

Cancer Journey Action Group

Guide to Implementing Screening for Distress, the 6th Vital Sign

Moving Towards Person-Centered Care

Part A: Background, Recommendations, and Implementation



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Document prepared by the Screening for Distress initiative of the Cancer Journey Action Group, Canadian Partnership Against Cancer. This project builds on the work undertaken within the Tom Baker Cancer Centre in Calgary, Alberta in partnership with colleagues in the BC Cancer Agency, Cancer Care Ontario, Cancer Care Nova Scotia and the Centre Hospitalier Universitaire de Québec. Thank you to all of these groups for their vision, foresight and commitment to Screening for Distress.

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Preface

Cancer and its treatment have more than a physical impact. There are emotional, social, psychological, functional, spiritual, and practical consequences as well. Life is never exactly the same again once a cancer diagnosis has been made.

The cancer journey often begins when a person first learns something might be wrong, and it can continue long after treatment, in some cases, until death. Throughout the journey, the person and his or her family will face a myriad of challenges. No two individuals will respond in exactly the same manner. All, however, will feel some degree of distress.

While some will mobilize their own resources and manage the situation on their own, others will benefit from additional assistance. That assistance may be required from various professionals or, in some cases, from peers. Getting the person connected to the right service in a timely fashion remains a challenge in our cancer system. Access to support, information, and practical assistance is often fragmented or non-existent. What is needed is a coordinated effort to get people into the system easily and to help them through it efficiently.

Patient and survivors have been advocating for a person-centered cancer system - one that intentionally focuses specifically on what is of importance to the person and attends to the range of his or her needs (not just the tumour). Patients and survivors want quality care that is comprehensive, co-ordinated and continuous. They want future patients to have a better experience during the cancer journey than is possible in the current system.

To achieve a vision of person-centered care, a change in health-care culture is required. Health-care professionals must broaden their perspectives to see the whole person and work collaboratively to meet the full range of human needs. The inter-professional team needs to work in partnership with the cancer patient and his or her family to ensure that care is responsive and tailored to their specific needs.

In recent years, two system interventions have been designed to move us toward this person-centered vision: Screening for Distress, the 6th Vital Sign, and Navigation (professional, lay, and virtual). Implementing these interventions sets the stage for required changes in culture and improvements to practice. By increasing timely and appropriate access to the full range of services throughout the cancer journey, the burden of suffering will be reduced for patients, survivors, and family members. In turn, they will feel an increased capacity to cope and experience a heightened quality of life.

Chapter 1: Background

Screening for Distress, the 6th Vital Sign

An increasing proportion of our population will be affected by cancer at some point in their lives. For instance, an estimated 171,000 individuals living in Canada will be diagnosed with cancer in 2009.¹ Clearly these staggering numbers represent a significant burden on the population and health-care system.

Cancer presents not only physical but also emotional, social, informational, spiritual, and practical challenges for patients and their families.² Consequently, there has been movement away from a predominantly tumour-focused treatment toward care for the patient as a whole. This approach is known as person-centred care.

Screening for Distress, the 6th Vital Sign, represents one driver to achieve person-centred care. Incidence rates of distress at all phases of cancer have been reported at 35% to 45% in North America.^{3,4} As such, there is widespread recognition that cancer patients are at high risk to experience distress and that there ought to be standardized ways to identify those who would benefit from additional assistance. Screening for Distress attempts to identify the concerns of patients in a timely manner, so those concerns can be addressed at the earliest point in time. In 2004, the Canadian Strategy for Cancer Control endorsed the concept of Screening for Distress.⁵ The National Comprehensive

Cancer Network (NCCN) has developed standards of care for distress which state that: "All patients should be Screened for Distress at their initial visit, and at appropriate intervals, as clinically indicated."⁶ Furthermore, in Canada, Screening for Distress is now included in cancer program accreditation standards.⁷ The uptake and interest in Screening for Distress raised the need for a development of a pan-Canadian strategy. The Canadian Partnership Against Cancer (hereafter referred to as the Partnership) has taken on a key role in the development and implementation of Screening for Distress, the 6th Vital Sign, as a priority of the National Cancer Control Strategy.⁸ The Partnership's Cancer Journey Action Group (CJAG) is responsible for advancing innovations in person-centred cancer care and for bringing the concept of nation-wide Screening for Distress to fruition.

Rationale for Screening for Distress, the 6th Vital Sign

Screening for Distress is a key component of the Cancer Journey Action Group's strategy to achieve person-centred care. However, screening alone is not sufficient to achieve systemic or cultural change; a programmatic approach means Screening for Distress is linked to appropriate follow-up activity.

Defining Distress

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

-NCCN Practice Guidelines in Oncology 2008 p.5

The following are characteristics of Screening for Distress programs:

- Sensitivity and recognition for the individual patient's unique and changing psychosocial, practical, and physical needs
- A person-centred approach that responds to a person's emerging needs
- Consistent compassion and support from all caregivers
- Coordinated services
- Accessibility of information (including patients' own medical information) and support
- Empowerment of patients through provision of information, respect, and options
- Understanding and accommodation of special needs and challenges of patients from rural/remote areas and from diverse backgrounds
- Identification and outreach to patients who lack an adequate support network

The Imperatives of Screening for Distress

Cancer presents psychosocial, practical, and physical challenges for patients and their families

Incidence of distress ranges from 35-45%^{3,4}

Like other vital signs, Distress, the 6th Vital Sign, should be monitored routinely

Screening for Distress includes screening for psychosocial, practical, and physical concerns

Screening for Distress offers the opportunity for health care providers to better understand the concerns of their patients

Objectives

The following are objectives for Screening for Distress programs:

1. Enhance the capacity for knowledge building, knowledge sharing, and knowledge translation
2. Improve collaboration between partners and stakeholders
3. Improve access to and knowledge about supportive and psychosocial care and services for patients

Screening for Distress vs. Assessment

It is important to differentiate between screening and assessment. This manual speaks to screening, which is the rapid identification of a patient's key concerns so that health-care providers can identify the need to conduct further assessments and/or pursue appropriate referrals. Assessment is conducted after the screening and involves a more comprehensive and focused examination of the patient's situation.

Definitions:

- Screening: pro-active rapid identification of key indicators that allow for further assessment and appropriate referral⁹
- Comprehensive assessment: an in-depth look at the patient's psychosocial health care needs, health status, risk factors, and the social, demographic, or pre-existing illness factors that might influence psychosocial needs¹⁰
- Focused assessment: may address specific domains, conditions, problems, and types of cancer; this level of assessment moves towards managing an issue¹⁰

Chapter 2: Recommendations for Screening for Distress Programs

From March 2008 to March 2009 a number of meetings were held that focused on the development of a pan-Canadian strategy for Screening for Distress. A Screening for Distress Workshop was held March 7-8, 2008 in Calgary, Alberta.¹¹ The objectives of the workshop were:

- To examine existing Screening for Distress programs across Canada
- To document differences in processes and procedures (who was screened and when), tools used for assessment, and the domains of distress assessed
- To review research results, resource implications, and to discuss potential challenges and opportunities posed by the implementation of Screening for Distress, the 6th Vital Sign, programs

Forty-three decision-makers and experts in the field attended the workshop. The attendees agreed that despite differences in definitions, tools, and approaches, all programs provide support to cancer patients by improving access to services and widening the range of assistance. The following points of consensus were reached at the Screening for Distress workshop:

- Distress is about more than anxiety and depression, it arises from difficulties in domains such as pain, fatigue, nutritional concerns, and other physical symptoms, as well as common concerns such as finances and drug coverage
- Screening for Distress should be considered a point of entry and should be followed by appropriate assessment, intervention, and/or referral to proper services
- There should be standardized psychometric measures used to Screen for Distress which possess good psychometric properties

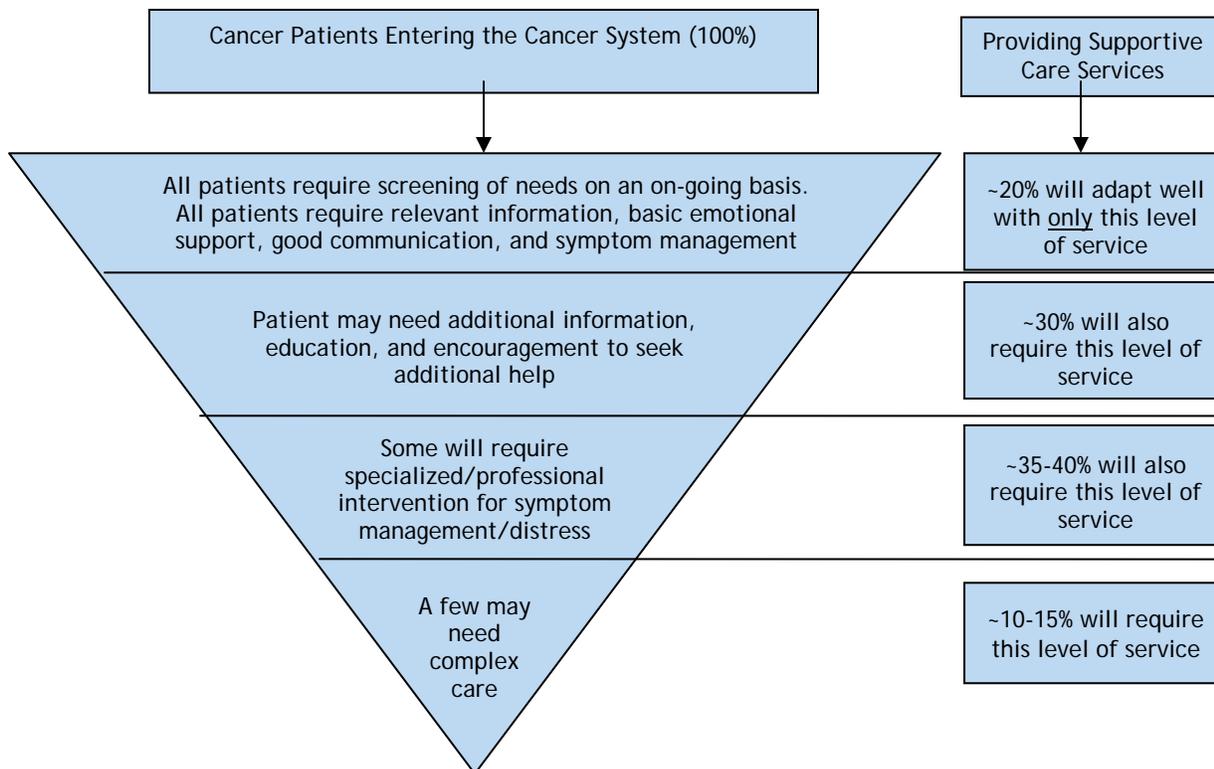
Given this consensus, the group fully endorsed Screening for Distress and urged rapid movement towards a pan-Canadian strategy for Screening for Distress for all cancer patients. The following steps towards implementing this strategy were identified:

- Establish national standards and guidelines for Screening for Distress
- Raise the profile of Screening for Distress, Distress as the 6th Vital Sign, and stakeholder acceptance of Screening for Distress as a standard of care
- Secure proper resources for national Screening for Distress implementation

Following this meeting, Screening for Distress, the 6th Vital Sign, became a priority item of the Cancer Journey Action Group.⁸ To move this work forward, a Screening for Distress Toolkit Working Group was formed. This group was comprised of experts in the area of Screening for Distress from across the country. The whole group met on October 10, 2008 and March 31, 2009 and a sub-group met on March 6, 2009. The goals of these meetings were to establish recommendations around who, when, and how to screen, and to establish the minimum tools that should be used when Screening for Distress.

Service Provision

The proportion of patients requiring support was discussed by the Screening for Distress Toolkit Working Group. Below is a pictorial representation of service requirements and the proportion of patients requiring each level of assistance. The following representation has been adapted from the Supportive Care Framework.²



In this model, Screening for Distress is the first step and all patients entering the cancer system are screened. Screening for Distress then leads to a conversation, and in some cases to further comprehensive and focused assessments that help direct patient care. This diagram helps to highlight that all patients need information and support and that only some patients will need specialized intervention.

Who to Screen

The Screening for Distress Toolkit Working Group agreed that all patients should be Screened for Distress regardless of cancer type or stage. The group acknowledged that different populations will vary in their concerns but that, regardless of the particular concerns, screening will open the door to further conversation and assessment if needed.

When to Screen

A common message throughout the meetings was that screening needs to be done on a routine basis upon entry to the system and at subsequent critical time points. Critical time points in the cancer journey include: initial diagnosis, start of treatment, during treatment, end of treatment, post-treatment or transition to survivorship, at recurrence or progression, during advanced disease, and during times of personal transition or re-appraisal (e.g. in a family crisis, when approaching death).¹⁰

How to Screen

Although no formal recommendations were put forward by the Screening for Distress Toolkit Working Group in regards to how to Screen for Distress, discussion on the subject did take place. Consistent with the March 2008 meeting, the general consensus was that, when possible, screening should be computerized.

Computerized screening has been widely examined in quality of life studies and is being quickly adopted by Screening for Distress programs. In a study by Velikova et al.¹² touch screen surveys were preferred by participants in a 2:1 ratio over paper surveys, within all demographic subgroups. Additionally, a significant learning effect was observed as participants completed the surveys quicker on the second administration. This study also noted that the process of scanning paper questionnaires was time consuming and error-prone. Additional studies have supported the greater efficiency of touch screens. In one study, 99% of patients found touch screens easy to use.¹³ In another study, participants reported that the computer was easy to use, enjoyable, helpful, and quick; participants' attitudes towards computerized questionnaires improved significantly from pre- to post-assessment.¹⁴

Although there is a great deal of support for computerized screening, it may be difficult for some centres to adopt this method immediately. For example, the centre may not have the technical requirements, and may lack funding to purchase the touch screens or necessary software.

Regardless of the method chosen, the pros and cons of paper and pencil versus computerized screening should be examined. Table 1 highlights some considerations:

Table 1 - Paper and Pencil versus Computerized Screening

Paper and Pencil Screening		Computerized Screening	
Advantages	Disadvantages	Advantages	Disadvantages
Patients are used to completing paper work	Need to enter in computer for evaluation, trending, etc.	Research indicates that most patients find computerized surveys easy to use	May need to assist patients who are uncomfortable with technology at least once
Do not need to invest in software or hardware	Can lead to piles of paper	Trending information can be printed immediately and reports posted on medical file	IT support is required; space may be required if using a kiosk
No new space is required	Can decrease data integrity	Easy to conduct program evaluation	May need to have paper and pencil version available for patients who are too sick to complete on a computer

One additional benefit of computerized screening is that once the software is developed, it may be used in various sites. This will help to minimize costs and provide a wealth of information that can be compared among centres and across geographical areas. The Partnership is currently examining the possibility of developing standardized software to be used by Screening for Distress programs across Canada.

Screening Domains

The Screening for Distress Toolkit Working Group agreed that Screening for Distress should screen for more than anxiety and depression, and should cover three domains: psychosocial, practical, and physical. As such, one goal of the current work is to move away from the idea of emotional distress screening alone to a concept of Screening for Distress that includes all three domains.

A study by Carlson et al.³ found through the use of a problem checklist, that the top 10 problems listed by patients were fatigue, pain, emotions, depression, anxiety, parking, appearance, coping, sexuality, and financial concerns. A study that involved African American breast cancer patients found that the most frequently reported problems were physical, financial, and worry about others.¹⁵ Another study found that the most common problems for lung cancer patients are finances (48%), child care (45%), transportation (35%), work/school (19%) and housing (19%).¹⁶ Furthermore, preliminary work at the Tom Baker Cancer Centre in Calgary suggests that different tumour groups experience different concerns, and that those concerns change over time.

While patients' needs shift over time, the three domains of psychosocial, practical, and physical concerns seem to encompass the majority of concerns identified. Furthermore, one benefit of a common dataset (discussed in the next section) is the ability to better understand the concerns of patients and how they vary from one type of cancer to another, from one location to another, and for an individual throughout the cancer journey. Hopefully, this knowledge will enhance health-care providers' abilities to meet the needs of their patients, and allow targeted interventions and programs to be developed.

Tool Selection

Cancer centres that are implementing Screening for Distress programs have reported challenges regarding the selection of the proper tools. A 2008 study examining screening programs across Canada found that a variety of measures were in use, including the Edmonton Symptom Assessment System (ESAS), the Hospital Anxiety and Depression Scale (HADS), the Psychological Screen for Cancer (PSSCAN), and Distress Thermometer (DT) and Problem Checklist were being used.¹⁷ In order to help shed light on how to select the most appropriate screening tools, the Screening for Distress Toolkit Working Group reviewed the most commonly used tools.

Various measures or combinations of measures were reviewed on the basis of whether they screened for three critical domains: psychosocial, practical, and physical. The group also examined tools in terms of their psychometric properties and clinical utility in a busy clinic environment. The measures that were explored were the Edmonton Symptom Assessment System (ESAS), the Personal Well-being Checklist (PWBC), the Psychological Screen for Cancer (PSSCAN), the Hospital Anxiety and Depression Scale (HADS), and the NCCN Distress Thermometer (DT) and Problem Checklist. More information about the tools that were reviewed can be found in Appendix A.

A key goal of the Screening for Distress Toolkit Working Group was to establish a minimum data set, which can be defined as the minimum tools that should be used when Screening for Distress. The Screening for Distress Toolkit Working Group unanimously endorsed the use of the ESAS and the Canadian Problem Checklist for collecting the minimum data set required for screening. The Canadian Problem Checklist is a tool that developed by the Screening for Distress Toolkit Working Group to screen for the most common problems experienced by patients. These recommended tools were selected as the briefest tools that met the basic agreed-upon requirements. It was noted that these tools allow centres to collect a minimum data set but centres may wish to add additional questions based on their specific needs. For example, a group from Quebec City at the Centre Hospitalier Universitaire de Québec (CHUQ) has developed a screening tool that uses the minimum data set but also contains additional items on the problem checklist and the distress thermometer. Appendix B contains a draft of the screening tool used by this group.

Recommended Minimum Data Set

One advantage of having a minimum data set is the ability to compare results across the country. One could examine, for instance, whether lung cancer patients in British Columbia report the same concerns as lung cancer patients in Nova Scotia. This type of comparison could contribute to improved care and the sharing of ideas. For example, if you know patients at your centre have higher anxiety than patients at a different centre, you can explore the differences between the two centres (for instance, possibly one offers an introductory class for patients that may be decreasing their anxiety). The benefits of a standardized minimal data set are likely to become apparent over time; it represents a key component of a national strategy for Screening for Distress and person-centered care. Below are descriptions of the two tools chosen to be part of the minimum data set:

Edmonton Symptom Assessment System (ESAS)

Across Canada, the ESAS is the most commonly used screening tool.¹⁸ It is a valid and reliable tool that screens for 9 common symptoms experienced by cancer patients. The severity of each symptom at the time of screening is rated on a numerical scale from 0 to 10; with 0 meaning that the symptom is absent and 10 that it is the most severe; results are trended over time. The symptoms screened for include pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath.

