

Guidance for the Development of a Provincial Approach to Toxicity Management

Summary of Recommendations from the Toxicity Management Advisory Committee

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1.0 Executive Summary

Introduction:

Cancer patients are often treated with radiation and systemic therapy; while outcomes are improved, both these treatment modalities carry risks of toxicities, many of which are expected and, in some cases, preventable. The lack of alternative models for timely toxicity management support have resulted in the ED becoming the default setting for addressing symptoms during treatment, despite its unsuitability for this purpose. For instance, within the ED, there is an increased risk of immunocompromised patients being exposed to infections and illnesses, as well as limited side-effect management expertise among care providers. Effective management of treatment-related side effects and symptoms in care settings other than the ED may contribute to optimizing acute care utilization and improving the quality of life for patients.

Approach:

Recognizing the need for appropriate toxicity management for Ontario's patients with cancer, a Toxicity Management Advisory Committee (TMAC) was established in December 2016 to provide guidance on the recommended areas of focus for formulating the provincial approach. The primary responsibility of TMAC was to develop the recommendations that would serve as the foundation for CCO to build a comprehensive, system-level approach to toxicity management across the province. These recommendations will serve as a guiding framework for future toxicity management planning and implementation by CCO and the Regional Cancer Programs, which will tailor the operationalization of recommendations per regional/local contexts. This report summarizes the approach undertaken to develop the TMAC recommendations, and the interventions for implementation.

Recommendations:

To enable the development of a standardized and comprehensive approach to toxicity management across the province, TMAC formulated eight recommendations for executive review by CCO. These consensus-based recommendations address focus areas such as implementing solutions for engaging patients and families, improving access to timely support, targeting high-risk patients for additional toxicity management support, and enabling effective & coordinated multidisciplinary teams.

1. Patients should be provided with ongoing self-management training and support tailored to their own needs. Providers should receive training to deliver self-management support to patients based on provincial self-management standards.
2. Patients and their caregivers should be provided with evidence based and up-to-date patient education. This education should be provided in a health literate manner, using proven adult education techniques.

3. Patients should have the option to capture and report their symptoms and/or side effects with the expectation of a timely response and guidance from a knowledgeable provider specific to their needs should the severity of their symptom report require it.
4. Patients should have access to remote toxicity and symptom management advice from a knowledgeable provider (e.g. tele-triage).
5. Facilities providing systemic and/or radiation therapy should have an urgent care process in place for patients who require an urgent assessment during regular clinic hours, extended or after hours, or on weekends/holidays.
6. CCO should develop a standardized process/tool for stratifying patients by toxicity risk. High risk patients should be offered the opportunity to participate in standardized proactive toxicity management protocols (e.g. call-back program).
7. The roles and responsibilities of team members should be defined and communicated to patients and team members both within and outside of the cancer program such as oncology, ED, and Primary Care Providers.
8. CCO should provide tools for providers (including Primary Care and ED) to support the dissemination of best practices in symptom and toxicity management.

Future Direction:

These final recommendations are intended to serve as a guiding framework for a provincial approach to toxicity management. As such they are not intended to be prescriptive, but rather allow for regional adaptation based on local and contextual needs. Next steps will involve executive review and approval by CCO and prioritization of recommendations for development and implementation. Recognizing the far-reaching impact of appropriate toxicity management for Ontario's cancer patients, CCO's toxicity management initiative, which stemmed out of a System Treatment Provincial Plan (2014-2019) strategic priority, grew into a multi-program quality improvement initiative (MPQII). The recommendations developed by TMAC will serve as the foundational pieces for the MPQII and guide the direction and prioritization of deliverables.

2.0 Introduction

Background

Radiation and systemic therapy are frequently used to treat oncology patients and to improve outcomes. However, both these treatment modalities carry risks of toxicities, many of which are expected and, in some cases, preventable. In addition, treatment related side effects may cause patients distress and impact their quality of life, which can be exacerbated by the lack of appropriate support for toxicity management.

Evidence suggests that patients often use acute care hospitals while on cancer treatment to address treatment-related side effects and symptoms, such as neutropenia, fever, infection, pain, and weakness.¹ Population-based studies from Ontario, as well as outside of Canada, indicate that emergency department (ED) visits and hospitalizations are common among patients receiving systemic therapy and/or radiation, with rates higher than those reported in clinical trials.² A study of women with early stage breast cancer receiving adjuvant chemotherapy found that patients receiving chemotherapy were significantly more likely to have acute care visits than matched non-cancer patients.³ Unplanned hospital visits are also common among oropharynx cancer patients undergoing radiation treatment in Ontario. Although evidence (Appendix A: ED Background) suggests that some of these side effects can be managed or even prevented outside of the ED, patient interviews conducted by Cancer Care Ontario (CCO) revealed that patients are often advised to go to the ED by providers. The lack of alternative models for timely toxicity management support have resulted in the ED becoming the default setting for addressing symptoms during treatment. Effective management of treatment-related side effects and symptoms in care settings other than the ED may lead to better acute care and improved quality of life.

At a system-level, implementing a coordinated toxicity management framework across the province aligns with a number of the Ontario Cancer Plan (OCP) IV goals, such as quality of life, integrated care and sustainability. As part of its key priorities, the System Treatment Provincial Plan (STPP) 2014-2019, which focuses on advancing the quality and safety agenda in systemic treatment in Ontario, has also articulated the need to decrease emergency room utilization through enhanced toxicity management, and to enhance coordination and communication to improve person-centred care.

A number of CCO initiatives have laid the foundation for developing a provincial toxicity management approach. For instance, the current state survey of systemic treatment facilities conducted in 2016, highlighted that while many treatment facilities have some form of telephone support available to patients during the day, less than 50% of facilities provide telephone support afterhours. Launched in September 2015, the New Ambulatory Models of Care (NAMoC) initiative partnered with health care organizations to identify, evaluate, implement and spread innovative, patient-centred, sustainable ambulatory models. The goals of

this initiative were to (1) improve symptom management, (2) improve access to care, (3) optimize nursing scope of practice, and (4) improve healthcare resource use. The initiative provided insights into how different multidisciplinary team-based models of care could facilitate better access to symptom management during cancer treatment, particularly through optimizing the role of nurses. The annual 2015 and 2016 Systemic Treatment Quality & Safety Symposia revealed that both patients and providers recognize the need for timely access to credible information for toxicity management. These initiatives showed that patients are interested in receiving more tailored information and support for toxicity management, including electronic symptom/self-management tools, which have shown clinical benefits among cancer populations.^{3, 4, 5} The emphasis on measuring, reporting and using patient reported outcomes to improve patient-centred care has also been highlighted by the Patient Reported Outcomes (PROs) and Symptom Management Program Strategic Framework 2016-2019.

