

Electronic Future¹ Care Plan Record for Wales

BACKGROUND

Context

Advance Care Planning (ACP) is widely recognised as a priority in End of Life care. There are two fundamental goals in ACP:

- 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.

Some important aspects of advance care planning, which will influence the requirements of any electronic ACP system, are:

- ACP 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.
- Advance Care Planning is a joint responsibility across healthcare teams i.e. ACP discussions may take place in primary or secondary care, with doctors or nurses.
- 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.
- ACP 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 life – with potentially very serious consequences for inaccuracies or errors.

¹ The terms Future care plans and Advance care plans are used interchangeably in this document. Future care plans include those prepared on behalf of patients who lack mental capacity; however, the term Advance care plan (which solely relates to care plans agreed with patients with mental capacity) is more widely recognised in clinical use.

Drivers

Strategic drivers

There are two key NHS Wales drivers:

- ACP is identified as a key priority in the End of Life Board (Wales) delivery plan.
- Written statement from the Cabinet Secretary supporting the importance of ACP, and the delivery of an electronic record

Benefits

The project is driven by the opportunity to deliver the following key benefits:

- Advance Care Planning may be considered the ultimate example of co-production, one of the key components of Prudent Health Care, providing improved quality of care given, respecting autonomy, and proven increased in satisfaction for the family and carers.
- Helps prevent unnecessary and/or unwanted medical interventions
- Helps prevent unnecessary and/or unwanted admissions to hospital

Business need

At present, there are multiple different pro-formas used across Wales to record ACP. In order to share the information, these forms are photocopied and mailed or faxed to numerous recipients: out-of-hours care, WAST, hospital records etc. This is time-consuming, difficult to keep updated when plans change, and unlikely to be available to healthcare professionals in all potential situations. These pose clinical governance and legal risks.

There are obvious benefits from an IT-based solution to this problem, providing a single electronic record, accessible to healthcare professionals (and patients) across Wales.

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May 2019