Ontario Palliative Care Network

Tools to Support Earlier Identification for Palliative Care

April 2019

Ontario
Local Health Integration
Network

Ontario
Cancer Care Ontario

TABLE OF CONTENTS

Ontario Palliative Care Network

The Ontario Palliative Care Network (OPCN) is a province-wide partnership of healthcare providers and organizations, health system planners, patients, families and caregivers. We are working together to ensure the delivery of coordinated, high-quality hospice palliative care for everyone in Ontario, regardless of their age, illness, or where they live. The OPCN is guided by the report Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action (The Declaration)[1].

Funded by the Ministry of Health and Long-Term Care, the OPCN was launched in March 2016.

Purpose of this Document

The aim of this document is to support providers and system level leadership in earlier identification of patients who would benefit from palliative care.

This document complements the OPCN Health Services Delivery Framework (Delivery Framework) Recommendations, and aligns with Health Quality Ontario's (HQO) quality standard, *Palliative Care: Care for Adults with a Progressive, Life-Limiting Illness*[2] ('Palliative Care Quality Standard'); it is also a priority in the Ontario Palliative Care Network (OPCN) Action Plan 1.

How to Use this Document

This document provides guidance on preferred identification tools and suggested assessment tools for all health care sectors along with implementation considerations. The tools can be used in various health care settings including primary care, home & community care, acute care and long-term care.

The document can be used by system planners, Regional Palliative Care Networks (RPCNs), provider agencies and hospitals to guide the selection of identification and assessment tools when implementing earlier identification initiatives. The tools recommended in this document can assist providers in determining when palliative care should be introduced, and what additional resources, supports and services should be initiated to address individual and family needs in a timely manner.

Importantly, this document can be used to promote the scale and spread of earlier palliative care, encouraging broader use of these tools across care settings.

Key Definitions

Palliative care (also known as hospice palliative care) is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It strives to help individuals and families to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- prepare for and manage end-of-life choices and the dying process;
- cope with loss and grief;
- treat all active issues;
- prevent new issues from occurring; and,
- promote opportunities for meaningful and valuable experiences, and personal and spiritual growth[1].

Palliative Approach: Meeting a person's and his/her family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and

families a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging[3].

The term 'palliative approach' is also used to refer to palliative care delivered at a generalist level of competency by family physicians, primary care NPs, oncologist, internists, etc. as opposed to specialist level palliative care provided by palliative care specialists.

Earlier Identification:

Individuals who have a progressive, life-limiting illness should have their palliative care needs identified early through a comprehensive and holistic assessment. The initiation of palliative care should not be determined by prognosis; it can begin as early as the time of diagnosis, and it can be provided alongside treatment. Earlier identification is a deliberate proactive decision point in a person's health care journey. The process should include assessing patient and families' needs across multiple domains including physical, psychosocial-spiritual, grief and loss. At this point, open and honest communication with the individual and their family is essential, and should include initiation of goals of care discussions[4].

The Process of Early Identification

In alignment with the Gold Standards Framework, used by the National Health System in the United Kingdom, palliative care can be broken down into a 3-step best practice model shown here:

1. IDENTIFY
Identify if the person would benefit from palliative care early in their illness trajectory

2. ASSESS
Assess the current and future needs and preferences of the individual and their family/caregiver across all domains of care.

3. PLAN/MANAGE
Plan and collaborate ongoing care to address needs identified during the assessment.

Identification is the first step, and focuses on identifying those individuals who may benefit from palliative care early in their illness trajectory. Being "identified" does not mean a referral to a palliative care specialist. Instead, identification should lead to a comprehensive and holistic assessment of the individual and their family/caregiver's current and future needs and preferences across all domains of care. Assessment should include validated screening tools, an in-depth history, physical examination and relevant laboratory and imaging tests. Although these are depicted as two distinct steps, and there are different tools available to support identification and assessment, there is significant overlap between them, and they should be considered together. Importantly, the initiation of palliative care requires a needs-based approach supported by a documented, comprehensive and holistic assessment reflecting disease management, physical, psychosocial-spiritual, and grief/loss issues. The assessment should be documented and shared with providers. The outcome of identification and assessment will help to determine the care required to meet a person's needs, enabling the third step of planning and management.