Toxicity Management Advisory Committee

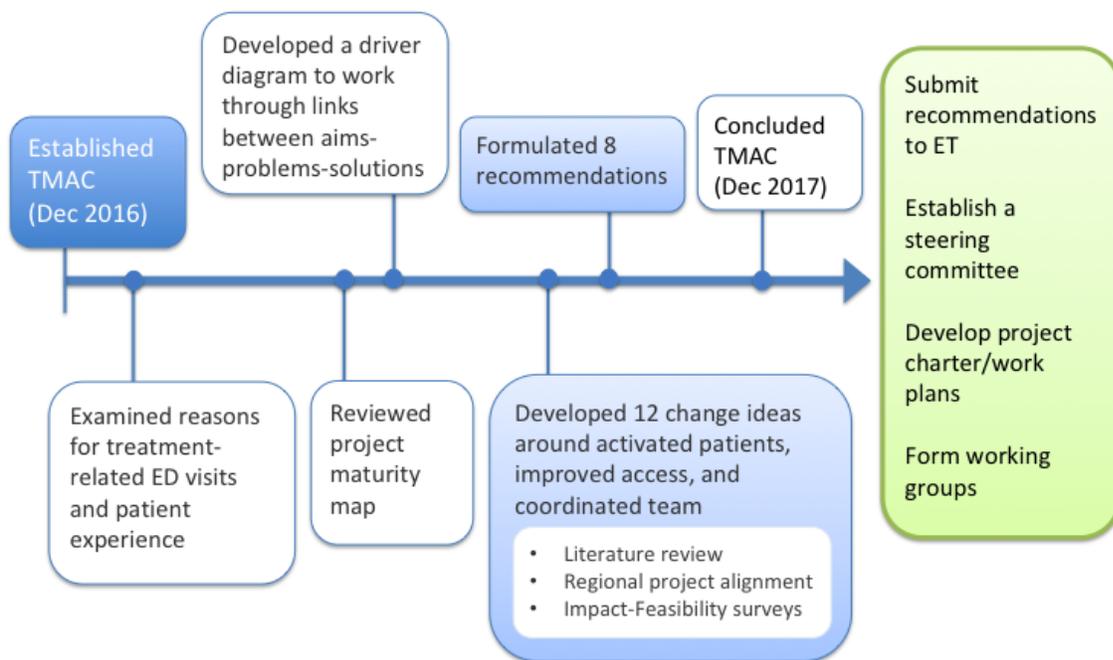
Recognizing the benefits of appropriate toxicity management for Ontario's patients with cancer, a Toxicity Management Advisory Committee (TMAC) was established in December 2016 to provide guidance on formulating the provincial approach (Appendix B. Terms of Reference)

TMAC comprised of twenty-nine internal and external multidisciplinary stakeholders from each LHIN (Appendix C: Membership). The primary responsibility of TMAC was to develop recommendations that would serve as the foundation for CCO to build a comprehensive, system-level approach to toxicity management across the province. These recommendations will serve as a guiding framework for future planning and implementation by CCO and the Regional Cancer Programs, which will tailor the operationalization of recommendations per regional/local contexts. This report summarizes the approach undertaken to develop the TMAC recommendations, and the areas of focus for implementation.

3.0 Approach

The Advisory Committee met on a monthly basis from December 2016 to December 2017. The committee used a quality improvement framework to produce recommendations that could then be further built out and adapted by CCO and the Regional Cancer Programs as part of implementation. Figure 1 illustrates the steps taken to create and achieve consensus on the final set of recommendations

Figure 1. TMAC Process Overview



As a first step, the committee examined reasons for treatment-related ED visits and patient experience with their symptom management among systemic and radiation treatment patients. This helped the group better understand and substantiate the requirements of a well-coordinated, multi-pronged approach to addressing toxicity issues across the province.

Having built a comprehensive contextual foundation, the committee then reviewed a maturity map (Appendix D: Maturity Map), which was created based on the clinical consensus and strategic vision of internal partners. Specifically, the maturity map was used by the committee to facilitate discussions on the current state of toxicity management in Ontario and envision the

optimal future state. Particular attention was paid to the interrelated dimensions of effort and the types of stakeholders that would need to be actively engaged and involved to achieve the strategic vision.

Having thoroughly considered the issues at hand and the shared vision, the committee then proceeded to develop a driver diagram (Appendix E: Driver Diagram) to discover how best to address the gaps in creating a patient-centred approach to toxicity management. The driver diagram is a widely used quality improvement tool to analyze and articulate the links between the particular aims of a project, the associated drivers for change, and the ultimate change ideas required to achieve the aims. As the driver diagram shows, the group developed twelve change ideas centred on three primary drivers: activated patients, improved access, and coordinated team.

In addition to evidence from the literature review, the formulation of change ideas were informed by local priorities, as well as existing needs and initiatives to ensure the relevance of the subsequent recommendations to the Ontario context. Moreover, TMAC members participated in two rounds of surveys, which showed differences in the perceived feasibility and impact of change ideas on ED utilization and patient experience (Appendix F: Feasibility-Impact Survey Outcomes). The survey also yielded feedback on key considerations for implementation and evaluation, which are further detailed in the next section of this report.

4.0 Recommendations

To enable the development of a system-level and comprehensive approach to toxicity management across the province, TMAC formulated eight recommendations for executive review by CCO.

1. Patients should be provided with ongoing self-management training and support tailored to their own needs. Providers should receive training to deliver self-management support to patients based on provincial self-management standards.
2. Patients and their caregivers should be provided with evidence based and up-to-date patient education. This education should be provided in a health literate manner, using proven adult education techniques.
3. Patients should have the option to capture and report their symptoms and/or side effects with the expectation of a timely response and guidance from a knowledgeable provider specific to their needs should the severity of their symptom report require it.
4. Patients should have access to remote toxicity and symptom management advice from a knowledgeable provider (e.g. tele-triage).
5. Facilities providing systemic and/or radiation therapy should have an urgent care process in place for patients who require an urgent assessment during regular clinic hours, extended or after hours, or on weekends/holidays.
6. CCO should develop a standardized process/tool for stratifying patients by toxicity risk. High risk patients should be offered the opportunity to participate in standardized proactive toxicity management protocols (e.g. call-back program).
7. The roles and responsibilities of team members should be defined and communicated to patients and team members both within and outside of the cancer program such as oncology, ED, and Primary Care Providers.
8. CCO should provide tools for providers (including Primary Care and ED) to support the dissemination of best practices in symptom and toxicity management.

These consensus-based recommendations focus on implementing solutions for engaging patients and families, improving access to real-time support, targeting high-risk patients for additional toxicity management support, and enabling effective & coordinated multidisciplinary teams. The final recommendations are intended to serve as a guide as CCO develops a provincial toxicity management approach

The following section summarizes the relevant components that comprise each recommendation including the rationale, the existence of interventions already in place, and considerations for implementation including potential feasibility, priorities, and opportunities for refinement. Recommendations have been stratified into key themes and presented as such.

