END OF LIFE
PROJECT

September 1, 2014
TV Net Project

End-of-Life Care Workflow & Functionality
## Document Control

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<td>- Label “Transition” changed to “Severity of Illness”</td>
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<td>- Colour change as an indicator of when a form is due, overdue, completed</td>
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<td>- Reminder to clinician to ask about privacy masking whenever generating a report that extracts data from EMR.</td>
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<td>- Consistency in naming of quality indicator terms</td>
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<td>- Revision of names of items in “dashboard” on main page</td>
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<td>- Clarification of where to insert comment in encounter note when distributing a document.</td>
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<td>- Define EOL functionality outside of stand-alone EOL module</td>
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|         | - Assessment tools: ESAS changed to allow entry of 1-
10 score across each domain in ESAS
- Forms that need to be approved by government (Palliative benefits) need a check box for “Approved”

- 0.6

Key changes:
- Terminology and labels revised for the “dashboard” area of home page
- Symptom management pages should each capture a score from 1-10. Note overlap with scores from ESAS form.
- Screen shots updated to reflect revisions

Colin Partridge | January, 2014

- 0.7

Added descriptions for symptom management pages

Colin Partridge | Feb-March, 2014

- 0.8, 0.9

Key changes:
- Additions and updates to list of forms that need to be returned
- Split out forms from “My Voice”
- Updated list of telephone numbers and websites resources for the “MD” button
- Updates to symptom management content for pain, nausea, and constipation
- Label “Severity of illness” changed back to “Transition”
- Reporting queries divided into queries for living and deceased, and both absolute numbers and percentages

Colin Partridge | April, 2014

- 0.91

Colin Partridge | April 28, 2014
### Key changes:

- “Forms” renamed “Documents”
- “Home” control highlighted in bold or colour
- Clarified when “My Voice” dashboard flag should be marked as completed.
- Clarification re ESAS_given and SAT_given
- 0.92 Edits as per Dennis and Neil re content of symptom management documents and links.
  - Further clarification about the dashboard flag about “My Voice”
- 0.92a Added creative common license sentence on page 1 of document
- 093 Minor edits to incorporate experience with EMR implementations to date

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Preface

In order to provide comprehensive EOL care, a multitude of processes need to be initiated and monitored. Doing this without the aid of an organized support tool is a practice likely to include care gaps.

An end-of-life (EOL) tool needs to be able to recognize the workflow typical of primary care practice when dealing with patients requiring end of life care. Coupled with this is the need to address the reality that EOL care can be approached from the perspectives of:

- Stage of terminal illness
- Role of the individuals involved
- Patient’s physical/emotional/spiritual needs
- Tasks to be done.

The end-of-life (EOL) tool specifications described below are designed to support primary care providers in providing optimal care to patients reaching end of life. Keeping the above perspectives in mind, the tool focuses on streamlining workflow while encouraging thorough EOL care that addresses both the clinician’s and the patient’s needs. The tool specifications also recognize that while comprehensive functionality is important, in primary care patient contact time is limited. Clinicians need rapid access to resources. Intrinsic usability and rapid access to commonly-used tools are key design considerations recognized during the development of the tool specifications.

The EOL specifications described in this document contain details about content that should be included, and a suggested user-interface. The authors realize that different EMRs offer varying functional capabilities. Therefore, to implement the specifications, the content, interface and implementation may need to be modified to work effectively within the confines imposed by different vendors. In some cases, users or developers may need vendor support to implement the EOL tool.
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Introduction
The EOL tool specifications described later in this document were developed after careful consideration of a variety of patient-centred, clinician-centred, workflow-centred, and usability factors. The outcomes of this analysis, and their implications for the design of an EOL tool are reviewed below.

1. Goals of tool:
   - Facilitate improved EOL care by:
     i. Consolidating clinician access to comprehensive EOL resources
     ii. Reminding clinicians of available patient resources in EOL care
     iii. Assisting clinicians in choosing appropriate resources at different levels of disease burden
     iv. Improving inter-provider and inter-disciplinary care
     v. Providing EOL assessment and scoring tools
     vi. Providing tools to assist in patient management (E.g. narcotic switching guidelines)
   - Facilitate the recording of EOL care interventions
   - Facilitate in-office analysis of EOL-related care

2. Design principles:
   - Tool should be portable across vendor platforms, recognizing that components will need to be deployed in different formats, depending on the vendor
   - EOL tool will only be used sporadically, so must be easy to use even after prolonged gaps between uses.
   - As much as possible, tool should match clinical workflow
   - Different clinical situations dictate different needs from the EOL tool, so certain functionality needs to be duplicated within the tool. For example, grief counselling resources are appropriately included under the EOL transition “death and bereavement”. However, access to grief counselling resources should also be made available under the topic of resources for family.
   - Tool should be user-friendly in:
     i. Being “lean” so as not to overwhelm casual users, and also to enhance usability on small-screen devices.
     ii. Minimizing the number of steps needed to perform tasks.
     iii. Hiding extraneous information (E.g. date that a handout was printed), yet making it visible if desired (E.g. by mouse hover over name of handout)
   - Data entered into the tool should be used to auto-populate forms, etc. where appropriate
   - Tool should implicitly and explicitly prompt/remind clinician to do tasks relevant to each stage of EOL care.
• Fonts and font sizes must be easily readable. Physicians beyond age 45 tend to have worse vision, yet these physicians also generally have older patients, and hence more need for end-of-life tools.
• Tool may be accessed from portable devices, so as much as possible, needs to display maximum content in minimal space, with minimal extraneous content.
• Toolbars and fields should adjust to accommodate smaller view-screens on portable devices.
• Tool will be used at the out of office, at house calls, in hospital, hospice, etc, so should be able to easily export care plans, patient handouts, etc. to on-site printers/flash drives or other devices
• Similarly, the tool should be designed to anticipate the need to be able to transmit patient handouts/forms/care plans/summary information directly from the EOL toolkit to patients, their caregivers, or clinical staff (E.g. home care nurses, hospice staff, ER physicians, etc. via fax/email/NFC/etc.

3. Components:
An EOL tool must include the ability to perform the following high-level functions:
• Register a patient as being on an end of life registry
• Record encounter information, including recording of clinical notes, interventions and testing scores
• Facilitate the completion of stage-appropriate tasks
• Facilitate rapid access to symptom assessment and management tools
• Facilitate access to patient self-management resources
• Facilitate inter-professional care (E.g. via dynamically-generated care plans/summaries, etc.)
• Generate clinical decision support (CDS)-initiated provider prompts to activate one or more components of EOL toolkit, including follow-up reminders
• Ensure patient privacy. Care plans will likely be viewed by family members, friends, etc., and may include historical information that patient may wish to literally “take to the grave”. EOL tool should cue clinician to ask patient about elements of their medical history that they would like masked. Such history might include history of fertility issues, giving up children for adoption, abortion, rape, abuse, infidelity, mental illness, HIV, Hep C, etc.
• Provide support for a patient’s loved ones before and after death
• Facilitate access to emotional support resources for clinicians
• Generate reports (E.g. Administrative report generation (E.g. population statistics for an individual provider)
Background for vendors and developers

The EOL tools are meant to address the needs of primary care clinicians in delivering optimal health care to patients who are dying or at risk of dying within the coming year. The BC Practice Support Program (PSP) aims to improve primary care health delivery. Among its projects, it has developed a comprehensive set of tools and training for delivering end-of-life (EOL) care. The **PSP End of Life Care Algorithm** (available online) is an excellent resource in this regard, and forms the basis on which the EOL tool is built.

As a patient moves progressively from a state of health, to decline, to death, their needs and the resources available to them change. These stages are described in the PSP algorithm, and are described as “Transitions”. These stages and their associated tasks are:

1. **Transition 1 – Disease Advancement**
   - Recognizing and registering patients at risk
   - Breaking the news
   - Discussing the illness, prognosis, etc.
   - Initiating advance care plans
2. **Transition 2 – Decompensation, experiencing life-limiting illness**
   - Assessing and treating symptoms
   - Activating palliative care resources
   - Support for family
3. **Transition 3 – Dependency & symptom increase**
   - Assessing and treating symptoms
   - Anticipating death
   - Support for family
4. **Transition 4 – Decline & last days**
   - Assessing and treating symptoms
   - Preparing for imminent death
   - Support for family
5. **Transition 5 – Death & bereavement**
   - Completing death certificates, etc.
   - Supporting family through bereavement

Note that depending on the context, and individual preference, a clinician may choose to access EOL resources by means other than chronologic order. For example, “Support for family” is a thread that occurs throughout end of life care. At times is may be more convenient for a clinician to be able to access all the family-related resources in a consolidated form. For example, if the spouse of a dying patient presents in the office, it could be useful for a clinician to be able to select from all the caregiver resources available.

Similarly, instead of dividing patient-care resources into chronologic stages, it can be useful to view the entire set of patient resources at a glance.
Therefore, the EOL tool specifications include some redundancy of content, to meet the needs of clinicians as best as possible, in different settings.
Design elements - description

This section of the document describes the design elements, along with graphical depictions of how they could be implemented. Detailed specifications are in the section Appendix A.

The EOL tools are meant to be an embedded component within the parent EMR, not a stand-alone or attached feature.

Here is an example screen shot of a possible implementation, with the expectation that the tool would be deployed as a sub-screen in an environment also displaying usual information such as demographic information, menu bars, and the like:

![Example Screen Shot]

Patient’s name, gender and age/date of birth should always be visible.

The EOL interface needs to display the following key design elements that should always be visible:

1. A menu control allowing the user to select from a set of key sections and functions. This could be a set of buttons, tabs, or another control, but ideally this would be a ribbon control or similar control that exposes the next level of tools, and obviates the need for an extra mouse click to access sub-menus.

   The sections that this control should expose are:
   - Home
   - Assessment Tools
   - Symptom Management
   - Family & Grief
• Reports
• MD

2. A central screen area that changes depending on which of the above main topics is selected

3. A button linking to the Practice Support Program (PSP) end of life (EOL) document

There are many forms and questionnaires within the EOL tool. Information about specifics is detailed further below. As a guiding principle, the tool should allow a clinician to either view or print this documents with minimal fuss. For forms that are too long or wide to fit on one screen, there should be means to easily scroll.

1. Sections in the menu

A. Home
The home screen allows clinicians access to the core EOL tools related to documenting a patient encounter, and accessing the forms and documents relevant to each transition of care from EOL registration through to a patient’s passing away. Detailed specifications

The key graphical components of screens in this segment of the tool are:

1. Four controls (e.g. buttons), which Ideally should be submenus in a ribbon control for the Home tab:
   • - clicking allows clinician to add patient to an EOL registry
   • - clicking allows clinician to enter and view information about patient’s care plan.
   • - clicking allows clinician to view a snapshot of patient’s information re EOL care.
   • - clicking allows clinician to access documents regarding managing the given transition of disease. It also includes access to the patient forms relevant to the transitions of illness. For each document, it also gives an indication of whether given handouts have been given out, and if necessary, whether a patient has returned the completed document.

2. A title area that shows:
   • The primary palliative diagnosis
   • In which transition of illness a patient has currently reached.
   • A chronology of the patient’s assessment scores, including the dates that the scores were obtained. At a minimum, this would include PPS scores, but could also include scores for pain, depression, and dyspnoea.

