BC Centre for Palliative Care

Best Practices and Core Elements
Advanced Care Planning Documentation in BC

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Background

The BC Centre for Palliative Care (BC CPC) promotes a person-centered approach to care that is respectful of, and responsive to, individual patient/family preferences, needs and values. The Centre is committed to collaboration with members of the public, policy makers, regional health authorities, professional bodies and community organizations to enable excellence in care for all British Columbians living with serious illness.

As a provincial organization, the Centre launched its Advance Care Planning initiative in December 2014 to enable best practices and improve access to Advance Care Planning (ACP) and palliative care supports for patients and families. The Centre's aim for this initiative is to encourage more, better and earlier conversations and to promote care that aligns with individuals' goals so that the wishes of all British Columbians facing a serious illness are expressed, heard and respected.

Best practice to improve open and sensitive communication with patients facing a serious illness is emerging from the Serious Illness Care program out of Ariadne Labs (Dr. Atul Gawande) at Harvard Medical School. This project has had broad uptake globally and since the publication of the article entitled "*Development of the Serious Illness Program: a randomized controlled trial of a palliative care communication intervention*" (Bernacki, R, et al, 2015 BMJ Open), various clinicians have been trained at Harvard and numerous clinicians in BC have begun using the guide in clinical practice.

The BC CPC has been looking at how this work can be supported at a system level. Documentation of ACP conversations, outcomes and treatment decisions is key to enabling patient centred care. Accessible documentation in platforms that allow information to be available to health care providers in all settings, including acute, residential and primary care is essential to ensure patient safety, continuity and quality of care.

In recent workshops with health care providers for the Serious Illness Conversation Guide, expert clinicians noted:

- documentation is facilitated by user friendly electronic interfaces
- platforms to document conversations and decisions are critical in encouraging providers to undertake the conversations

Why are ACP Documentation best practices needed?

Discussion of patient values and preferences and communication that identifies goals of care and treatment decisions supports patient centred care and quality of life throughout the illness trajectory,

even if death is not imminent. The American College of Physicians High Value Care Task Force (JAMA Intern Med. 2014;174(12):1994-2003. doi:10.1001/jamainternmed.2014.5271) reviewed best practices in communication in serious Illness and showed that conversations about goals of care are associated with:

- Better Quality of Life
- Reduced use of aggressive or invasive treatments near death and
- Increased likelihood that patient's wishes were known and followed i.e. they received goal-concordant care 86% vs 30% of the time (Detering, K. BMJ. 2010;340:c1345.)

The review also discussed that patients receiving early palliative care reported improved quality of life, and, in some diseases may survive longer. Preparation for EOL was also associated with improved bereavement outcomes for family/caregivers.

The recent Canadian ACCEPT study (**A**udit of **C**ommunication, **C**ar**e** **P**lanning and Docume**n**tation), involving 10 hospitals from across Canada (including four large BC hospitals), interviewed elderly or seriously ill patients to determine engagement in key ACP process steps and preferences for End of Life (EOL) care. Then a chart audit was done to determine the concordance between preferences and documentation in the medical record. There was agreement only 32% of the time between patient preferences and documentation of their preferences for care (Heyland, D, Barwich D et al, JAMA, Vol 173, May 13t, 2013, (No9) pp 778-787). As noted in the invited commentary in JAMA, the fact that nearly 70% of physician orders relating to intensity of treatment (i.e. CPR and intubation) were discordant with patient wishes should be viewed as a medical error (JAMA Vol. 173, May 13, 2013, p. 787).

Documentation of communication and decision making at end of life is considered a quality indicator that can be used at a system level to guide decision makers as they introduce policies to improve end of life care (Heyland, D. et al, CMAJ, 2017 July 31:89: E980.doi:10.1503/cmaj.1605515). Bernacki (JAMA, 2014) cites a previous study (Wilson C.J. et al, Journal of Palliative Medicine 2013) that no consistent standard exists for location and quality of documentation in electronic health records. ACP information was found 69% of the time in progress notes, 43% in scanned documents and 34% of the time in problem lists with many patients having documentation in multiple locations. This can lead to errors in the provision of care.