Implement Solutions for Engaging Patients and Families

Context and Rationale

With the advancement of *Patients First*, there is renewed recognition that patients play an important role in managing their own care. To do this effectively, patients need to be better supported and enabled. Self-management support involves a collaborative relationship between patients and health care providers, to identify the need for education and supportive interventions, provided by the health care team, to enhance patients' skills and confidence in managing their health and wellbeing. This includes regular assessment of progress and problems, problem-solving support, goal setting, and action planning. Self-management support takes the communication skills of health care providers into account and includes patient education resources and tools that are needed to reinforce and augment self-management support.⁷

In patients with chronic diseases, self-management and provision of self-management support have been shown to be associated with better outcomes. However, while relevant and applicable, self-management has been less studied within the context of cancer care. Self-management and self-management support have been shown to improve access to and the quality, safety and value of health care services.⁷⁻⁹ Additionally, self-management reflects a patient-centred approach to oncology by enabling the delivery of personalised care that supports individuals in managing their own health and care by giving them information they can understand and act on, and by providing them with support that is tailored to their needs. As such, attention has turned to self-management support as a means of supporting patients to self-manage throughout the cancer continuum, from the point of diagnosis, through treatment and beyond to prevent or reduce health risks and optimize health and quality of life.^{7, 10-12}

Ensuring the provision of timely and relevant information in a manner that is easily understood is especially important when supporting patients and their caregivers in managing their care. In a series of patient and family advisor (PFA) interviews conducted by CCO, patients receiving systemic and radiation therapy reported that having specific instructions about when to go to the ED would have helped them decide on the necessity of their own ED visit. The PFAs also agreed that provision of individually tailored information and the dissemination of resources such as CCO's 'How to manage your symptoms' patient guides to ED staff would help support their interactions with those patients that visit the ED for toxicity related symptoms.

Findings from a randomized controlled trial (RCT) showed that a self-management program was effective in managing antiemetic-induced constipation during chemotherapy among breast

cancer patients.¹³ Similarly, a structured teaching program for patient self-identification and management of hand-and-foot syndrome resulted in statistically significant improvement in the knowledge of self-management among colon cancer patients on chemotherapy.¹⁴ A systematic review demonstrated that providing preparatory information (e.g., via written information, audiotapes, videotapes, computer programs) can improve patient-reported outcomes among those undergoing systemic therapy and radiotherapy, especially with respect to satisfaction and knowledge. In addition, psychological outcomes and, in some cases, physical symptoms were also shown to improve.¹⁵ Furthermore, providing patients with effective patient education will lead to improved patient experience and potentially a reduction in unnecessary acute care utilization due to toxicity.¹⁵

Recommendation 1: Patients should be provided with ongoing self-management training and support tailored to their needs. Providers should receive training to deliver self-management support to patients based on provincial self-management standards.

Recommendation 2: Patients and their caregivers should be provided with evidence based and up-to-date patient education. This education should be provided in a health literate manner, using proven adult education techniques.

Implementation Considerations

- Existing local patient education and self-management programs can serve as the basis for the design of future models for the delivery of provincially consistent programs. These programs should be reviewed to identify barriers, facilitators and enablers, opportunities for improvement, and evaluate delivery mechanisms.
- Further investigation into the most effective mechanisms for delivering patient education is necessary. This is especially apparent with information presented through printed patient material, which is widely available, yet may require an alternate mode of delivery (e.g. YouTube videos, non-written materials) for more effective uptake.
- Patient self-management support should be provided through a combination of patient-facing self-management tools and coaching programs that are built upon best available evidence in the fields of adult and patient education including the application of universal health literacy provisions.
- CCO is in the process of developing Self-Management Quality Statements to drive the development of strategies to implement self-management and self-management support in cancer care throughout the cancer continuum. These statements do not prescribe how

organizations and individuals should achieve compliance with the statements, but they establish a standard for how care is optimally designed to support self-management in Ontario. The standards are also meant to encourage administrators and individual providers to begin to examine how self-management and self-management support can be implemented and measured in their individual organizations and practices. To facilitate the delivery of consistent self-management support to patients and caregivers across the province, CCO should work with regions to disseminate and facilitate implementation of these standards

- To support health care providers with the delivery of patient self-management support, CCO should train providers on delivering self-management coaching to their patients, and provide tools and resources to sustain and disseminate best practices.
- Toxicity management education for patients should encompass where to seek advice or care and in which situations. CCO should continue to develop and expand on the content in the Patient Symptom Management Guides.
- CCO should assess the quality of education provided during the systemic therapy and radiation education classes and consider opportunities for provincial standardization. Areas for further exploration, include how different populations could be better served by different modes of education delivery. For example, regular in-person radiation education is helpful, although the same model may not be feasible for systemic therapy patients given the patient volume and treatment model (i.e., how often systemic therapy vs. radiation therapy patients are required to come in to clinics, and hence have an opportunity to have in-person time with clinicians/providers)
- The delivery of patient education via an eTool could enable more real-time support as symptoms arise.

Improve Access to Real-Time Support

Context and Rationale

Technology provides the opportunity to expand access to appropriate, standardized, evidence-based symptom monitoring and management for patients undergoing radiation and systemic therapy. Implementation of teletriage enables facilitated access to expert advice, and support for patients and families. This more specifically involves real-time, remote exchange of physiological or symptom data between patients in the community and care providers within a treatment facility, and can include the use of internet, telephone, mobile apps, and video links. Existing data indicate that technology has enabled successful assessment of symptoms in patients with chronic disease resulting in improved patient outcomes as well as decreased hospital stays and health system costs.¹⁶⁻²³ There also exists potential for increased patient satisfaction, and possibly a moderate impact on ED use.

There is growing interest to enhance symptom monitoring during routine cancer care using patient-reported outcomes. Real-time patient reporting of toxicities will allow for earlier intervention and symptom management support, and literature shows that most patients are willing and able to self-report via the web, even when close to the end of life.²⁴ Several web-based systems exist and have been shown to prompt clinicians to intensify symptom management, to improve symptom control and to enhance patient-clinician communication, patient satisfaction, and well-being.⁴ Likewise, a mobile phone-based, remote monitoring, advanced symptom management system (ASyMS) has been shown to support the management of symptoms in patients with lung, breast and colorectal cancer receiving chemotherapy.²⁵

There is an increasing amount of evidence that highlights the beneficial impact of symptom monitoring during routine cancer care using patient-reported outcomes and/or clinical outcomes. Findings from a large single-center randomized controlled trial (RCT) comparing web-based symptom monitoring with patient-reported outcomes (PROs) vs. usual care in patients receiving chemotherapy for metastatic solid tumors reported significant improvement in the quality of life, patient satisfaction, emergency room utilization and overall survival outcomes through monitoring.^{4,26} Another RCT used to evaluate the impact of a web-application for the early detection of symptomatic relapse, complications and need for early supportive care in high-risk lung cancer patients between visits demonstrated significant improvement in survival.²⁷ Several other studies are underway to further evaluate the impact of real-time electronic remote symptom monitoring on health outcomes^{28, 29, 30} and may potentially identify even more benefits on patient outcomes and system efficiencies.

