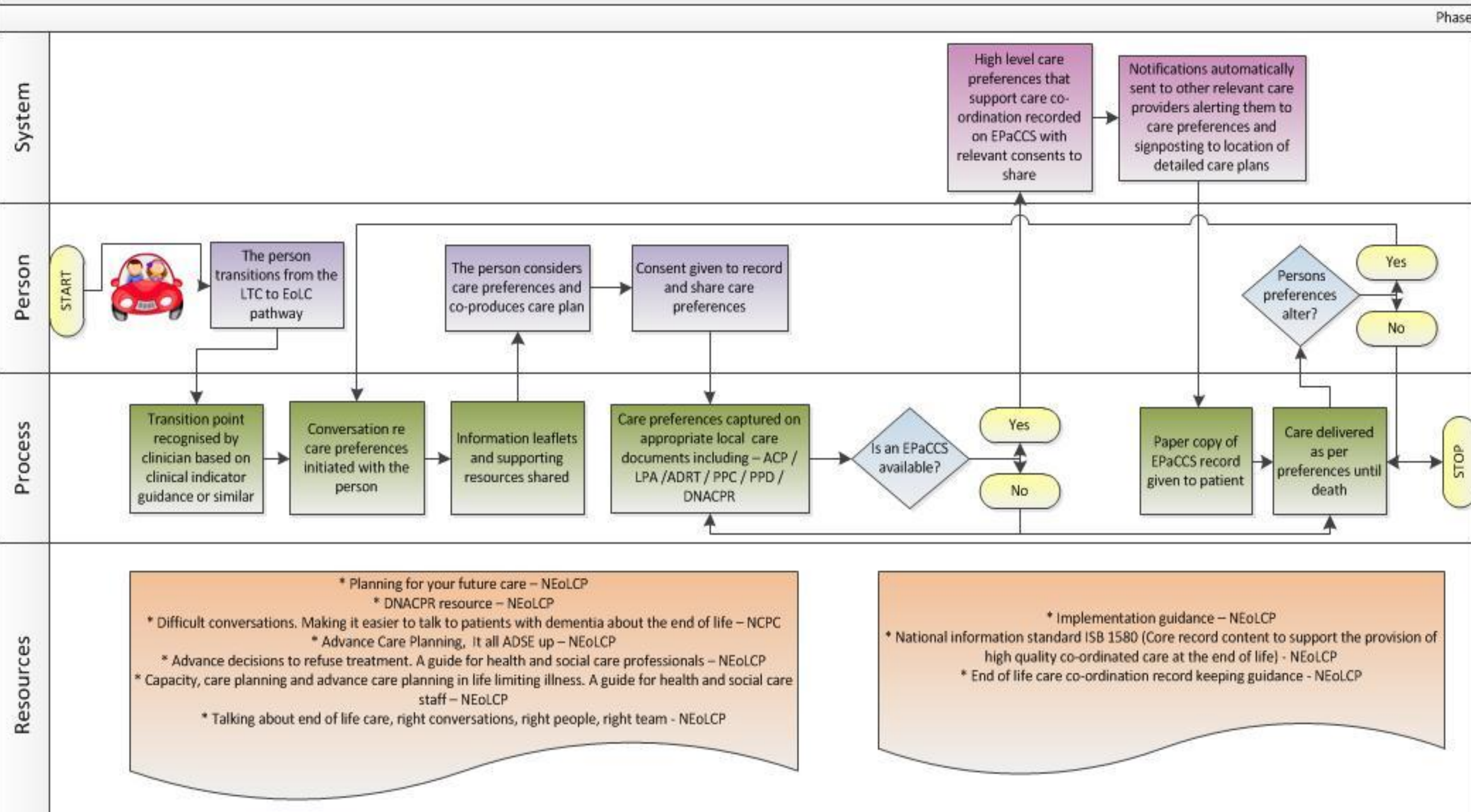

Core content for End of Life Care Coordination
Summary of data items

(Source: Public Health England
End of Life Care Coordination: Summary of record keeping guidance
National Information Standard ISB 1580)

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1 **Consent status***

2 **Record creation* date and record amendment* dates**

3 **Planned review date***

4 **Person's details:**
Name* including preferred name
Date of birth*
Usual address*
NHS number
Telephone contact details
Gender (self declared)
Need for interpreter
Preferred spoken language
Functional status and disability

5 **Main informal carer:**
Name
Telephone number
Is the nominated person aware of the person's prognosis?
Availability of Informal Carer Support*

6 **GP details**
Name of usual GP*
Practice name, address, telephone, fax numbers*