3. A list indicating whether certain key tasks have been completed (either by the MD or the patient). These tasks are:
   • Registration of the patient in an EOL registry
   • Giving the patient the “My Voice” document
   • Completion of an Advance care plan
• Completion of the BC Palliative Benefits form
• Completion of a “No CPR” form.

4. An area for entering an encounter note in the standard “SOAP” format.
   • The EMR tool must insert information into the relevant part of the SOAP note, documenting relevant activities that have been done during the encounter.
   • For example, if a PPS score is calculated, an entry “PPS=nn” should be inserted under “O”bjective. If a document is given to the patient, this should be documented under “P”lan – e.g. “My Voice handed out”.

5. A text label reminding the physician to schedule a follow-up appointment for the patient.

Mouse hover over a data field should display information about the date that a data item was entered, and the name of the author.
Controls on the home screen:

1) Registry
It is important for the EOL tool to be able to maintain a registry of patients who are identified as being at risk of dying within the coming year. Selecting the Registry control should bring up a screen allowing a user to add a patient to this registry.

The registration screen also allows the clinician to populate key facts such as the diagnosis(es) for which the patient is added to the registry. This information should be manually entered, and not pulled from encounter diagnosis or billing diagnosis.

As well, at this time, patients should be given the opportunity to mark certain information as being masked from public display. In the course of care, it is possible that medical summary information may be included in documents viewed by family members. There may be elements of this information that patients wish to keep private even from those closest to them. PITO certification requires the ability of an EMR to mask individual data fields specified by the MD. Implementation will vary by vendor. Clinician may need to temporarily leave the encounter note to do this.

2) Care plans
The Care Plans control allows a clinician to both document, view, and modify a patient’s care plans. The detailed content is described in the “Detailed Specifications” area. The care plans can include information such as a patient’s preferred caregivers, substitute decision makers, preference re place at which to die, etc., and serves as a guide to all care providers, as to how a patient would like their end of life care delivered.

Two kinds of care plans need to be available:

• Advance care plan – describe patient wishes re their future care, goals of care, etc. There is no such thing as a “basic care plan”. Advance care plans could more accurately be called “anticipatory care plans”, or “planning for the future”, but the terminology Advance care plan has come into common usage.

• Collaborative care plan – describe the individuals involved in a patient’s care, the delegation of tasks, etc.

Here’s an example of an Advance care plan stripped down to fit on one screen:
3) **Summary**

Selecting the Summary control should bring up a screen that summarizes key information about the EOL patient. This is intended to aid locums and other alternate caregivers in rapidly getting up to speed on a patient’s status. It should also summarize information like all of a patient’s pain and palliative performance ratings since being registered in the EOL registry.

The user should be able to print out the summary page. For any information that is masked for privacy reasons, the printed version should include no indication that masking has occurred.

4) **Documents**

Selecting the Documents control should bring up a list of documents that clinicians use in managing a patient as they move the different transitions of illness progression from care planning through to death.

Though in the PSP EOL module, the documents are listed by stage (transition) of illness, for convenience it makes sense to consolidate all the palliative care documents into one place. Multiple documents can thus be printed en masse. For example, if a patient is diagnosed at a late stage of illness, there are documents from multiple disease stages that should be distributed to the patient and/or their family. This presentation format facilitates the process.

Here is a partial example:
B. Assessment Tools

This main menu option consolidates the assessment tools useful in managing end of life patients. There are three tools that should be included:

- Palliative Performance Scale (PPS) – an assessment of a patient’s level of functioning, on a scale from 100% to 0%, in 10% increments.

- Edmonton Symptom Assessment Scale (ESAS) – a tool to assess symptom severity in a variety of spheres. There is not a single numeric result deriving from this form.

- Seniors Assessment Tool (SAT) – a tool assessing a seniors’ level of functioning. There is no numeric result from this form.

The scores from the PPS tool should be stored as a discrete data element in the EMR. These values are re-assessed over time. When a new score is calculated, the prior values need to kept as well. The most current score for a PPS must also automatically populate any form or screen that references the value.

Here is a sample demonstrating an implementation of the PPS:
C. **Symptom Management**

Symptom management is a key part of managing patient’s whose goals of care have changed from cure, to symptom control and comfort. There are several common symptoms encountered in palliative care, including pain, nausea, constipation, etc. This section of the tool is meant to offer direct, concise and practical advice on managing symptoms, as well as access to more detailed information if desired.

The key symptom topics are:

- Pain
- Nausea & vomiting
- Constipation
- Dyspnoea
- Delirium
- Depression
- Anxiety
- Fatigue
- Anorexia
- Intractable symptoms
- Last days and hours
- Crisis orders
For each specific symptom the tool should offer the ability to record the level of disability on a scale of 1-10. E.g. Nausea 5/10. Note that most of these symptom scores are also captured by the ESAS document. Where there is cross-over, the same variables should be used to capture the values of these scores. Details are described in Appendix A, under “ESAS”, and in Appendix B, which describes the individual variables.

The scores can be captured within the part of the tool relevant to the topic, or on the Home page table of scores. Ideally, a user should be able to enter a score on the home screen, and have the score automatically populate the relevant symptom management screen, and vice versa.

For each symptom, the general format of the content is:

- Possible Causes
  - Disease-specific management advice
- Initial Management
- Further Management
- Intractable Symptoms

The symptom management tools often contain links to patient and clinician resources.

Pain management in particular can be a complicated matter, as different kinds of pain (e.g., boney pain vs. neuropathic pain vs. visceral pain, etc.) need different treatment strategies. Dosing of narcotics can be a tricky business, particularly when changing narcotics. The Pain submenu needs to include access to at least three key tools:

1. Advice re changing narcotics
2. Advice re managing different kinds of pain (e.g., bone pain vs. neuropathic pain, etc.)
3. Advice re the medication hierarchy of stronger analgesics for stronger pain

An example:
Dyspnoea

Consider, and treat:

CV: anemia, arrhythmia, CHF, MI, pulmonary embolus, pericardial effusion, SVC obstruction
Reep: asthma, COPD, infection, bronchial obstruction, radiation pneumonitis, pleural effusion, lymphangitic carcinomatosis, interstitial fibrosis
Other: anxiety, ascites, cachexia, neuromuscular disease, deconditioning

Initial Management:

1. History and physical
2. Investigations as appropriate:
   - CBC, D-dimer, troponin, CXR, EKG, etc.
3. If hypoxemic -> home oxygen
4. Handout re comfort measures
5. Pharmacological
   - a. Immediate release opioid
   - b. Lorazepam 0.5 to 1 mg q4h SL prn for anxiety

Further Management

Crisis Management
D. Family and Grief
Though family resources are embedded in each of the PSP EOL stages of illness, it is useful to be able to consolidate family resources in one place.

The resources under this menu control are a subset of those under the Documents menu, restricted to those relevant to caregivers. This is augmented with more detailed information about support services for family members.

An example. Note that this example is not meant to be comprehensive:

![Menu screenshot](image)

E. Reports
This main menu option allows a clinician to quickly generate reports re the specific patient. It also allows generation of tracking sheets. Though also available in other areas of the tool, this option also allows printing of summary reports.

Importantly, this menu option allows generation of a report of the clinician’s pattern of practice re EOL care, using the quality indicators described in Appendix A.

An example:
This menu option allows access to four components:

- A list of billing codes related to EOL care
- A list of contact telephone numbers for EOL-related resources
- A list of links to a physician’s personal list of favourite documents and websites related to EOL care
- Contact information for emotional support services for physician

It allows a physician fast access to tools specific to the physician. Billing codes related to EOL care should be visible. As this information changes with time, this must be user-editable.

The list of contact numbers will need to vary depending on the region in which the clinician practices. The user should be able to edit this list to suit their individual needs. The list may include telephone numbers, email addresses, mailing addresses, etc.

Very similar to the Contacts option, Resources presents the user with a list of EOL-related reference resources that they can access by clicking on the reference of choice. The vendor should initialize this list with default links as specified in the detailed specifications. However, the user should be free to edit the list to remove or add references of their choice. The reference materials might include websites, text or word documents, audio files, images, etc.

Lastly, clinicians can experience emotional distress themselves while helping a dying patient. Contact information for the BC College of Physicians and Surgeons physician support line must be displayed.
An example:

G. **PSP**

This is a control (e.g. a button) that must remain visible at all times when using the EOL tool. It allows a clinician a direct link to the PSP EOL module. Selecting this control should bring up the main page of the PSP tool:
4. **Design elements to be embedded within the EMR**

Some elements of the EOL module need to be integrated within the EMR itself, and not housed in a standalone module:

1. When a patient registered on an EOL registry comes to a clinician’s office for an appointment and notifies the MOA that they have arrived, the EMR should prompt the MOA to give the patient a copy of the ESAS form for the patient to review and complete while waiting to see their clinician.

2. Similarly, when the patient notifies the MOA of their arrival, if the patient has been given documents that should be returned (for example the “No CPR” form), then the MOA should be reminded to ask the patient for those documents, so that she can scan them into the EMR. In conjunction with this, the EMR should directly, or indirectly (via the EOL module), allow the MOA to update the status of those documents from “given” to “returned”.

5. **Optional design elements**

Besides the mandatory elements above, significant usability enhancement can be achieved by displaying the following in the interface:

1. A list of pending tasks relevant to the given patient. I.e. a “To do” list as in the screen shot above. Most EMRs include this feature, and PITO-approved EMRs are required to include it, but in some implementations the task list is hidden during creation of an encounter note.
2. PITO-approved EMRs allow access to a list of lab results, reports, etc. for a given patient. It is also desirable for the EMR to be able to filter the display to new reports, images, and lab results that have accrued since the last patient encounter.
Workflow
This section of the document discusses and describes workflow, and an example of how the EOL tool could be used.

1. Planning
Everyone is at risk of sudden illness or death from unanticipated injury or circumstance. Therefore, in theory, everyone should have advance care directives including a will and health care (representation) agreement. The reality however, is that many people don’t consider end-of-life/critical illness planning until faced with a serious illness.

For those who are proactive, they may see their family physician to make them aware of their wishes, or to seek advice on future planning.

For those patients who are proactive, an example workflow in using the EOL tool is as follows:

- Patient comes to office, and tells clinician that they would like to discuss their end-of-life wishes.
- Clinician activates EOL tool, which opens on the Home screen.
- Clinician selects the Documents control
  - Clinician selects the “My Voice” form
  - Clinician presses the Print button, prints off the document, and hands it to the patient

Note that the patient would not be “Registered”, as they are not expected to die within the next year.

- At a later date, the patient brings back the completed sections of “My Voice”.
- Either the clinician or their Medical Office Assistant (MOA) scan the “My Voice” information into the EMR.
- They then activate the EOL tool

2. New EOL care
When a patient becomes seriously ill, and it is anticipated that they might die within the coming year, the clinician needs to break the news, and introduce a patient to the idea of planning ahead (if they haven’t done this before).

Here’s an example workflow of using the EOL tool for a patient that has just been diagnosed with metastatic breast cancer:

- Patient with newly-discovered terminal illness has been called to office, and is sitting in waiting room.
- Clinician opens patient’s chart and activates EOL tool, which opens on Home screen.
- Clinician selects the Documents control
  - Clinician selects “How to break bad news”, to review best practices in breaking bad news
Clinician closes Documents window and returns to Home screen

• Clinician calls patient in to exam room
• Clinician reviews diagnosis and prognosis
• Clinician opens the Documents window
  o Clinician selects the “My Voice” form for printing
  o Clinician selects the “EOL care plan” form for printing
  o Clinician presses the Print button, prints off the documents, and hands them to the patient
  o Clinician closes the Documents window
• Clinician enters encounter note

3. New EOL care – follow-up visit
After the patient has had a chance to contemplate the bad news that they’ve received, ideally they will return to see their physician and review their wishes, including “My Voice”, and the EOL care plan document that they were given.

