

CLINICAL MANAGEMENT, THE HEALTHCARE TEAM AND PATIENTS

PATIENTS AND FAMILIES: Information, Education and Engagement

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A. INTRODUCTION

Informed and engaged patients are key contributors to high-quality care ¹. Cancer patients and their families need access to a wide range of information, education, training and services to understand their cancer diagnosis and treatment, make informed decisions, actively participate in their care and manage the impact of cancer on all aspects of their lives.

Patients and families interact with the cancer centre and its staff through a multitude of clinical and non-clinical interactions. Their needs must be considered in all aspects of the cancer centre that affect their experience. Key considerations include:

- Establishing and upholding the level of service that every patient and caregiver should expect to receive for all programs and services
- Respecting and considering each patient's personal values, beliefs, experiences and preferences
- Fostering empathy, compassion and trust amongst patients and care providers
- Enabling patients to make informed decisions and actively participate in their care

Establishing programs and services that effectively address patient needs have many benefits for patients and health system. Effective patient communication, education and engagement can ²:

- Build patient knowledge and understanding of their disease and its treatment
- Reduce decisional conflicts and regret
- Promote patient autonomy
- Improve patient navigation of care
- Improve treatment compliance
- Improve symptom management
- Reduce patient anxiety and enhance the ability to cope
- Improve overall patient satisfaction with care
- Improve the experience for patients and families
- Increase patient safety
- Improve resource efficiency

This chapter presents the foundational principles of patient-centred care as well as key programs and services designed to inform, educate and engage patients and caregivers, from suspicion of cancer to end of life or survivorship.

B. FOUNDATIONAL PRINCIPLES

1. PATIENT-CENTRED CARE AND THE PATIENT EXPERIENCE

Patients and their families play a pivotal role in informing care and making joint treatment decisions. ³ The principles of patient-centred care and the patient experience are central to moving from a medical- and provider-centric model of care to one that is patient-centric.

Patient-centred care, also known as person-centred care, is a component of quality in healthcare and can be viewed as an overarching philosophy and principle that stresses the importance of the individuality of the patient. Engaging and empowering patients to be active participants at an individual and cancer centre level requires an environment and culture that encourages patient engagement and values diverse preferences and perspectives.⁴ Greater engagement of patients and families has helped a number of healthcare organizations to improve quality, safety and the patient experience.⁵

The **patient experience** encompasses the full range of interactions that patients have with the cancer centre and the larger healthcare system. It includes, but is not limited to, respect, partnership, care co-ordination, high-quality care, efficiency, and safe and clean environments.⁶ A good patient experience has been shown to have a positive association with other healthcare processes and outcomes, such as patient safety and better clinical outcomes.⁷ It is critical that the cancer centre's strategy and operational plans include explicit commitments to understanding and improving the patient experience as a key component of patient-centred care.

For guidelines and approaches to patient-centred care and the patient experience, see the following resources.

- Cancer Care Ontario's [Person-Centred Care Guideline](#)³
- [The Person-Centred Care Guideline: From Principle to Practice](#)⁸
- The Commission on Cancer's [Cancer Program Standards: Ensuring Patient-Centered Care](#)⁹
- The National Institute for Health and Care Excellence's [Patient experience in adult NHS services](#) clinical guideline¹⁰
- The National Health Service's [patient experience improvement framework](#)¹¹
- [The Beryl Institute Experience Framework](#)¹²
- [How to Transform Patient Experience: Patient Journey and Culture](#)¹³

2. HEALTH LITERACY

Health literacy refers to the degree to which individuals can obtain, process and understand the basic health information and services they need to make appropriate health decisions.¹⁴ Low health literacy is recognized as a threat to the health of individuals and to healthcare systems.¹⁵¹⁶ Health literate approaches to cancer care provision can influence better patient experiences and outcomes, lower healthcare costs, and result in more engaged patients and communities.¹⁷

Health literacy “entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course” is the product of individuals’ capacities and the health literacy-related demands and complexities of the healthcare system.¹⁸ System changes are needed to better align healthcare demands with the public’s skills and abilities. To that end, the Institute of Medicine has defined [Ten Attributes of Health Literate Health Care Organizations](#)¹⁹ that are required for an organization to be health literate. These attributes are summarized in Figure 1.

FIGURE 1: THE ATTRIBUTES OF A HEALTH LITERATE ORGANIZATION¹⁹

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.

