PALLIATIVE AND END OF LIFE CARE (PEOLC)

Adult and Pediatric Clinical Documentation
Current State, Dependencies & Desired Standardization

Palliative and End of Life Care (PEOLC)
Clinical Documentation Working Group
Revised December 17, 2018
Introduction

In preparation for the provincial Clinical Information System (CIS) the PEOLC Clinical Documentation Working Group has initiated the identification and standardization of future state documentation requirements. This report outlines work completed on defining current state documentation, identifying dependencies and recommendations or desire to standardize.

The Connect Care Clinical Documentation Working Group Terms of Reference (Appendix A) provide a more detailed description of the deliverables and include Working Group membership.

The palliative and end of life care health information and tools available within the MyHealth.Alberta.ca website and The Alberta Health Services Palliative and End of Life Care Alberta Provincial Framework 2014 provided the foundation to the work outlined in this report. The following Connect Care Guiding Principles and the Clinical Documentation Framework 2017 provided additional guidance:

1. **Put patients and families first.**
   Enhance safety and improve the healthcare experience.
2. **Move fast.**
   Make timely, clear and actionable decisions, staying on schedule.
3. **Integrate across the continuum.**
   Favour seamless information flows over niche solutions.
4. **Avoid unhelpful variation.**
   Adopt evidence-informed, provincially standardized, guidance and workflows.
5. **Adopt and adapt.**
   Express AHS best practice, leveraging Epic content to fill gaps.
6. **Use tools for transformation.**
   Do not entrench old inefficiencies with new technologies.
7. **Lead with purpose.**
   Maximize engagement of clinical and operational leaders.
8. **Partner to advantage.**
   Fully leverage Epic’s experience, offerings and relationships.
9. **Transform With Intent.**
   Monitor and measure expected benefits and unexpected harms.
10. **Heed best experience.**
    Collaborate to make the most of Epic’s Good Install program.
## Acknowledgements

The Palliative and End of Life Care Clinical Documentation Working Group has contributed to the development of the information included in this report and includes the following members.

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PEOLC Clinical Documentation Representation

PEOLC Current state clinical documentation requirements have been identified in the following clinical streams:

- Intensive Palliative Care Unit/Tertiary Palliative Care Unit
- Hospice/PEOLC community supported beds in Supported Living
- Integrated Home Care/Palliative Home Care
- Outpatient Clinic
- Consult Team (various care settings)
- Acute Care, including but not limited to Inpatient Cancer Care and designated PEOLC beds

Within each of the following areas:

- Referral to service
- Screening for service
- Admission assessment
- Initial consult/visit
- Daily/every consult
- Discharge/death
- Referral from service
- As needed
Adults

Adult Provincial Standardization

Existing:
1. Palliative Performance Scale (PPS)
2. Advanced Care Planning/Goals of Care Designation Policy, procedure, tools and resources [www.conversationsmatter.ca](http://www.conversationsmatter.ca)
3. Palliative and End of Life Policy (for continuing care and is a Continuing Care Health Service Standard)
4. Clinical Knowledge Topic: Advanced Care Planning/Goals of Care Designation (ACP/GCD)

Note: Covenant Health has their own similar policies for #2 and 3.

In progress:
1. Guideline: Patient’s Death in the Home Setting HCS-213-01 (provincial implementation to be completed by April 30, 2018); includes Expected Death in the Home form and instructions re: documentation
2. Clinical Knowledge Topic: Care of the Imminently Dying
3. Clinical Knowledge Topic: Palliative Sedation

Note: Covenant Health is updating a policy for Care of the Imminently Dying.

Adult Primary PEOLC Tools

*Primary PEOLC tools refers to those tools specific to the clinical area.*

Used by most PEOLC streams:
1. Palliative Performance Scale (PPS)
2. Edmonton Symptom Assessment Scale-Revised (ESAS-R)

Used by one or more PEOLC streams:
1. Agape Hospice Family Survey
2. Bereavement Risk Assessment Tool (Victoria Hospice Society 2008)
3. Complexity Tool (Grief Assessment)
4. Eastern Cooperative Oncology Group Performance Status (ECOG)
5. Edmonton Classification System for Cancer Pain (ECS-CP)
6. Palliative Prognostic Index (PPI)
7. Palliative Outcome Scale (POS)-modified

Home Care Specific Primary Tools (Used in all zones):
1. End of Life (EOL) Comprehensive
Home Care Specific Primary Tools (Used in 4/5 zones; Meditech electronic health record):

1. Palliative General Physical Assessment
2. Death at Home: Expected
3. End of Life Prearrangement
4. Palliative Care Intake
5. Palliative Psychosocial Assessment

There is nothing palliative specific built into PARIS. Calgary home care does use an end of life comprehensive assessment but it is not built in PARIS.