Here’s an example workflow using the EOL tool:

• Clinician opens patient’s chart and activates EOL tool, which opens on Home screen.
• Clinician selects the Register control
  o Clinician selects the Registered checkbox, to add patient to EOL registry
  o Clinician enters Primary palliative diagnosis of “Metastatic breast cancer”
  o Clinician enters any secondary diagnoses: “Diabetes, Osteoporosis”
  o EOL tool prompts clinician to enter names of people with whom the terminal illness can be discussed. Patient explicitly states that her health care can be discussed with her spouse, “Rob Quincy”, and sister “Mary Jones”.
  o EOL tool prompts clinician to enter names of people with whom the terminal illness can not be discussed. Patient explicitly states that her health care can not be discussed with her ex-spouse, “Dastardly Dowrong”, and estranged sister “Cruella Jones”.
  o EOL tool prompts clinician to ask patient if there is information that she wants to be kept confidential from everyone. She responds that yes, she had an abortion at age 16, and hasn’t even told her husband about it. As health information may be moving among multiple caregivers, and such information may be left at her home for palliative care, she wants this information masked.
    • Clinician uses the PITO-required masking capabilities of the EMR to mask information about the past abortion. (This may require temporarily leaving the EOL tool).
  o Clinician closes the Register window.
• Clinician sets the “Transition” drop-down to “1 (Advance Planning)”
• Clinician selects the Care Plans control
  o Clinician selects Advance Care Plans
Clinician populates the fields of the Advance Care Plan, using the information that the patient has brought in.

Clinician exits the Care Plans form

Clinician does an encounter note.

Clinician selects the MD control to check the billing code for palliative care planning, then closes the form

Clinician exits the EOL tool.

4. EOL Care – later stages
As a patient’s health deteriorates from their illness, symptom managements becomes increasingly important.

An example for the same patient, who is experiencing boney pain from metastases from her breast cancer, and has become unable to work:

- Clinician opens patient’s chart and activates EOL tool, which opens on Home screen.
- Patient describes worsening health, with weight loss, and boney pain
- Clinician selects Assessment Tools control
  - Clinician selects Palliative Performance Scale
  - Clinician selects “50%”
  - Clinician exits Assessment Tools Form
- Clinician sets the “Transition” drop-down to “3 (<6 months, PPS 50%)”
- Clinician selects Documents control
  - Clinician selects:
    - BC Palliative Benefits form
    - EI Compassionate Care form
    - Caregiver Tax credit
    - No CPR form
  - Clinician selects Print, and completes the Palliative Benefits form and No CPR forms.
  - Clinician gives copies of forms to patient
  - Clinician exits Documents window
- Clinician selects Symptom Management control
  - Clinician selects Pain
  - Clinician reviews pain management recommendations for boney pain, and is satisfied with information provided
  - Clinician exits Symptom Management window
- Clinician recalls that they attended a conference on pain management, and selects MD control
  - Clinician searches the My Resources list
    - Clinician selects the link to their document on pain management, reviews document, and exits it
Clinician wants further advice on managing patient, and reviews the Contacts list, to find telephone number for BCCA 24 hr symptom management line.

- Clinician exits MD window

- Clinician writes encounter note
- Clinician writes prescription for pain medication
- Clinician exits EOL tool

5. EOL Care – Family & grief

A patient’s family members may come in asking for help in dealing with a loved one’s terminal illness. The EOL tool can help, as grief resources are consolidated within the tool:

- Family member comes to clinician office, expressing difficulty coping with their spouse’s worsening health.
- Clinician activates EOL tool, which opens on Home screen.
- Clinician selects Family & grief control
  - Clinician selects the documents:
    - EI compassionate care
    - Caregiver tax credit
    - A Caregiver’s guide
    - Home Death protocol
    - What to consider when caring for those dying at home
    - Preparing for death of a loved one.
  - Clinician selects Print control to print these documents
  - Clinician exits Family & grief window
- Clinician completes an encounter note for patient.

6. EOL Care – Reporting

For quality assurance purposes, a clinician may want to identify patients who might benefit from a palliative approach to care, and to see how they are doing re their management of patients already requiring EOL care.

To do so:

- Clinician activates EOL tool, while in the chart of any patient (Alternatively, this functionality could be made available in a “Reports” or “Reporting” section, if the EMR has such an area)
- Clinician selects Reports control
  - Clinician selects Find Patients for EOL registry
    - Computer analyzes all patients in EMR that are registered with the given physician, looking for those patients that qualify, as per the selection criteria for Reports in Appendix A.
    - Computer prints out a list of such patients.
 Clinician forwards list to MOA, asking that the patients on the list be called in for an office visit.
  o Clinician selects EOL Quality of Care Report
    ▪ Computer analyzes all the patients who are on the EOL Registry (i.e. have the “Registered” flag set, and calculates statistics re the quality indicators specified in Appendix C.
    ▪ Computer prints out the report
      o Clinician exits the Reports window
  • Clinician exits the EOL tool
Appendix A - Design elements detailed description

This section of the document describes the EOL tool requirements in detail. The descriptions, terminology, and forms referenced, have their foundation in the **PSP End of Life Care Algorithm**, available online at
[http://www.gpscbc.ca/system/files/62_EOL_PSP_algorithm_v7%205%20Nov%202013.pdf](http://www.gpscbc.ca/system/files/62_EOL_PSP_algorithm_v7%205%20Nov%202013.pdf) Please note that there are regional variations of the module. These are also available on the website.

When there is a data element associated with a particular field, and there is detailed information about the data element in Appendix B, then the name of the data element is shown in (blue).

<table>
<thead>
<tr>
<th>Requirement</th>
<th>User Action</th>
<th>Functionality Required</th>
<th>Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Global requirements</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Populating data fields</td>
<td>Wherever possible, forms and windows should be pre-populated with as much information as possible extracted from the EMR database.</td>
<td>One of the key benefits from migrating from the (static) PSP EOL module to an EMR version, is the ability of the EMR to obviate the drudgery of entering information that is already in the EMR.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>These include:</td>
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<tr>
<td></td>
<td></td>
<td>1. Demographic information</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>2. PPS scores, pain and depression scale results</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Primary palliative diagnosis (except when adding a patient to the EOL registry).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Care plan information re substitute decision makers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The reverse is also the case. I.e. when an EOL form is being completed, information entered into the form should be used to populate the EMR’s database.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Print” button</td>
<td>Pressing the “Print” button from within a document, or via the “Print” button described, should offer more than just the option of printing to a local printer in the clinician’s office.</td>
<td>Clinicians may be using a mobile platform at a patient's home, at hospital, etc. Using “Print” should allow the physician to print to a</td>
</tr>
<tr>
<td>Main EOL tool window</td>
<td></td>
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<tr>
<td>----------------------</td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Activate EOL tool</strong></td>
<td>EOL tool activates. The tool will display a window containing the key components:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. A selection control containing the headings:</td>
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<tr>
<td></td>
<td>▪ Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>▪ Assessment Tools</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>▪ Symptom Management</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>▪ Family &amp; Grief</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>▪ Reports</td>
<td></td>
<td></td>
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<td></td>
<td>▪ MD</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>2. A control “PSP”, which links directly to the PSP EOL module (link is below).</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. The preferred implementation would be via a <strong>ribbon</strong> control. This allows user to immediately view subheadings once a topic is selected, and without the fine motor skills needed to select from nested pick lists. The ribbon tool also offers the advantage of dynamically adjusting to small screens on portable devices.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>2. Alternatives would be via tabs or buttons.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>User selects “PSP” control</td>
<td>The system opens up the PSP end of life module <a href="http://www.gpscabc.ca/system/files/62_EOL_PSP_algorithm_v7%20%20Nov%20%202013.pdf">http://www.gpscabc.ca/system/files/62_EOL_PSP_algorithm_v7%20%20Nov%20%202013.pdf</a>. This control should remain visible at all times that the EOL tool is in use.</td>
<td>Many clinicians will be familiar with the PSP EOL algorithm, and may want fast access to it.</td>
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<tr>
<td>---</td>
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</tr>
<tr>
<td>4</td>
<td>User activates EOL tool</td>
<td>The control structure of the EOL tool is: EOL Tool - Home - Register - Care Plans - Summary - Forms - Assessment Tools - Pain Scale - Palliative Performance Scale (PPS) - Edmonton Symptom Assessment Scale (ESAS) - Seniors Assessment Tool (SAT) - Symptom Management - Pain - Nausea &amp; vomiting</td>
<td>The tool should open with the “Home” button active.</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Main Menu
<table>
<thead>
<tr>
<th>User clicks on “Home” option</th>
<th>The text “Home” should be bolded, highlighted, or otherwise marked such that it is easy to identify and distinguish from the other options.</th>
</tr>
</thead>
<tbody>
<tr>
<td>The following sub-headings should be displayed:</td>
<td>The following sub-headings should be displayed:</td>
</tr>
<tr>
<td>Registry</td>
<td>Registry</td>
</tr>
<tr>
<td>Care Plan</td>
<td>Care Plan</td>
</tr>
<tr>
<td>Summary</td>
<td>Summary</td>
</tr>
<tr>
<td>Forms</td>
<td>Forms</td>
</tr>
<tr>
<td>The display area below this should contain several key areas:</td>
<td>The display area below this should contain several key areas:</td>
</tr>
<tr>
<td>1. <strong>A panel/pane/area</strong> that displays:</td>
<td>1. <strong>A panel/pane/area</strong> that displays:</td>
</tr>
<tr>
<td>a. <strong>A checkbox</strong> indicating whether the patient has been registered as being in an end-of-life registry.</td>
<td></td>
</tr>
<tr>
<td>(EOL_registered)</td>
<td>(EOL_registered)</td>
</tr>
<tr>
<td>b. An editable <strong>text box</strong> that displays the main diagnosis for which the patient is receiving end of life care.</td>
<td></td>
</tr>
<tr>
<td>(EOL_Primary_Diagnosis)</td>
<td>(EOL_Primary_Diagnosis)</td>
</tr>
<tr>
<td>c. <strong>A drop-down list</strong> labelled “Transition” that displays, and allows the user to specify the patient’s current transition or state.</td>
<td></td>
</tr>
</tbody>
</table>

The Home page is where clinicians are likely to spend most of their time in the EOL tool. Ideally, the sub-headings should be displayed via a ribbon control. By default, the tool should open on the submenu relevant to the patient’s latest Stage of disease state. If this has not been specified, then the tool should open on the submenu for “Stage 1”. Any fields that have existing content should display their content.
stage of dying. These five transitions are described in the PSP EOL module, and should be a list with these titles:

(EOL_transition)

i.  1 (Advance Planning)
ii. 2 (<6 months, PPS 50%)
iii. 3 (Increased dependency)
iv. 4 (Days-weeks to live)
v. 5 Death
d. A list indicating whether certain key tasks and forms have been done. Each form should be completed by the time a patient reaches a given stage of illness, and if not, the clinician should be warned that it is overdue.