To expedite access to appropriate in-person care, and mitigate unnecessary ED visits, facilities providing treatment for systemic therapy and radiation would benefit from developing protocols for assessing patients with treatment related signs and symptoms, both during and after hours. A hospital based study conducted in the North East LHIN revealed that 34% of ED admissions occurred during business hours, while 66% took place after hours on weekdays and weekends/holidays. An ED utilization study of systemic treatment patients at Windsor Regional Cancer Centre paints a similar picture of acute care visits. Compared to ED visits during clinic hours, the proportion of ED visits was higher after hours (including weekends) in both 2015 (35% v 65%) and 2016 (40% v 60%). Urgent care units combined with teletriage which have already been implemented in Ottawa, Hamilton, and Princess Margaret Cancer Centre, enable prompt and efficient access to providers in the event of treatment-induced toxicity.

Recommendation 3: Patients should have the option to capture and report their symptoms and/or side effects when and where they want with the expectation of a timely response and guidance from a knowledgeable provider specific to their needs should the severity of their symptom report require it

Recommendation 4: Patients should have access to remote toxicity and symptom management advice from a knowledgeable provider (e.g. tele-triage).

Recommendation 5: Facilities providing systemic therapy and/or radiation should have an urgent care process in place for patients who require an urgent assessment during regular clinic hours, extended or after hours and on weekends/holidays.

Implementation Considerations

- A provincially standardized and accessible mechanism for patient toxicity reporting and monitoring would require:
 - the development of new or the modification of existing patient-reported measures of toxicities
 - the development and provincial integration of a real-time reporting platform
 - the testing and operationalization of real-time patient reporting of toxicities
 - regular monitoring and evaluation of patient reported data
 - modifications to patient care plans based on reported data
- Investment to set up enabling infrastructure A feasibility test of an internet-based self-reporting of toxicities at home found that while monthly compliance with home Web reporting was high, weekly compliance was lower, which indicates a need to further develop strategies to enhance compliance.
- Key considerations for the establishment of a provincial teletriage network, include:
 - extended hours and/or expanded geographical region of service provision
 - more systemic or radiation treatment facilities offering teletriage
 - providers trained on standardized triage process & symptom assessment
 - teletriage provided using standardized processes & symptom algorithms
 - partnerships among centres to provide after-hours access; sharing of patient information and documentation may be appropriate, depending on volume of patients at different centres
 - a focus on refining existing local teletriage initiatives, including consideration of staffing needs dependent on how many hours past regular hours the teletriage is expanded to

- There is a need to implement provincial standards for the minimal level of provider training for teletriage, to ensure adherence to best practices in safety, clinical competency, and ethics. There is a potential opportunity to adapt and endorse the pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) evidence-based protocols for nurses to assess, triage and guide patients in self-management of the symptoms from cancer treatments through remote support. Incorporating standardized COSTARS protocols has been shown to improve patient/provider satisfaction and confidence in the care received/provided³¹
- The model of combining urgent care units with teletriage would require:
 - on-site space for urgent symptom assessment and intervention both during regular hours and after hours
 - a thorough review of staffing impacts and resourcing
 - standardized protocols in place for urgent care within cancer facilities (e.g., referral or drop-in, symptom assessment, interventions, documentation, follow up activities as necessary)
 - providers trained on the protocols
 - a mechanism to facilitate knowledge exchange between centres regarding implementation issues including funding sustainability of urgent care process
- Implementation of urgent care processes should be phased with embedded quality improvement methodology (e.g. PDSA cycles) and appropriate outcome and process measures.
- Further evaluation around optimal funding and model of care to develop and recommend a sustainable business model that could be implemented across the province is required

Target High-Risk Patients for Additional Toxicity Management Support

Context and Rationale

Proactive monitoring for toxicity might allow earlier intervention thereby preventing the symptoms from escalating and could potentially reduce inappropriate and/or preventable ED visits. Examples of evidence from the literature that supports proactive monitoring of patients include:

- Proactive symptom monitoring using a computer tablet improved survival (e.g., 5 month survival benefits) and treatment completion among patients receiving chemotherapy for advanced solid tumours, and reduced ED admission and hospitalization⁴
- Telephone call back was shown to improve assessment, follow-up and support for outpatients with managing chemo-induced nausea & vomiting³²
- Proactive telephone-based toxicity management was also shown to be feasible, associated with lower rates of acute care use, and perceived as valuable by clinicians and patients receiving neo-adjuvant or adjuvant chemotherapy for early stage breast cancer³³

- Proactive symptom monitoring through a weekly NP-led symptom management clinic was found to reduce hospitalization and chemotherapy dose deviation, and increased chemotherapy completion among head and neck concurrent patients³⁴

Identifying patients at high risk for toxicity through a standardized tool or process could expedite access to appropriate care and proactively mitigate the escalation of toxicity in those who are most vulnerable while supporting efficiency and sustainability from a health systems perspective. Though a validated approach to stratifying patients by toxicity risk does not yet exist, the ultimate goal is to eventually develop a methodology that uses population level data from Ontario to identify high risk populations. The vision is to use this to ultimately deliver more personalized care, which could potentially have a significant impact on patient experience, quality of life, and outcomes.

Recommendation 6: CCO should define a standardized process/tool for stratifying patients by toxicity risk. High risk patients should be offered the option to participate in standardized proactive toxicity management protocols (e.g. call-back program).

Implementation Considerations

- CCO should define a standardized process for stratifying patients based on toxicity risk, this could be done through the creation of an algorithm or tool that proactively identifies at risk patients.
 - The risk identification tool should be embedded into models of care, but decisions about who administers the tool would be left to the cancer centres.
 - Ongoing evaluation of the standardized process and tool will be necessary to assess the accuracy of the tool in predicting toxicity risk and to make enhancements as new evidence emerges.
 - Assessing the feasibility of developing an algorithmic approach to identify high risk patients is still needed. Immediate implementation may focus on cohort identification (e.g., by disease site, drug, regimen, comorbidity) and data collection (e.g., of known high risk group) to enable future stratification as part of a subsequent phase. Additional considerations for the development of an algorithm include assignment of toxicity management interventions by risk and standardization of data collection; as a first step, the priority may be to set up the data elements needed to operationalize the cohort.
- CCO should endorse a standardized proactive toxicity management protocol which might include tools in a variety of modes, such as telephone or electronic symptom monitoring.

