How can the outcomes of Advance care planning be recorded and made accessible?
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NHS Improving Quality
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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.
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?

- 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

• 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’.

English example 1


Dunbrack, J. Advance care planning: the Glossary project. Health Canada
Specific outcomes in the context of the Mental Capacity Act (2005)

- Advance care planning
  - Advance Statement
  - Advance decisions to refuse treatment
  - Lasting power of attorney
Preferred priorities for care

Preferred Priorities for Care (PPC) NOTIFICATION/AUDIT

Dear Colleague

Our patient:
NH8 Number:
DOB:

Address:
Telephone No:

Diagnosis:
GP:
Practitioner:

Has completed the above document and has stated a preference to be cared for at:
HOME/CARE HOME/HOSPICE/HOSPITAL (Acute/Community)

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:
Date:
Contact No:
Place of Work:

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)

PPP 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, DOH, 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

**System**
- The person transitions from the LTC to EoLC pathway
- The person considers care preferences and co-produces care plan
- Consent given to record and share care preferences
- Care preferences captured on appropriate local care documents including ACP / LPA / ADRT / PPC / PP3 / DNACPR
- Is an EPaCCS available?
- Are persons preferences altered?
- Paper copy of EPaCCS record given to patient
- Care delivered as per preferences until death

**Person**
- Transition point recognised by clinician based on clinical indicator guidance or similar
- Convention re care preferences initiated with the person
- Information leaflets and supporting resources shared
- High level care preferences that support care coordination recorded on EPaCCS with relevant consents to share
- Notifications automatically sent to other relevant care providers alerting them to care preferences and signposting to location of detailed care plans

**Resources**
- * Planning for your future care – NEoLCP
- * Difficult conversations. Making it easier to talk to patients with dementia about the end of life – NCPC
- * Advance Care Planning, it all ADSE up – NEoLCP
- * Advance decisions to refuse treatment. A guide for health and social care professionals – NEoLCP
- * Capacity, care planning and advance care planning in life limiting illness. A guide for health and social care staff – NEoLCP
- * Talking about end of life care, right conversations, right people, right team - NEoLCP

* Implementation guidance – NEoLCP
* National information standard ISB 1580 (Core record content to support the provision of high quality co-ordinated care at the end of life) - NEoLCP
* End of life care co-ordination record keeping guidance - NEoLCP
# 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)

<table>
<thead>
<tr>
<th>1</th>
<th>Consent status*</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Record creation* date and record amendment* dates</td>
</tr>
<tr>
<td>3</td>
<td>Planned review date*</td>
</tr>
</tbody>
</table>

### 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

### Main informal carer:
- Name
- Telephone number
- Is the nominated person aware of the person’s prognosis?
- Availability of Informal Carer Support* |

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

### Key worker
- Name
- Telephone number

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

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

### “Just in case box”/anticipatory medicines
- Whether they have been prescribed
- Where these medicines are kept

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

### Advance statement
- Requests or preferences that have been stated

### Preferred place of death
- 1st and 2nd choices if made

### 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

### 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

### 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

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

### Other relevant issues or preferences about provision of care?

### Actual place of death

### Date of death
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
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
SCRs 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
EPaCCS Technical Approach – Examples

• Clinical Portals:

Benefits
• EPaCCS Information can be collated from a range of systems and presented in a single “view”
• Could be extended to provide a patient portal.

Concerns
• 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
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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