



Cancer Care Ontario



Follow-Up Model of Care for Cancer Survivors

Recommendations for the Delivery of Follow-up Care for
Cancer Survivors in Ontario

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 - Genitourinary Cancers Advisory Committee
 - Patient and Family Advisory Council
 - Provincial Primary Care & Cancer Network
 - Provincial Radiation Treatment Program Committee
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OVERVIEW

Background

With advances in early detection and treatment, the survival rate from all cancers combined rose from 53% (1992-1994) to 60% (2006-2008).¹ The continuing improvement in survival rate, coupled with a growing and aging population, is contributing to an increasing survivor population. As a result, the demand for follow-up care to monitor for new cancers, recurrence, and late effects from cancer treatment continues to rise. Traditionally, cancer survivors continued to see one or more specialists for their follow-up care for many years (sometimes decades) after their treatment was completed. However, recent evidence indicates that community-based primary care can also provide safe and effective follow-up care for many cancer survivors, especially for those who have a lower chance of recurrence and with few or no treatment complications.²

Beginning in 2011, Cancer Care Ontario supported Ontario's regional cancer centres (RCCs) in implementing a new follow-up model of care for breast and colorectal cancer survivors. In this model, eligible patients were transitioned from specialist teams to primary care for ongoing follow-up if they completed their cancer treatment at a RCC, had no ongoing cancer-related issues, and were deemed appropriate for care in the community. For patients who could not fully transition to primary care, some RCPs implemented a model of care, where specialists and primary care shared the responsibility for follow-up care.³

All 14 RCCs participated in the above initiative. Based on self-reported data and interviews, over 10,000 breast and colorectal cancer survivors transitioned to primary care for follow-up care between 2012 and 2015. In 2016, Cancer Care Ontario and the Institute for Clinical Evaluative Studies conducted a study that examined the impact of this follow-up model of care. This study showed that, when compared to a matched control cohort, transitioning breast cancer survivors to primary care was associated with more appropriate use of healthcare services, lower healthcare cost per survivor, and higher rate of appropriate surveillance tests such as mammography.⁴ The study also found that while the number of specialist visits decreased, the number of primary care visits did not increase during the same time period. This suggests that the primary care-led model can be a cost-effective way to deliver follow-up care for eligible breast cancer survivors. Several Canadian provinces have also implemented the primary care-led follow-up model of care in other cancer survivor populations such as lung, lymphoma, and prostate.⁵

Although RCCs have made progress in implementing the new follow-up model of care, provincial data suggest that there is still variability in its uptake and, therefore, room for improvement. To promote the uptake and spread of the model, Cancer Care Ontario initiated the development of a set of recommendations that describes a follow-up model of care for all cancer survivors. The result is this document, entitled **Follow-Up Model of Care for Cancer Survivors: Recommendations for the Delivery of Follow-Up Care for Cancer Survivors in Ontario ('Recommendations')**. When implemented, the Recommendations should achieve the following:

- **Survivors** will be well-informed and will receive high-quality follow-up care in the most appropriate setting;

- **Providers** will be engaged and supported in providing high-quality follow-up care for survivors; and,
- **Healthcare system** resource utilization will be optimized.

Purpose of This Document

The Recommendations aim to provide guidance to healthcare providers and administrators on implementing optimal delivery of follow-up care for all cancer survivors by clarifying:

- The roles of primary care providers and specialist teams;
- Settings in which this care should be provided; and,
- Processes involved in organization of follow-up care.

APPROACH

This document summarizes the recommendations developed by the Survivorship Care Improvement Project Models of Care Working Group ('Working Group'; see Acknowledgement for the membership list). This work was informed by a review of the scientific and grey literature and Cancer Care Ontario's earlier work on the follow-up model of care for breast and colorectal cancer survivors. In addition, we conducted a patient journey mapping exercise⁶ that brought together a group of patient and family advisors, clinicians, and administrators to identify areas of improvement in follow-up care. The findings from this exercise contributed to the development of the Recommendations. Finally, broad stakeholder engagement was conducted to streamline and validate the Recommendations (see Acknowledgement for the list of stakeholders).

SCOPE

The Recommendations in this document apply to all cancer survivors, regardless of their cancer type.

The Working Group acknowledges that survivors who participate in clinical trials and those who are part of Cancer Care Ontario's Evidence Building Program for certain medications (e.g., Trastuzumab and Oxaliplatin) may require ongoing follow-up from specialist teams. The organization of follow-up care for these survivors is outside the scope of this document.

