Electronic Advance Care Planning Record- Challenges and solutions for electronic records documenting Advance and Future Care Planning and DNACPR decisions

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Introduction:

Advance and Future Care Planning (AFCP), also known as Advance Care Planning, is recognised as a priority in End of Life care. There are two fundamental goals in AFCP:

I.   Everyone approaching the end of their life should be given the opportunity to discuss their wishes about future care;

II.   Anyone who expresses wishes should have those wishes respected (where feasible)

Essential for goal (ii) is the ability to share the information so that it is available to the right people, in the right place, at the right time, including accident and emergency staff, out-of-hours GPs and paramedics. At present there is no electronic solution to support this, and Advance Care Plans are currently shared by making paper copies and faxing them to the necessary organisations. This is inefficient, and often ineffective. It also raises governance issues when a scanned copy needs to be reviewed, cancelled or revoked.
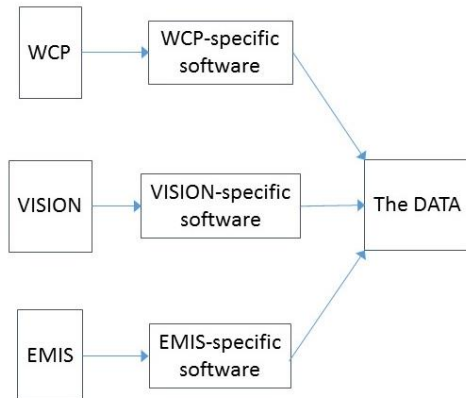
Some important aspects of advance care planning, which will influence the requirements of any electronic AFCP system, are:

• AFCP is a broad concept, covering many diverse actions e.g. DNACPR decisions, treatment escalation plans, writing a will, and appointing a Lasting Power of Attorney.

• Advance Care Planning is an ongoing *process*, rather than a one-off event; there is much evidence that people's wishes change as their health deteriorates. Such plans need to be easy to update,

• Advance Care Planning is a joint responsibility across healthcare teams i.e. ACP discussions may take place in primary or secondary care, with doctors, nurses or other healthcare professionals.

• Advance Care Planning can be led (or driven) by either the healthcare professional or the patient e.g. a renal physician knowing that a person's renal function is deteriorating to the point of requiring dialysis may wish to discuss with the patient whether they wish to consider dialysis or conservative management; a Jehovah's witness may wish to record their desire not to receive blood.

• AFCP most commonly has considered patients whose health is deteriorating in a relatively predictable way; however, healthy people may wish to write an ACP to express their preferences in case of an unexpected, sudden, catastrophic event e.g. a road traffic accident leading to brain injury resulting in persistent vegetative state.

• If a health care professional is to act on the basis of a (digital) ACP record, it may involve decisions about treatments which can prolong or shorten life – with potentially very serious consequences for inaccuracies or errors.
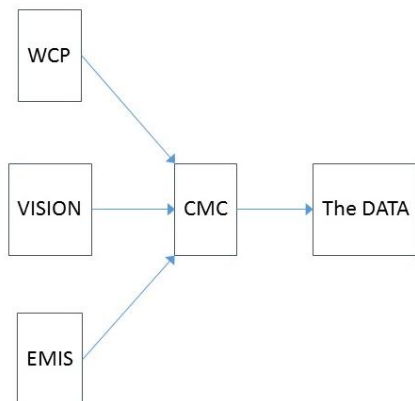
Electronic patient record challenges:

Single interface challenge: As used by healthcare professionals in wales, the term 'Welsh Clinical Portal' (WCP) refers to both the 'portal' and WCP-specific

functionality (that is functionality only available via the 'portal'). For others, such as GPs and WAST to access and process the same data, any WCP-specific functionality relating to AFCP would need to be reproduced in other environments and / or software such as EMIS/VISION/ADASTRA etc.

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'Commercial' AFCP 'solutions' (such as Co-ordinate My Care (CMC)' require minimal software changes to integrate them into the electronic patient record, and use one instance of software to process and handle the data, and communicate with other systems.

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So developing AFCP **into** WCP-specific software does not address the fundamental issue of access by primary care, or thinking further ahead, by patients and carers.