For each of these key forms, there should be an indication of which of four states the form is in. This could be done via check boxes, or colour change:

- Form or process not yet done, and not due
- Form or process not yet done, and due
- Form given to patient, or completed by clinician, but not yet returned or acknowledged
- Form returned or acknowledged

The recommended implementation is via colour change:

- If the form is not due to be done, based on stage of illness, it should be in grey font.
- If the form is due to be done, it should be in black font.
- If the form is overdue based on stage of illness, it should be in a distinguishing font.
- If the form is completed, it should be in a different distinguishing font.

The list should contain the following content and labels:

i. “Not yet registered” – an indication of whether the patient has been registered in an EOL registry.

It is very useful to be able to view a brief synopsis of a patient’s diagnosis, current stage of illness, and chronology of their PPS scores.

The encounter note should be automatically populated with information entered in other parts of the tool.

For example, PPS scores and pain scale scores should be automatically entered into the “Objective” section of the encounter note.

If a form is printed or otherwise transmitted to a patient, this fact should be automatically documented in the “Plan” section of the encounter note.
This indicator should be start in black font, as a patient could always potentially be registered. It becomes overdue if a patient is in Transition 2 or beyond. When it is complete, the label should change to “Registered”.

ii. “My Voice not yet given” – this is an indicator of whether the patient has been given a copy of “My Voice” or the subforms in My “Voice”. (My_voice_given)
This form is due in Transition 1, and overdue when a patient is in Transition 2 or beyond. As “My Voice” contains multiple sub-forms, when any of the subforms has been given, this task can be deemed to have been completed, and the label should be changed to “My Voice given”.

iii. “Advance Care plan not yet done” – this is an indicator of whether the patient has had any information entered in the Advance care plan (via the Care Plans control). (Advance_Care_Plan_done)
This form is due in Transition 1, and overdue when a patient is in Transition 2 or beyond. When this task has been completed, the label should be changed to “Advance Care plan done”.

iv. “Palliative Benefits not yet approved” – an indicator of whether an application for BC Palliative Benefits has been submitted to the government, and whether the patient has been approved for same. (EOL_BC_Palliative_benefits_approved)
This form is due in Transition 2, and overdue when a patient is in Transition 3 or beyond. When this task has been completed, the label should be changed to
“Palliative Benefits approved”.

v. “No-CPR form not yet completed”, – an indicator of whether a patient has signed a No CPR form, and whether the clinician has submitted it to the government. (No_CPR_form_completed). This form is due in Transition 2, and overdue when a patient is in Transition 3 or beyond. When this task has been completed, the label should be changed to descriptor “No-CPR form completed”.

e. A table that at a glance shows a patient’s assessment scores over time. At a minimum, this will include their PPS (palliative performance scale). (PPS_score). Ideally, their pain score (Pain_score), depression score (Depression_score), and dyspnoea score (Dyspnœa_score) should also be displayed.

i. Each row in the table should contain scores for a given tool such as the PPS.

ii. Each row should be immediately preceded by a button that opens up information about the given assessment score.

iii. The table should contain 3-5 columns, with one column allowing entry of scores re the current patient encounter, and the other columns showing the scores from prior encounters.

iv. Each column in the table should be labelled with a patient encounter date. Initially, only one column will be labelled (with the current date).

v. The columns of the table should have labels showing on what date the information was obtained.

vi. When a value is entered for a score, it should also be duplicated as an entry in the encounter note, under
vii. If all the columns in the table have been used, then the displayed scores should be scrolled so that scores for only the most recent five encounters are displayed.

2. While the EOL tool is active, the EMR vendor’s task list/to do list should be visible, and should include an indication of EOL care tasks that are overdue. The contents are described later.

3. There must be a text box in which the clinician can enter their standard encounter notes in “SOAP” format.

4. A labelled calendar control “Follow-up by”, that allows clinician to specify a date by which patient should be reassessed. (Follow_up_deadline) If patient is not seen in follow-up by that date, the system should remind clinician that the patient is overdue for EOL reassessment.

Main menu - Home option – Submenu Registry

User selects “Registry” submenu under “Home”

The system displays a screen that allows the user to enter information that registers the patient into an EOL registry. The page includes the following controls:

1. A labelled checkbox “Registered” that indicates whether the patient should be entered into an EOL registry. (EOL_registered)

2. A labelled text box “Diagnosis” into which user can specify the primary palliative diagnosis leading to the patient being entered into the registry. (EOL_Primary_Diagnosis) This field should NOT automatically populate a patient’s past medical history/problem list. Whenever the field is changed, the clinician should be asked whether the diagnosis should be added to the history/problem list.

3. A labelled text box “Secondary diagnoses” into which user can enter other diagnoses leading to the patient’s being added to the EOL registry. (EOL_secondary_diagnoses)

Adding a patient to an EOL registry allows the clinician to keep track of patients needing a palliative approach to care.

Report generation on patients on the registry allows a clinician to monitor how well they are achieving their goals in care delivery for EOL patients.
4. A labelled text box “Permission to discuss with” specifying individuals for which the patient explicitly grants permission to discuss their medical information. (Permission_to_discuss)

5. A labelled text box “Do not discuss with” specifying individuals for which the patient has denied access to their medical information. (Not_permitted_to_discuss)

6. A labelled check box “Privacy discussed” indicating whether the clinician has discussed masking of parts of the patient’s medical history. (EOL_masking_asked) Spouses, children, homecare nurses, etc. will likely become privy to medical information left at the patient’s home during the course of palliative care.

The system should therefore remind the clinician to review with the patient any information that they would like masked and remind the clinician how to mask information. Such information might typically include psychiatric history, or sexual history including abortions, rape, adopted children, etc.

Here is example text:
“Ask patient if there are parts of their past history that they would like hidden from family and friends”.

Main Menu – Home option – Submenu Care Plans

| 8 | User selects “Care Plans” button from Home option | The system displays a screen that allows the user to enter and view information about care plans for the patients. This information might be gathered directly from the patient, or manually extracted from documents, handouts, and notes that a patient or their family has prepared. Documents might include forms from within “My voice”, Advance Care Planning Questions, etc.

The types of care plans are:
• Advance care plans - describe the patient’s wishes, goals, etc.
• Collaborative care plans – describe the caregivers involved, delegation of |
tasks, etc.

Information entered for a collaborative care plan will be used to partially pre-populate the full Collaborative Care Plan (shown in the PSP EOL module), which can then be printed for completion by a patient or their caregivers.

Where possible, these fields should be populated from elsewhere in the EMR. E.g. Primary palliative diagnosis, Name of physician.

The clinician must be able to print out the care plan.

If a clinician enter information into any of the data fields below, then the EMR variable `Advance_Care_Plan_done` is to be set TRUE

Necessary fields in the **Advance care plans** are as listed below. Unless otherwise specified, each of these fields is a text blob. Unless a field has an explicitly-listed associated data element name, any name can be used. Each field should have an associated label:

1. Primary palliative diagnosis (**EOL_Primary_Diagnosis**)  
2. Secondary palliative diagnoses (**EOL_secondary_diagnoses**)  
3. Patient values, preferences, and key goals  
4. Substitute decision makers and contact information  
5. Patient’s preferred place for care  
6. Names of those individuals for whom the patient has granted permission to be made aware of their medical condition (**Permission_to_discuss**)  
7. Names of those individuals for whom the patient has denied permission to be made aware of their medical condition (**Not_permitted_to_discuss**)  
8. Living arrangements  
9. Home supports  
10. A Yes/No check box “Extended benefits?” indicating whether the
patient has extended benefits coverage (Extended benefits)

11. A Yes/No check box “Registered for BC Pharmacare Plan P?” indicating whether the patient is registered for BC Pharmacare Palliative Benefits drug coverage (EOL_BC_Palliative_benefits_approved)

12. Religious affiliations (and perhaps contact information)

13. Patient concerns and goals

14. Caregiver concerns and goals

15. Funeral arrangements (and contact information)

Fields in the **Collaborative care plans** can be found in the PSP EOL module on page 27. The fields are as follows:

1. Primary palliative diagnosis (EOL_Primary_Diagnosis)
2. Date of diagnosis
3. Secondary diagnoses (EOL_secondary_diagnoses)
4. Patient values and preferences
5. Family values and preference
6. Allergies
7. Preferred place of death
8. Primary care provider and phone number
9. Substitute decision maker and phone number
10. Key family members and phone numbers
| User presses “Summary” button under “Home” | Pressing the “Summary” button should bring up a view-only window that summarizes the following information The majority of the information should come from the Advance and collaborative care plans. (The names of the data elements are not repeated):

1. Primary palliative diagnosis
2. Secondary diagnoses
3. Main symptoms of concern
4. Caregiver concerns and goals
5. List of current care providers
6. Patient values, preferences, and key goals
7. Substitute decision makers and contact information
8. Name and phone number of family doctor
9. After-hours contact number for family doctor
10. Name and contact information for after-hours hospice/home nursing support
11. Names of those individuals to whom the patient has granted permission to be made aware of their medical condition
12. Names of those individuals for whom the patient has denied permission to be made aware of their medical condition
13. Living arrangements (as described in “Care plans”)
14. Home supports (as described in “Care plans”)
15. A check box indicating whether the patient has extended benefits coverage through a private insurer.
16. If the patient has extended benefits, there should be a text box displaying the name of the extended benefits provider. E.g. “Blue Cross”
17. An indication of whether the patient is eligible for BC Pharmacare Palliative Benefits drug coverage
18. Religious affiliations (and contact information where known)
19. List of completed documents (including date completed)
20. PPS and other scores, along with prior scores and the dates on which they were assessed
21. Name and phone number of patient’s preferred pharmacy
22. Funeral arrangements (and contact information) | See above note re functionality of pressing “Print”. |
23. Other

The summary page should include a “Print” **button** that allows the clinician to print out the above, including demographic information. Pressing the Print button should also cause the system to include:

1. Medical history and surgical history (As the summary sheet may be viewed by family members, etc. there should be the option to mask information that the patient considers sensitive)
2. Psychiatric history
3. Current medications
4. Allergies and intolerances
5. Substance use

Pressing “Print” should also allow the option to include relevant attachments such as lab or imaging results, consultant’s reports, etc.

<table>
<thead>
<tr>
<th>Main Menu - Home option – submenu Documents</th>
</tr>
</thead>
<tbody>
<tr>
<td>User selects “Documents” submenu under “Home”</td>
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</tbody>
</table>
be renewed. The system needs to generate a task/alert/reminder/warning to the clinician when a No CPR form is about to expire. This warning needs to come up even if the EOL tool is not active.

The details of these documents are in the PSP EOL module. Clicking on the name of either a clinician resource or patient resource should open up the document for viewing, and possible printing.

For each of the two columns of information, there should be a single “Print” button, and for each item in the column, a checkbox. Clicking the Print button should allow the user to print all documents that have their checkbox checked.

For each available patient handout or other document, there should be:
1. A second checkbox indicating whether the handout has been given to the patient.
2. A means of showing when and by whom the document was generated, including a field for a comment, though this information should be hidden unless requested (e.g. by mouse hover)
3. Once a document has been printed, the above fields should be automatically populated.
4. The user should be able to manually check/uncheck any of the checkboxes, in case a document has been generated/distributed outside of the EMR.
5. For documents that need to be filled/signed by a patient or provider, the tool should include a third checkbox to indicate when this step has been completed.
6. When a document that needs to be filled/signed by a patient is printed, a TASK should be generated to remind the clinician to ask patient to return the completed form.
7. For documents which need to be filled or signed, there should be a clear indication/warning when this has not yet been done, with the ability for users to manually update/override this flag.
8. For forms that need to be approved by the government, there

It would be a helpful indicator if the name of a form changed colour depending on the status of the form.