A systematic review of cancer symptom assessment instruments found that the ESAS is a psychometrically-sound instrument.¹⁹ The ESAS has been validated in a variety of populations, including both advanced cancer populations and patients earlier in the cancer trajectory.^{20,21} The ESAS adequately screens for psychosocial and physical concerns but does not capture practical concerns. The minimum data set will be collected using the original published validated version of the ESAS (without the body diagram).

There are several advantages associated with the ESAS:

- The ESAS is free for use (go to the link below and click on Edmonton Symptom Assessment System)
<http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/AssessmentToolsIDX.html>
- The ESAS is available in a number of languages (click on the link below to obtain the ESAS in different languages)
<http://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=8298>
- Because of the wide spread use of ESAS there are clear guidelines and instructions for use as well as a wealth of additional information such as care plans available

Canadian Problem Checklist

The Canadian Problem Checklist asks a series of questions to screen for psychosocial, practical, and physical concerns. The Canadian Problem Checklist was developed by the Screening for Distress Toolkit Working Group. The group agreed that items included in the checklist should meet the following criteria:

1. Be prevalent and fall into one of the screening domains (psychosocial, practical, and physical)
2. Have a potentially negative outcome if not addressed
3. Are not already covered in the ESAS

With these criteria in mind, the group endorsed 21 items to be part of the minimum data set (see below):

Canadian Problem Checklist

Please check all of the following items that have been a concern or problem for you in the past week including today:

Practical:

- Work/School
- Finances
- Getting to and from appointments
- Accommodation

Social/Family:

- Feeling a burden to others
- Worry about family/friends
- Feeling alone

Emotional:

- Fears/Worries
- Sadness
- Frustration/Anger
- Changes in appearance
- Intimacy/Sexuality

Informational:

- Understanding my illness and/or treatment
- Talking with the health care team
- Making treatment decisions
- Knowing about available resources

Spiritual:

- Meaning/Purpose of Life
- Faith

Physical:

- Concentration/Memory
- Sleep
- Weight

The Screening for Distress Toolkit Working Group also discussed the use of headings and the order of items. It is recommended that the order is kept the same, especially for the ESAS since changing the order will impact the validity of the measure. Additionally, use of headings with the problem checklist was endorsed. It was felt that using headings would facilitate the development of algorithms if the problem is identified. If additional items are added to the checklist, it is recommended they be added to the bottom of the appropriate categories. To view the ESAS combined with the Canadian Problem Checklist, see Appendix C.

Demographics

The Screening for Distress Toolkit Working Group also discussed demographic variables. The group recommends that, at minimum, information about age, gender, and tumour site is collected. When possible, additional demographic variables such as ethnicity, income, education, and marital status (and possibly others) should be reported. Capturing this type of demographic data can help us to better understand supportive care needs at the level of different jurisdictions, as well as, at a national level.

Steps to Choosing a Screening for Distress Measure

Below are a number of steps jurisdictions establishing Screening for Distress programs or those who are modifying current programs can use to guide their decisions around tools:

- Explore with clinicians what information would be meaningful for them, keeping in mind the needs of the patient population
- Discuss the advantages and disadvantages of using different measures

**APA Policy Statement
adopted August 2005**

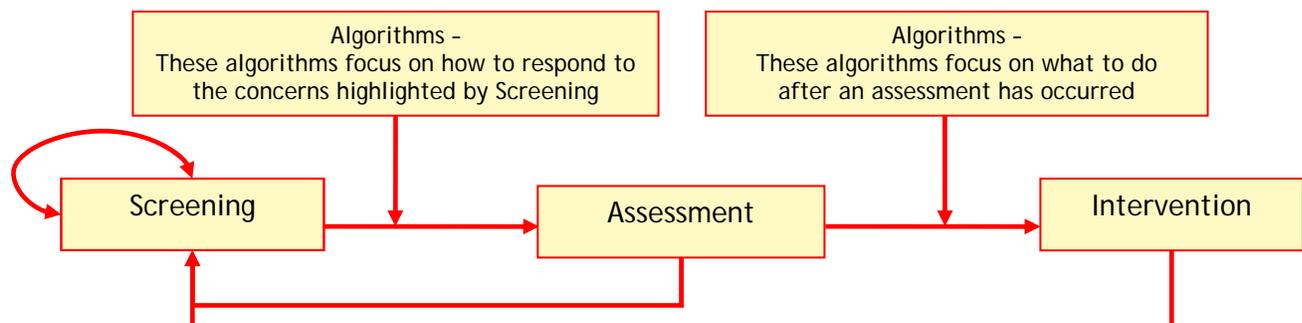
“Evidence-based practice in psychology is the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences.”

-adapted from IOM, 2001 & Sackett, 2000
Bonnie Spring, Ph.D., Northwestern University

- Review the recommendations of the Screening for Distress Toolkit Working Group. Discuss the pros and cons of adopting the minimum data set and explore whether additional items are needed
- When possible, have a discussion with someone who is already conducting Screening for Distress to gain insight
- Keep in mind the distinction between screening and assessment tools
- When possible, choose a validated and scientifically-supported measure. This can be important for both looking at the data later and improving buy-in from clinicians and researchers
- Consider how screening will be linked to further assessment, intervention, and referral, and what resources will be available for patients

How to Handle the Results of Screening: Algorithms

As discussed earlier, Screening for Distress is the pro-active identification of key indicators. With this definition in mind, screening needs to be followed by a more comprehensive and/or focused assessment.¹⁰ The Screening for Distress Toolkit Working Group agreed that it is necessary to have clearly stated methods for handling the results. This has led to the development of algorithms. Algorithms, sometimes referred to as referral pathways, can be defined as the instructions around what to do after a patient has completed screening. As depicted below, algorithms guide the conversation/assessment by highlighting what concerns should be addressed and can also guide the decision about what intervention is appropriate.

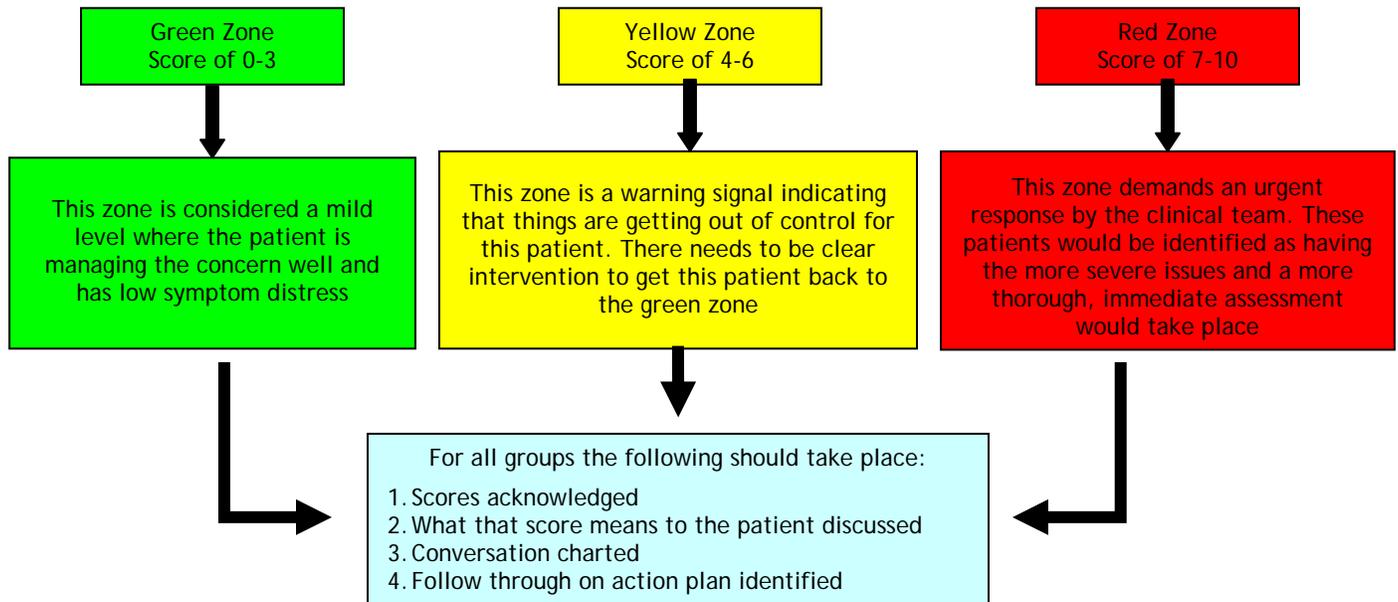


Below are some steps to consider when developing algorithms:

- Determine screening tools
- Begin to articulate how the responses should be viewed (e.g. traffic light algorithm below)
- Review clinic procedures
- Review internal and external resources
- Gather feedback/brainstorm ideas about algorithms
 - Focus groups and/or working groups composed of a variety of staff in different roles may be helpful in establishing procedures that are more likely to succeed
- Develop protocol for screening, assessment, and intervention
- Develop materials to easily communicate procedures
- Educate staff about the screening program
- Modify algorithms as required

The Screening for Distress Toolkit Working Group suggested the following analogy to interpret the concerns highlighted by screening (this is specific for 0-10 point scales). This concept is

taken from the work of implementing pain as the 5th Vital Sign and focuses on the algorithms between screening and assessment. It uses the concept of traffic lights to motivate action:



It is important to note that algorithms are unique to the context in which they exist. Each cancer centre offers different programs and therefore the algorithms will be different based on the centre's own unique experience and services. Additionally, algorithms will be consistently refined and changed based on changes in local resources and feedback from patients and staff. Algorithms also offer the opportunity to engage various stakeholders. It is important that they are widely endorsed and accepted in order to be effective.