A key strategy to enhance health literacy is provider training, which should build competencies in several areas including plain language communication and the teach-back method.

Provider Training

Health literacy training aims to enhance provider understanding of the strategies, methods and tools that can help patients to better understand and access health information and services. A number of health literacy competencies can greatly benefit provider-patient interactions, and patient understanding of and engagement in care. For a detailed discussion, see [*Health Literacy Practices and Educational Competencies for Professionals: A Consensus Study*](#).²⁰

Plain language and the teach-back method have been identified as two important health literacy practices and competencies for healthcare providers and are discussed in more detail below.

Plain Language

Plain language uses familiar words and a conversational style to convey information clearly. This minimizes the effort required to understand information. Even skilled readers may prefer plain language because it enables them to quickly read and use essential health information.

Effective plain language techniques include:

- Writing naturally, the way we speak, preferably using an active voice and personal pronouns such as “you” and “we”

- Focusing on practical and need-to-know information, with an emphasis on the actions the patient should take
- Organizing content from the patients' point of view, providing an introduction and context for new information and using summaries throughout the text that make need-to-know information easy to find
- Making ideas, conclusions and instructions explicit, using stories to illustrate and bring clarity when appropriate
- Using consistent and common words and phrases, avoiding jargon, slang, idiomatic expressions and abbreviations
- Providing a definition for medical terms that patients and families need to know
- Keeping average sentences to about 10 to 15 words and one idea, and keeping paragraphs to two or three sentences
- Using a simple sentence structure and limiting the range of punctuation to commas and periods
- Being specific about quantities, numbers and frequencies, using numerals instead of writing out numbers
- Using tables, charts and graphs only if we know readers are trained to use them
- Using simple, realistic and culturally appropriate drawings and pictures to illustrate points and support the text

For more information about plain language, see the following resources:

- The Michener Institute's [Certificate in Plain Language for Patient/Public Health Communication](#) ²¹
- The Plain Language Action and Information Network's [plain language in healthcare resources](#) ²²

The Teach-Back Method

The teach-back method can be used to confirm a patient's level of understanding. This involves providers asking patients to repeat – in their own words – the key ideas, decisions or instructions that were just discussed. A variation is the return demonstration or show-back method, in which the patient demonstrates to the caregiver how they will do what was taught.

For more information about the teach-back method, see The Agency for Healthcare Research and Quality's *Health Literacy and Universal Precautions Toolkit, 2nd edition* [Use the Teach-Back Method: Tool #5.](#) ²³

3. CULTURAL COMPETENCE

Cultural competence in healthcare encompasses the ability to provide care to patients with diverse values, beliefs and behaviors, including tailoring healthcare delivery to meet patients' social, cultural and linguistic needs. ²⁴ Culturally competent organizations work to understand the background of their community and patient population, the effect that cultural influences have on care delivery, and the associated skills needed by clinicians and staff. Depending on the local context, cancer centres are likely to serve diverse populations that could include local racial

and ethnic minorities, immigrants, refugees and expatriates. Strategies that enhance cultural competence are language services, comprehensive approaches to care and provider training.

Language Services

Access to healthcare and health outcomes can be adversely affected by language barriers. Professional interpretation and translation services can minimize language barriers in both verbal and written communication. For language services best practices, see the following resources.

- The U.S. Department of Health and Human Services' [*A Patient Centered Guide to Implementing Language Access Services in Healthcare Organizations*](#)²⁵
- The National Council on Interpreting in Health Care's [publications](#)²⁶
- The Agency for Healthcare Research and Quality's [*Addressing Language Access Issues in Your Practice: A Toolkit for Physicians and Their Staff Members*](#)²⁷

Comprehensive Approaches to Care

Cancer centres should work to understand and integrate comprehensive approaches to care that include the physical, mental, emotional and spiritual needs of patients. The demand for traditional and complementary medicine (T&CM) is increasing globally, and T&CM is now used often to both treat and cope with cancer.^{28,29} The WHO defines traditional medicine as “the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness”. Complementary medicine is defined as “a broad set of health care practices that are not part of that country’s own tradition or conventional medicine and are not fully integrated into the dominant health-care system”. Together, these two definitions encompass a wide range of products, practices and practitioners. Cancer centres should develop policies and strategies to integrate T&CM approaches of proven safety and efficacy. For more information, see the [*WHO Traditional Medicine Strategy 2014-2023*](#)²⁹ and the [*Cancerpedia: Supportive Care*](#) chapter.