As for the home screen list of key tasks to complete, the recommended font colours to use are:
- For forms that are not yet due, based on transition of illness – grey font.
- For forms that are due, but not yet done – black font.
- For forms that have been given out, but not yet returned (if necessary) – yellow font.
- For forms that are overdue – red font.
should be a **fourth checkbox** to indicate when approval has been received. This applies specifically to the “BC Palliative Benefits form”

***Appendix C lists further details about the forms, and which ones require more than one checkbox.***

At a minimum, the documents for each transition of illness should include the following:

1. Transition 1:
   i. Clinician Resources:
      1. How to break bad news
      2. Advance care planning questions
   ii. Handouts
      1. My Voice
      • My Beliefs, Values and Wishes*
      • Advance Care Plan – Summary*
      • Advance Directive*
      • Putting Your Papers in Order (on Page 25)*
      • Representation Agreement (section 9)*
      • My Temporary Substitute Decision Maker (TSDM) List*
      • My Representative - Standard Agreement (section 7)*
      • Certificate of Representative or Alternate Representative*
      • Certificate of Monitor*
      • Certificate of Person Signing for the Adult*
      • Certificate of Witnesses*

1. End of life care plan
2. MOST form (Fraser Health)
2. Transition 2:
   i. Clinician Resources:
      1. Palliative Care Formulary
      2. How to hold a family meeting
      3. Medical supplies covered
   ii. Handouts
      1. EI Compassionate care
      2. Information re the Caregiver Tax Credit
      3. Information re organ donation
      4. BC Palliative care benefits
      5. No CPR
      6. HCC/Palliative care form

3. Transition 3
   i. Clinician Resources:
      1. EOL care checklist
   ii. Handouts
      1. Home death protocol
      2. Notification of expected death at home
      3. What to consider when caring for someone dying at home
      4. When someone dies
      5. Preparing for the death of a loved one
      6. A caregiver’s guide
      7. Canadian Virtual Hospice (website)

4. Transition 4
   i. Clinician Resources:
   ii. Handouts
      1. When Death is close at hand
      2. List of online resources for caregivers

5. Death
   i. Clinician Resources:
      1. Bereavement Algorithm
      2. BC Bereavement guidelines
3. Bereavement Risk Assessment Tool
4. Screening Tools for Measuring Distress
5. Cultural Diversity and Individual Preferences
6. Guide to Bereavement Assessment and Support

ii. Handouts

1. Death Certificate
2. The following resources extracted from the PSP links under death and bereavement:
   a. Be Gentle with Yourself
   b. Caregiver Questionnaire
   c. Normal Manifestations of Grief
   d. BC Bereavement helpline/website
   e. Distinguishing Grief and Depression
   f. Children and Death

If a death certificate, or patient form is printed, this should generate the insertion of a comment into the encounter note, under the “Plan” section. E.g. “Death certificate printed”, “My Voice printed”.

<table>
<thead>
<tr>
<th>Main Menu – Assessment Tools option</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>User selects “Assessment Tools” from main menu</strong></td>
</tr>
<tr>
<td><strong>Selecting this option exposes a button for each of the assessment tools commonly used in palliative and end of life care:</strong></td>
</tr>
<tr>
<td>1. Palliative Performance Scale (PPS)</td>
</tr>
<tr>
<td>2. Edmonton Symptom Assessment Scale (ESAS)</td>
</tr>
<tr>
<td>3. Seniors Assessment Tool (SAT)</td>
</tr>
</tbody>
</table>

Upon pressing one of the assessment tool buttons, the user is presented with information about the given tool, and instructions on how to use it.

**PPS:**
The screen for the PPS should display the PPS scoring system as on page 8 of the PSP EOL document. There should also be a radio button for each PPS score from 100% to 0%, allowing the clinician to select a PPS score. 

**(PPS_score)**

There are four assessment tools in the main page of the PSP EOL module. The PPS and pain scales both give single-value scores, and are not time-consuming to assess. They are also the most commonly-used of the four.

If a score is calculated using one of these tools, the score should be inserted into the “Assessment” part of the encounter note. E.g. “Pain scale 5/10”.

11
ESAS:
The ESAS (page 10 of the PSP EOL module) is a five page document evoking a patient’s level of functioning across multiple dimensions. The EOL module should allow a clinician to enter a value from 1-10 for each of the domains. Since the ESAS tool includes scores about different symptoms that a patient might suffer, the Assessment Tools area can also offer direct links to the relevant symptom management information for the symptoms included in the ESAS.

The EOL tool must capture the individual values as follows:

- Pain (Pain_score)
- Fatigue (Fatigue_score)
- Nausea (Nausea_score)
- Depression (Depression_score)
- Anxiety (Anxiety_score)
- Drowsiness (Drowsiness_score)
- Appetite (Appetite_score)
- Wellbeing (Wellbeing_score)
- Dyspnoea (Dyspnoea_score)

For any value greater than 0, the values for these scores should be inserted into the encounter note, in the “Assessment” section, with the name of the symptom followed by the score. Eg. “Pain 3/10 Nausea 2/10”. Including scores that are zero would be distracting and clutter the clinical note.

Selecting the ESAS option should allow the clinician to either enter scores for the symptoms on the ESAS form, OR print the form. The EOL tool should document when the ESAS has been used or printed. (ESAS_given) The ESAS_given flag only needs to be set TRUE once. Even if the ESAS tool is used during multiple patient visits, it is adequate to just store the fact that the tool was ever used. The ESAS_given flag is a patient-based flag, not an encounter-based flag.

If an assessment tool is distributed to a patient, then a note to that effect should be inserted into the “Plan” part of the assessment note. E.g. “ESAS form given”.
### SAT:
The SAT (Page 19 of the PSP EOL module) is a questionnaire meant for completion by the patient. Selecting the SAT option should display the document to the clinician, and allow them to print it. The EOL tool should document that a SAT has been printed. (SAT_given). As with the ESAS, a patient may be given the SAT document on multiple dates, but the intent of the SAT_given flag is just to indicate that the SAT was used at least once.

### Main Menu – Symptom management option

| User selects “Symptom Management” option | This menu option is the gateway to managing symptoms commonly-encountered in managing the care of ill and dying patients. As this option contains significant narrative content, a separate appendix – Appendix E describes the content in depth |

### Main Menu – Family & Grief option

| User selects “Family & Grief” option | The Family and Grief option allows access to a consolidated package of the PSP EOL module resources for family members coping with a dying loved one. As with other lists of printable documents available in the tool, for each item, there should be a check box to indicate if a given document has been printed, and if necessary, also returned. A user should be able to pick multiple items for printing en masse. The list of documents to be included in the Family & Grief option include:  
1. Caregiver Relief  
   a. EI compassionate care form  
   b. A Caregiver’s guide  
2. Preparing for Death  
   a. Home Death Protocol | A family member of a dying patient may be seen on their own. It improves workflow if all the caregiver resources can be accessed in one place, and without extraneous information. |
b. Notification of expected death
c. What to consider when caring for those dying at home
d. Preparing for the death of a loved one

3. Death and bereavement
   a. When someone dies
   b. Bereavement helpline (contact information)
c. Children and death

This option aims to expand upon the usability of the PSP EOL module by directly exposing the documents and links in the PSP’s “Caregiver resources” and “Online resources” buttons.

**Main Menu – Reports option**

| User selects “Reports” option | Depending on the way that different users look for a means of printing a care summary, some may be looking for a place called “Reports”. The EOL tool needs to be able to generate reports not just on an individual patient, but also reports to:
| | • Extract a list of patients that may be candidates for the EOL registry.
| | • Describe how well a clinician is meeting his/her EOL patient population as a whole. This option allows the user to do both.
| | • Allow a clinician to generate a custom report re the quality indicators for EOL care.
| | The Reports option needs to display the names of the following reports, along with the ability to print:
| | 1. Patient summary (as described earlier)
| | 2. Advance Care Plan (as described earlier)
| | 3. A tracking sheet, allowing a caregiver or patient to track their pain levels, medication changes, etc.
| | 4. A list of patients who are candidates for the EOL registry
| | This report should be generated based on:
| | • Patients who have an associated billing code for complex care
| | • Patients who have a diagnosis of metastatic cancer |

| | There is redundancy here, to help users who otherwise might have difficulty in knowing where to locate certain reports.
| | Depending on the functionality inherent in the vendor EMR, some or all of the reporting could be done via the EMRs inherent reporting functions. |
The details of these selection criteria are described on page 2 of the PSP EOL module.

5. Statistics on how well a clinician is meeting quality indicators for patient's in their EOL registry. The necessary data elements to include in this report are documented in depth in Appendix A.

6. Custom statistics on the above, based on clinician-specified criteria including age range, PPS range, and date range.

### Main Menu - MD option

<table>
<thead>
<tr>
<th>User selects “MD” control</th>
<th>The display area shows the following:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>o A scrollable list labelled “Billing Codes”, that lists billing codes specific to EOL care</td>
</tr>
<tr>
<td></td>
<td>o A button labelled “Fee Guide” that links directly to the BC MSP fee guide information relevant to palliative care. The link is: <a href="http://www.health.gov.bc.ca/msp/legislation/bcmaagree_faqfsfp.html">http://www.health.gov.bc.ca/msp/legislation/bcmaagree_faqfsfp.html</a></td>
</tr>
<tr>
<td></td>
<td>o A scrollable list labelled “Contacts” that lists contact information for palliative care resources</td>
</tr>
<tr>
<td></td>
<td>o A scrollable list labelled “My Resources” that lists links to a physician’s personal list of favourite documents and websites related to EOL care</td>
</tr>
<tr>
<td></td>
<td>o Contact information for the BC College of Physicians &amp; Surgeons support program for physicians</td>
</tr>
</tbody>
</table>

The scrollable lists should each be pre-populated, however, the clinician should be able to easily edit all three.

**Billing Codes:**
Suggested initial content of the list of billing codes is:

Palliative care ICD-9 code: V58

**Contacts:**
Having a list of contact phone numbers consolidated in one place saves time.

Individual clinicians will need to be able to populate the list with information relevant to their local palliative care team, pain clinic, ER, etc.

**My Resources:**
Clinicians may have their personal favourites re websites, and will
G14063  Palliative Care Planning Fee
G14069  Palliative Care Telephone/E-mail

00127  Terminal care facility visit
00103  Home visit (0800 - 2300)

Call-Out Charges (Extra to consultation):
01200  Evening (called 1800 - 2300 & visit 1800 - 0800)
01201  Night (called & visit 2300 - 0800 hours)
01202  Weekend & stat holiday (call 0800-2300)

G14015  Facility Patient Conference Fee
G14016  Community Patient Conference Fee
G14017  Acute Care Discharge Planning Conferencing Fee

Contacts:
The list of contact information should be initialized with:
BC Palliative Care Consult Line (24/7) 1-877-711-5757
BC palliative care drug plan (Plan P) – 1-800-663-7100
Pharmacare special authority 1-800-657-1188
Family Caregiver Network Society 250-384-0408
BC Bereavement Helpline 1-877-779-2223
BC Hospice Palliative Care Association 1-877-410-6297
Canadian Cancer Society – 1-888-939-3333

My Resources:
Selecting an item in the My Resources list should directly open it, whether it be a weblink, or a link to a document, spreadsheet, Powerpoint presentation, or other document entered into the list by the clinician. The actual file path or web address does not need to be displayed.