The Importance of Earlier Identification

The World Health Organization indicates palliative care should be initiated in an early phase of a disease and not restricted to terminal care[5]. Identification of palliative care needs earlier in the disease trajectory has been recognized as a significant success factor in positive patient/family and system outcomes[4]. Identification of palliative care needs activates care planning, and discussions to define goals of care, and facilitates access to appropriate resources and supports required to meet individual and family needs. Limiting palliative care to the last days of life deprives patients of the opportunity to improve symptom control, quality of life and to make important care decisions earlier in the illness trajectory.

Earlier identification creates opportunities to engage in conversations to improve the patient's understanding of their illness and to identify their values and goals. Conversations can be more meaningful and thoughtful when they are pre-planned, and occur earlier, rather than in a period of rapid decline, or crisis. Importantly, these conversations can help to anticipate the patient's needs as the illness progresses and lead to reduced health care costs[4]. Initiating palliative care earlier in the patient's illness trajectory has also been shown to minimize unnecessary emergency department visits and hospital admissions[6].

The Declaration emphasized identification and early palliative care as important in addressing a patient's quality of living and dying. As well, the OPCN Action Plan 1: 2017-2020 Action Item C: Enabling Early Identification of People Who Would Benefit from Hospice Palliative Care[7] and the Palliative Care Quality Standard Statement #1: Identification and Assessment of Needs out "identification" as a priority in transforming the Hospice Palliative Care health system[2].

Challenges Related to Earlier Identification

Despite the emphasis placed on the importance of initiating palliative care early in a person's illness trajectory, available evidence demonstrates that the majority of this care remains focused on the end of life. For example, Health Quality Ontario's 2016 *Palliative Care Report* showed that in Ontario, among those receiving palliative care, only about half receive it within their last month of life. Similar results were found in the Canadian Institute for Health Information's 2018, *Access to Palliative Care in Canada* report, which showed a lack of palliative care services available to Canadians in the last year of life. The report indicated that in Ontario, in 2016/17, only 40% of adult decedents received homecare in the last year of life, while in 2012/2013 only 10% received a physician home visit in their last year of life. In the long-term care sector, across Canada, only 6% of all residents identified as having less than 6 months to live were recorded as having palliative care in the last year of life[6].

Various factors impact access to palliative care, including societal, cultural and professional barriers that influence a clinician's ability to identify patients who would benefit from palliative care earlier in their health care journey.

Society finds it difficult to grasp that death and dying are inevitable parts of the continuum of life. As a result, fear, anxiety, or discomfort may prevent people from talking about it. This "death denying" mentality results in care interventions being introduced close to death, usually in the last months of life[8].

Other challenges include clinicians' personal feelings toward death and dying, and a lack of understanding and comfort level with supporting the individual and their family to the end of life and through their grief/loss and bereavement. Clinicians need assistance in managing their personal feelings and beliefs so that open and honest conversations with their patients and families' can occur[9].

Finally, the process of identification typically relies heavily on clinician judgement. Although a greater focus on shifting perceptions beyond the end-of-life is required, the dying trajectory can be

unpredictable for many chronic, progressive illnesses, making it difficult for clinicians to determine the appropriate time to initiate palliative care[9]. Similarly, the use of subjective criteria for identification is influenced by both a clinician's knowledge of, and experiences in palliative care. The current value of prognostication tools is that they are familiar to clinicians, and can assist with prompting clinicians to consider introducing a palliative approach. These tools can be efficient, and easily embedded into work pathways. While prognostication based on clinical judgement is the typical approach, evidence suggests that predictions can be inaccurate[10]. For example, recent evaluations of the "Surprise Question" (i.e. Would you be surprised if this patient died in the next 12 months?) have shown that it has variable accuracy as a screening tool, and as such, it should not be used in isolation as an identification tool[11,12]. Instead of relying solely on prognostication to trigger the initiation of palliative care, the identification process should be supported by a comprehensive and holistic assessment. The assessment process plays an essential role in determining unmet needs, and the appropriate care and services required to address them. This is a fundamental shift in thinking that requires broader system change to facilitate earlier palliative care.