7 **Key worker**
Name
Telephone number

8 **Formal carers** (Health and social care staff and professionals involved in care with lead clinicians (clearly indicated))
Name
Professional group
Telephone number

9 **Medical details**
Primary end of life care diagnosis*
Other relevant end of life care diagnoses and clinical issues
Allergies or adverse drug reactions

10 **"Just in case box"/anticipatory medicines**
Whether they have been prescribed
Where these medicines are kept

11 **End of life care tools in use**
Name of tools, eg Gold Standards Framework, Integrated Care Pathway, Preferred Priorities for Care

12 **Advance statement**
Requests or preferences that have been stated

13 **Preferred place of death**
1st and 2nd choices if made

14 **Do not attempt cardio-pulmonary resuscitation (DNACPR) decision made**
Whether a decision has been made, the decision, date of decision, location of documentation and date for review

15 **Person has made an advance decision to refuse treatment (ADRT)**
Whether a decision has been made, the decision, date of decision and the location of the documentation

16 **Name and contact details of Lasting Power of Attorney**
Has someone been appointed Lasting Power of Attorney (LPA) for personal Welfare?
- without authority to make life-sustaining decisions
- with authority to make life-sustaining decisions

17 **Names and contact details of others (1 and 2) that the person wants to be involved in decisions about their care**

18 **Other relevant issues or preferences about provision of care?**

19 **Actual place of death**

20 **Date of death**

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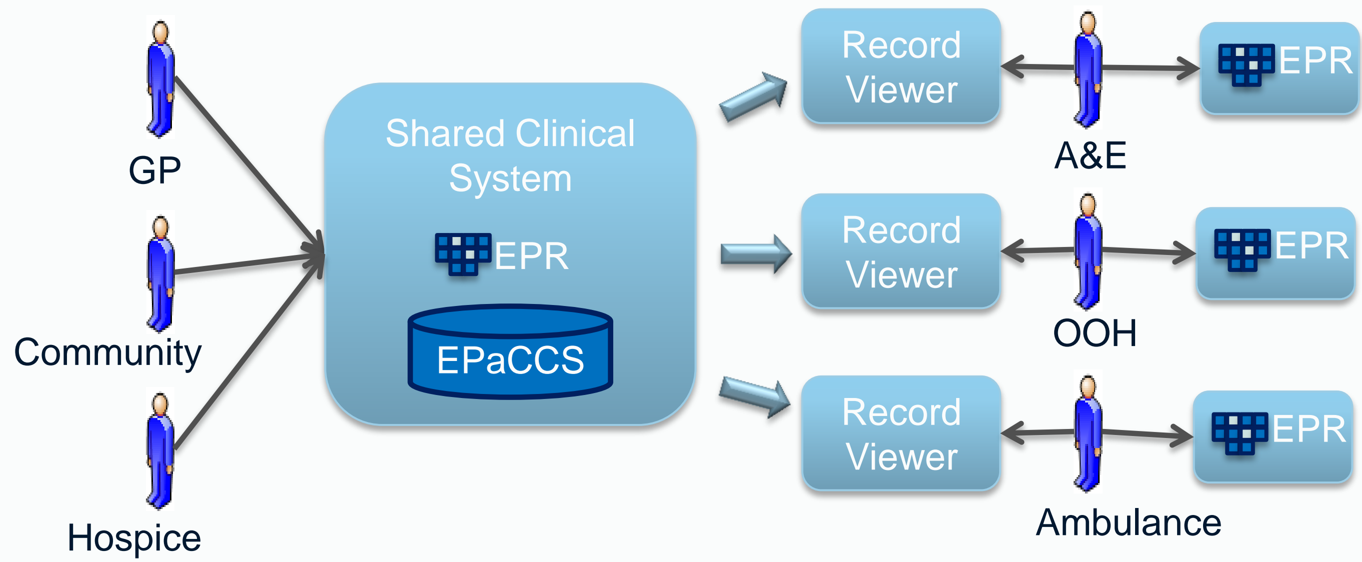
EPaCCS Technical Approach – Examples

- Shared Clinical System:



Benefits

- Re-using existing shared system may be quicker and cheaper initially
- IG controls and agreements may already be in place
- Familiarity for users

Concerns

- Unlikely to ever be used by all care settings
- Granting access outside services already using the system may be difficult or costly
- Getting EPaCCS-specific changes may be challenging if small part of a bigger system
- Could lock services into a single supplier