Initially, the list should point to a text file giving instructions on how to set

want to be able to modify the list to suit their needs.

1. The list of resources should be defined in a file containing
   a. A description of the items
   b. For each item, either a
      file path or a website

2. The list displayed on screen should only show column “a.” above.

3. By clicking on the item, the underlying specified file, or website should open for viewing.
up further links.
Other initial information should include web links as follows:
BCCA cancer management guidelines –
www.bccancer.bc.ca/HPI/CancerManagementGuidelines/default.htm

BC Palliative care drug plan formulary –
www.health.gov.bc.ca/pharmacare/outgoing/palliative-formulary.pdf

BC palliative care guidelines –
www.bcguidelines.ca/submenu_palliative.html

Home and community care – www.health.gov.bc.ca/hcc/

Canadian Cancer Society (BC) – www.cancer.ca/en/?region=bc

Victoria Hospice – www.victoriahospice.org

Vancouver Coastal – Hospice Palliative Care –
www.vch.ca/your_health/health_topics/home_hospice_palliative_care/hos
pice_palliative_care

Fraser Health Hospice Palliative Care –
www.fraserhealth.ca/your_care/hospice_palliative_care

Interior Health Hospice Palliative Care –
www.interiorhealth.ca/YourCare/EndOfLife/Pages/default.aspx

Northern Health Palliative Care –
www.northernhealth.ca/YourHealth/HomeandCommunityCare/HomeandCo
munityCareServices/EndofLifeCareHospicePalliativeCare.aspx

Canadian Virtual Hospice – www.virtualhospice.ca
Appendix B – Data Elements

This section of the document describes the data elements necessary to implement the EOL tool.

Unless otherwise specified, all Boolean variables should initialize to FALSE, all text objects should initialize with empty strings.

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Data Type</th>
<th>Windows in which used</th>
<th>When populated</th>
<th>Data used by</th>
<th>Description &amp; Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global audit trails</td>
<td>Defined by EMR vendor</td>
<td>Globally</td>
<td>With any use of EMR</td>
<td>Audit log</td>
<td>All the data elements need to include associated audit trail information including history of the dates that a data element was modified, and by whom. Of course a data element can be modified multiple times, so the audit trail needs to be a time series. PITO-approved EMRs have audit trail functionality built-in</td>
</tr>
<tr>
<td>Audit trails for forms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>For each form or handout that can be printed, there must be an audit trail to track:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Who printed it</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• When it was printed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Whether it was</td>
</tr>
</tbody>
</table>
given out

- If necessary, whether it was returned
  Where/how it was printed
  (e.g. local printer, patient’s printer, sent by email, email address, etc.)

Of course, a form may be printed or reprinted multiple times, so the audit trail needs to be a time series.

| EOL_registered | Boolean | Registry window | When set TRUE in Registry or Home windows | Propagated into encounter note – Plan section, with the entry “Registered in EOL registry”.
|               |         | Home window      |                                       | Used in Quality indicators
|               |         |                 |                                       | Used when reporting on patients in EOL registry
|               |         |                 |                                       | A 2-state Boolean variable that flags whether or not a patient is registered on an EOL registry.
|               |         |                 |                                       | Initially FALSE

| EOL_transition | Index in list | Home window | When changed in Home window | Summary window
|               |             |             |                           | Advance Care Plan window
|               |             |             |                           | Collaborative Care Plan window
|               |             |             |                           | Reports re the above
|               |             |             |                           | Patient’s severity of illness
|               |             |             |                           | Initially Transition 1
|               |             |             |                           | Valid values are:
|               |             |             |                           |   1. 1 (Advance Planning)
|               |             |             |                           |   2. (<6 months, PPS 50%)
|               |             |             |                           |   3. (Increased...
<table>
<thead>
<tr>
<th>Description</th>
<th>Type</th>
<th>Register window</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alerts (see Appendix D)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. 4 (Days-weeks to live)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EOL_PrimDiagAll</td>
<td>Text</td>
<td>Registry window</td>
<td>The primary diagnosis for which a patient is registered in the EOL registry. Free text, as clinician may include a comment with the diagnosis. E.g. “Metastatic CA lung (stable since 2009)”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home window</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EOL_SecDiagAll</td>
<td>Text</td>
<td>Registry window</td>
<td>One or more other significant diagnoses in free text</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Permission_to_discuss</td>
<td>Text</td>
<td>Registry window</td>
<td>Names and comments about people or organizations with whom a patient is explicitly allowing their medical information to be discussed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not_permitted_to_discuss</td>
<td>Text</td>
<td>Registry window</td>
<td>Names and comments about with whom a patient is explicitly NOT allowing their medical information to be discussed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>Type</td>
<td>Window</td>
<td>Description</td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------------</td>
<td>---------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>EOL_masking_asked</td>
<td>Boolean</td>
<td>Registry window</td>
<td>When set TRUE in Registry window</td>
</tr>
<tr>
<td>PPS_score</td>
<td>List of numeric values</td>
<td>Home window Assessment Tool – PPS window</td>
<td>When edited in Home window, or entered via radio button in Assessment Tool - PPS</td>
</tr>
<tr>
<td>PPS_score_date</td>
<td>List of dates</td>
<td>Home window Assessment Tool – PPS window</td>
<td>To be populated by EOL tool whenever a PPS is entered.</td>
</tr>
<tr>
<td>ESAS_given</td>
<td>Boolean</td>
<td>Assessment Tool – ESAS window</td>
<td>Set TRUE if an ESAS is ever printed. If the ESAS is embedded within the EOL tool implementation, then the flag should be set true if any of the Boolean values has</td>
</tr>
</tbody>
</table>

58
Symptom scores for symptoms in the ESAS form, and those in the Symptom Management page. These include:
- Pain_score
- Fatigue_score
- Nausea_score
- Depression_score
- Anxiety_score
- Drowsiness_score
- Appetite_score
- Wellbeing_score
- Dyspnoea_score

<table>
<thead>
<tr>
<th>Field</th>
<th>Type</th>
<th>Tool/Window</th>
<th>Population/Compliance</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESAS_given_date</td>
<td>Date</td>
<td>Assessment Tool – ESAS window</td>
<td>Populated by EMR whenever an ESAS is given</td>
<td>Currently unused</td>
</tr>
<tr>
<td>SAT_given</td>
<td>Boolean</td>
<td>Assessment Tool – SAT window</td>
<td>Set TRUE if a SAT is ever printed for a patient</td>
<td>A Boolean value indicating the event of a SAT form being handed out.</td>
</tr>
<tr>
<td>SAT_given_date</td>
<td>Date</td>
<td>Assessment Tool – SAT window</td>
<td>Populated by EOL tool whenever a SAT is given</td>
<td>Date at which a SAT was last handed out.</td>
</tr>
<tr>
<td>Symptom scores</td>
<td>Integer</td>
<td>Assessment Tool – Pain score window</td>
<td>When entered in one of the windows listed.</td>
<td>Propagated into encounter note – Assessment section, with the entries of the form: &lt;symptom&gt;, followed by the score and “/10”. E.g. “Depression 2/10”</td>
</tr>
<tr>
<td>Field</td>
<td>Type</td>
<td>Source</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------</td>
<td>-------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Constipation_score</td>
<td>boolean</td>
<td>Home – Care Plans</td>
<td>Set TRUE by EOL tool when clinician enters any information onto Advance Care Plan in Home – Care Plans</td>
<td></td>
</tr>
<tr>
<td>Delirium_score</td>
<td>boolean</td>
<td>Home – Care Plans</td>
<td>Propagated into encounter note – Plan section, with the entry “Advance Care Plan done”.</td>
<td></td>
</tr>
<tr>
<td>Anorexia_score</td>
<td>boolean</td>
<td>Home – Care Plans</td>
<td>A flag indicated that an Advance care plan has been completed for the patient.</td>
<td></td>
</tr>
<tr>
<td>Advance_Care_Plan_done</td>
<td>boolean</td>
<td>Home – Care Plans</td>
<td>Set TRUE by EOL tool when clinician enters any information onto Collaborative Care Plan in Home – Care Plans</td>
<td></td>
</tr>
<tr>
<td>Collaborative_Care_Plan_done</td>
<td>boolean</td>
<td>Home – Care Plans</td>
<td>Propagated into encounter note – Plan section, with the entry “Collaborative Care Plan done”.</td>
<td></td>
</tr>
<tr>
<td>EOL_BC_Palliative_benefits_approved</td>
<td>Boolean</td>
<td>Home – Documents</td>
<td>A flag indicating that an application for BC Palliative benefits has been received by a clinician. (The assumption is that the application form has then been sent to the government and accepted)</td>
<td></td>
</tr>
<tr>
<td>Extended_benefits</td>
<td>Boolean</td>
<td>Home – Care Plans – Advance Care Plan</td>
<td>It is helpful to know if a patient has extended benefits, for coverage of medications not covered by MSP.</td>
<td></td>
</tr>
<tr>
<td>Follow_up_deadline</td>
<td>Date</td>
<td>Home window</td>
<td>At the end of patient encounter, a clinician has the option of setting a deadline by which time they expect to see the patient back for follow_up.</td>
<td></td>
</tr>
</tbody>
</table>
If the patient has not had another encounter prior to that date, then the alert system of the EMR should trigger a task to the MD.
Appendix - C Documents

Data elements related to Documents

The EOL tool includes the ability to view and print numerous documents and forms. Some of these forms need to be given to a patient, then returned back to the clinician. For each form given to a patient, the EOL tool must record that a document has been given, and where appropriate, record when a form has been returned. Rather than listing every form and the associated field names, the forms are listed below.

The data element name to indicate that a form has been given, is simply the name of the form (with spaces converted to underscores) with the suffix “_given” appended. Similarly, for documents that must be returned, the name of the relevant data element is the name of the form with the suffix “_returned” appended.

The fact that a form has been distributed should be documented as an insert in the progress note, in the “Plan” section. For example, if the “My Voice” document is distributed, the Plan section of the encounter note should include a note “My Voice form given”.

There is no need to insert a comment when a form is returned, as this fact might be documented by an MOA, by their clicking the “Returned” check box, without any encounter note.

E.g. For the “My Voice” document, there is only one associated data element:  My_voice_given.

The My Voice document is unique in that it contains several forms that can be completed and returned by a patient. Alternatively, a patient may see a lawyer or otherwise obtain individual forms such as Representation Agreements, that they might bring to their clinician.

Therefore, On the screen displaying documents, each of the following documents should be listed as sub-documents below “My Voice”. The clinician should be able to print out one or more of the forms, and as with other forms, the EOL tool needs to be able to indicate whether one of the forms has been given, and whether it has been returned.