Context and Background for Developing the Recommendations

To better understand the evidence to support existing tools that facilitate earlier identification, the OPCN commissioned two reports:

1. CCO's Evidence Search & Review Services (ESRS) conducted a literature search of tools, indicators, triggers and algorithms used to identify patients needing hospice palliative care earlier in their health care journey (October 2017)

2. CCO's Product Management Cancer Services(PMCS) conducted an environmental scan of current tools and eTools addressing the identification of patients who might benefit from palliative care and the types of services needed by patients who are receiving palliative care (June 2017)

The OPCN struck an Earlier Identification Expert Panel (the Expert Panel) to analyze and make recommendations related to earlier identification. The Expert Panel was established in February 2018. Its mandate included developing recommendations on tools that would enable the earlier identification of patients who could benefit from palliative care. Please refer to Appendix 1 for more information about the Expert Panel.

The Expert Panel reviewed the ESRS literature search results, and the PMCS Tool/eTools Report. To understand local utilization of identification tools, the Expert Panel also reviewed the OPCN's Provincial Summary of Regional Activity Report (PSRA) (2017/18). The PSRA provides a high-level overview of regional activities underway across Ontario.

Findings to Support the Recommendations

In the 2017 ESRS report, 40 studies were reviewed that met the literature search criteria. This review resulted in 53 tools and algorithms being identified. The tools and algorithms were divided into two categories – identification and assessment.

Most of the tools and algorithms outlined in the literature utilize prognostication of patient death or deterioration as a proxy for the identification of patients who would benefit from palliative care, or have unmet palliative care needs. However, the initiation of palliative care should not solely be determined by prognosis and is not limited to the last 12-months of life.

It is important to remember that the research and literature validating these tools was focused on measuring their ability to identify patients in their last 6 or 12 months of life rather than identifying a

patient's needs. Patients that screen positive when utilizing these tools will be at risk of deteriorating or dying, but they will still need **assessment** to determine whether they would benefit from palliative care, or if they have unmet palliative care needs.

The top four identification tools most often reported in the ESRS report were:

1. NECesidades PALiativas Centro Colaborador de la Organizacion Mudial de la Salud (NECPAL CCOMS-ICO tool) (n=5)
2. Supportive and Palliative Care Indicator Tool (SPICT) (n=4)
3. Gold Standard Framework/Prognostic Indicator Guidance (GSF/PIG) (n=4)
4. RADboud Indicators for Palliative Care Needs (RADPAC) (n=3) (Cancer Care Ontario, 2017)

The ESRS report indicated that these tools are mostly used in primary care settings and acute care settings. The tools are most commonly used by clinicians as part of routine assessments and consultations. Tools were applied at time of admission and during hospital stays[13].

All the tools offer similar clinical indicators to assist clinicians in identifying patients who are at risk of clinical deterioration or death. The NECPAL, GSF/PIG and Ontario adapted versions of the GSF/PIG are reliant on the Surprise Question as the initial step in application of the tool. The NECPAL has a high level of sensitivity where there is a high probability that most patients will be classified as being in their last 12 months of life. A 2016 *GSF Update on Evaluations and Evidence* listed 13 published articles demonstrating that use of the GSF and GSF Prognostic Indicator Guidance supports earlier identification of patients considered to be in their last year of life[14].

A review of the OPCN's Provincial Summary of Regional Activity Report (2017/18) revealed the top four tools from the ESRS report being used in Ontario. Seven LHINs were using the GSF/PIG in local processes. Five LHINs indicated that the SPICT was being applied. One LHIN acknowledged limited application of the NECPAL tool. None of the LHINs were using RADPAC.