**Adult Secondary PEOLC Tools**

*Secondary tools refers to those tools used, but not lead by the clinical area.*

*A complete list of the secondary tools can be found in Appendix B.*

Categories of Secondary tools used by some PEOLC streams

1. Alcohol Use
2. Anticholinergic Burden
3. Anxiety/Depression
4. Bowel Function
5. Confusion Assessment/Delirium
6. Depression
7. Dyspnea
8. Endurance
9. Falls
10. Frailty
11. Function
12. Grief and Bereavement
13. Medication related
14. Mental Status
15. Motor
16. Nephrology
17. Outcomes
18. Oral Health
19. Pain
20. Problem Checklist
21. Prognostic
22. Respiratory
23. Sedation Scale
24. Spiritual Care
25. Satisfaction Survey
26. Social Work
27. Tissue Donation
28. Tuberculosis
29. Wound/Skin Assessment
Adult PEOLC Dependencies

The current primary PEOLC tools and the secondary tools used within the PEOLC streams support palliative and end of life care standards and reporting requirements.

1. Care planning
2. Zone specific reporting (PPS/ESAS-R/POS-modified)
3. Provincial prioritized indicators and parameters
4. Continuing Care Health Service Standards (CCHSS)
5. Alberta Continuing Care Information System (ACCIS)
6. Accreditation
7. Canadian Institute for Health Information (CIHI)
8. Resident Assessment Instrument (RAI-HC and RAI-LTC 2.0)
9. Other information systems
   a. Netcare
   b. Strata PathWays
   c. Pixalere Wound Management System
10. Alberta Health (TBD)
11. Information Flow (may be out of scope for the working group)
   a. Examples include integration with vendors and the Palliative website
12. Advance Care Planning Collaborative Research and Innovation Opportunities Program (ACP CRIO)
   a. Nine Advance Care Planning/ Goals of Care Designation indicators were created by CRIO and have been integrated into the provincial AHS evaluation of ACP/GCD.
13. Emergency Medical Services (EMS) PEOLC Assess, Treat, Refer program phase 1, 2 and this fiscal year phase 3. An evaluation logic model is attached to this program with specific data elements being captured for outcome measurement.

Adult Desired Standardization

Recommendations/Decisions by Working Group (WG):

1. January 29, 2018 PEOLC Clinical Documentation WG Meeting
   The PEOLC Clinical Documentation Working Group requests the Victoria Hospice Palliative Performance Scale (PPS) as a provincial documentation standard inclusive of ambulation, ability to do activities, self-care, intake and level of consciousness.

2. February 12, 2018 PEOLC Clinical Documentation WG Meeting
   The PEOLC Clinical Documentation Working Group requests both the Edmonton Symptom Assessment System Revised (ESAS-R) and Palliative Outcome Scale (POS) modified as provincial documentation standards.

3. April 2, 2018 PEOLC Clinical Documentation Working Group Meeting
   The Working Group requests PEOLC specific comprehensive and intake assessments that can be flexibly applied across care settings. These assessments do not yet exist (across care settings) and would need to be built, possibly leveraging existing assessments in certain PEOLC streams.
Pediatric Provincial Standardization

Existing:
1. Advanced Care Planning/Goals of Care Designation (ACP/GCD) Policy, procedure, tools and resources
2. Clinical Knowledge Topic: Advanced Care Planning/Goals of Care Designation

In progress:
1. Guideline: Patient’s Death in the Home Setting HCS-213-01(provincial implementation to be completed by April 30, 2018); includes Expected Death in the Home form and instructions re: documentation
2. Organ Donation after Death (Calgary Acute Care sites)

To be developed in 2018-2019:
1. Clinical Knowledge Topic: Pediatric Care of the Imminently Dying
2. Clinical Knowledge Topic: Pediatric Palliative Sedation

Pediatric Primary PEOLC Tools

Primary PEOLC tools refers to those tools specific to the clinical area.