Some Screening for Distress programs across Canada have been working to develop thorough algorithms. Three examples are the Tom Baker Cancer Centre (TBCC) in Calgary, the Centre Hospitalier Universitaire de Québec (CHUQ) in Quebec City, and Cancer Care Ontario (CCO). The TBCC's algorithms specify what the patient indicated as a concern and, if they needed further support, what resource they were referred to. The CHUQ's algorithms explain which professionals respond to each of the concerns of patients. CCO's algorithms involve the further assessment of the symptoms.¹ See examples of these algorithms in Appendix D. Each centre will need to adapt these examples provided here to fit their needs.

Further work is currently taking place in this area at a national level. The Pan-Canadian Clinical Practice Guidelines: Psychosocial and Supportive Care of Adults with Cancer will help facilitate algorithm development. Additionally, the Screening for Distress Implementation Group plans to develop templates to assist with Screening for Distress algorithm development.

¹ If you wish to use these algorithms please consult with Deborah Dudgeon, Provincial Program Head, Palliative Care, Cancer Care Ontario, and acknowledge their source when used

Summary of Recommendations

The recommendations put forward by the Screening for Distress Toolkit Working Group aim to assist those centres wanting to Screen for Distress in developing their programs, and to facilitate consistency across Canada, which will allow for cross-national comparisons.

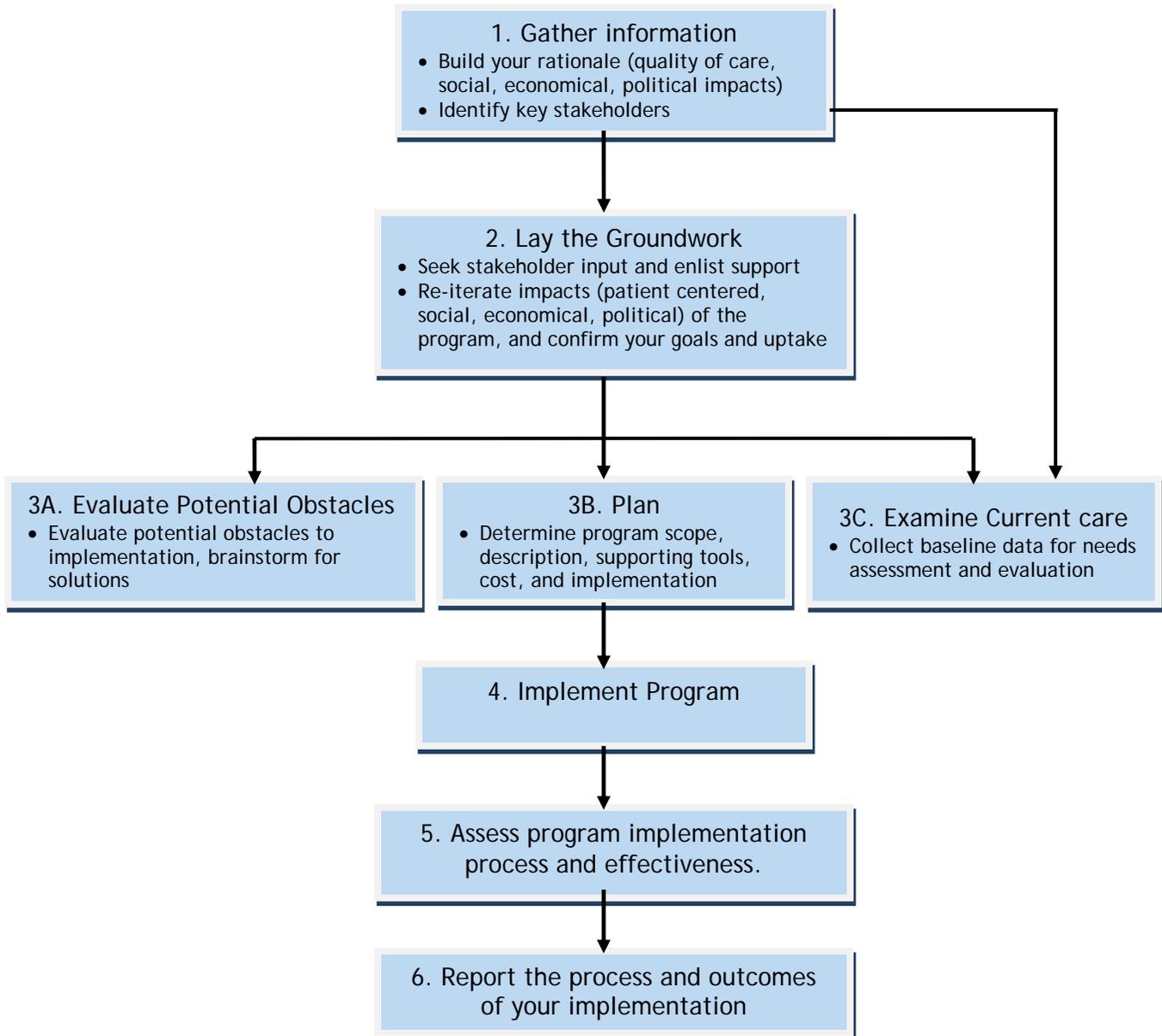
Table 2 summarizes the recommendations and/or conclusions from the Screening for Distress Toolkit Working Group:

Table 2 - Summary of recommendations and/or conclusions

Area	Recommendations/Conclusions
Rationale for Screening	Pro-active identification of key indicators that allow for further assessment and appropriate referral.
Who to Screen	All cancer patients should be screened for distress
When to Screen	Standardized routine screening - including at point of entry and at critical time points
How to Screen	<i>No formal recommendation was put forward.</i> It was noted that when possible electronic screening offers advantages over paper and pencil screening (e.g. less paper work, automatic data entry, etc).
Screening Domains	Screening tools should screening for three domains: <ol style="list-style-type: none"> 1. Psychosocial 2. Practical 3. Physical
Minimum Data Set	Screening for Distress programs should use the recommended tools to screen for the minimum data set but can also incorporate additional items based on specific needs of each program. The recommended minimum data set includes the following tools: <ol style="list-style-type: none"> 1. Edmonton Symptom Assessment System 2. Canadian Problem Checklist
Algorithms	Algorithms are clear guidelines that outline how to handle the results of screening. Algorithms are unique to the context in which they exist and will need to be developed by each centre.

Chapter 3: Program Implementation

Below is a model which may be of assistance when establishing a Screening for Distress program. The following flowchart² has been adapted from the Healthcare Association of New York State Breast Cancer Demonstration Project (HANYC BCDP[®]).



² Obtained from Patient Navigation in Cancer Care: Guiding patients to quality outcomes. © 2005 Pfizer

1. Gather Information

Explore the potential benefits of a Screening for Distress Program for your specific context or elucidate the reasons for implementing this program in your centre. Below are some points to consider when gathering information:

- What are the needs of various stakeholders, including:
 - Patients (e.g. better patient centered outcomes)
 - Providers (competencies, interprofessional skills, education needs)
 - Organization (administrators and managers goals, better use of human resources), cancer care system (better use and knowledge of resources)
 - Political system (priorities, accreditation process, or other relevant incentives)?
- Consider the scientific context: Previous literature will assist you in making a case for the need for Screening for Distress. Appendix E contains a number of references for articles that are useful when summarizing the need for Screening for Distress
- Define your target population and identify the population impact: Who is the focus of Screening for Distress and what are their needs? What is the impact of better addressing these needs? (patient demographics, population statistics, incidence trends, and projected or known outcomes).
- Consider the economical and social contexts the program will be running under. What is already offered? Are there additional costs involved? Does the potential impact justify additional investment?
- Understand where the gaps or weaknesses exist in your care pathway and define these specifically in order to understand the nature of the problem as thoroughly as you can.
 - Gather information to understand your perceptions of these weaknesses (previous studies, quality improvement initiatives, satisfaction surveys etc.)
 - Gather information from your stakeholders to understand the perspectives of your target population and potential collaborators.
 - If necessary, conduct a needs assessment to gather targeted information.

2. Lay the Groundwork

Steps for laying the groundwork will be slightly different for each centre depending on factors such as the program champion's (key promoter/advocate) position in the organization, current recognition/endorsement of the need for Screening for Distress, and the institutional structure. Consider the following actions when laying the groundwork for support:

- Engage high level administrators - begin discussions about the need for Screening for Distress. Let the administrators know what you need from them. For example, are you hoping they will provide their endorsement for the work to move forward, do you want them to appoint members to a steering committee, etc? Points which may garner the interest of decision-makers and health-care providers include:
 - Improved person-centered care (addressing needs and improving satisfaction)
 - Improved satisfaction with health providers' competencies, skills, teamwork and/or collaboration
 - Improved health-care service efficiencies (better use of the resources)
 - Identification of gaps in service (quality of care)
 - Meeting the 2009 Accreditation Standards
- Put together a steering committee - a steering committee is vital to gathering support and should act as a visible champion of the program. Try to include members from all levels of care and throughout the continuum of care such as administration, interdisciplinary health care professionals, and support staff. If possible, choose individuals who inspire and

motivate others around them. It may be useful to engage high level administrators in choosing individuals for the steering committee.