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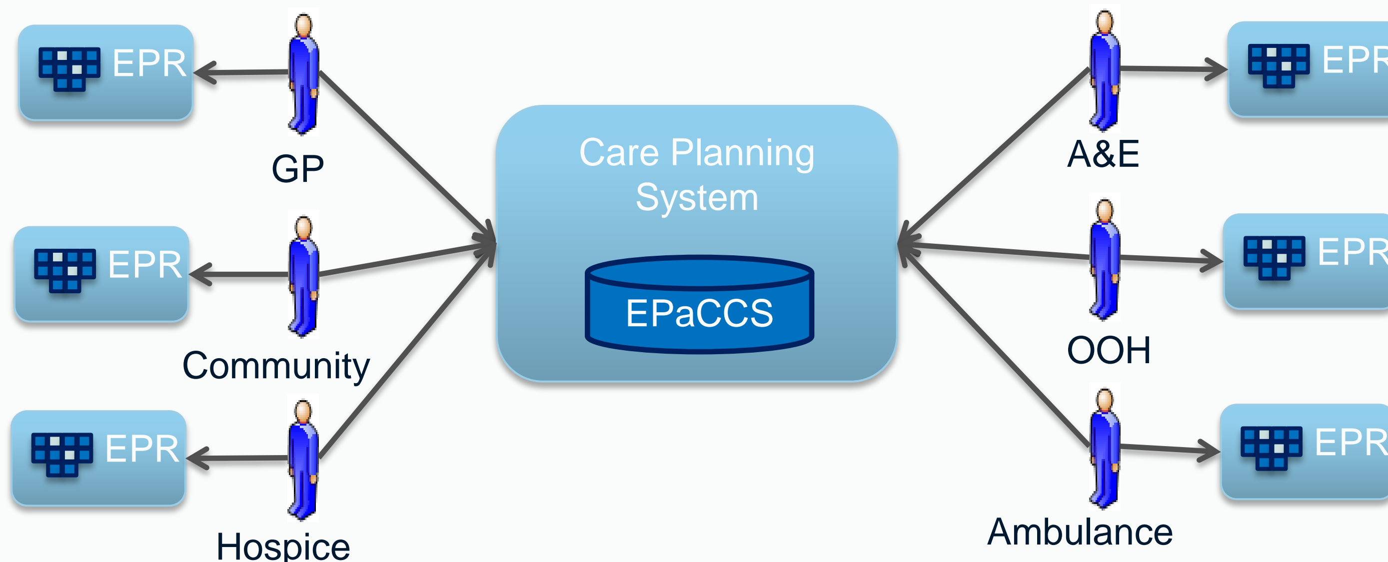
EPaCCS Technical Approach – Examples

- Dedicated Care Planning System:



Benefits

- Can provide access to any clinician over N3
- Does not require any changes to existing clinical systems

Concerns

- Information duplicated from clinical systems – requiring re-keying
- More logins and passwords to remember
- Processes needed to “flag” in other systems so that clinicians know an EPaCCS record exists

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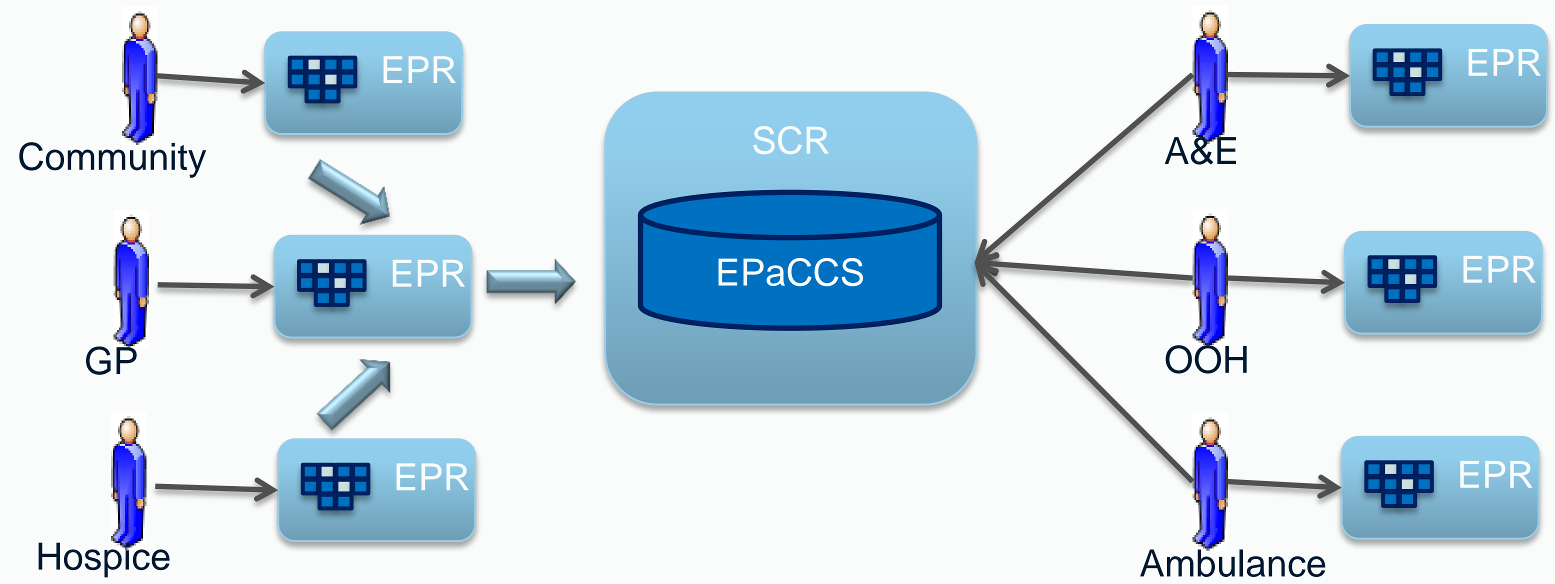
EPaCCS Technical Approach – Examples