1. Pediatric Client Comprehensive (Meditech)
   - This is being done across the province but there is not one standard form in use
2. Palliative General Physical Assessment (Meditech)
3. End of Life Prearrangements (Meditech)

These three tools are from Meditech and are used by home care in Meditech zones.

PARIS (Calgary home care system) includes similar assessments to those built in Meditech but may have different information.

Pediatric Secondary PEOLC Tools

Secondary tools refers to those tools used, but not lead by the clinical area.

A complete list of the secondary tools can be found in Appendix C.

Categories of Secondary tools used by some Pediatric PEOLC streams
Note: A complete listing of the tools included in each category is attached.

1. Development
2. Early Learning
3. Falls
4. Motor
5. Pain
6. Performance Measurement
7. Quality of Life
8. Sedation Scale
9. Wound/Skin Assessment

**Pediatric PEOLC Dependencies**

*Includes the reporting and analytics requirements related to clinical documentation.*

1. Care planning
   a. Nothing formal in place
2. Zone specific reporting
   a. Currently, pediatric PEOLC utilization data is being collected at the zone or local level
3. Advance Care Planning Collaborative Research and Innovation Opportunities Program (ACP CRIO)
   a. Nine Advance Care Planning/ Goals of Care Designation indicators
      i. Indicators relevant to pediatrics have been aligned. These are not being reported at a provincial level.
4. Emergency Medical Services (EMS) PEOLC Assess, Treat, Refer for pediatrics is in the process of being developed this fiscal year (2018-2019).
5. Alberta Health (TBD)

**Desired Standardization**

Recommendations by Pediatric Sub-Working Group (WG):

1. April 9, 2018 Pediatric PEOLC Clinical Documentation Sub-Working Group Meeting
   a. Interest in standardizing pediatric PEOLC comprehensive assessment and care plans across the continuum of care
      i. May require more than one assessment to meet the requirements of the different PEOLC streams
   b. An AHS protocol on discontinuing life sustaining care would be helpful
   c. Interest in exploring opportunity to standardize templates for provincial pediatric PEOLC consult services

**Next Steps**

This report will be shared with the Continuing Care Area Council. The PEOLC Working Group will continue to meet to identify, prioritize and standardize future state documentation requirements and will address other needs that arise from working group discussion or as directed by the Continuing Care Area Council.
Appendix A

Purpose

Under the direction of the Connect Care Clinical Documentation Committee, the Clinical Documentation Working Group will develop provincially agree upon standardized clinical documentation best practice clinical content guidelines in preparation for the provincial Clinical Information System (CIS). Consistent documentation practices benefit everyone. Communication, access to information and care planning improve when practitioners speak the same language the same way. Effective clinical documentation includes patient assessments, statements of goals, care plans and transition tracking; all supporting integrated teams working across the continuum of care.

The Clinical Knowledge & Content Management (CKCM) team coordinates and facilitates the activities of program-specific and discipline-specific clinical documentation working groups comprised of physicians, nursing and allied health. This promotes adoption of best practices, builds consensus about documentation norms, exposes clinically essential documentation components, and reduces unhelpful program-to-program variation.

Clinically relevant documentation will best be achieved by identifying all data elements that are necessary for a clinician to consider in their practice, including information that is important but not necessarily documented by them. Clinical documentation should be collaborative and consider all clinicians who might document or view it.

Validation by the working groups will be based on the collective knowledge and availability of information and best evidence at the time. Ongoing review and validation will occur as new information becomes available.

Deliverables

As per the Clinical Documentation Framework, each clinical area or discipline is responsible for identifying and standardizing future state documentation requirements for their clinical program area or discipline (section 3.3). The working group is accountable for the following tasks required to achieve deliverable:

1. Define current state documentation requirements:
   a. Admitting
   b. Intake/Admission Assessment
   c. Daily Assessment
   d. Care Plan
   e. Transition Planning
   f. End of Service

2. Analyze and incorporate dependencies:
   a. Role based documentation
   b. Reporting requirements
   c. Analytics
   d. Performance Outcomes/Measure/KPIs
   e. Accreditation requirements
f. Best practice standards (local, national, international)
g. AHS policy & procedure

3. Define future state requirements for clinical documentation:
   a. Admitting
   b. Intake/Admission Assessment
   c. Daily Assessment
   d. Care Plan
   e. Transition Planning
   f. End of Service

4. Support design of the provincial clinical information system and paper forms
5. Support implementation and change management plans
6. Support plan for review and optimization

**Membership Model**

The program-specific working group is comprised of clinical subject matter experts from each zone including nursing, allied health, physicians.