- Seek input from stakeholders and the interdisciplinary team to identify issues and concerns (through, for example, focus groups, contracted research, round tables, forums, surveys, or workshops). Gathering the opinions of others early on in the process can enhance their sense of ownership of the program when it is ready to be implemented. Additionally, engage patient representatives and patient advocate groups to get feedback and suggestions.
- Some tips from programs across Canada include:
 - Recognize and acknowledge champions (members of the interprofessional team)
 - Physician buy-in early in the implementation process is very important for overall success
 - Customized Workshops - For example, “train the trainer” workshops in which a select group of staff members are trained and then they train their colleagues may help to promote staff buy-in
 - Focus on the big picture; caregiver buy-in is promoted if there is a clear improved outcome for the patient and family
 - Stress for staff, who are facing heavy workloads and time constraints, that the use of common language and screening tools will facilitate efficient communication and documentation

3A. Evaluate potential obstacles

The following are key considerations which may be difficult to foresee when implementing your program:

- Cultural change: How the implementation may require or cause a cultural change for the practice setting and patients. Is there openness to change?
- Internal Resources: Will you be able to hire a coordinator or is there someone internally who is able to take on this project? Will there be administrative support for the program?
- Resource mobilization: What internal and external resources are available to meet the supportive care needs of patients? Mobilize resources required to meet supportive care needs internally and in the community; consider, for example, current gaps in supportive care and available education materials
- Infrastructure development: Developing an environment that will enable patients and staff to engage in activities related to building the Screening for Distress program and sustaining the program (e.g. space for patients to complete the screening, materials to collect information, data support)
- Team building: Understand proposed type of team work (multidisciplinary versus interprofessional) - how will this change practice and what is required to support effective implementation of team work?
- Marketing strategy: may be required to sustain the work and should include: communication to stakeholders/community, branding as a unique program, and development of patient education materials
- Identify any organizational issues and challenges you may face and contingencies to deal with these issues
- Responsibility and accountability framework: Who is responsible for developing the program and to whom are they accountable?
- What involvement do you require from other programs; how will you secure this involvement?
- Who are the community partners and what is their level of involvement?

- What is the timeline for implementation? Is it realistic? (A common theme from programs across the country is that screening takes longer to implement than you may expect. There is also a trade-off between obtaining buy-in and doing things quickly)
- Do you need to complete a privacy impact assessment? How does this affect the timeline? What expertise is needed for its development?
- If you are choosing an electronic screening format do you have the required technical support? If choosing paper and pencil, will the scores be entered into a computer system and by whom?

3B. Plan

Below are the basic components of a plan for your Screening for Distress program. Thinking about each component should help to formulate a clearer picture of what Screening for Distress will look like at your centre. The steering committee should play a large role in the development of the plan but it may also be advantageous to bring in feedback from other staff; this may also help to ensure that staff feels a sense of ownership of the program.

a. Goals and Objectives

- How do you define distress (are you using the NCCN definition)?
- What are the goals of Screening for Distress?
- What is the scope of practice for Screening for Distress?
- Keep in mind that the goals for Screening programs may be different for different groups of stakeholders. Some common goals – across different stakeholder groups, or those planning the program are:
 - To identify the concerns of patients
 - To Ensure patients are connected to the appropriate resources
 - To meet the 2009 Accreditation Canada guidelines

b. Timeline

- What is a realistic timeline overall as well as for each component of the plan?
- Some factors that are often overlooked when developing a timeline are:
 - Time for decisions to be made
 - Time to set up meetings
 - Vacation schedules

c. Privacy Impact Assessment (PIA)

Determine early on whether or not you need to submit a privacy impact assessment. The purpose of PIAs is to ensure that the use and storage of patient information meets the provincial standards; if you are doing computerized screening, you will most likely need to complete a PIA. Steps to completing this process normally include:

- Setting up a meeting with your privacy officer to discuss whether your project requires a PIA
- Checking to see if other screening programs exist in your province, and if so, talk with them about their PIA
- If a PIA is required, determining what needs to be included. Often the focus is on the data and how it is obtained, stored, and utilized

It is often possible to write and submit the PIA prior to working out all of the implementation details. As application processes can be lengthy, it may be advisable to submit the PIA as soon as possible and plan to do revisions later if required. For general information on PIAs visit http://www.privcom.gc.ca/pia-efvp/index_e.asp

d. Outcomes/Evaluation

Evaluation plans should always be incorporated at the beginning of the project. Some questions to consider are:

- What changes do you expect to see after the program has been implemented?
- How can you measure the expected outcomes? What data elements need to be collected?
- Is there information that is currently available that could be useful?

The process of collecting data often begins with setting up a meeting with a research officer to discuss the project and what steps are required to store and collect the data. Ensure that it will be permissible to share the data with others through conference presentations or written papers (while the current focus is on clinical care, information sharing is often important at a later date; the ability to do this must be confirmed early on). Include in your evaluation your plan for sharing your findings. When and how do you plan on sharing your findings? It is important to update contributors and users periodically about the program's progress.

e. Financial Support and Budget

- What are your sources of funding?
- Is there an opportunity to work with the Partnership's Cancer Journey Action Group, and if so, how might the Group assist you?
- Consider the cost of a coordinator's salary, office supplies, hardware and software (if using computerized screening), and administrative support (e.g. data entry)

f. Resources

Implementing a screening program will require support from a number of individuals. Some of the resources that may be required:

- A coordinator
- Staff time to be involved in the program development
- Staff time for training
- Office supplies - paper, posters, pens, etc.
- Information technology support
- Hardware/software or admin support to enter data (if applicable)

g. Communication Plan

It is beneficial to consider how you will communicate your program plans to staff during the initial planning stages, but it is likely that additional communication needs will be discovered throughout implementation. Some methods to communicate plans with staff are:

- Newsletters
- Tumour group presentations
- Presentations at grand rounds
- Presentations at nursing in-service
- Presentations at staff meetings

h. Screening Plan

Considering the questions posed here can help to envision the form your program will take (NOTE: guidelines and more information around these questions are provided in the "Who, When, How to Screen" section)

i. Who will be screened?

- Will you follow the recommendation to screen all patients? Will you screen all patients from the beginning, or start with one tumour group? What are the potential challenges in screening different populations?

ii. When will screening occur?

- Will you follow the recommendation to screen patients routinely (at point of entry and at critical time points)
 - How will your organization define critical time points?
 - What are the challenges to routine screening?
 - Are there logistic issues that may affect when screening can occur?
- iii. How to screen?
- What method of screening best fits your needs (i.e. paper-and-pencil or computerized)?
 - Will you start with paper-and-pencil and move to computerized screening later?
- iv. What tools will be used?
- What screening tools will you use? Who will be involved in determining the tools to be used and possible additional questions to be asked?
 - How and how often will you assess the need for changes to the screening tools?
- v. What will be done with the screening results?
- How will you involve staff in developing algorithms or care plans? Could you make use of focus groups or brainstorming sessions, for example?
 - Who will be the first person to talk with the patient about his or her responses? This could be the nurse, doctor, or other health care professional.
 - What indicators will you use to determine responses to problems (e.g. cut-off scores, or the priorities identified by the patient)?
 - Will you incorporate a patient education component? For example, providing patients with written materials on managing certain symptoms. Will patients' be able to self-refer to resources?
 - How will you ensure that all members of the health care team have access to the screening in an efficient manner?
- vi. How will the screening become part of the patient's file?
- Will the screening be posted on the patient's file for future reference and for other health care providers to view?
 - Will there be a section of the patient's file specifically for screening information?
 - If you are using paper files who will put the screening report in the file?
 - If on an electronic filing system is there a way to automatically post the reports to the file?
- i. Language Barriers
- The Partnership aims to establish an integrated, person centered system that has the capacity to address the diverse needs of all Canadians. In working towards this objective, the Cancer Journey Action Group has created a toolkit of resources for those who want to promote equitable policies and practices in their workplaces.²²
- Screening requires communication with diverse populations. As professional interpreters are not always available, family members or friends often provide this service for patients. It is important to consider how your program will address communication barriers with either professional or informal translators. For instance, how will you familiarize translators with the program and its objectives? Are there tools and methods available to help clarify the concepts addressed in the screening

questions (i.e. what is meant in a question about appetite or hunger vs. enjoyment of food)? Communication issues are discussed in more detail in the literature.²³

- Providing translators and patients with clarification around the meaning of terms helps to ensure patients select the appropriate items. What are the language barriers in your jurisdiction?

j. Risks

- Your plan should consider the risks that are involved. For example, what factors might reduce patient compliance with screening? Another risk could be the impact of an organization change on the program. For example, if your institution in a state of change (e.g. restructuring), how could this impact your ability to implement a screening program?

k. References

- It is useful to include literature references when developing your plan to provide support for Screening for Distress initiatives. See Appendix E for some articles related to Screening for Distress that may be useful to you.

3C. Examine Current care

- What data is your organization collecting already? How can this information be useful for you? What additional information will you need to collect?
- How will you know you are achieving what you set out to do?
- What information can be used to track the implementation and success of the Screening for Distress program?