- Standardized documentation & communication would be required. Monitoring protocols could include details on proactive calls, subsequent follow-up, and linkage with other interventions as required by symptom severity.
- To support provider standardization, CCO could create best practice online symptom management modules considering key areas of toxicity (e.g. n/v, diarrhea, etc.). These would be mandatory for review by new learners/hires or persons changing disease sites (e.g. nurse transitioning from radiation to a systemic therapy practice). A robust and collaborative stakeholder engagement strategy should be used to ensure input from other organizations that deliver education to providers so as to both ensure alignment (e.g. regulatory bodies, professional associations) and avoid duplication of efforts.

Enable Effective & Coordinated Multidisciplinary Teams

Context and Rationale

When delivering health care, a high functioning team can effectively and efficiently improve patient safety and outcomes. The need for effective teams is heightened due to the increasing number of co-morbidities and increasing complexity of care. A study of primary care physicians and oncologists found that strategies are needed to promote a more active role for primary care physicians in managing comorbidities, psychological distress, and behaviour modification, as well as to overcome communication challenges to improve shared cancer care.³⁵

Delivering quality patient care requires provider professional development to occur in parallel to meet the demands of keeping abreast of advancements in care. The dissemination of tools and provider training has been demonstrated to be an effective knowledge translation and exchange (KTE) strategy for the dissemination of best practices. A multinational survey of 2388 health care providers showed a wide range of educational interests in chemotherapy-induced nausea and vomiting (CINV), including managing breakthrough CINV, keeping up with novel antiemetic agents, and learning about emerging approaches for CINV prevention/management.³⁶

Recommendation 7: The roles and responsibilities of team members should be defined and communicated to patients and team members both within and outside of the cancer program such as oncology, ED, and Primary Care Providers.

Recommendation 8: CCO should provide tools for providers (including Primary Care and ED) to support the dissemination of best practices in symptom and toxicity management.

Implementation Considerations

- Areas of focus for the clear definition of team roles and points of contact include the following:
 - team roles and points of contact clearly communicated among providers across disciplines and care settings
 - identification of which responsibilities will fall to specific provider types, and which others can be organized according to the needs and structure of the particular cancer centre
 - roles and responsibilities defined from the perspective of patients and caregivers to support patient centred care
- CCO could consider facilitating or providing the necessary information and tools to undertake process mapping exercises to support the delineation of roles and responsibilities for care providers
- To provide and facilitate training in best practices, CCO should consider creating and standardizing tools that can be used by providers for symptom and toxicity management
- KTE best practices (e.g. audit and feedback) should be utilized and hospitals should be provided with the knowledge to deploy these best practices internally to ensure consistent uptake and concordance with best practices

5.0 Future Directions

As previously mentioned, these final recommendations are intended to serve as a guiding framework for a provincial approach to toxicity management. As such they are not intended to be prescriptive, but rather allow for regional adaptation based on local and contextual needs. Next steps will involve executive review and approval by CCO and prioritization of recommendations for development and implementation.

Recognizing the far-reaching impact of appropriate toxicity management for Ontario's cancer patients, CCO's toxicity management initiative, which stemmed out of a STPP strategic priority, grew into a multi-program quality improvement initiative (MPQII). The recommendations developed by TMAC will serve as the foundational pieces for the MPQII and guide the direction and prioritization of deliverables. As such, the MPQII on toxicity management will focus on empowering patients with validated tools, education and support to effectively manage treatment-related symptoms and side effects. Appropriate solutions for better (1) access to oncology healthcare providers, (2) communication within the circle of care, and (3) access to high-quality symptom management education, will be identified, assessed and implemented to improve symptom management for patients during treatment. This concerted effort also enables us to pool resources and learn from previously isolated projects across portfolios/programs, like

NAMOC and the regional System Treatment Program Quality Improvement Initiatives, in a more seamless, efficient manner.

References

1. Cancer System Quality Index (CSQI) 2017. Cancer Quality Council of Ontario. <http://www.csqi.on.ca/>.
2. Prince RM, Atenafu EG, Krzyzanowska MK. Hospitalizations during systemic therapy for metastatic lung cancer: A systematic review of real world vs clinical trial outcomes. *JAMA Oncology*. 2015 Dec; 1(9): 1333-9.
3. Enright K, Grunfeld E, Yun L, Moineddin R, Ghannam M, Dent S, Eisen A, Trudeau M, Kaizer L, Earle C, Krzyzanowska MK. Population-based assessment of emergency room visits and hospitalizations among women receiving adjuvant chemotherapy for early breast cancer. *Journal of Oncology Practice*. 2015 Mar; 11(2): 126-122.
4. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbantini P, Rogak L, Bennett AV, Dueck AC, Atkinson TM, Chou JF, Dulko D, Sit L, Barz A, Novotny P, Fruscione M, Sloan JA, Shrag D. Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *Journal of Clinical Oncology*. 2016 Feb; 24(6): 557-65.
5. Berry DL, Hong F, Halpenny B, Patridge AH, Fann JR, Wolpin S, Lober WB, Bush NE, Parvathaneni U, Back AL, Antmann D, Ford R. *Journal of Clinical Oncology*. 2014 Jan; 32(3): 199-205.
6. Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, Selby PJ. Measuring quality of life in routine oncology practice in communication and patient well-being: A randomized controlled trial. *Journal of Clinical Oncology*. 2004 Feb; 22(4): 714-24.
7. CCO Self-Management in Cancer – Quality Statements [In Draft – 2018]
8. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient education and counseling*. 2002 Oct - Nov;48(2):177-87.
9. Lorig KR, Sobel DS, Stewart AL, Brown BW, Jr., Bandura A, Ritter P, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Medical care*. 1999 Jan;37(1):5-14
10. Berlinger N, Gusmano M. Cancer chronicity: new research and policy challenges. *Journal of health services research & policy*. 2011 Apr;16(2):121-3.
11. Howell D, Harth T, Brown J, Bennett C, Boyko S, and the Patient Education Program Committee. . Self-management education for patients with cancer: evidence summary. . Toronto, Ontario: Cancer Care Ontario, 2016.
12. McCorkle R, Ercolano E, Lazenby M, Schulman-Green D, Schilling LS, Lorig K, et al. Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: a cancer journal for clinicians*. 2011 Jan-Feb;61(1):50-62.
13. Hanai A, Ishiguro H, Sozu T, Tsuda M, Arai H, Mitani A, Tsuboyama T. Effects of a self-management program on antiemetic-induced constipation during chemotherapy among breast cancer patients: A randomized controlled clinical trial. *Breast Cancer Research and Treatment*. 2016; 155: 99-107.