Here is a list of the forms needing field names. Unless otherwise specified, these forms can be found either in the “My Voice” document, or in the EOL_PSP_Algorithm. Those that need to be returned are marked with an asterisk:

1. My Voice
   - My Beliefs, Values and Wishes*
   - Advance Care Plan – Summary*
   - Advance Directive*
• Putting Your Papers in Order (on Page 25)*
• Representation Agreement (section 9)*
• My Temporary Substitute Decision Maker (TSDM) List*
• My Representative - Standard Agreement (section 7)*
• Certificate of Representative or Alternate Representative*
• Certificate of Monitor*
• Certificate of Person Signing for the Adult*
• Certificate of Witnesses*

2. End of life care plan*
3. MOST form (Fraser Health)*
   (http://physicians.fraserhealth.ca/media/Medical%20Orders%20for%20Scope%20of%20Treatment%20(MOST)%20and%20Advance%20Care%20Planning%20(ACP).pdf)
3. EI Compassionate care (http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml#Where)
5. BC Palliative care benefits*
6. No CPR*
7. Home death protocol*
8. Notification of expected death at home*
9. What to consider when caring for someone dying at home
10. When someone dies (PSP EOL Algorithm document)
11. Preparing for the death of a loved one (PSP EOL Algorithm document)
12. A caregivers guide (PSP EOL Algorithm document)
13. Be Gentle with Yourself
14. Caregiver Questionnaire
15. Normal Manifestations of Grief
16. Distinguishing Grief and Depression
17. Children and Death
Appendix D – Quality Indicators

This section of the document describes the data elements necessary to generate reporting information on use of the EOL tool.

NOTE: For each of these quality indicators, there should be a report that includes only living patients, and a report that includes all patients on the registry.

For any quality indicator ending with “_count”, the report should include three results:

- The actual count of the number of patients meeting the criteria
- The ratio of count/denominator
- The ratio expressed as a percentage

<table>
<thead>
<tr>
<th>ID</th>
<th>Name</th>
<th>Description</th>
<th>Data elements used</th>
<th>Report content</th>
</tr>
</thead>
<tbody>
<tr>
<td>EOL_1</td>
<td>QI_EOL_patient_list</td>
<td>Number of patients &gt;= 55 years old who were at risk of dying over the specified reporting period. These are patients who have been specifically identified as receiving or could benefit from a palliative approach to care. This number should include all patients who are on the EOL registry PLUS all patients identified by a database query using the selection criteria identified on page 2 of the PSP EOL module.</td>
<td>EOL_registered</td>
<td>Union of (Patients with EOL_registered set TRUE AND age &gt;=55) with (Patients meeting the selection criteria specified)</td>
</tr>
<tr>
<td>EOL_2</td>
<td>QI_EOL_patient_list2</td>
<td>Number of patients assigned to the BC Hospice Palliative Care Program over the specified reporting period. These are patients from EOL-1 who are expected to die within 6 months and have a PPS of 50% or less</td>
<td>EOL_BC_Palliative_benefits_approved</td>
<td>Patients with EOL_BC_Palliative_benefits_approved set TRUE AND in EOL-1</td>
</tr>
<tr>
<td>-------</td>
<td>----------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------</td>
<td>------------------------------------------------------------------</td>
</tr>
<tr>
<td>EOL_3</td>
<td>QI_EOL_ACP_count</td>
<td>Number of patients from EOL-1 that have a documented advance care plan in the EMR.</td>
<td>Advance_Care_Plan_done</td>
<td>Count of (Patients with Advance_Care_Plan_done set TRUE AND in EOL-1)</td>
</tr>
</tbody>
</table>
| EOL_4 | QI_EOL_PPS_count     | a. Palliative Performance Scale (PPS)  
PPS is on page 8 of the EOL PSP Algorithm.                                                                                     | PPS_score                          | Count of (Patients with any PPS_score in their record AND in EOL-1) |
|       |                      | b. Edmonton Symptom Assessment Scale (ESAS)  
The ESAS is on page 10 of the EOL PSP Algorithm.                                                                                   | ESAS_given                         | Count of (Patients with any ESAS_given = TRUE in their record AND in EOL-1) |
| EOL_5 | QI_EOL_ESAS_count    | b. Edmonton Symptom Assessment Scale (ESAS)  
The ESAS is on page 10 of the EOL PSP Algorithm.                                                                                   | ESAS_given                         | Count of (Patients with any ESAS_given = TRUE in their record AND in EOL-1) |
| EOL_6 | QI_EOL_SAT_count     | c. Seniors Assessment Tool  
The Seniors Assessment Tool is on page 19 of the                                                                 | SAT_given                          | Count of (Patients with any SAT_given = TRUE in their record AND in EOL-1) |
| EOL_7   | QI_EOL_MyVoice_count | d. MyVoice  
MyVoice is on page 124 of the EOL PSP Algorithm. | My_voice_given  
Count of (Patients with My_voice_given= TRUE AND in EOL-1) |
|---------|----------------------|------------------------------------------------------|---------------------------------------------------------------|
| EOL_8   | QI_EOL_referral_count | Number of patients in EOL-1 who have had at least one documented referral in the EMR to another health care provider,  
A referral could be to a physician, home and community care, palliative care, etc. as part of their EOL care. | EMR-dependant  
Value, and percentage of Value/EOL-1 |
| EOL_9   | QI_EOL_CCP_count     | Number of patients in EOL-2 who have a documented collaborative care plan in the EMR.  
A collaborative care plan includes the individuals in the patient’s care team and what has been discussed regarding the patient’s care. There is a care plan template on page 27 of the EOL PSP Algorithm and descriptions of roles on page 115. | Collaborative_Care_Plan_done  
Count of (Patients with Collaborative_Care_Plan_done set TRUE AND in EOL-1) |
| EOL_10  | QI_EOL_bereavement_count | Number of patients in EOL-2 who have a documented bereavement  
??? - could be difficult to parse encounter note. | Count of (Patients with any of the listed data elements |
follow-up for loved ones or documented note in the EMR that they were given caregiver resources related to dealing with an imminent/upcoming death. Documentation in the patient’s record indicating that a loved one was given resources about bereavement or received bereavement follow-up. The EOL PSP Algorithm links to BC Guidelines for assessment and management of grief and bereavement.

Alternate option is that EOL toolkit does document which family resources have been printed out for a patient, but does not have any way of knowing whether family received them. The relevant data elements are:

- A caregivers guide given
- EI compassionate care given
- Home death protocol given
- Notification of expected death at home given
- What to consider when caring for someone dying at home given
- Preparing for the death of a loved one given
- When someone dies given
- Children and death given

<table>
<thead>
<tr>
<th>EOL_11</th>
<th>QI_EOL_billing_count</th>
</tr>
</thead>
<tbody>
<tr>
<td>For the patients in EOL-1, the unique billing codes that have been entered in the EMR since they were determined to be an EMR-dependant.</td>
<td>List of billing codes, and for each code, number of times it is used, and percentage of</td>
</tr>
<tr>
<td>ID</td>
<td>Description</td>
</tr>
<tr>
<td>--------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>EOL_12</td>
<td>EOL patient. This is a list of billing codes related to EOL care used for the EOL patients after they were determined to be an EOL patient along with a short description of the code. (E.g. G14063 – Palliative Care Planning Fee). A list of codes is available on the GPSC site. This should include only billing codes related to EOL encounters.</td>
</tr>
<tr>
<td>EOL_12</td>
<td>QI_EOL_diagnosis_count For the patients in EOL-1, the unique diagnostic codes that have been entered in the EMR since they were determined to be an EOL patient. This is a list of diagnostic codes related to EOL care used in the problem list for the EOL patients after they were determined to be an EOL patient along with a short description of the code (e.g. ICD-9-CM V66.7 – Encounter for palliative care). A list ICD codes is available. This should include only EMR-dependant</td>
</tr>
</tbody>
</table>

1. [GPSC site](https://www.gpsc.ca)
2. [ICD codes](https://www.icd10data.com)
<table>
<thead>
<tr>
<th>EOL_13</th>
<th>QI_EOL_encounter_count</th>
<th>The number of encounters that the patients in EOL-1 have had with their primary care provider (or alternate) over the specified reporting period. This should include only encounters related to EOL care.</th>
<th>EMR-dependant</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>EOL_14</td>
<td>QI_EOL_encounter_average</td>
<td>The average number of encounters that the patients in EOL-1 have had with their primary care provider (or alternate) over the specified reporting period.</td>
<td>QI_EOL_encounter_count/EOL-1</td>
<td></td>
</tr>
<tr>
<td>EOL_15</td>
<td>QI_EOL_encounter_GP_count</td>
<td>Number of these encounters initiated by the GP. This may be difficult to extract from the EMR. A partial solution could be to parse the “subjective” part of encounter notes to see if the clinician called in the patient, by looking for the terms: “called-in”, “called in”, “C/I”, “TCI”. It may also be possible to extract these same phrases from the appointment calendar, as most EMRs allow a “reason for visit” for each appointment in the calendar.</td>
<td>EMR-dependant</td>
<td>Value, and percentage of value/QI_EOL_encounter_count</td>
</tr>
<tr>
<td>EOL_16</td>
<td>QI_EOL_encounter_pt_count</td>
<td>Number of these encounters initiated by the patient</td>
<td>EMR-dependant</td>
<td>Value, and percentage of value/QI_EOL_encounter_count</td>
</tr>
<tr>
<td>--------</td>
<td>---------------------------</td>
<td>---------------------------------------------------</td>
<td>---------------</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td>EOL_17</td>
<td>QI_EOL_hospital_count</td>
<td>Average number of times patients in EOL-1 have been to the hospital over the reporting period. This can include both admissions to hospital, and visits to ER.</td>
<td>EMR-dependant</td>
<td>Value/EOL-1</td>
</tr>
</tbody>
</table>
## Appendix E – Alerts & Reminders
This section of the document describes the alerts that should be generated by the system, the conditions under which they will be generated. These should appear as items in the EMR’s Task/to-do list for the patient. Most EMRs distinguish between two kinds of tasks: those that tasks are in the clinician’s to-do list, and those that are alerts within the patient’s file.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Action</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinician advances Transition to a higher level</td>
<td>System should generate an alert in the patient file, reminding clinician to distribute any forms deemed critical to the earlier transition of illness, that have not yet been marked “Given”. The “critical” forms are: • My Voice • EOL care plan • Palliative Benefits application • No CPR • Notification of expected death Once the form has been marked “Given”, the alert should be removed.</td>
<td>It is important that clinicians be reminded to complete tasks relevant to each stage of disease. A clinician must be allowed to ignore/remove any alert they deem irrelevant. For example, if a clinician advances a patient’s Transition from “1 (Advance Planning)” to “2 (&lt;6 months, PPS 50%)”, then the system should generate a reminder task if neither the “My Voice” document (or the subforms in “My Voice”) have not yet been given to the patient.</td>
</tr>
<tr>
<td>Clinician distributes a form that is expected to be returned, and it is not returned within a month</td>
<td>System should generate a task in the clinician’s task list, reminding the clinician to contact patient about the overdue</td>
<td></td>
</tr>
<tr>
<td>Scenario</td>
<td>System Action</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Clinician adds patient to end of life registry, but has not checked off</td>
<td>System should generate an <strong>alert</strong> in the patient’s file, reminding clinician to discuss with the patient if there is any sensitive medical history that they would like masked. The alert should be removed when the Masking discussed flag has been checked.</td>
<td>It is important that clinicians discuss masking of sensitive data, as patients may have secrets in their medical history that they want to take to the grave.</td>
</tr>
<tr>
<td>“Masking discussed”, in the Registration window.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Clinician advances Transition beyond “1 (Advance Planning)”, and patient is not on EOL registry</strong></td>
<td>System should generate an <strong>alert</strong> in the patient’s file, reminding clinician to add the patient to the EOL registry. This alert can be removed when the patient is added to the registry.</td>
<td>A patient in transition 1 might be acting in a very proactive manner, with no anticipated death in the next year. They do not need to be entered into the EOL registry. A patient who is in transition 2 or beyond is dying, and should be on the EOL registry.</td>
</tr>
<tr>
<td><strong>Clinician entered a value for “Follow-up by”, on the home page, and patient has not been seen in follow-up by that date</strong></td>
<td>System should generate a <strong>task</strong> in the clinician’s task list, reminding clinician that the patient is overdue for EOL reassessment.</td>
<td></td>
</tr>
<tr>
<td><strong>Clinician advances Transition beyond “1 (Advance Planning)”, and patient has no PPS score</strong></td>
<td>System should generate an <strong>alert</strong> to clinician, reminding them to do a PPS score. This alert can be removed when the patient has at least one PPS score.</td>
<td>A patient who is in transition 2 or beyond is dying, and should have a PPS score on file. This score will also be necessary when applying for BC Palliative benefits.</td>
</tr>
<tr>
<td><strong>No_CPR_date is more than 2 years old</strong></td>
<td>System should generate a <strong>task</strong> in the</td>
<td>A “No CPR” form has a two year life-span,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>clinician’s task list, reminding clinician that the patient’s No CPR form has expired.</td>
<td>after which it needs to be renewed. The system needs to generate a task for the clinician when a No CPR form is about to expire. This warning needs to come up even if the EOL tool is not active.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix F– Symptom management
This section of the document describes the content for the symptom management component of the EOL tool.