4. Implement Program

- Identify, recruit, and train or orient staff
- Execute the plan developed in 3B
- Prepare documents (i.e. posters, brochures, policies, forms)
- Implement support systems, referral processes, outreach strategies
- Track responses, appointments and other relevant data

5. Assess program implementation process and effectiveness

In order to understand the progress of implementation and to ensure the success of your program it will be necessary to collect information related to your primary expected outcomes. This could include:

Process Related Data:

- Number of patients screened
- Number of patients with distress to whom assessment, intervention, or referral were offered
- Number of patients who accepted referral
- Perception of the screening usefulness, effects, and potential impacts (on patients, on health-care system)
- Patient participation in and reaction to being Screened for Distress

Outcome Related Data:

- Patient outcome data as available
- Patient and/or provider satisfaction data
- Review of data from similar programs to compare processes and outcomes

- Conducting evaluation to gather specific information about your program and how it can best meet the defined goals

6. Report the process and outcomes of your implementation

At this stage you will want to report to the various stakeholders on the implementation and outcomes:

- Compile an overview of the goals and outcomes of the program
- Re-confirm your indicators and targets and consider how your identified intent carried through the process of program development and implementation
- Summarize your conclusions
- Summarize your recommendations for the future

Appendices

Appendix A - Screening for Distress Tools

Appendix B - Draft of Screening Tool Used in Quebec City by the CHUQ Group

Appendix C - Minimum Data Set: ESAS and Canadian Problem Checklist

Appendix D - Algorithms

Appendix E - Screening for Distress Articles

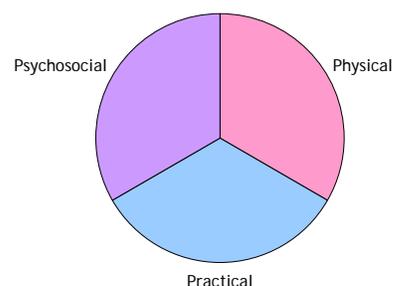
Appendix A - Screening for Distress Tools

Screening for Distress Tools

Below are the measures reviewed by the Screening for Distress Toolkit Working Group. There are pie charts associated with each measure that indicate whether or not, and to what extent, the domains (psychosocial, practical, and physical) are screened for with that particular measure.

1. Edmonton Symptom Assessment System (ESAS) + Canadian Problem Checklist

These two tools are recommended by the Screening for Distress Toolkit Working Group as the briefest tools that meet our basic agreed-upon requirements for Screening for Distress programs. This combination assesses all 3 domains and possesses good psychometric properties. Additionally, this combination can be viewed as the minimum data set recommended by the Screening for Distress Toolkit Working Group but additional questions may be added to it.



Edmonton Symptom Assessment Scale (ESAS)

Across Canada, the ESAS is the most commonly used screening tool.¹⁸ It is a valid and reliable tool that screens for 9 common symptoms experienced by cancer patients. The severity of each symptom at the time of screening is rated on a numerical scale from 0 to 10; with 0 meaning that the symptom is absent and 10 that it is the most severe; results are trended over time. The symptoms screened for include pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath.

A systematic review of cancer symptom assessment instruments found that the ESAS is a psychometrically-sound instrument.¹⁹ The ESAS has been validated in a variety of populations, including both advanced cancer populations and patients earlier in the cancer trajectory.^{20,21} The ESAS adequately screens for psychosocial and physical concerns but does not capture practical concerns. The minimum data set will be collected using the original published validated version of the ESAS (without the body diagram).

Advantages:

- The ESAS is free for use (go to the link below and click on Edmonton Symptom Assessment System)
<http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/AssessmentToolsIDX.html>
- The ESAS is available in a number of languages (click on the link below to obtain the ESAS in different languages)
<http://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=8298>
- Because of the wide spread use of ESAS there are clear guidelines and instruction for use as well as a wealth of additional information such as care plans available

Disadvantages:

- The ESAS does not capture the domain of practical concerns (this is one reason it is combined with the Canadian Problem Checklist)
- Although it is available in other languages minimal validation research has been conducted in this area
- The majority of work validating the ESAS has been done with a palliative population

Canadian Problem Checklist

The Canadian Problem Checklist asks a series of questions to screen for psychosocial, practical, and physical concerns. The Canadian Problem Checklist was developed by the Screening for Distress Toolkit Working Group. The group agreed that items included in the checklist should meet the following criteria:

1. Be prevalent and fall into one of the screening domains (psychosocial, practical, and physical)
2. Have a potentially negative outcome if not addressed
3. Are not already covered in the ESAS

With these criteria in mind, the group endorsed 21 items to be part of the minimum data set:

Emotional:

- Fears/Worries
- Sadness
- Frustration/Anger
- Changes in appearance
- Intimacy/Sexuality

Spiritual:

- Spiritual and/or religious concerns
- Faith

Practical:

- Work/School
- Finances
- Getting to and from appointments
- Accommodation

Social/Family:

- Feeling a burden to others
- Worry about family/friends
- Feeling alone

Informational:

- Understanding my illness and/or treatment
- Talking with the health care team
- Making treatment decisions
- Knowing about available resources

Physical:

- Concentration/memory
- Sleep
- Weight

The Screening for Distress Toolkit Working Group also discussed the use of headings and the order of items. It is recommended that the order is kept the same, especially for the ESAS since changing the order will impact the validity of the measure. Additionally, use of headings with the problem checklist was endorsed. It was felt that using headings would facilitate the development of algorithms if the problem is endorsed. If additional items are added to the checklist, it is recommended they be added to the bottom of the appropriate categories. To view the ESAS combined with the Canadian Problem Checklist, see Appendix C.

2. Personal Well-being Checklist (PWBC)

The Personal Well-being Checklist consists of a number of measures including the Distress Thermometer, Calgary Problem Checklist, nutrition questions, pain and fatigue thermometers, and part C of the PSSCAN (Anxiety and Depression). It is currently being used at the Tom Baker Cancer Centre in Calgary as part of a large randomized control trial. The PWBC involves the use of thermometers, checklists, and Likert point scales. More information about the PWBC is available at www.personalwellbeing.ca

Domains:

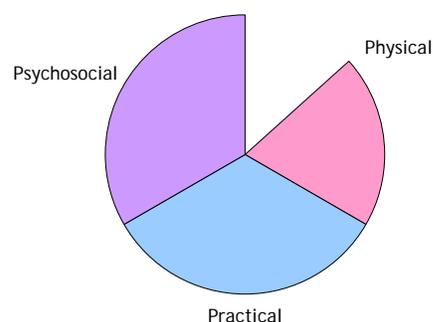
The PWBC adequately screens for psychosocial and practical concerns. It does not fully screen for physical concerns as it does not include drowsiness, shortness of breath, or nausea.

Advantages:

- The PWBC is comprehensive in its inclusion of a large number of concerns
- Algorithms have been developed which direct care once a concern is indicated or above a certain cut-off.

Disadvantages:

- The PWBC has not been validated
- Due to its comprehensiveness it is one of the longer measures being used



3. Psychological Screen for Cancer (PSSCAN)

In a survey of screening tools used across Canada the PSSCAN was the second most common measure used.²³ It is 21 items and screens for emotional concerns, social support concerns, and distress/quality of life.

Domains:

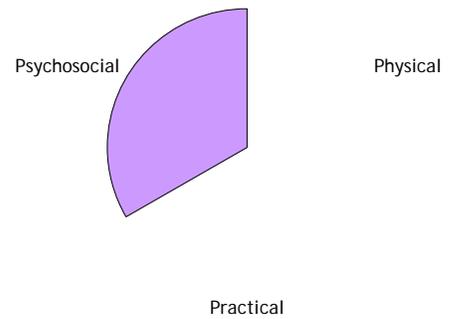
The PSSCAN adequately screens for psychosocial concerns. It does not screen for practical or physical concerns.

Advantages:

- It is free for use and available on line:
http://www.bccancer.bc.ca/NR/rdonlyres/42F7B8A8-6803-4E97-9A55-4EE6E0A79A32/23566/PSSCAN_Final.pdf
- It is one of the most comprehensive tools for screening for social support and quality of life issues

Disadvantages:

- It does not capture the physical or practical domains



4. Hospital Anxiety and Depression Scale (HADS)

The HADS is a 14 item questionnaire assessing for anxiety and depression in a medical population. It is a well validated measure of anxiety and depression that is commonly used to compare other scales to.

Domains:

The HADS screens for only part of the psychosocial domain and it does not address physical or practical problems.

Advantages:

- Its subscales and total scale have good internal consistency and are sensitive to change

Disadvantages:

- May perform better in populations with stable disease
- It is under copy write; therefore, you will need to make appropriate financing arrangements if choosing the HADS. We contacted the vendor to obtain more information and the approximate cost is outlined below.