Provider Training

Clinical cultural competence interventions aim to enhance provider understanding of the link between sociocultural factors and health beliefs and behaviours. These interventions aim to equip providers with the tools and skills to communicate with patients and manage these factors appropriately.²⁴ For more information on key considerations and pitfalls to avoid when developing provider training, see [*Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic Disparities in Health and Health Care*](#).²⁴

4. CONSENT AND SHARED DECISION-MAKING

In cancer care, consent, informed decision-making and shared decision-making with patients is particularly important, given that decisions can have a significant impact on the patient’s quality of life and outcomes.¹ For the patient, consent is a declaration of acceptance. For the provider, consent can act as an assurance that they are respecting the patient’s wishes and values.

Consent can be categorized into three categories: implied, expressed and informed consent. The majority of patient care is based on implied or expressed consent. Consent is often implied either by the words or the behaviour of the patient; for example, by volunteering a history, answering questions or submitting to physical examination. Expressed consent can be achieved through stating in advance the intended purpose of an examination and requesting expressed verbal consent. Informed consent constitutes a signed confirmation that the patient understands his or her condition and the clinical service being recommended, including the benefits, potential risks, limitations, alternatives and uncertainties.³⁰

All forms of consent should employ the use of health literate approaches that ensure clear communication and respectfully ensure a mutual understanding between the patient and care provider. This includes communicating in plain language, allowing sufficient time for questions and verifying understanding using the teach-back method and open-ended questions. More details in these tools are provided later in this chapter.

Informed decision-making is based in informed consent. Shared-decision making goes beyond informed consent and informed decision-making, both of which focus on sharing of information rather than two-way communication, engagement, understanding and joint planning. Shared decision-making with patients is particularly important in cancer care, given that decisions can have a significant impact on the patient's quality of life and outcomes.¹ Research has found that patients who are more engaged in their healthcare decisions are more likely to experience confidence in treatment decisions, compliance with treatment regimens, satisfaction with treatment, trust in their providers and better health outcomes, including decreased anxiety and a quicker recovery.^{31 32} For more information, see the *Cancerpedia: Clinical Management* chapter.

C. PROGRAMS AND SERVICES

A number of programs and services can be implemented to address the information, education and navigation needs of patients and families, as well as important opportunities for engagement. Dependent on the cancer centre's size, structure and funding, these programs and services may be aligned under one or multiple areas. Patient-focused programs should have director-level oversight from senior leaders who are responsible for developing, integrating and assessing the quality of patient-facing programs and services as well as clinical and research initiatives that affect the patient experience.

5. PATIENT NAVIGATION

Patient navigation is a patient-centred healthcare service delivery model designed to facilitate timely access for all patients to quality standard care. Navigation interventions address patient barriers to accessing the healthcare system in a culturally sensitive manner.³³ Navigation interventions can improve patient access to screening, treatment initiation and adherence, and quality of life.³⁴ Specifically, they have been shown to improve access to proper cancer care for underserved individuals and those who encounter barriers to quality care, such as financial and

economic, language and cultural, communication, healthcare system and transportation barriers, as well as fear.³⁵

Patient navigation programs can vary greatly in scope, size and approach. At the patient level, cancer centres can establish programs that provide one-on-one navigation support throughout the care trajectory. At the cancer centre level, there are standard procedures and/or services that can promote access to timely diagnosis and treatment of cancer. These may include pre- and/or post-appointment telephone calls, email reminders, mailings or technology-enabled solutions, such as digital applications and patient portals.³⁶

Program Requirements and Best Practices

- **Patient navigators:** Cancer patient navigators may be professionals (e.g., nurses and social workers), paraprofessionals (e.g., community health workers), or recognized community leaders and peers (i.e., including cancer survivors) who are responsible for overseeing and co-ordinating all phases of a patient's care journey.³⁷
- **Tailored orientation and training:** Training should cover the role and scope of the navigator, listening and communication skills, administering assessments, identifying barriers, and accessing resources that address patient- or system-related barriers. In addition, navigators may require an overview of the basics of cancer diagnosis and treatment. For more information on types of education, including specialized psychosocial training for lay volunteers, see the *Cancerpedia: Education* chapter.
- **Digital tools:** Navigators require access to the electronic patient health record. They also require customized care management tools that allow for the tracking of patients throughout their care journey and provide relevant alerts and messages related to care.