14. Murugan K, Ostwal V, Carvalho MD, D'souza A, Achrekar MS, Govindarajan S, Gupta S. Self-identification and management of hand-foot syndrome (HFS): effect of a structured teaching program on patients receiving capecitabine-based chemotherapy for colon cancer. *Support Care Cancer*. 2016 Jun;24(6):2575-81.
15. Waller A, Forshaw K, Bryant J, Mair S. Interventions for preparing patients for chemotherapy and radiotherapy: a systematic review. *Support Care Cancer*. 2014 Aug;22(8):2297-308.
16. Barnett T, Chumbler N, Vogel W. The effectiveness of a care coordination home telehealth program for veterans with diabetes mellitus: a 2-year follow-up. *Am J Manag Care*. 2006;12:4467-74.
17. Chumbler N, Neugaard B, Kobb R. Evaluation of a care coordination/home-telehealth program for veterans with diabetes. *Eval Health Prof*. 2005;28:464-78.
18. Rasmussen LM, Phanareth K, Nolte H, Backer V. Internet-based monitoring of asthma: a long-term, randomized clinical study of 300 asthmatic subjects. *J Allergy Clin Immunol*. 2005;115:1137-42.
19. Louis A, Turner T, Gretton M, Baksh A, Cleland JGF. A systematic review of tele-monitoring for the management of heart failure. *Eur J Heart Fail*. 2003;5:583-90. doi: 10.1016/S1388-9842(03)00160-0.
20. Santamaria N, Carville K, Ellis I, Prentice J. The effectiveness of digital imaging and remote wound consultation on healing rates in chronic lower leg ulcers in the Kimberley region of Western Australia. *Prim Intent*. 2004;12:62-70.
21. Noel HC, Vogel DC, Erdos JJ, Cornwall D, Levin F. Home telehealth reduces healthcare costs. *Telemed J E Health*. 2004;10:170-83. doi: 10.1089/tmj.2004.10.170.
22. Cleland JGF, Louis AA, Rigby AS, Janssens U, Balk AHMM, TEN-HMS Investigators. Noninvasive home telemonitoring for patients with heart failure at high risk of recurrent admission and death: the Trans-European Network-Home-Care Management System (TEN-HMS) study. *J Am Coll Cardiol*. 2005;45:1654-64. doi: 10.1016/j.jacc.2005.01.050.
23. Bartoli L, Zanaboni P, Masella C, Ursini N. Systematic review of telemedicine services for patients affected by chronic obstructive pulmonary disease (COPD) *Telemed J E Health*. 2009;15:877-83. doi: 10.1089/tmj.2009.0044.
24. Judson TJ, Bennett AV, Rogak LJ, et al. Feasibility of long-term patient self-reporting of toxicities from home via the Internet during routine chemotherapy. *J Clin Oncol*. 2013;31:2580-2585.
25. Kearney N, McCann L, Norrie J, Taylor L, Gray P, McGee-Lennon M, Sage M, Miller M, Maguire R. Evaluation of a mobile phone-based, advanced symptom management system (ASyMS) in the management of chemotherapy-related toxicity. *Supportive Care in Cancer*. 2009 Apr; 17(4): 437-44.
26. Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, Schrag D. Overall survival results of a trial assessing patient-reporting outcomes for symptom monitoring during routine cancer treatment. *JAMA*. 2017; 318(2): 197-198.

27. Denis F, Lethrosne C, Pourel N, Molinier O, Pointreau Y, Domont J, Bourgeois H, Senellart H, Trémolières P, Lizée T, Bennouna J, Urban T, El Khouri C, Charron A, Septans AL, Balavoine M, Landry S, Solal-Céligny P, Letellier C. Randomized Trial Comparing a Web-Mediated Follow-up With Routine Surveillance in Lung Cancer Patients. *J Natl Cancer Inst.* 2017 Sep 1;109(9).
28. Absolom K, Holch P, Warrington L, Samy F, Hulme C, Hewison J, Morris C, Bamforth L, Conner M, Brown J, Velikova G on behalf of eRAPID systemic treatment work group. Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice (eRAPID): a randomised controlled trial in systemic cancer treatment. *BMC Cancer.* 2017; 17: 318.
29. Maguire R, Fox PA, McCann L, Miaskowski C, Kotronoulas G, Miller M, Furlong E, Ream E, Armes J, Patiraki E, Gaiger A, Berg G, Flowerday A, Donnan P, McCrone P, Apostolidis K, Harris J, Katsaragakis S, Buick AR, Kearney N. The eSMART study protocol: a randomised controlled trial to evaluate electronic symptom management using the advanced symptom management system (ASyMS) remote technology for patients with cancer. *BMJ Open.* 2017 Jun 6;7(5):e015016
30. Mooney KH, Beck SL, Wong B, Dunson W, Wujcik D, Whisenant M, Donaldson G. Automated home monitoring and management of patient-reported symptoms during chemotherapy: results of the symptom care at home RCT. *Cancer Med.* 2017 Mar; 6(3): 537–546.
31. Stacey D, Green E, Ballantyne B, Tarasuk J, Strutkowski M, Carley M, Chapman K, Kuziemyk C, Kolari E, Sabo B, Saucier A, Shaw T, Tardif L, Truant T, Cummings GG, Howell D. Implementation of symptom protocols for nurses providing telephone-based cancer symptom management: A comparative case study. *Worldviews on Evidence-Based Nursing.* 2016 Dec; 13(6): 420-431.
32. Underhill ML, Chicks L, Berry DL. A nurse-led evidence-based practice project to monitor and improve the management of chemotherapy-induced nausea and vomiting. *Clinical Journal of Oncology Nursing.* 2015 Feb; 19(1): 38-40.
33. Krzyzanowska MK, McKay C, Han H, Gandhi S, Laferriere NB, Atzema C, Chan KC, Howell D, Kukreti V, Leung Y, Pardhan A, Mitchell S, Nayer M, Pasetka M, Yao J, Redwood E. Feasibility, acceptability and efficacy of a proactive telephone intervention to improve toxicity management during chemotherapy. Poster for 2016 ASCO Quality Care Symposium
34. Mason H, DeRubeis MB, Foster JC, Taylor JMG, Worden FP. Outcomes evaluation of a weekly nurse practitioner-managed symptom management clinic for patients with head and neck cancer treated with chemotherapy. *Oncology Nursing Forum.* 2013 Nov; 40(6): 581-586.
35. Sada YH, Street RL Jr, Singh H, Shada RE, Naik AD. Primary care and communication in shared cancer care: A qualitative study. *American Journal of Managed Care.* 2011 Apr; 17(4): 259-65.
36. Van Laar ES, Desai JM, Jatoi A. Professional educational needs for chemotherapy-induced nausea and vomiting (CINV): Multinational survey results from 2388 health care providers. *Supportive Care in Cancer.* 2015 Jan; 23(1): 151-7.