The discipline-specific working group is comprised of clinical subject matter experts from each zone, including representation across the continuum of care that the discipline works.

In order to ensure continuity of decisions between working groups, working groups shall have cross-representation (i.e., social workers on the Social Work Clinical Documentation Working Group will represent social work on different Program Clinical Documentation Working Group; and, where appropriate, a specific social work will be identified to work on a standing basis with that program).

See appendix for membership list.

**Responsibilities**

**CKCM Admin Support**

1. Schedule meetings in outlook
2. Book meeting rooms as indicated
3. Manage logistics (including travel, lodging) as indicated

**CKCM Clinical Informatics Lead**

1. Prepare and circulate agendas
2. Prepare materials for meetings
3. Co-facilitate with program area Co-Chairs

**Working Group Co-Chair(s):**

1. Primary contact with working group members
2. Co-facilitates with CKCM Clinical Informatics Lead
3. Facilitates decision making and sign off of deliverables
4. Primary liaison with operational leadership
5. Assists in escalation of issues according to Resolution Process (see below)
6. Communicate and advocate changes with operational leadership

**The Working Group members:**

1. Represent clinical program area or discipline, providing clinical and contextual expertise
2. Make decisions on behalf of their zone/area/program/discipline
3. Ensure decisions and actions of the work group give consideration to:
   a. Impact to patient safety, accreditation and quality
   b. Identification of any challenges and barriers
   c. Identification of impact across the province
4. Communicate about how the change directly impacts zone/area/program/peers by being the local voice and acting as a conduit for both formal & informal communications
5. Advocate the benefits of the change
6. Identify, manage and address specific issues and concerns within their zone/area/program/discipline
7. Identify resource, geographic or training challenges for implementation

**Meetings**
- Assumption: Approximately 30-40 hours will be required to complete deliverables.
- Working group members will establish how meetings will be arranged and scheduled.
- All deliverables are aligned with the provincial CIS implementation timelines.

**Quorum:**
Attendance of 50% of members (or their designate with decision making authority) in person or by teleconference, will be required to conduct a meeting.

**Agendas:**
Agendas will be established for each meeting, maintained and distributed by CKCM team.

**Minutes:**
Meeting notes and action items will be recorded during the meeting by the CKCM team. The notes and action items will be circulated for review and comment after each meeting and will be amended and approved at the next meeting. Notes will focus on key decisions and actions noted during the meeting.

**Document Management:**
SharePoint will be used for document access and retention.

**Decision Making**
Decisions will be made by consensus and voting is required. Significant dissenting opinions will be captured and included in meeting notes. When an item cannot be resolved, the working group co-chair can invoke the Resolution Process.

**Situation:**
Working Group cannot come to agreement

**Step #1**
Working Group’s Co-Leads completes the Resolution Request, takes to the Program Leadership for possible resolution

**Step #2**
If Program Leadership unable to resolve, request is taken to the ClinDoc Executive Sponsors for final resolution

**Accountability and Reporting**
The working group is accountable to the Continuing Care Area Council. The program-specific working group has the autonomy to make decisions, and after consultation and program agreement, can approve standards. Discipline-specific working groups have autonomy over content specific to their discipline upon approval of their professional practice council or operational leadership, as appropriate.
Terms of Reference Review

These Terms of Reference will be reviewed on an annual basis or as required.

Appendix

Team Membership:

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<td>Working Group Member</td>
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Addendum to the PEOLC Clinical Documentation Working Group Terms of Reference

Dr. Jim Silvius will sponsor the PEOLC Clinical Documentation Working Group.

Decision Making

Principles:

- Our goal is to reach consensus. Voting and approval by majority will not be utilized.
- All Working Group members are encouraged to participate in discussions requiring decisions.
- Items of dissent can be brought forward by those areas directly impacted by the decision i.e. pediatrics, inpatient, hospice etc.