Three Regional Palliative Care Networks (RPCNs) have adopted and started to implement an Ontario version of the GSF/PIG. The Mississauga Halton Palliative Care Network adapted the GSF/PIG to create The Early ID Prognostic Indicator Guidance Tool with permission from Keri Thomas. An adaptation of the GSF/PIG was also created for the INTEGRATE project, a three year pilot project funded by the Canadian Partnership Against Cancer (CPAC) and Cancer Care Ontario (CCO). The project focused on implementing an integrated model of care at specific disease sites in four cancer centers and four primary care practices in three participating regions in Ontario.

The Earlier Identification Project Team further expanded their review to include Ontario specific tools, which identified two additional tools to support early identification of patients at risk of clinical deterioration or death:

1. Risk Evaluation for Support: Prediction for Elder-life in the Community Tool (RESPECT)
2. Hospital-Patient One-Year Mortality Risk (HOMR)

The Risk Evaluation for Support: Prediction for Elder-life in the Community Tool (RESPECT) is a newly developed electronic prognostic algorithm that is currently in process of research validation and community-based evaluation. It was not included in the ESRS review as minimal research articles existed around this tool at the time of the review. The aim of the RESPECT is to improve identification of individuals who are frail (i.e., in need for long-term support) but are not necessarily in the last year of life. It uses a wider range of predictors – routinely collected in the home care setting – to determine the survival of low-risk and high-risk community-based individuals. RESPECT can be used to support clinical judgement and care planning[15]. Since it uses data routinely collected in home care, it can be

used to identify all individuals within home care populations across Ontario who are at risk of clinical decline and may benefit from palliative care. The RESPECT Tool is a web-based tool that asks questions that can be readily self-reported by individuals. The tool can be used either by patients themselves or supported by clinicians. Use in care environments may be limited if individuals do not have computer access as the tool is online.

Hospital One-year Mortality Risk (HOMR) is an automated tool for identifying patients at elevated risk of death in the coming year using administrative data. It uses data already present in electronic records and can work in real time at the point of admission to hospital. It has the ability to identify patients with a non-cancer illness and frailty. It can be used as a reliable and inexpensive trigger that can be scaled for palliative interventions. The HOMR tool is used in acute care settings.

Recommended Tools for Identification

The list of Preferred Earlier Identification Tools are listed below in Table 1.

Table 1: Preferred Earlier Identification Tools

Tool/Guide/Indicator/ Trigger/Score Name[i]	Summary	Use in Ontario
SPICT Supportive & Palliative Care Indicator Tool https://www.spict.org.uk/	**Aim:** To identify patients at risk of deteriorating and dying with a life-limiting illness who may benefit from palliative care **Description:** A single page tool that includes general (i.e. weight loss, hospital admissions, etc.) and broad specific disease indicators (i.e. breathlessness at rest for heart and respiratory disease). Also includes an assessment paradigm. **Setting**: Applicable across care settings **Disease states**: Not disease specific	• Moderate (5 LHIN's)
Early ID Guide Adaption of UK GSF - PIG for Ontario use Link to MH Tool	**Aim**: To identify patients in their last year of life who may benefit from palliative care **Description:** A 3 step process multiple page tool that uses the surprise question, along with general and disease specific indicators of decline. Also includes an assessment paradigm. **Setting**: Applicable across care settings **Disease states**: Not disease specific	• Moderate • Implemented in HNHB, MH, & CW and within Ontario Renal Network
NECPAL CCOMS-ICO tool NECesidades PALiativas Centro de la Organizacion Mudial de la Salud Link to checklist version	**Aim**: To identify patients with limited life prognosis (less than 1 year) who may benefit from palliative care **Description:** A 1-2 page checklist that starts with the surprise question and uses yes/no questions (patient or family request or need for PC; general clinical indicators of severity and progression, including co-morbidity, resource use; and disease-specific indicators). This may require some data that may not be readily available in all settings. **Setting**: Applicable across care settings **Disease states**: Not disease specific	• Minimal (1 LHIN)

---

[i] In creating the list of preferred identification and assessment tools (Attachment 2), the most common name for the tool has been used, and may not specify the most current version of the tool. It is expected that the most current version of the tool would be selected for implementation at the local level.