- SCR as an EPaCCS:



Benefits

- Once information is recorded in SCR it is available to any clinician in England
- SCR already used in emergency care, where EPaCCS information would be very valuable

Concerns

- The current policy to only allow GPs to update SCR introduces a human bottleneck for all updates
- SCR cannot provide reporting

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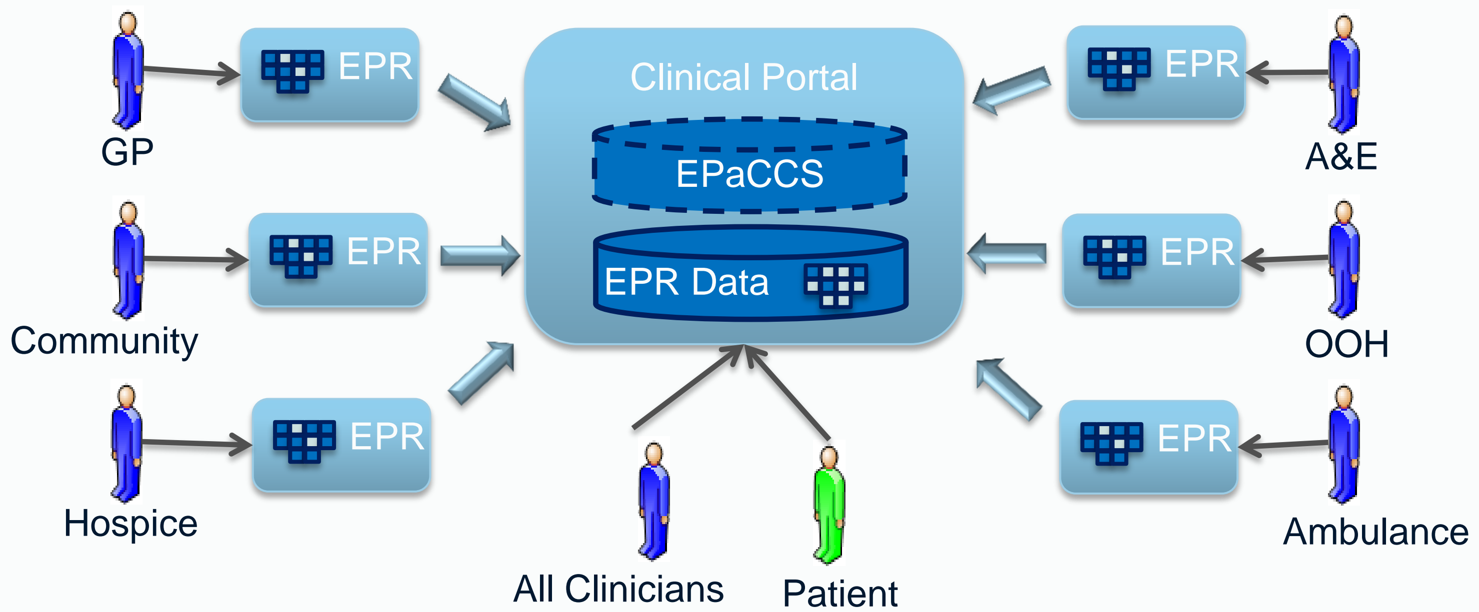
EPaCCS Technical Approach – Examples

- Clinical Portals:



<u>Benefits</u>

- EPaCCS Information can be collated from a range of systems and presented in a single "view"
- Could be extended to provide a patient portal.