6.0 Appendices

Appendix A: TMAC Terms of Reference (ToR)

Background

Systemic therapy and radiation treatment can improve patient outcomes but these therapies often carry a significant risk of toxicity. Population-based studies from Ontario as well as outside of Canada suggest that emergency department (ED) visits and hospitalizations are common among patients receiving systemic therapy and/or radiation, and that the rates are higher than observed in clinical trials.

Unplanned hospital visits have also been noted among patients with oropharynx cancer who were receiving radiation treatment in Ontario cancer centres.

Effective management of these treatment-related side effects in care settings other than the ED would both decrease hospital ED visits and likely improve the quality of life for patients. This multi-program quality improvement initiative (MPQII) on Toxicity Management will focus on empowering patients with validated tools, education and support to effectively manage treatment-related symptoms and side effects. Appropriate solutions for better (1) access to oncology healthcare providers, (2) communication within the circle of care, and (3) access to high-quality symptom management education, will be identified, assessed and implemented to improve symptom management for patients during treatment.

Mandate

The Advisory Committee will guide the development and implementation of validated tools, education and support to effectively manage toxicities related to chemotherapy and/or radiation therapy in ambulatory patients on adjuvant or curative treatment, excluding complex malignant hematology.

The Advisory Committee will:

- Provide guidance and oversight to the development and implementation of the MPQII to ensure quality and consistency at the provincial level;
- Review data, reports and recommendations presented by the Cancer Care Ontario team and relevant stakeholders and working groups;
- Make recommendations for action to Executive Sponsors;
- Engage relevant members within their profession and/or institutions as needed to identify/address gaps in service and opportunities for program improvement;
- Identify risks, challenges or issues related to program development and implementation; and
- Act as champions for the program.

Membership Term

Members are asked to commit to a one-year term upon joining the Advisory Committee. Membership will be reviewed and may be renewed at the end of the one-year period with the consent of the member on the recommendation of the Committee Chair(s).

Meeting Schedule and Expectations

The Advisory Committee will meet monthly by teleconference. Members will be expected to attend 80% of scheduled meetings and review material and provide input in between meetings. Additionally, there may be opportunity for an in-person meeting each year.

Representation

The Advisory Committee will include at least one representative from each region, in either a clinical or administrative role. In addition, the Advisory Committee composition will be reflective of facility service mix.

Membership

Representatives from each of the following roles will be invited to participate:

- Clinical Lead, Quality Care and Access, Systemic Treatment, Cancer Care Ontario (Chair)
- Regional Vice Presidents
- Clinical/RCC Directors
- Medical and radiation oncologists
- Self-management expert
- Oncology nurses
- Radiation therapists
- Oncology pharmacists
- Patient education leads
- Patient/family member representatives
- Provincial Head, Systemic Treatment, Cancer Care Ontario
- Provincial Head, Radiation Treatment, Cancer Care Ontario
- Provincial Lead, Patient Reported Outcomes, Cancer Care Ontario
- Clinical Lead, e-Tools and Technology, Cancer Care Ontario
- Provincial Lead, Patient Education, Cancer Care Ontario
- Director, Person Centred Care, Clinical Programs and Quality Initiatives (CPQI), Cancer Care Ontario
- Director, Cancer System Quality Improvement Initiatives, CPQI, Cancer Care Ontario

We will seek variations in the membership from a regional, disciplinary and facility service perspective.

Additionally:

- A Co-Chair may be selected from the above membership
- Other parties will be invited from time to time, as necessitated by the agenda
- Members will be invited to participate in the Advisory Committee by invitation of Cancer Care Ontario
- Members will be approached based on their specific knowledge and expertise as related to the mandate of this group

Reporting Relationship

The Advisory Committee will report to and make recommendations to Cancer Care Ontario Executive Sponsors, who will be the final decision makers.

Recommendations:

Recommendations will be developed through a consensus building process. If consensus cannot be achieved during the timeframes required, the (Co-) Chair(s) may choose to call for a vote. A simple majority will determine the recommendation to be made to the Executive Sponsors.

Meeting Minutes

Minutes will be kept of all meetings and be distributed to all members.