Tool/Guide/Indicator/ Trigger/Score Name[i]	Summary	Use in Ontario
RADPAC RADboud Indicators for Palliative Care Needs Link to tool	**Aim**: To identify patients who suffer from progressive chronic illnesses that may benefit from palliative care **Description:** Single page tool that uses general and disease specific indicators of decline (i.e. CHF: frequent hospital admissions, COPD: Karnofsky score ≤50%, etc.). **Setting**: Applicable across care settings **Disease states**: Used only in CHF, COPD, or Cancer populations	• Currently not used in Ontario
RESPECT Risk Evaluation for Support: Prediction for Elder-life in the Community Tool	**Aim**: To calculate life expectancy for the frail **Description:** Online algorithm that uses patient demographics (age, gender, marital status), comorbidities, functional and cognitive status, symptoms, and health care use. Can be used by clinicians, patients and caregivers **Setting**: Applicable across care settings but requires online access **Disease states**: Not disease specific	• In validation phase in Ontario
HOMR Hospital One-year Mortality Risk	**Aim**: To predict 12-month mortality **Description:** An automated tool that uses administrative data (i.e. admitting service, arrival by ambulance, readmission, Charlson Comorbidity index score, etc.) to calculate mortality risk at 12-months after an acute admission, and sends a notification for all patients whose risk exceeds a preset threshold. **Setting**: Applicable only in acute care settings **Disease states**: Not disease specific	• Implemented in 3 LHINs

Implementation Considerations

A. Identification does not mean a referral to a palliative care specialist. Instead, identification should prompt a comprehensive and holistic **assessment** to determine the patient's full range of needs.

B. Identification has often been linked to prognostication. While a shorter prognosis can increase the need for palliative care, early palliative care has also been shown to be beneficial. Earlier identification can improve quality of life by ensuring adequate pain and symptom management, as well as relief of burdens by employing active person centered decision-making.

C. From a systems perspective, increasing the number of patients receiving palliative care in the last year of life is an important metric for change.

D. Earlier identification for non-malignant diseases, such as heart disease (congestive heart failure, cardiovascular disease), respiratory illness, renal failure, and neurodegenerative disease is often difficult[16,17]. Knowledge and understanding of chronic illness trajectories, including common indicators of deterioration and decline will require education at all levels of care.

E. Local conversations will be required to determine the operational and system processes required for both identification and assessment tools. Recommendations should be considered locally, within the context of existing tools, processes, and resources, and should build on strengths. Where possible, identification tools and associated assessments should be incorporated into existing workflows to help automate these processes. As an example, embedding a tool within the Electronic Medical Record (EMR) is likely to increase uptake and change practice behavior.

F. Implementation of identification tools requires adequate clinical assessment and evaluation skills, along with knowledge of local resources. Clinicians using identification tools must have access to palliative care education, communication skills training, and an understanding of the

need for timely conversations when they are appropriate. Local system structures as well as team based education is needed in order for early identification to be successful.

G. Regular system leadership collaboration is recommended. Implementing this approach will require support from administrative leaders in acute care hospitals, long-term care homes, home and community care. It will also require support from LHIN-based primary care leadership to promote this broadly in the primary care community. Clinical process changes are likely required, so a change management approach should be considered.

H. System leadership should create opportunities for generalist-specialist relationship building, mechanisms for formal and informal mentorship, and ongoing point of care teaching.

I. System leadership should monitor and evaluate tool implementation rates and trends in order to identify gaps that need to be addressed, and to leverage opportunities to build on strengths.

J. Patients and families should be empowered to initiate conversations about palliative care with their primary care practitioners and specialists at any point in their disease trajectory. Materials and resources about palliative care should be readily accessible for patients and families to increase their awareness and understanding, as well as encourage them to engage in these conversations.

Recommended Tools for Assessment

A list of Assessment tools are included in Appendix 2. The ESRS report did not examine the evidence on assessment tools, and these were not considered a priority focus for the work of the Expert Panel. As such, the Expert Panel has included only a high-level overview of assessment tools that are currently being used in Ontario across various care settings.