<u>Concerns</u>

- Not an actual "EPaCCS" per-se, rather a way of presenting information
- Doesn't address the issues of managing changes to this information.

Operational status of EPaCCS in CCGs

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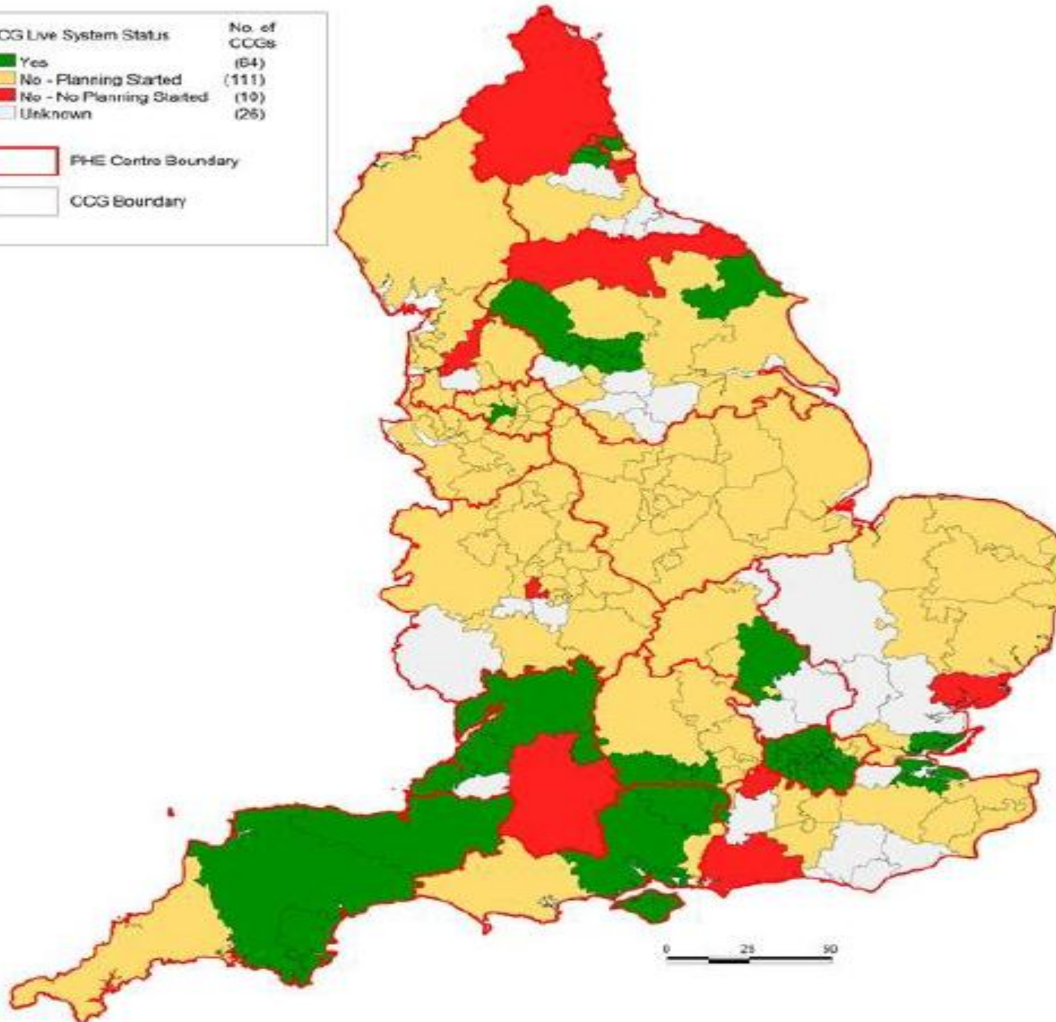

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Summary: Communication and exchange of records

- ACP is a process which involves talking and thinking about one's future care / illness / life with illness
- It can lead to leaving instructions to help others decide, in the event of incapacity
- It can help a person to think about what is important to them as they prepare for illness or the last phase of life, and help them refocus
- Nothing recorded from an ACP discussion should be used in decision making until the person can no longer make current decisions
- Information sharing central to care delivery across boundaries and enabling person centred care
- Consideration of approach critical
- ACP only effective if supported by information systems
- Multi-faceted interventions involving key workers; staff education; recording 'flags' or registers work.

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