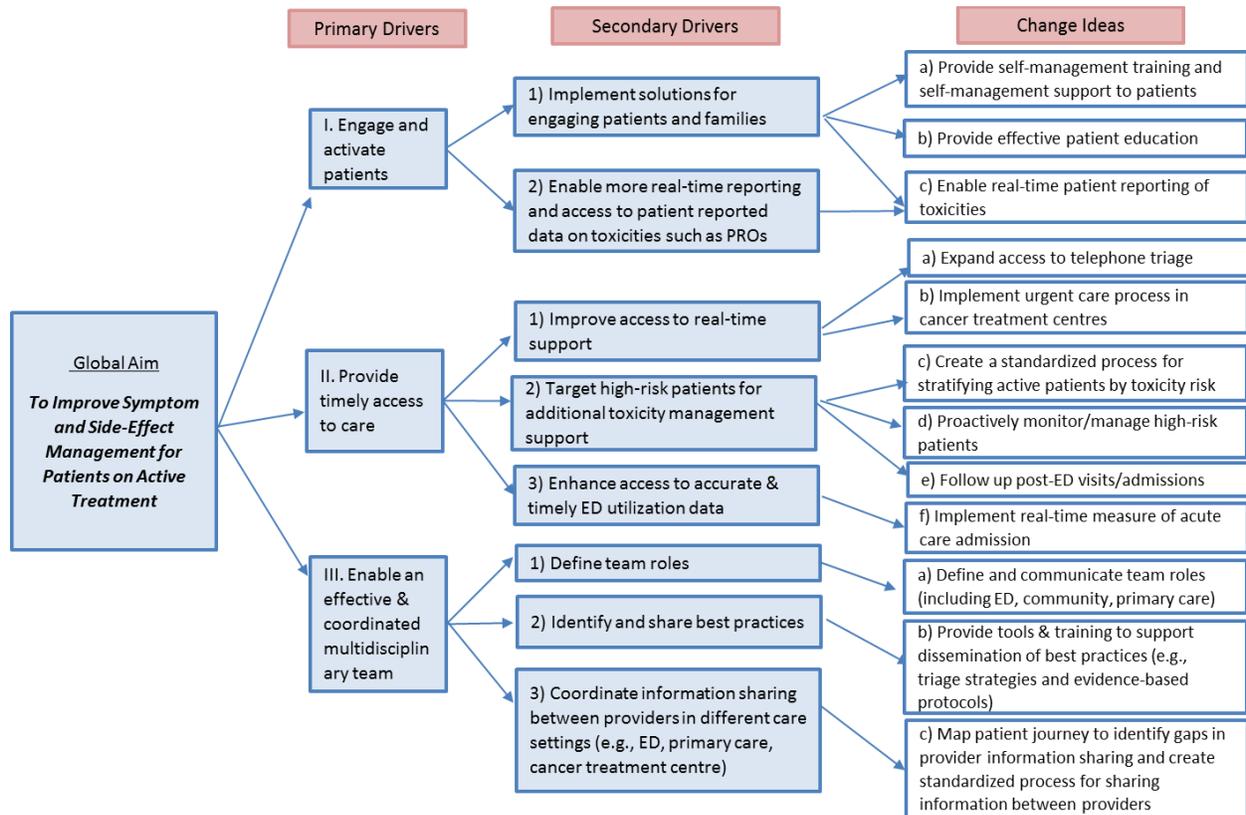
Appendix B: TMAC Membership List

Name	Role
Monika Krzyzanowska (Chair)	Clinical Lead, Quality Care and Access, Systemic Treatment, Cancer Care Ontario
Lisa Barbera	Provincial Lead, Patient Reported Outcomes, Cancer Care Ontario
Christine Black	Manager, Radiation Therapy, Central East
Colleen Campbell	Advanced Practice Clinical Coordinator, North Simcoe Muskoka
Catherine de Metz	Radiation Oncologist, South East
Patricia Disperati	Malignant Hematologist, Toronto Central North
Jeannie Faubert	Patient Representative, North West
Leta Forbes	Provincial Head, Systemic Treatment, Cancer Care Ontario
Derek Finnerty	Patient and Family Advisor, Mississauga Halton Central West
Daniela Gallo-Hershberg	Group Manager, Systemic Treatment Program, Cancer Care Ontario
Chris Girolametto	Radiation Therapist, Waterloo Wellington
John Goffin	Medical Oncologist, Hamilton Niagara Haldimand Brant
Gurpreet Grewal	Patient Education Lead, Mississauga Halton Central West
Tamara Harth	Provincial Lead, Patient Education, Cancer Care Ontario
Mark Hartman	Regional Vice President, North East
Doris Howell	Self-Management Researcher, Toronto Central South
Vishal Kukreti	Clinical Lead, e-Tools and Technology, Cancer Care Ontario
Michael Lock	Radiation Oncologist, South West
Lorraine Martelli	Provincial Head, Oncology Nursing, Cancer Care Ontario
Robin McLeod	Vice President, Clinical Programs and Quality Initiatives, Cancer Care Ontario
Elaine Meertens	Director, Diagnosis and Treatment Clinical Programs
Ralph Meyer	Regional Vice President, Hamilton Niagara Haldimand Brant
Lesley Moody	Director, Person Centred Care, Cancer Care Ontario
Mark Pasetka	Clinical Pharmacy Coordinator, Toronto Central North
Colleen Reaume	Regional Director, Erie St. Clair
Jillian Ross	Director, Cancer System Quality Improvement Initiatives, Cancer Care Ontario
Padraig Warde	Provincial Head, Radiation Treatment, Cancer Care Ontario
Meaghan Wright	Functional Manager, Cancer System Quality Improvement Initiatives, Cancer Care Ontario
Jane Yao	Senior Specialist, Systemic Treatment Program, Cancer Care Ontario

Appendix C: Toxicity Management Maturity Map (ver. 4)

Functional Area		Phase 1	Phase 2	Phase 3	Phase 4	
		Genero/Passive/Static		Customized/Active/Dynamic		
Patient	Education Self-management Personalization	<ul style="list-style-type: none"> Basic provider-driven education materials (e.g. consent, printed drug/radiation info) are available No self-management teaching is provided No dimensions of personalization 	<ul style="list-style-type: none"> Patient receives education based on disease/treatment (phases) or symptoms. Generic self-management support is provided 1-2 dimensions of personalization (e.g. needs assessment of patient's ability to self-manage) 	<ul style="list-style-type: none"> Patient receives timely education based on PROs and/or symptoms and side effects Patient symptom score acknowledged and patient receives tailored advice Customized self-management training 2+ dimensions of personalization 	<ul style="list-style-type: none"> Patient is activated through a variety of customized self-management training and education from multiple sources 2+ dimensions of personalization 	Empowered
	Roles Standardization Training	<ul style="list-style-type: none"> Resources/tools (e.g. guidelines) available to providers No specialized training in symptom management 	<ul style="list-style-type: none"> Clinicians are aware of algorithms and incorporate components into routine clinical practice Some/subset of administrative and clinical providers trained on symptom management and support 	<ul style="list-style-type: none"> Algorithms are fully integrated into practice Symptom management expert(s) are available to provide additional support to providers 	<ul style="list-style-type: none"> Algorithms are customized to specific clinical settings and providers Relevant providers trained and assigned to deliver high-quality, standardized care/information to patients 	Knowledgeable
	Models of Care Access Evaluation	<ul style="list-style-type: none"> Reactive, remote support (generic) during business hours Largely in-hospital based patient symptom support services 	<ul style="list-style-type: none"> Standardized, reactive remote/in-person support Generic proactive support Ad hoc urgent care support 	<ul style="list-style-type: none"> Extended hours, reactive support PRO-based proactive support during business hours Urgent care clinic with designated resources & organized space Standardized patient symptom support administrative and clinical team role functions 	<ul style="list-style-type: none"> Needs assessment informs personalized care for: <ul style="list-style-type: none"> Proactive support "Just-in-time" information 24/7 remote/in-person access to providers Optimal use of appropriate resources (HHR and settings) 	Responsive
	Roles Communication Coordination	<ul style="list-style-type: none"> Coordination within cancer centre Consent (incl. communication about the treatment plan) 	<ul style="list-style-type: none"> Coordination across treating facilities, including ED Generic care plan 	<ul style="list-style-type: none"> Coordination between Community Support, such as: Primary care, Home care, Community Pharmacy, ED Comprehensive & personalized care plan (including all modalities) 	<ul style="list-style-type: none"> Effective, engaged circle of care (incl. community support) that: <ul style="list-style-type: none"> Has clearly defined roles & responsibilities Is team-based & coordinated for continuous care Allows real-time communication Care plan that is: IT-enabled, standardized, sharable, accessible 	Effective
	Access Communication Care plan	<ul style="list-style-type: none"> Static content Minimal use of technology to support patient education/symptom management 	<ul style="list-style-type: none"> Customized content Interactive with system Intermittent use of technology to support reactive, remote patient access to education and symptom management 	<ul style="list-style-type: none"> Personalized based on user profile Interactive with user(s) Standardized technology to support reactive patient access to education and symptom management 	<ul style="list-style-type: none"> Fluid provider-patient interactions Standardized processes and technology to support proactive remote access for patients to education and symptom management 	Accessible

Appendix D: TMAC Driver Diagram



Appendix E: TMAC Feedback: Feasibility-Impact Survey Outcomes

Average impact and feasibility ratings across change ideas