Measurement and Evaluation

The Expert Panel and Project Team recommends leveraging the quality indicators from the Palliative Care Quality Standard[2] to evaluate implementation of the identification tools. These have been adapted for the purpose of evaluating the preferred tools outlined in this document. The suggested indicators are not an exhaustive list. The suggested indicators should be used to inform local leaders and other provincial partners in evaluating Earlier Identification initiatives.

Process Indicators

Percentage of people identified (using the preferred tools) who have a documented assessment of their palliative care needs including physical, psychological, social, linguistic, cultural, legal, ethical, spiritual, and other needs

- Numerator: number of people in the denominator who have a documented assessment of their palliative care needs including physical, psychological, social, linguistic, cultural, legal, ethical, spiritual, and other needs

- Denominator: total number of people identified using the preferred tool(s)

- Data source: local data collection

- Note: consider measuring separately by each palliative care need and/or grouping them together as an overall measure

Number of days between receiving first palliative care service and death

- Calculation: can be measured as mean, median, or distribution

- Data sources: National Ambulatory Care Reporting System (NACRS), Discharge Abstract Database (DAD), Continuing Care Reporting System (CCRS), Home Care Database (HCD), Ontario Health Insurance Plan (OHIP), Registered Persons Database (RPDB)

Structural Indicator

Evidence of locally adopted tools from the preferred lists to:

- Identify people in need of palliative care

- Assess their needs

Data source: local data collection

Appendix 1: The Expert Panel

Purpose:

To develop a list of preferred palliative care identification tools to support the testing of the Health Services Delivery Framework (Delivery Framework) Recommendations.

Short Term Goal: Determine tools to support earlier identification of palliative care needs.

Context for this work

To better understand the evidence supporting existing tools that facilitate earlier identification, the OPCN commissioned CCO's Evidence Search & Review Services (ESRS) to conduct a literature search of tools, indicators, triggers and algorithms to identify patients needing hospice palliative care earlier in their health care journey (October 2017).

In April 2017, CCO Product Management Cancer Services conducted an environmental scan of current tools and eTools being used regionally and/or provincially (14 LHINs, hospices, supportive care facilities, etc.) to support:

- Identification of patients who might benefit from palliative care
- Identification of the types of services needed by patients who are receiving palliative care

As part of OPCN Action Plan 1 implementation, a Health Service Delivery Framework (Delivery Framework) Working Group was established in August 2017. The Delivery Framework Working Group included the element of "Identification and Assessment" as key component of the service delivery model.

It is also known that six of fourteen LHIN Regional Palliative Care Networks have "Identification" as part of their 2018 HQO IDEAS Palliative Care Cohort projects.

An OPCN Expert Panel and Project Team was established in February 2018 to develop recommendations on tools that would enable the earlier identification of unmet palliative care needs, that would support implementation of the OPCN's Health Service Delivery Framework.

In Scope

- Develop a list of preferred identification tools to be tested and evaluated within the primary care, and home and community care settings.
- Outline clinical processes that enable earlier identification of palliative care needs
- Develop evaluation questions and indicators to inform testing of the Delivery Framework and IDEAS projects.
- Define Delivery Framework criteria for the identification component of the recommended model of care for implementation.

Out of Scope

- Final recommendations, which will be developed after testing of the Delivery Framework and evaluation

Project Activities and Governance

A project team and Expert Panel were established in February 2018, and these groups met monthly from February until June 2018. The OPCN Clinical Advisory Council (CAC) provided oversight for the project and progress updates were provided regularly at the CAC meetings. Stakeholder engagement was conducted with the Regional Palliative Care Network Clinical Co-Leads and Directors, other

OPCN Advisory Committees, and partnership organizations through existing meeting structure and/or other feedback mechanisms. Progress updates were also provided to the OPCN Executive Oversight, the MOHLTC representatives, and through the OAGO bi-annual progress report.