For details on establishing patient navigation programs, see the following resources.

- [*The History and Principles of Patient Navigation*](#)³⁵
- [*Establishing Effective Patient Navigation Programs in Oncology: Proceedings of a Workshop*](#)³⁸

6. ELECTRONIC PATIENT PORTALS

There is growing consensus that the information contained in health records belongs to the patient, and that patients have the right to review their records. In the United States, this concept was a key part of the *Health Insurance Privacy and Portability Act*.³⁹ In Canada, it is a key part of the *Personal Health Information Protection Act*.⁴⁰

A patient portal is web-based application that connects an electronic health record system with a patient-facing online portal, allowing patients to access their personal health information at any time and from anywhere.⁴¹ Patient portals give patients access to their personal health information as they move between health providers and throughout a health system. Patient portals can vary in their functionality, from read-only views of appointments, results and health history to online appointment booking and secure messaging with the healthcare team. Patient portals can be a vital tool for actively engaging patients in managing their care, reducing missed

appointments, improving treatment adherence, enhancing health knowledge, and increasing self-reported confidence in health self-management.⁴²

A number of patient portal vendors offer varying functionalities and customizable options to match cancer centre goals and priorities for online patient access to their personal health information.

Patient portals require infrastructure and guidelines for the management of health records; for more information, see the [Cancerpedia: Health Records](#) chapter.

7. PATIENT EDUCATION AND INFORMATION

Cancer patients need access to a wide range of information and education to help them understand their cancer diagnosis and treatment, actively participate in their care, and manage the impact of cancer on all aspects of their lives. Well-informed, educated and engaged patients and caregivers contribute to cancer care by:

- Taking an active role in cancer prevention
- Monitoring their condition and care plan
- Managing side-effects and symptoms
- Partnering in follow-up care and survivorship
- Bridging the gap between different healthcare providers and settings

The cancer centre should include an information and education program with a mandate to ensure access to reliable and current information. These resources should span the full care trajectory, as illustrated in Figure 2. A patient education program can curate existing cancer-related resources from reliable health organizations, and work with clinical experts to develop original resources for use within the cancer centre. Ideally, the program should provide a balance of both types of resources to patients and caregivers.

FIGURE 2: TOPICS OF EDUCATION AND INFORMATION FOR PATIENTS AND CAREGIVERS

- Prevention and detection (i.e., cancer risk reduction, screening, warning signs)
- Types and subtypes of cancer
- Coping and support
- Treatment options and modalities
- Side-effects management
- Post-treatment issues, including self-care after treatment and practical programs and supports located at the cancer centre and elsewhere (e.g., cancer organizations, community-based organizations, government agencies, etc.)
- Caring for someone with cancer
- Options for care when cancer cannot be treated or cured
- End-of-life care options
- Additional sources of credible information, resources, services and support in the community

Program Requirements and Best Practices

Patient education can be provided in many ways. This can vary from passive strategies, such as the use of consumer health information (e.g., pamphlets, webpages, videos), to more active strategies, such as self-management teaching by a healthcare provider. Every method used to engage patients, families and caregivers should consider best practices for health literate communication.

To maximize patient understanding, the cancer centre should make use of a wide range of multi-modal resources that can be tailored to the patient need or situation. For example, patients may choose to pursue self-directed learning to understand their diagnosis and treatment. In this case, the cancer centre should provide a library (i.e., virtual and/or physical) of reliable, vetted information. Patients also require materials to supplement in-clinic teaching by healthcare providers to support understanding and retention. Examples of multi-modal patient education materials include:

- Print resources (e.g. pamphlets, books)
- Audiobooks or podcasts
- Videos
- Pictures or illustrations
- Demonstrations, models or props
- E-based tools, such as websites, e-learning modules and mobile applications
- Classes, including virtual and in-person options

Classes may be provided on a wide range of subjects, from an introduction to various types of treatment to specific coping skills. The patient education program may also provide expertise in the development of self-management education interventions. Self-management encompasses tasks an individual undertakes to manage symptoms, treatment, physical and psychosocial effects, and lifestyle changes related to their health.⁴³

For more information about health literate approaches to patient education, see the following resources.