Non-commercial fees - (not including VAT, if applicable)

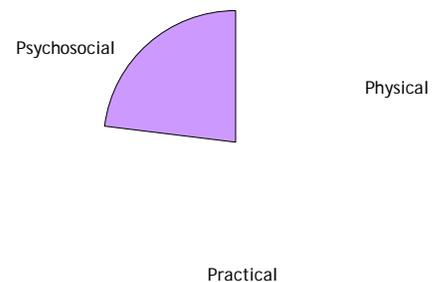
0-1000 administrations @ £0.25 each

0-2500 administrations @ £0.20 each

2500 + administrations @ £0.15 each

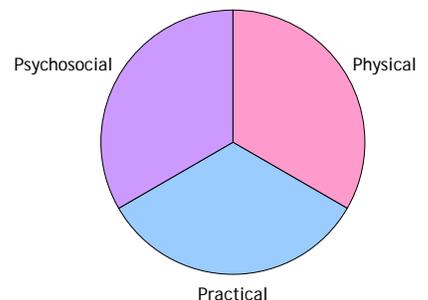
Click here to find out more:

<http://shop.nfernelson.co.uk/icat/hospitalanxietyanddepress>



5. Distress Thermometer (DT) and Problem Checklist

The National Comprehensive Cancer Network (NCCN) developed the DT and Problem Checklist. The Distress Thermometer was introduced over a decade ago and measures emotional distress with one item on an 11-point (0-10) rating scale. Accompanying the DT is a Problem Checklist that contains psychosocial, practical, and physical concerns. One advantage of this tool is



that there are Distress Management guidelines to accompany it. The full guidelines are available at

http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.

Domains:

The DT and Problem Checklist screens for all domains

Advantages:

- The tool is quick to complete and widely used

Disadvantages:

- Because of the yes/no response options there is not range of score to use for cut-offs
- Copy write owned by NCCN
 - i. If you wish to use this measure you must submit information to NCCN. There is no fee associated with its use; however, you need to report its use and get approval for any changes made to the measure. For more information go to:

<http://www.nccn.org/about/permissions/default.asp>

Appendix B - Draft of Screening Tool Used in Quebec City by the CHUQ Group



Experts et humains

- CHUL
- L'HDQ
- HSFA

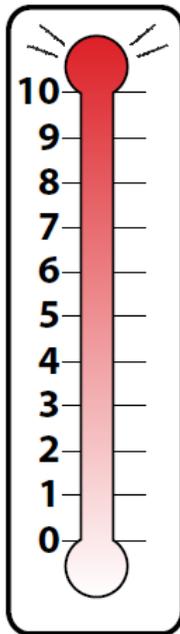
OUTIL DE DÉPISTAGE DE LA DÉTRESSE (ODD)

La **détresse** est une émotion désagréable qui diminue la qualité de vie et peut nuire au fonctionnement de la personne

1. COTE AU THERMOMÈTRE

Comment évaluez-vous votre détresse durant la dernière semaine, incluant aujourd'hui ? SVP Encercler un chiffre sur le thermomètre.

Détresse extrême



Aucune détresse

2. LISTE DE PROBLÈMES

SVP cochez tous les éléments qui ont été une source de préoccupation ou un **problème** pour vous durant la dernière semaine, incluant aujourd'hui.

Pratique

- Travail/études _____
- Finances _____
- Se rendre aux rendez-vous _____
- Logement _____

Social / familial

- Me sentir comme un fardeau _____
- Préoccupations envers la famille / les amis _____
- Me sentir seul(e) _____

Émotionnel

- Peurs / inquiétudes _____
- Tristesse _____
- Colère/ frustration _____
- Changement d'apparence _____
- Intimité / Sexualité _____
- Perte d'intérêt face aux activités habituelles _____
- M'adapter à la maladie _____

Spirituel

- Me questionner sur le sens ou le but de ma vie _____
- Me sentir ébranlé(e) dans mes croyances _____
- Me questionner dans ma relation à Dieu _____

Information

- Comprendre la maladie et les traitements _____
- Communiquer avec l'équipe soignante _____
- Prendre une décision face aux traitements _____
- Connaître les ressources disponibles _____

Physique

- Concentration / mémoire _____
- Sommeil _____
- Poids _____
- Constipation ou diarrhée _____

Suite au verso

3. ÉCHELLE D'ÉVALUATION DES SYMPTÔMES D'EDMONTON (ESAS)

Pour chaque item suivant, encerclez le chiffre qui décrit le mieux votre état de santé au cours des **DERNIERES 24 HEURES**.

Aucune douleur	0	1	2	3	4	5	6	7	8	9	10	Pire douleur possible
Aucune fatigue	0	1	2	3	4	5	6	7	8	9	10	Pire fatigue possible
Aucune nausée	0	1	2	3	4	5	6	7	8	9	10	Pires nausées possibles
Aucune dépression	0	1	2	3	4	5	6	7	8	9	10	Pire dépression possible
Aucune anxiété	0	1	2	3	4	5	6	7	8	9	10	Pire anxiété possible
Aucune somnolence	0	1	2	3	4	5	6	7	8	9	10	Pire somnolence possible
Très bon appétit	0	1	2	3	4	5	6	7	8	9	10	Pire appétit possible
Meilleure sensation de bien-être	0	1	2	3	4	5	6	7	8	9	10	Pire sensation de bien-être possible
Aucun essoufflement	0	1	2	3	4	5	6	7	8	9	10	Pire essoufflement possible
Autre problème	0	1	2	3	4	5	6	7	8	9	10	

Souhaitez-vous avoir de l'aide pour l'un des problèmes nommés ci-haut? Oui Non

À l'usage exclusif du professionnel

Information sur la maladie	Suivi du dépistage
<p>Diagnostic : _____</p> <p>Moment du diagnostic : _____ (mois / année)</p> <p>Stade : <input type="checkbox"/> Local <input type="checkbox"/> Loco-régional <input type="checkbox"/> Métastatique <input type="checkbox"/> Non applicable</p> <p>Moment du dépistage (cochez toutes les cases qui s'appliquent) :</p> <p><input type="checkbox"/> Autour du diagnostic (0-3 sem)</p> <p>Chirurgie : <input type="checkbox"/> Pré-opératoire <input type="checkbox"/> Post-opératoire</p> <p>Radio-oncologie : <input type="checkbox"/> Consultation ou début du traitement <input type="checkbox"/> Per-traitement <input type="checkbox"/> Fin des traitements</p> <p>Hémo-oncologie : <input type="checkbox"/> Consultation ou début du traitement <input type="checkbox"/> Per-traitement <input type="checkbox"/> Fin des traitements</p> <p>Suivi : <input type="checkbox"/> 1^{re} année post-traitement <input type="checkbox"/> 2^e année et + post-traitement</p> <p><input type="checkbox"/> Récidive <input type="checkbox"/> Phase palliative</p>	<p>Révisé par : _____</p> <p>Signature : _____ (lettres moulées)</p> <p>Fonction : _____</p> <p>Référence offerte à : <input type="checkbox"/> Aucune <input type="checkbox"/> Travailleur social <input type="checkbox"/> Infirmière pivot <input type="checkbox"/> Nutritionniste <input type="checkbox"/> Infirmière <input type="checkbox"/> Pastorale <input type="checkbox"/> Médecin : _____ <input type="checkbox"/> Pharmacien <input type="checkbox"/> Psycho-oncologie (psychiatre, psychologue, ergothérapeute) <input type="checkbox"/> Autre établissement (préciser) : _____</p> <p><input type="checkbox"/> Ressource communautaire (préciser) : _____</p> <p>Référence acceptée par le patient : <input type="checkbox"/> Oui <input type="checkbox"/> Non : _____</p> <p>Autre suivi ou information additionnelle : _____ _____ _____</p>

Adaptation par l'équipe d'oncologie psychosociale et spirituelle du CHUQ - Mai 2009 Soutien de Santé Canada, par le Partenariat canadien contre le cancer.

652147 (Rév. 09-03)

OUTIL DE DÉPISTAGE DE LA DÉTRESSE

R-2128

Appendix C - Minimum Data Set: ESAS and Canadian Problem Checklist

Edmonton Symptom Assessment System:

Date of Completion: _____ **Time:** _____

Completed by:

- Patient
- Family
- Health Professional
- Assisted by family or health professional

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Canadian Problem Checklist:

Please check all of the following items that have been a concern or problem for you in the past week including today:

Emotional:

- Fears/Worries
- Sadness
- Frustration/Anger
- Changes in appearance
- Intimacy/Sexuality

Practical:

- Work/School
- Finances
- Getting to and from appointments
- Accommodation

Informational:

- Understanding my illness and/or treatment
- Talking with the health care team
- Making treatment decisions
- Knowing about available resources

Spiritual:

- Meaning/Purpose of life
- Faith

Social/Family:

- Feeling a burden to others
- Worry about family/friends
- Feeling alone

Physical:

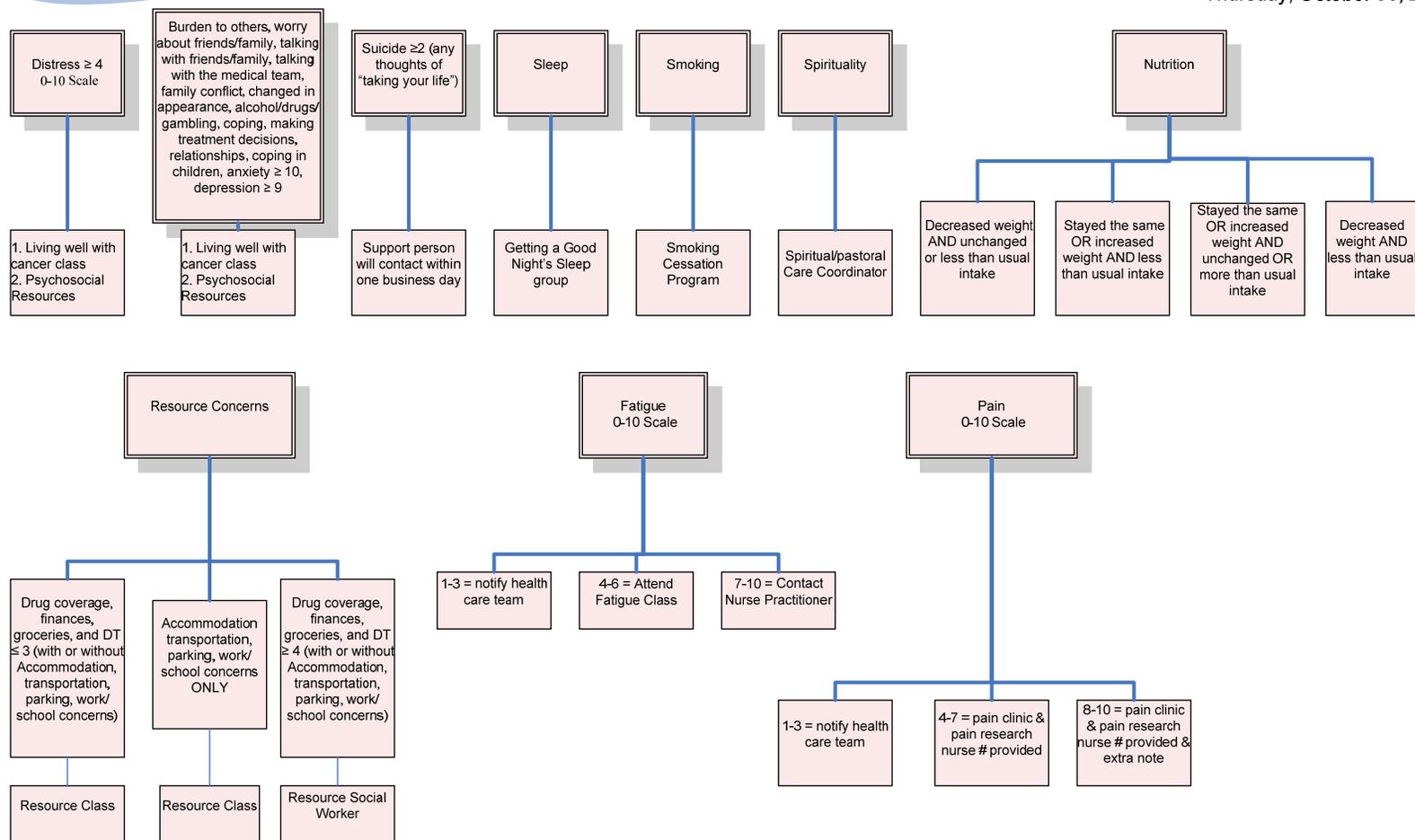
- Concentration/Memory
- Sleep
- Weight

Appendix D - Algorithms

Tom Baker Cancer Centre Example Algorithm:

Referral Algorithms for Screening for Distress - TBCC

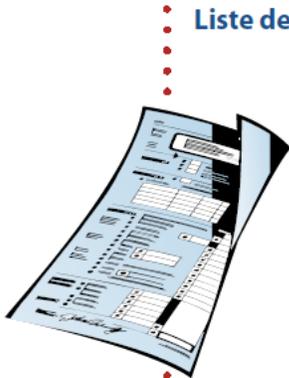
Thursday, October 30, 2008





Trajectoire globale de réponse à la détresse

Outil de dépistage de la détresse (ODD)



Liste de problèmes

- Pratique
- Social / familial
- Information / communication
- Physique
mémoire / concentration, sommeil, poids, constipation / diarrhée
- Spirituels / religieux
- Sexualité
- Difficultés émotionnelles

Intervenant

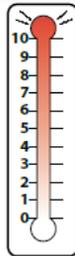
Équipe soignante
ou
Travailleurs sociaux

Équipe soignante

Services spirituels

Psychologue spécialisé en sexologie

Cote au thermomètre



- Si ≤ 4
- Si > 4

Équipe soignante
Travailleurs sociaux
Groupe de gestion de l'anxiété

Évaluation diagnostique en psycho-oncologie
(psychologue, médecin/psychiatre, infirmière en psycho-oncologie)

Échelle d'évaluation des symptômes d'Edmonton (ESAS)



- Dépression-Anxiété Si ≤ 4
- Si > 4
- Douleur, fatigue, nausées, somnolence, appétit, essoufflement Si ≤ 4
- Si > 4

Équipe soignante
Travailleurs sociaux
Groupe de gestion de l'anxiété

Évaluation diagnostique en psycho-oncologie
(psychologue, médecin/psychiatre, infirmière en psycho-oncologie)

Équipe soignante
Évaluation le plus rapidement possible selon disponibilité des services

Équipe soignante
Évaluation le jour même

Soutien de Santé Canada, par le Partenariat canadien contre le cancer.

Cancer Care Ontario Example Algorithm

**CHAMPLAIN PALLIATIVE / EOL NETWORK
LOSS OF APPETITE / ANOREXIA / CACHEXIA SYMPTOM ALGORITHMS**

CRITICAL QUESTIONS TO CONSIDER

1. Has there been recent loss of appetite ?
2. How much weight loss & in what time period ?
3. Is there supplements to be used ?

*"This is only a guide to provide direction for a thorough assessment of the symptom"
For more detailed information, please refer to the Champlain Palliative Resource Manual*

ALWAYS TRY TO REMOVE THE CAUSE

PROBABLE CAUSES	ASSESSMENT	OPTIONS FOR INTERVENTIONS
Constipation	<ul style="list-style-type: none"> ➤ Frequency ➤ Consistency 	<ul style="list-style-type: none"> ✓ Increase fluid intake ✓ See pharmacological approaches
Dehydration	<ul style="list-style-type: none"> ➤ Hypokalemia ↓ K ➤ Hyponatremia ↓ Na 	<ul style="list-style-type: none"> ✓ Hydration- artificial (S/C – IV) ✓ Increase fluid intake ✓ Replace K & Na (as per goal of care)
Mouth Discomfort/ Pain	<ul style="list-style-type: none"> ➤ Complete Oral Assessment (see mouth module) ➤ Dehydration ➤ Thrush (candidas) 	<ul style="list-style-type: none"> ✓ Mouth Care Q4H (see mouth module) or more frequently if necessary ✓ Treat accordingly
Secondary to Treatment/ Medication	<ul style="list-style-type: none"> ➤ Medication Review (NSAID) 	<ul style="list-style-type: none"> ✓ Reassess according to the cause
Pain	<ul style="list-style-type: none"> ➤ Pain Algorithm 	<ul style="list-style-type: none"> ✓
Appetite Suppression (outcomes)	<ul style="list-style-type: none"> ➤ After all other possible causes have been assessed 	<ul style="list-style-type: none"> ✓ Megace po x 7 days (titrate according to effect) ✓ Decadron po (if not contraindicated)

PHARMACOLOGICAL APPROACH	NON-PHARMACOLOGICAL STRATEGIES
<ul style="list-style-type: none"> ➤ Stool Softener Colace ➤ Bowel Stimulant Senekot Dulcolax ➤ Osmotic Laxative Lactulose ➤ Saline Laxative Fleet ➤ Prokinetic: Maxeran Motilium ➤ Anti-fungal (if thrush) Nystatin Fluconazole (if Nystatin ineffective) 	<ul style="list-style-type: none"> ➤ Small frequent meals - appealing ➤ Decrease odors in environment ➤ Mouth Care Q4H (refer to Mouth Module) ➤ Cannabinoids ➤ Ambulation if possible ➤ Separating solids from liquids

Revised: January 2008

REASSESS – IF PROBLEM STILL AN ISSUE, CALL PPSMCS FOR DISCUSSION OF OTHER POSSIBLE OPTIONS AT 1-800-651-1139

Appendix E - Screening for Distress Articles

References:

The below reference may be useful when building a business case for Screening for Distress. The first two articles are recommended to be provided to a general audience as they provide an intro to Screening for Distress:

Recommended Articles:

1. Bultz, B.D. & Carlson, L.E. (2006). Emotional Distress: The sixth vital sign - future directions in cancer care. *Psycho-Oncology*, 15, 93-96.
2. J.C. Holland, Bultz, B.D. The NCCN Guideline for Distress Management: Case for making distress the 6th vital sign. *Journal of the National Comprehensive Cancer Network* 5(1) (2007).

Additional Materials:

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6. Rebalance Focus Action Group. A position paper: screening key indicators in cancer patients: pain as a fifth vital sign and emotional distress as a sixth vital sign. *Canadian Strategy for Cancer Control Bulletin* 2005; 7(Suppl): 4.
7. Carlson, L.E. & Bultz, B.D. (2004). Efficacy and medical cost offset of psychosocial interventions in cancer care: Making the case for economic analyses. *Psycho-Oncology*, 13, 837-849.
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14. Taenzer, P., Bultz, B.D., Carlson, L.E., Speca, M., DeGagne, T., Olson, K., Doll, R., & Rosberger, Z. (2000). Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients. *Psycho-Oncology*, 9(3); 203-213.
15. NCCN Clinical Practice Guidelines in Oncology™ NCCN practice guidelines for the management of psychosocial distress. © 2009 National Comprehensive Cancer Network, Inc. Available at: NCCN.org. Accessed May 20, 2009. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org.

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2. Fitch MI. Providing supportive care. In: Fitch MI, Porter HB, Page GG, eds. *Supportive Care Framework: A Foundation for Person-Centred Care*. 1st ed. Pembroke, Ontario: Pappin Communications; 2008:23-24.
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