Expert Panel Members

Ahmed Jakda MD, MBA, CCFP (PC) (Project Chair)
Provincial Clinical Co-Lead, OPCN
Palliative Physician, Grand River Regional Cancer Centre
Associate Professor, McMaster University, University of Western Ontario

Samantha Winemaker HBSc., MD, CCFP(PC), FCFP
Palliative Care Physician
Associate Clinical Professor, Department of Family Medicine, Division of Palliative Care, McMaster University

Susan King BScOT, MBA
Patient/Family Advisor

Liz Laird RN, BScN, CHPCN(C)
Palliative Pain and Symptom Management Consultant
Southwest Palliative Pain and Symptom Management Consultation Program (Grey and Bruce Counties)

James Downar MDCM, MHSc, FRCPC
Head, Division of Palliative Care, University of Ottawa

Pete Wegier PhD
Scientist, Temmy Latner Centre for Palliative Care, Sinai Health System (Primary appointment)
Associate Member, Lunenfeld-Tanenbaum Research Institute, Sinai Health System
Assistant Professor, Division of Palliative Care, Department of Family & Community Medicine, University of Toronto

Peter Tanuseputro MD, MHSc, CCFP, FRCPC
Investigator, Bruyere Research Institute and Department of Medicine, University of Ottawa

Deanna Bryant BAh, MPA (Project Manager)
Group Manager, OPCN Secretariat

Andrea Binkle RN, MA (Project Lead)
Lead, Regional Liaison, OPCN Secretariat

Tara Walton BSc, MPH
Lead, Clinician Engagement, OPCN Secretariat

Daphne Sniekers PhD
Senior Methodologist, Quality & Performance Measurement, CCO

ROLE OF THE EXPERT PANEL
- To provide feedback on relevant literature and project materials (e.g. ESRS review)
- To provide advice on the selection of the identification tools and criteria for implementation of the Delivery Framework
- To provide advice on the evaluation questions/indicators related to identification for the Delivery Framework test of change projects that could also be leveraged for the HQO IDEAS projects as appropriate
- To assist in stakeholder engagement and presentations at agreed upon meetings or events
- To attend scheduled meetings from February to June 2018 (one-hour in length)

KEY AREAS FOR THE PROJECT DELIVERABLES
1. Determine a needs based approach for identifying unmet palliative needs of patients and their families earlier in their disease trajectory
2. Provide guidance on preferred identification tools to support providers and system level leadership in earlier identification of patients who would benefit from palliative care
3. Provide implementation considerations for application of the preferred identification tools
4. Recommend indicators to evaluate the implementation of the preferred identification tools

Appendix 2: Identification and Assessment Tools by Care Setting

Identification Tools

Tool/Guide/Indicator/ Trigger/Score Name	Applicable in Primary Care	Applicable in Home & Community Care	Applicable in Acute Care	Applicable in Long-Term Care
NECesidades PALiativas Centro de la Organizacion Mudial de la Salud (NECPAL CCOMS-ICO tool)	X	X	X	X
Supportive & Palliative Care Indicator Tool (SPICT)	X	X	X	X
Early ID Guide *Adaption of the UK GSF - PIG for Ontario use	X	X	X	X
RADboud Indicators for Palliative Care Needs (RADPAC)	X	X	X	X
Risk Evaluation for Support: Prediction for Elder-life in the Community Tool (RESPECT)	X	X	X	X
Hospital-patient One-year Mortality Risk (HOMR)			X	

Assessment Tools

Tool/Guide/Indicator/ Trigger/Score Name	Applicable in Primary Care	Applicable in Home & Community Care	Applicable in Acute Care	Applicable in Long-Term Care
Bereavement Risk Assessment Tool (BRAT)	X	X	X	X
ECOG	X	X	X	X
Edmonton Symptom Assessment Tool (ESAS-R) 2011	X	X	X	X
InterRAI (HC, PC, CHA, CHESS-MDS)		X	X	X
Inter-RAI DIVERT	X	X		
Inter-RAI eScreener (Access to Care eEnablers)	X	X	X	
Clinical Frailty Tool	X	X	X	X
Palliative Performance Scale (PPS)	X	X	X	X
Patient Reported Functional Status (PRFS)	X	X	X	X

References

1 Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action [Internet]. Queen's Printer of Ontario; 2013 [cited 2018 October 26]. Available from: http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf.