Resolutions invoked by the PEOLC Clinical Documentation WG will be forwarded to the Co-Chairs (Dr. Jim Silvius and Barbara O’Neill) of the Provincial Palliative and End of Life Innovation Steering Committee (PPAL/EOL ISC) for review. Where necessary, the Continuing Care Area Council will be informed of decisions requiring resolution.
Appendix B

PEOLC Clinical Documentation Working Group
Adult Secondary Tools used by some PEOLC Streams by Category

(Secondary tools refers to those tools used, but not lead by the clinical area)

Note: These were the tools received as part of the clinical documentation inventory conducted in the Fall of 2017 as well as in follow up emails and conversations in spring 2018. They may not represent all secondary scales, scores and tools used in the PEOLC streams. This is a list of tools used by one or more PEOLC services, and is not a list of tools the Working Group is proposing be standardized provincially and/or added to Epic.

- Alcohol Use
  - CAGE Questionnaire

- Anticholinergic Burden
  - Anticholinergic Burden Scale

- Anxiety/Depression
  - Hospital Anxiety Depression Scale (HADS)

- Bowel Function
  - Constipation Score
  - Victoria Bowel Performance Scale

- Confusion Assessment/Delirium
  - 2015 CAM_PRISME for Delirium
  - Confusion Rating Scale (CRS)
  - Nudesc delirium scale
  - Modified Confusion Rating Scale (CRS) (Agape Hospice)
  - Montreal Cognitive Assessment (MoCA)

- Depression
  - Geriatric Depression Scale (Long Form)
  - Geriatric Depression Scale (Short Version)

- Dyspnea
  - Modified Medical Research Council Dyspnea Scale (MMRC)

- Endurance
  - Body mass, airflow Obstruction, Dyspnea, & Exercise (BODE Index)
○ Falls
  • Integrated Facility Living Falls Risk Screening Tool
  • Schmid Falls Risk Assessment
  • SCOTT Fall Risk Screen CV 0525(2016/04)
  • Fall Risk Assessment (Rosedale Hospice)
  • Fall Risk Assessment Tool (Agape Hospice)

○ Frailty
  • Frailty Scale

○ Function
  • Functional Assessment Staging Tool (FAST)
  • ALS Functional Rating Score – Revised (ALSFRS-R)
  • Karnofsky Functional Scale

○ Grief and Bereavement
  • 2017 Complexity Tool
  • ACH Grief Support Program Info Sheet and Informed Consent
  • Art of compassionate communication
  • Assessment_electronic
  • Bereavement Care Telephone follow up -Things to consider
  • Bereavement Follow up
  • Bereavement Plan of care tracking
  • CAD - Care of the Family - Practical Matters - 2015 May 29 vsd_Final
  • CAD - Care of the Family - Preparing to Talk with Families -2015 May 29 vsd_Final
  • Closing Summary_2014
  • Consent to Treatment Plan or Procedure 2013
  • Creating a Grief Metaphor
  • Definition of Self compassion 2011
  • Dual Process Model of Coping with Bereavement
  • EMDR
  • EMDR Informed Consent Process_2013
  • EMDR progress note
  • Exploring your grief landscape
  • Genogram Ecomap 2014
  • GRIEF CARE IN THE MOMENT SKILLS
  • Grief in WP sugg. for bereaved Employees
  • Grief in WP Sugg. for Management Sept 2018
  • Grief letter (Covenant Health)
  • GSPwelcomeletettertoclient
  • GSP Documents (includes the following)
    – Client Intake Form
    – Multidisciplinary Progress Record
- Grief Support Program Counselling Record
- Grief Support Program Assessment (Version 1 and 2)
- Progress Notes
- Six Week Grief Group Program
- Education documents
  - *Coping with our grief* ....
  - *Cycles of grief*
  - *Tasks of grief*
  - *Grief styles*
  - *Grief vs Trauma*
  - *Grief vs Depression*
  - *Signs of Healing*
  - *Grief impacts our*. ....
  - *Self care is ....*
  - *Grief*
  - *54321 Senses Exercise*
  - *Self-Care Domains Exercise*
  - *My support network exercise*
- Informed Consent Process_2013
- Layers of Grief Brochure_SCS
- Mindfulness and Self care Grief Group
- One Time Bereavement Visit
- patient contact record
- Personal Loss Experiences Timeline
- Progress Notes Template_2014.docx 1
- Prolonged Trauma Exposure Exercise documentation template
- Teach – Grief Management
- Therapeutic questions for Grief Care 2 May 2013
- Together Forever grief group documentation template
- Tri-fold Brochure FINAL May 2017