- Cancer Care Ontario's *Establishing Comprehensive Cancer Patient Education Services*²
- The Plain Language Action and Information Network's [plain language in healthcare](#) resources²²
- The Agency for Healthcare Research and Quality's *Health Literacy and Universal Precautions Toolkit, 2nd edition* [Use the Teach-Back Method: Tool #5](#)²³
- [Effective teaching strategies and methods of delivery for patient education: a systematic review and practice guideline recommendations](#)⁴⁴
- Cancer Care Ontario's [Self-Management Education for Patients with Cancer: Evidence Summary](#)⁴⁵
- The Agency for Healthcare Research and Quality's [The Patient Education Materials Assessment Tool and User's Guide](#)⁴⁶
- The National Institutes of Health's [choosing effective patient education materials](#)⁴⁷

The patient education program requires staff with health education and communication expertise who work with patients, healthcare providers and cancer centre leadership to ensure that patients have access to the information they need. The following specialist roles are required.

- **Patient education specialist:** Responsibilities of this role include: applying health literacy principles to resource and program development; working with clinical subject matter experts to develop multi-modal resources; planning and co-ordinating education activities; and developing and implementing resource and program evaluation.
- **Consumer health librarian:** Responsibilities of this role include: developing and maintaining the physical and online patient library collection; conducting health information searches for patients and caregivers; assisting patients and staff with navigating health information systems; and maintaining library usage statistics.

Patient education also requires physical facilities, equipment and information systems that support formal and informal education, including the following.

- **Satellite resource centres:** Patient education should be accessible and visible throughout the cancer centre. This can be achieved through installing racks and holders for educational materials in patient waiting areas.
- **Patient library:** A patient library's core functions are to: provide patients and families with high-quality, current and reliable consumer health information; consult with cancer centre staff about patient education resource needs; maintain satellite clinic and unit resource centres across the organization; and maintain a current library catalogue.
- **Classrooms:** Dedicated spaces or classroom are important for facilitating educational activities. A number of classrooms of varying size can be used to for one-on-one or group education sessions.
- **Learning management system:** A learning management system can provide online access to a range of virtual learning experiences, including education sessions, videos and other resources.
- **Patient education resource repository:** As the patient education library grows, a system that allows for cataloguing resources is required to ensure that information is searchable and accessible.
- **Public website:** The cancer centre public website can be an important central source of patient education resources and information about the cancer centre. For more information, see the *Cancerpedia: Communication* chapter.

8. PATIENT ENGAGEMENT

Patient engagement involves patients, families, caregivers and healthcare providers actively collaborating to improve the healthcare system. Patient engagement efforts recognize that patients can be experts in their own care and offer valuable insights as experienced users of the healthcare system.⁴⁸ They seek the patient's unique perspective at multiple levels, including decisions about their own health and treatment, care design and processes, and policies that shape the healthcare system.⁴⁹

Patient engagement can occur within a broad spectrum of activities that range from sharing and consulting to more intensive engagement, such as deliberating and collaborating.⁴⁸ Although a

range of engagement is possible, there are a number of methods that are gaining broad application in hospitals and healthcare in general, including: ⁵

- Recruiting and training past or current patients and caregivers to serve official roles within the cancer centre, often referred to as patient partners or patient advisors.
- Encouraging and requiring patient consultation and involvement in the development and evaluation of services and programs.
- Integrating patient engagement into provider training. Patients play an important role in educating healthcare professionals by sharing their personal care experiences and providing ideas on how to improve the delivery of care.

Program Requirements and Best Practices

A concerted and sustained effort towards patient engagement requires staff with a focus on developing and building patient engagement across the organization, including the following.

- ***Patient engagement specialist:*** The responsibilities of this role include: recruiting, selecting, training and supporting patient partners; setting up and supporting patient and family advisory councils; planning and implementing engagement activities; developing and delivering training to patients and providers; monitoring and reporting on patient engagement. ⁴⁹
- ***Patient partners or patient advisors:*** Patient partners are individuals who have had experience with the cancer centre as a patient or caregiver. They are trained advisors who can serve on committees, councils, boards and other bodies within the organization. Patient advisors can also form an advisory council, to which staff and cancer centre leadership can submit inquiries and requests for consultation.

For more information about patient engagement frameworks and toolkits, see the following resources.