2 Health Quality Ontario. Quality Standards. Palliative Care: Care for Adults with a Progressive, Life-Limiting Illness [Internet]. Toronto (ON): Queen's Printer for Ontario; 2018 [cited 2018 October 26]. Available from: https://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-en.pdf.

3 Canadian Hospice Palliative Care Association. The Way Forward Initiative: An Integrated Palliative Approach to care. Lexicon [Internet]. Ottawa (ON): The Association; 2014 [cited 2018 October 26]. Available from: http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf.

4 Baidoobonso S. Patient care planning discussions for patients at the end of life: an evidence-based analysis. Ont Health Technol Assess Ser [Internet]. 2014 December; 14(19):1–72. Available from: https://www.hqontario.ca/Portals/0/Documents/evidence/reports/eba-eol-planning-discussions-1411-en.pdf.

5 WHO Definition of Palliative Care. World Health Organization. [cited 2018 October 26]. Available from: http://www.who.int/cancer/palliative/definition/en/.

6 Canadian Institute for Health Information. Access to Palliative Care in Canada [Internet]. Ottawa, Ontario; 2018 [cited 2018 October 26]. Available from: https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf.

7 Ontario Palliative Care Network. Action Plan 1: 2017 – 2020 [Internet]. Toronto (ON): The Network; 2017 [cited 2018 October 26]. Available from: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNActionPlan1.pdf.

8 Patel KM. Palliative and End-Of-Life: Issues, Challenges and Possible Solutions in the United States. American Journal of Managed Care [Internet]. 2015 April. Available from: https://www.ajmc.com/journals/evidence-based-oncology/2015/april-2015/palliative-and-end-of-life-care-issues-challenges-and-possible-solutions-in-the-united-states-.

9 Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ: British Medical Journal. 2005; 330(7498), 1007.

10 White N, Reid F, Harris A, Harries P, Stone P. A Systematic Review of Predictions of Survival in Palliative Care: How Accurate are Clinicians and Who are the Experts?. PLOS One. 2016; 11(8), e0161407.

11 White N, Kupeli N, Vickerstaff V, Stone P. How Accurate is the 'Surprise Question' at Identifying Patients at the End of Life? A Systematic Review and Meta-Analysis. BMC Medicine. 2017; 15(1), 139.

12 Downar J.M, Goldman RM, Pinto Englesakis M, Adhikari N.M. The "Surprise Question" for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-Analysis. CMAJ. 2017; 484-493.

[13] Early Identification Tools for Palliative Care: Ontario Palliative Care Network. Evidence Search and Research Services. Toronto: Cancer Care Ontario.

[14] Evidence that use of GSF improves early identification of patients in different settings. Thomas K, Armstrong Wilson J A., Tanner T, National GSF Centre. September 2016. Available from: https://www.goldstandardsframework.org.uk/cd-content/uploads/files/1%20%20vs%204%20%20Evidence%20that%20use%20of%20GSF%20Improves%20identification.pdf

[15] Tanuseputro P, Hsu A, Manual D, Taljaard M, Chaskill CM, Kobewka D. Algorithm for Predicting Death Among Older Adults in the Home Care Setting: Study Protocol for the Risk Evaluation for Support: Prediction for Elder-life in the Community Tool (RESPECT). BMJ Open. 2016.

[16] McKinley RK, Stokes T, Exley C, Field D. Care of People Dying with Malignant and Cardiorespiratory Disease in General Practice. British Journal of General Practice. 2004; 54:909–913.

[17] Fitzsimons D, Mullan D, Wilson JS, Conway B, Corcoran B, Dempster M. et al. The Challenge of Patients' Unmet Palliative Care Needs in the Final Stages of Chronic Illness. Palliat Med. 2007; 21:313–322. doi: 10.1177/0269216307077711.