- Medication related
  - Morphine Equivalent Daily Dose (MEDD)
  - Opioid Risk Tool
  - Opioid Risk Tool Clinician Form
  - Risk Assessment Screening Tool for patients requesting medication self-administration (Hospice – Calgary)

- Mental Status
  - Blessed Orientation Memory Concentration (BOMC) scale
  - Folstein Min Mental State Examination (MMSE)
  - Mini Cog
  - Molloy Standardized Mini Mental
- Nephrology
  - ESAS-R – Nephrology

- Outcomes
  - Canadian Cardiovascular Outcomes Research Team (CCORT)

- Oral Health
  - Oral Health Assessment Tool (OHAT) for Long Term Care

- Pain
  - Behavioural pain assessment for elderly presenting with verbal communication disorders (DOLOPLUS)
  - Calgary Interagency Pain Assessment tool
  - DN4 Questionnaire (neuropathic pain diagnostic)
  - Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II (PACSLAC-II)
  - Pain Assessment IN Advanced Dementia (PainAd)
  - Pain assessment Tool (Hospice – Calgary)
  - Checklist of Nonverbal Pain Indicators (CNPI)
  - Calgary Inter Agency Pain Assessment (Agape Hospice)

- Problem Checklist
  - Canadian Problem Checklist

- Prognostic
  - Prognostat Nomogram and Survival Table
  - CHESS – a scale that is a part of interRAI; used to predict mortality

- Respiratory
  - Respiratory Distress Observation Tool

- Sedation Scale
  - Richmond Agitation Sedation Scale (RASS)

- Spiritual Care
  - Spiritual FICA tool
  - Spiritual Screening Tool
  - Spiritual Assessment (Hospice - Calgary)
  - Spiritual Screen Assessment (Hospice Calgary)

- Satisfaction Survey
  - FAMCARE/FAMCARE-2 Scale
• Social Work
  • Social Work Assessment (Hospice – Calgary)

• Tissue Donation
  • Tissue Donating Screening Tool for Patients on the TPCU

• Tuberculosis
  • Tuberculosis Assessment for Continuing Care Centre Residents

• Wound/Skin Assessment
  • Bates-Jensen Wound Assessment Tool #801905
  • Present on Admission (POA) Skin Assessment
  • Braden
  • Waterlow (Agape Hospice)
Appendix C

Pediatric PEOLC Clinical Documentation Sub-Working Group
Secondary Pediatric Tools used by some PEOLC Streams by Category

(Secondary tools refers to those tools used, but not lead by the clinical area)

Note: These were the tools received as part of the clinical documentation inventory conducted in the Fall of 2017 as well as in follow up emails and conversations in spring 2018. They may not represent all secondary scales, scores and tools used in the PEOLC streams. This is a list of tools used by one or more PEOLC services, and is not a list of tools the Working Group is proposing be standardized provincially and/or added to Epic.

- Development
  - AIMS (if family/child still want developmental work to be done)
- Early Learning
  - HELP (0-3 and 3-6 scales) – Hawaii Early Learning Plan (if family/child still want developmental work to be done)
- Falls
  - Berg Balance scale
  - Falls, Entanglement and Strangulation (FES)
  - Little Schmidy Falls Risk (2-18 years)
  - Pediatric Falls Risk Assessment (0-24 months)
  - Pediatric Falls Risk Assessment (2-18 years)
- Motor
  - Alberta Infant Motor Scale (Used by PT)
- Pain
  - NON Verbal pain scale
  - Pain scale – FACES
  - Pain scale – FLACC
  - Visual Analogue Scale
- Performance Measurement
  - Canadian Occupational Performance Measurement (COPM)
- Quality of Life
  - Pediatric QL (quality of life index)
- Sedation Scale
  - Richmond Agitation Sedation Scale (RASS)
- Wound/Skin Assessment
  - Bates-Jensen Wound Assessment Tool #801905
  - Braden Q Scale #19865
  - Glamorgan Pressure Ulcer Screening Tool