- The Agency for Healthcare Research and Quality's [*Guide to Patient and Family Engagement in Hospital Quality and Safety*](#) ⁵⁰
- The Change Foundation's Patient/Family Advisory Councils in Ontario Hospitals [*reports*](#) ⁵¹
- Health Quality Ontario's [*Patient Partnering Framework*](#) ⁴⁸

9. PATIENT RELATIONS

A dedicated patient relations office, or patient ombudsman, offers patients and families a confidential process to voice and/or resolve concerns, suggestions and compliments about the care they have received to someone outside of the healthcare team. The office can also provide consultation and advice for staff on addressing difficult patient situations, make recommendations on risk mitigation, ensure appropriate stakeholders are consulted and provide suggestions on additional parties to involve (i.e. legal, privacy, etc.). ⁵²

Patients who voice their complaints may help prevent the same problem from occurring again, which influences positive development in the healthcare system, keeping both the patient and healthcare professionals accountable. ⁵³ It is, therefore, imperative for these experiences to be shared as a means of quality improvement and an opportunity to learn from positive and negative

patient encounters.⁵⁴ Cancer centres can leverage their patient relations office to both measure and monitor patient satisfaction and experience, as well as to identify areas for improvement.⁵³

Program Requirements and Best Practices

The patient relations office should have an effective process in place for responding to patients and families in a timely manner. In addition to receiving and addressing complaints and suggestions for improvement, processes for documenting, monitoring and analyzing the feedback received, the parties involved (i.e., both the patient and providers) and the eventual resolution are essential. Complaints should be recorded in such a way that an organization can easily determine the status of each complaint and track the complaints management process.⁵⁵

The primary requirement of a patient relations program is trained staff, including the following. Depending on the size of the organization and the volume of feedback received, more than one individual may be needed for this role.

- ***Patient relations specialist:*** The responsibilities of this role include: receiving all calls, emails and letters addressed to the office; monitoring, documenting and resolving complaints; and consulting on and assisting staff with resolving complaints.

For more information about patient relations frameworks and toolkits, see the following resources.

- Health Quality Ontario's [*Striving for Excellence in Patient Relations Processes in Ontario's Hospitals*](#), including The 10 Principles of Effective Patient Relations⁵⁵
- The Queensland Ombudsman's [policy and procedure guide](#) for complaints management⁵⁶
- The Patients Association's [improving complaints](#) resources⁵⁷

D. PERFORMANCE MONITORING AND REPORTING

10. MEASURING THE PATIENT EXPERIENCE

A strategy to assess and improve the patient experience represents an organizational commitment to partnering with patients to identify and address aspects of their experience that are most important to them. The patient experience has been increasingly integrated into organizational assessments of quality. Improving the patient experience requires a cancer centre-wide initiative to collect, analyze and use patient feedback to drive quality improvement.¹¹ Sample measures of the patient experience are provided in Figure 3.

FIGURE 3: SAMPLE MEASURES OF PATIENT EXPERIENCE FROM CANCER CARE SURVEY, AGENCY FOR HEALTHCARE RESEARCH AND QUALITY ⁵⁸

- Getting timely appointments, care, and information.
- How well the cancer care team communicates with patients.
- Cancer care team’s use of information to coordinate patient care.
- Helpful, courteous, and respectful office staff.
- Cancer care team supports patients in managing the effects of their cancer and treatment.
- Cancer care team is available to provide information when needed.
- Involvement of family members and friends.
- Availability of interpreters.
- Patients' rating of the cancer care team.
- Patients’ rating of overall cancer care.

Examples of tools developed to assess the experiences of patients in outpatient and inpatient settings across the care trajectory include:

- The Agency for Healthcare Research and Quality’s [Consumer Assessment of Healthcare Providers and Systems: Assessing Health Care Quality from the Patient’s Perspective](#) ⁵⁹
- The National Health Service’s [National Cancer Patient Experience Survey](#) ⁶⁰
- Cancer Care Ontario’s [Patient Experience Survey - Your Voice Matters](#) ⁶¹

For more information about engaging patients in a systematic quality improvement strategy, see the [Cancerpedia: Quality](#) chapter.

11. PROGRAM-SPECIFIC MEASURES

Programs designed to address the information, education, navigation and engagement needs of patients and families should develop performance indicators based on the nature and scope of services. Table 1 presents a list of sample metrics for each program or area.