Patient portal challenges:

A truly effective system for documenting and disseminating information about AFCP decisions needs to be accessible not just by healthcare professionals, but by the individuals themselves, so that they can create, view, review, amend and disseminate information about their decisions. Some of these Welsh citizens will be patients at the time they are making these decisions, whilst others will not be in regular contact with any healthcare professional.

The system will therefore need to provide 'Patient Portal' functionality, including the ability to verify a citizen's identity, and the ability for any individual to allow others to view their AFCP record (for example, anybody to whom the individual has donated a Lasting Power of Attorney for Health and Welfare).

Minimum System Requirements:
The AFCP Strategy Group for Wales came up with some minimum requirements for a system, which included:
1. A single source of truth that would contain the latest version of an AFCP.
2. Real-time viewing access to that data by primary/secondary care, OOH, WAST etc.
3. The ability to read AND write to and from the record in both primary and secondary care, and closely integrated into the usual clinical record systems used in each.
4. A system which would allow scanning and/or uploading of ACP documents which the patient may have written, as well as an e-Form.
5. The ability for patients to enter and view their own ACP (even if not available initially, for this to be added in later stages)
6. A clear consent model.

Developing ACP into WCP-specific software would not satisfy points 3-5.

Presumably AFCP is not the only matter that requires a common data source, editable in primary and secondary care, such as patient allergies.

Consent and adding nuanced discussions:
All dedicated 'commercial' AFCP software (Black Pear, CMC, ePACCS etc) has a clear consent model. Either a record is an AFCP, discussed and agreed with the patient, or it is a decision made on behalf of a patient without capacity following the best interests principles of the Mental Capacity Act, which includes discussion with family or carers.

A number of clinicians have expressed the wish to share other clinical recommendations or notes. Examples would be:
- If this patient is admitted to hospital with XXXX, please contact XXXX for further advice.
- This patient is in my opinion imminently dying from metastatic pancreatic cancer. He becomes very distressed talking about dying and refuses to discuss a DNACPR form in the house. His mother who he lives with fully recognises that he is dying and that CPR would be inappropriate in those circumstances.

Sharing this sort of information outlined above, may **not** form part of the ACP record model, because it is inconsistent with the concept of *consented*, shared care plans, so this adds a layer of complexity.

Current Canisc ACP Record
The current Canisc palliative care module includes an ACP record. When used as a record of discussions this is helpful e.g. *"DNACPR discussed – form completed and left in house"*. If it is used to specify exact ACP wishes e.g. *"Patient does not wish to receive antibiotics for life-threatening infection and to be kept at home"* – there are the concerns that:
- Primary care cannot update or change it.
- Consent to share etc. is not documented.
- It is not reliably seen by primary care or WAST etc. (unless they look specifically into WCP).

These are not problems until they are a problem i.e. this probably does not matter most of the time, until something goes wrong e.g. an out of date ACP is followed, and later contested.

Proposed Solution for Canisc replacement /Cancer Informatics Solution / WCP
One solution would address the above concerns about nuanced information:
- Every clinical contact record in the new WCP model could contain a field for "Information pertaining to future care wishes or plans". This would be like the field in Canisc contact used for "Comments regarding Preferred Place of Care".
  Ideally this would also be added to all other clinical contact e-Forms in current use (or in development) by all healthcare professionals e.g. clinic letters, DALs etc.
- A summary report view should be added to WCP, which would filter all records in chronological order which contain text entered in that field.
- The summary report view should have a health warning at the top stating:
  *"The following is a chronological record of clinical entries which contain information relevant to future care wishes or plans. It should **NOT** automatically be assumed that these represent the up to date arrangements or views of the patient/welfare proxy. Please check if there is a more formal Advance & Future Care Planning document in place."*

Every effort should be continued to commission a proper central e-ACP record, but once that is done, the aforementioned functionality would continue to serve the purpose of recording nuanced discussions and/or clinical recommendations which lie outside a formal ACP or RBID. But they would still help a clinician arriving at a patient's home, form a view on what has been discussed and help her/him to form a view on whether to give certain treatments or not.