When activated, the Symptom Management component of the EOL tool displays the following options:

- Pain
- Nausea & vomiting
- Constipation
- Dyspnoea
- Delirium
- Depression
- Anxiety
- Fatigue
- Anorexia
- Intractable symptoms
- Last days and hours
- Crisis orders

For each specific symptom, the EOL tool must be able to capture a level-of-severity score from 1-10. Most of these scores are also captured in the ESAS form. The exceptions are:

- Constipation (Constipation_score)
- Delirium (Delirium_score)
- Anorexia (Anorexia_score)

There is no need to capture a score for “Intractable symptoms”, “Last days and hours” and “Crisis orders”.

As with scores from the ESAS form, if a symptom score is non-zero, then an entry should be inserted into the “Assessment” section of the encounter note. E.g. “Constipation 7/10”.

For each symptom, for most symptoms, the general format of the content is:
• Possible Causes
  o Disease-specific management advice
• Initial Management
• Further Management

For reference, here is an example for “Dyspnoea” from the main narrative of the this document:
***EVERY page of the symptom management component must display a disclaimer “*** These are guidelines only. Clinicians must use their judgement when using these guidelines to make clinical decisions.”***

Here is the content for the symptom management modules:

1. **Pain**

Main page should contain the contents of the document “Initial Pain Management April 2014”. Text in blue should be converted to buttons that link to either print or display the content of other subdocuments as described below:

1. Buttons linking to information re management re the types of pain:
   
   a. [Uncontrolled Cancer Pain](#)
   b. [Opioid Rotation](#)
   c. [Neuropathic Pain](#)
   d. [Bony Cancer Pain](#)
   e. [Visceral Pain](#)
   f. [Intractable Symptoms](#)

2. Button for “Print Opioid Manager”, labelled as such. Clicking this button should cause the document “Opioid manager.pdf” to be printed.

3. Button for “in Chronic Non-Cancer Pain”, labelled as such. Clicking this button should cause the document “PAD Opioids CNCP (JULY 2013).pdf” to be displayed.

4. Button for “Print patient handouts”, labelled “Print”. Clicking this button should cause the documents “Opioid patient handout.doc” and “BCCAbowelprotocol.pdf” to be printed.

5. Button for “Uncontrolled Cancer Pain”, labelled as such. Clicking this button should cause a new window to be displayed, containing the contents of the document “Uncontrolled cancer pain April 2014.docx” to be displayed.
   
   a. Similarly, this document has several areas of blue text that should be substituted with buttons, that open windows containing the contents of the following documents:
      
      i. [SC medications – “Subcutaneous Pain Medications April 2014.docx”](#)
      ii. [Opioid Rotation – “Opioid Rotation.docx”](#)
1. This window contains a button “Conversion table”. On being clicked, the contents of “Fentanyl Conversion table April 2014. docx” should be displayed.

iii. Neuropathic Pain – “Neuropathic pain (2)”
   1. This window contains a button “Intractable symptoms”. On being clicked, the contents of “Intractable symptoms. docx” should be displayed.

v. Visceral Pain – “Visceral pain.docx”
i. Incident Symptoms – “Dyspnoea incident symptoms.docx”
ii. Opioid comparative pricing – “Opioid Drug Pricing Comparisons.pdf”

2. Nausea & Vomiting
Main page should contain the following text blob:

**Nausea and Vomiting**

- Targeted Treatment
- Malignant Bowel Obstruction
- Hypodermoclysis
- Intractable Symptoms

These are guidelines only. Clinicians must use their judgement when using these guidelines to make clinical decisions.

Consider and treat:

**GI:** constipation, malignant bowel obstruction, large volume ascites (need paracentesis)
**CNS:** increased intracranial pressure (Tx with dexamethasone, Diamox), medication-induced (opioids, chemotherapy, spironolactone, etc.), vestibular, hepatic failure
**Metabolic:** dehydration (Tx with IV fluids, or hypodermoclysis)
  hypercalcaemia (Tx with IV fluids, calcitonin SC, pamidronate IV, dexamethasone)
  renal failure (Tx with V fluids for pre-renal failure, renal ultrasound to identify post-renal failure?)

**Infection:** sepsis
Initial Management:
1. History and physical
2. Look for and treat underling causes (CBC, lytes, creatinine, Ca++, albumin, LFTs, 3-views abdomen?, CT head?)
3. If dehydrated, consider IV fluids or hypodermoclysis
4. Ask about severity of nausea (1-10): now, best, worst
5. Non-pharmacological management (Summary Handout Detailed Handout)
6. Pharmacological management:
   a. Use regular antiemetic if on PRN antiemetic
   b. Initial Treatment (Targeted treatment)
   c. Further Treatment (Refractory nausea)
   d. Intractable nausea and vomiting

Links:
1. Link “constipation”
   Clicking on this link should cause the symptom management page about constipation to be activated.
2. Link “malignant bowel obstruction”
   Clicking on this link should cause the document, or the text of “Malignant Bowel Obstruction April 2014.docx” to be displayed.
3. Link “hypodermoclysis” (2 occurrences)
   Clicking on this link should cause the document, or the text of “Hypodermoclysis.docx” to be displayed.
4. Link “Summary Handout”
   Clicking on this link should cause the document “Nausea and Vomiting Patient Handout.docx” to be printed.
5. Link “Detailed Handout”
   Clicking on this link should cause the document “NauseaVomiting Patient Handout.docx” to be printed.
6. Link “Refractory nausea”
   Clicking on this link should cause the document, or the text of “Refractory Nausea and Vomiting April 2014.docx” to be displayed.
7. Link “Intractable nausea and vomiting”
   Clicking on this link should cause the document, or the text of “Nausea Intractable Symptoms.docx” to be displayed.
8. Link “Targeted treatment”
   Clicking on this link should cause the text in “Nausea and vomiting Initial Management” to be displayed.
4.1 **Within “Targeted treatment”**
Within the window for “Targeted treatment, beside the text “malignant bowel obstruction” there should be a button “Link”. Clicking on this button should cause the document, or the text of “Malignant Bowel Obstruction.docx” to be displayed.

9.2 **Within “Targeted treatment”**
Beside the text “Hyperdermoclysis”, there should be a button “Link”. Clicking on this button should cause the document, or the text of “Hypodermoclysis.docx” to be displayed.

3. **Constipation**
Main page should contain the following text blob:

**Constipation**

- **Malignant Bowel Obstruction**
- **Bowel Protocol**
- **Further Management**

These are guidelines only. Clinicians must use their judgement when using these guidelines to make clinical decisions.

“Consider and treat:

GI: malignant bowel obstruction
CNS: Opioid-induced
**Hypomotility**: ascites, peritoneal carcinomatosis, autonomic neuropathy

**Initial Management:**
1. Rule out bowel obstruction
2. Rectal exam
3. Ask about severity (1-10)
4. Bowel protocol (No rectal measures if neutrophils < 0.5 or platelets < 20!)

**Further Management”**
**Links:**

Clicking on the text “Malignant Bowel Obstruction”, or “bowel obstruction” should cause the document, or the text of “Malignant Bowel Obstruction April 2014.docx” to be displayed.

Clicking on the text “bowel protocol”, should cause the document “BCCABowelProtocol April 2014.pdf” to be printed.

Clicking on the text “Further Management” should cause the text of “Constipation Further management April 2014.docx” to be displayed.

Clicking on the text “Further Management” should cause the text of “Constipation Further management April 2014.docx” to be displayed.

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**4. Dyspnoea**

Main page should contain the contents of “Initial dyspnoea management (revised).doc”. Note that there are several areas in blue font, which indicate buttons that either link to other documents, or cause them to be printed. These are:

1. Button for **“home oxygen”**, labelled “Print”. Clicking this button should cause the system to either print the home oxygen application form “FHA Home oxygen program application.pdf”, or auto-fill it, and allow the clinician to fill in fields.
2. Button for **“comfort measures”**, labelled “Print”. Clicking this button should print out the document “Dyspnoea Patient handout”.
3. Button for **“Opioid management of dyspnoea”**, labelled “Link”. Clicking this button should cause the document, or the text of “Opioid management of dyspnoea (2).docx” to be displayed.
4. Button for **“Link to Incident symptoms”**, labelled “Link”. Clicking this button should cause the document, or the text of “Dyspnoea Incident Symptoms.docx” to be displayed.
5. Button labelled **“Crisis management”**. Clicking this button should cause the document, or the text of “Crisis orders.docx” to be displayed.
6. Button labelled **“Intractable dyspnoea”**. Clicking this button should cause the document, or the text of “Intractable symptoms.docx” to be displayed.
5. **Delirium**
Main page should display the contents of the document “Delerium Management (revised).docx”. Text in blue should be converted to buttons that link to either print or display the content of other subdocuments as described below:

1. Button for “Intractable symptoms”, labelled as such. Clicking this button should cause the document “Intractable Symptoms” to be displayed.

6. **Depression**
Display the contents of “Depression at the End of Life.docx”.

7. **Anxiety**
Display the contents of “Anxiety.docx”.

8. **Fatigue**
Main page should contain the following text blob:

   “Consider:
   
   **Fatigue:**
   
   Lab & lytes: anemia, low Na⁺, low K⁺, low Mg⁺⁺, low Ca ++, high Ca ++, low TSH, dehydration
   
   Medication-induced: opioids, benzodiazepines, antidepressants, antihistamines, chemotherapy
   
   Other: alcohol/drug abuse, depression, malnutrition, infection, sleep disorder, obstructive sleep apnea, chronic fatigue syndrome
   
   Weakness:
   
   Localized: cerebral metastases, cerebral vascular accident, radiculopathy
   
   Generalized: deconditioning, malnutrition, paraneoplastic syndrome, polymyalgia, polymyositis, steroid-induced myopathy, steroid withdrawal, abrupt”
9. Anorexia
Main page should display the contents of “Anorexia (revised).docx”

10. Intractable symptoms
Display the contents of “Intractable symptoms.docx”

11. Last days and hours
12. Display the contents of “Last days and hours.docx”

13. Crisis orders
Display the contents of “Crisis Orders.docx”