Harms of Failure to Address Goals of Care and/or EOL issues

- Patients receive care not consistent with personal goals or stated wishes
- Worse/poor Quality of Life
- Prolonged death with increased suffering
- Worse bereavement outcomes for family/caregivers
- Increased costs without benefit to patients

Current state in BC

The *Health Care Consent and Care Facility (Admission) Act* of B.C. confirms adults' control over their own health care by legally recognizing prior expressed instructions or wishes. However, there is no provincial standard related to the documentation of Advance Care planning other than availability of a provincial Advance Directive form which is an optional form. While common practice in some health authorities is to store ACP documents in a "green sleeve" within an acute care chart, there is no provincial standard around storage or communication of such directives or medical orders, such as MOST (Medical Orders for Scope of Treatment) or Goals of Care orders. Numerous health authorities use an ACP checklist

(optional) to document the presence of POA's, advance directives, SDM's etc.; but these are often not available to view across the same health authority (i.e. acute and community settings) or to other health authorities. Most often patients or family members are responsible to present their ACP information to a health care provider.

Identified barriers to respecting communication of ACP preferences and medical orders are:

1. Multiple locations in EMR for ACP documentation
2. No structured place to document patient values and goals
3. Multiple EMR's that do not communicate with each other

Foundational Principles/Best Practices in ACP documentation in Electronic Health Record

Electronic Health Records (EHRs) should have a designated location for the single source of truth about each patient's advance care planning wishes where all relevant information is easily entered and displayed.

With the implementation of an electronic clinical information system for Vancouver Coastal, Providence and Provincial Health Services Authorities (VPP Cerner), all health authorities will be using either Cerner or Meditech platforms for their hospitals. Since patients may move or be transferred from one health authority to another, it is important that documentation of previous goals of care discussions be readily accessible to health care providers (HCPs). While there is no direct interface between platforms, it would be more efficient for HCPs if all ACP electronic documentation shared a common approach and design. This would also enable the future vision of a fully integrated provincial or federal electronic medical record system.

ACP documentation systems across British Columbia should be designed in accordance with Best Practices so that:

- **Patients' wishes, values and ACP documents** are recorded centrally in a structure that is accessible across the system - analogous to the allergy record.
- **The centralized documentation is broadly and intuitively accessible**,
- **ACP documentation includes a narrative focus** that tells the *story* of the patient's values and wishes
- **Centralized documentation displays the longitudinal arc** of the ACP narrative story and the MOST in a highly visible, easily accessible way
- **ACP discussion and documentation is promoted for <u>all</u> patients** – not just those formally identified as (or anticipated to be) "palliative" or followed by a palliative care team
- **Multiple disciplines can document in the centralized location**.
- **ACP documentation functionality is available to and viewable by all care providers in the healthcare system, including primary care**

Specifically for EHR systems:

- **ACP documentation in EHR crosses** all encounters (i.e. ***not*** EHR encounter-specific) so that all the information is collected into one place for the user (including MOST/code status/Goals of Care orders, narrative descriptions of patient values and wishes, advance directive, power of attorney, substitute decision maker etc.). Specifically, for EHR systems, the MOST on the banner bar must be the chronologically most recent, noting this may not be the MOST for the current encounter.

- **The centralized ACP documentation location is accessible** by no more than 2 clicks
- **ACP documentation is displayed in chronological order** in a table view with documentation dates and details including author, date, and content. Content/document details should be available on click to open. This allows information to be traced and shared across the system.
- **Scanned documents are included** (e.g. paper documents from other care settings, patient's signed "living will" or completed "My Voice" documents) and indexed according to standardized category and date that the document was signed.
- **Direct patient access** and input into ACP documentation (e.g. via EHR patient portal) is possible
- **EHR Functionality is built to allow ACP information to be automatically pulled** from progress notes into ACP note repository ("tag and send" function)
- **ACP metrics are built into EHR products as discrete data elements** to facilitate data extraction and reporting **as long as that does not diminish usability; usability, at least in the short term, should be prioritized over data extraction and reporting** Cochrane Review of the iHealth System, BC Ministry of Health, November 2016;

In a recently published article by Lamas et al (*Advance Care Planning Documentation in Electronic Health Records: Current Challenges and Recommendations for Change*, Journal of Palliative Medicine, 2018 Jan 23) recommendations were made for administrative agencies, health systems and EHR vendors, clinicians and patients (Table 2). Key recommendations that were made in the Lamas paper, in addition to those already cited in this paper that need to be considered in BC include:

1. Develop quality metrics for ACP that can be extracted from the EHR
2. Expand access and input across the care continuum and in those settings where there is not a system-wide robust EHR, ensure that equivalent documents are upload in a registry or some equivalent
3. Set minimum requirements for ACP documentation in specific populations i.e. older patients, persons with serious illness etc.,
4. Encourage front line clinicians to utilize ACP functionalities to ensure documentation of ACP is complete and available for other clinicians
5. Provide adequate education and training related to the use of EHR as a tool for ACP communication to frontline clinicians.

A concerted effort by all involved stakeholders to undertake this work will reduce error and enhance patient centred, goal-concordant care across the health care system.

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