TABLE 1: SAMPLE PROGRAM METRICS AND INDICATORS

Program/Service	Sample Metrics
Patient Education	<ul style="list-style-type: none"> • Number of learning opportunities and resources co-developed by patients/caregivers and staff • Number of patient/family learning opportunities offered • Number and range of patient/family education resources available • Number of patients/families participating in each opportunity • Patient assessment of and satisfaction with education opportunities • Currency of resources • Number of print resources disseminated • Number and type of electronic interactions (e.g., education videos, blogs, etc.) • Number of staff trained in health literacy competencies
Patient Navigation	<ul style="list-style-type: none"> • Number of patients served

	<ul style="list-style-type: none"> • Number of patients who complete tasks, attend appointments, events, etc. • Number of assessments • Analysis of outcome measures (e.g., missed appointments, readmissions, emergency visits, patient reported outcomes) • Number of programs/resources
Patient Engagement	<ul style="list-style-type: none"> • Number of patient partners/advisors • Number of committees with patient partner/advisor representation • Number of programs and initiatives seeking patient input
Patient Relations	<ul style="list-style-type: none"> • Number of complaints and compliments • Analysis on trends in complaints • Length of time to resolve complaints

E. EXTERNAL RESOURCES

In cancer, non-government organizations (NGOs), cancer societies and community-based organizations can play a critical role in reducing the effects of cancer on communities by offering programs or services that complement public or private healthcare services.⁶² These organizations typically operate at a local and national level, have strong local community ties and offer information, education and support for patients and their families. The cancer centre has an important role in forging a connection with NGOs, cancer societies and community-based organizations to facilitate access to important services and supports throughout the care trajectory. Formalized partnerships can also allow the cancer centre to work with external organizations to identify unmet patient needs and advocate for patient services and supports that are outside the scope of the cancer centre, or best delivered in the community.

Examples of services and resources offered through external organizations include:

- Public awareness campaigns about cancer-related issues
- Information and education through national/local cancer websites and telephone lines
- Community-based support groups and activities for people affected by cancer
- Services that offer transportation, meals, financial planning, and support for navigating access to health and social services

Select examples of external cancer organizations offering a wide scope of services include:

- [Oman Cancer Association](#)⁶³
- [Singapore Cancer Society](#)⁶⁴
- [Nigerian Cancer Society](#)⁶⁴
- [China Anti-Cancer Association](#)⁶⁴
- [Canadian Cancer Society](#)⁶⁴
- [American Cancer Society](#)⁶⁴

F. THE FUTURE

Extending the Boundaries of Care

Patients are increasingly required to manage more of their care from home. For example, surgical procedures are increasingly done in outpatient settings, some types of hematopoietic stem cell transplantation are moving to outpatient care, and both oral chemotherapies and chemotherapy infusions delivered through portable pumps can now be given at home. In order to improve outcomes and optimize the delivery of care to patients, cancer centres must increasingly adopt innovative solutions to deliver quality care in unconventional settings.

eHealth

The influx of health information technology affects the patient experience in many ways. While many solutions provide opportunities to increase value, reduce costs and improve the patient experience, it is imperative to evaluate the overall impact of e-based solutions on the patient, provider and healthcare system. Emerging tools that are gaining increasing adoption in cancer care include:

- **Virtual clinics**, which employ the use of telemedicine and web-based applications to support remote patient assessment and management.
- **Wearables and remote monitoring** devices and applications, which allow healthcare providers to remain connected to patients outside the walls of the cancer centre through the electronic transmission, analysis and interpretation of clinical patient data, such as patient-reported outcomes, vitals and symptoms. This technology can allow patients and providers to be proactive in cases where medical intervention is required, and also lower healthcare costs by eliminating unnecessary visits.
- **E based self-management interventions**, which can better equip patients with the tools and support they need to manage the acute and long-term effects of cancer treatment in the physical, emotional, psychological and practical domains.

Addressing the Needs of Caregivers

Cancer affects the whole family. The role of informal caregivers – such as family and friends – can encompass a wide range of activities. This can include helping patients understand and retain information, co-ordinating care at home, performing some clinical tasks (e.g., bandage changes) and providing emotional support. Caregivers can experience distress and burnout as a result of a loved one's diagnosis. In order to provide care that is responsive to patient needs, the cancer centre should view informal caregivers as part of the community it serves and allow patients to involve caregivers in their care when and how they wish.

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