DEFINITIONS

For the purpose of this work, the Working Group adopted the following definitions for several key terms (see the Glossary for the definition of additional terms).

- **Survivors:** While there are many uses and meanings for this term, this document defines survivors as patients who have completed primary cancer treatment and have no evidence of active disease. Individuals who may be receiving ongoing adjuvant hormonal therapy are also considered to be survivors. For streamlining purposes, any reference to survivors in this document also include their family and/or caregivers.
- **Follow-up care:** Also known as "post-treatment follow-up care," follow-up care consists of activities and processes related to prevention of recurrent and new cancers;

surveillance for cancer spread, recurrence, or secondary cancers; management of the consequences of cancer treatment (e.g., side effects and late effects); and coordination of care.⁷

- **Primary care provider:** This is a healthcare provider or a team who manages the patient's existing health issues and is usually the first contact for the patient seeking access to the healthcare system for a new health issue.^{7,8,9} Primary care providers can include, but are not limited to family physicians, general practitioners, nurse practitioners, and family health teams.
- **Specialist team:** This is a team of healthcare providers (e.g., physicians, advanced practice nurses) who have completed advanced training in a specific area of medicine (e.g., oncology, urology, hematology, and surgery).¹⁰
- **Most responsible provider (MRP):** The MRP is a regulated healthcare professional (e.g., physician, nurse practitioner) who is responsible for directing and coordinating care for survivors. Their role includes, but are not limited to, ordering surveillance tests, prescribing medications, assessing needs for and coordinating supportive care, and updating the follow-up care plan.¹¹

Guiding Principles for Follow-Up Model of Care

In alignment with Health Quality Ontario's attributes of a high-performing healthcare system,¹² the Working Group agreed to the following guiding principles for follow-up model of care:

- Ensure that the care and information needs, goals, and preferences are centered around the survivor;
- Ensure that the survivor receives timely, high-quality, evidence-based care that is beneficial and does not cause harm;
- Provide access to services as close to home as possible, regardless of factors such as the survivor's location of residence, age, gender, ethnicity, or socioeconomic status;
- Ensure that healthcare providers work to their full scope of practice, and;
- Leverage current and potential advances in technology (e.g., digital health services through eHealth Ontario, OntarioMD).

RECOMMENDATIONS

The document is organized into four sections of recommendations: 'Follow-up Care Planning,' 'Surveillance,' 'Management of Consequences of Cancer,' and 'Health Promotion and Prevention.' A separate section, entitled 'Implementation Considerations,' identifies and describes key challenges associated with implementation of the Recommendations. This section identifies areas where provincial, regional, and/or local efforts are required to address these challenges to enable the implementation of the Recommendations.

Follow-Up Care Planning

High quality, patient-centred, and coordinated follow-up care requires good communication between providers, as well as between providers and survivors.^{2,7,13,14} In particular, when

specialists share key information on cancer treatment and follow-up needs with primary care providers early (e.g., during cancer treatment), it can help ensure continuity of care.^{7,15} Clinicians have reported that they would be more likely to use the follow-up care plan if it is short and concise, and information can be auto-populated from electronic health records.^{16,17} The follow-up care plan has also been identified as an important written document that facilitates communication between survivors and their care providers (i.e., specialist teams and primary care providers) because it helps ensure that survivors are well-informed about their follow-up care and can assume shared responsibility for their care.^{7,18}

1. When an individual has been diagnosed with cancer, one of the specialist teams (i.e., surgical, radiation, or systemic) should inform the individual that they may be transitioned back to their primary care provider for ongoing follow-up after their treatment is completed.
2. If the individual receives more than one modality of treatment (e.g., surgery, radiation, and/or systemic treatment), one of these specialist teams should assume the responsibility for follow-up care planning near the completion of the treatment.
3. Close to the end of treatment, the specialist team responsible for follow-up care planning should work with the survivor and all relevant care teams (e.g., surgical, radiation, and/or systemic) to develop a follow-up care plan.
4. The survivor should have a follow-up care plan that is comprised of two components: (a) a treatment summary and (b) an individualized plan of care for follow-up based on the needs of the survivor.
 - 4.1. The treatment summary should include a minimum set of key clinical information that includes, but is not limited to, cancer diagnosis, treatment(s) received, and a reconciled list of medications (see Appendix A for a list of recommended clinical information). The responsibility of developing this summary should lie with the specialist team responsible for the follow-up care planning.
 - 4.2. The individualized plan of care for follow-up should include a minimum set of information regarding the management of care post-treatment. This includes, but is not limited to, appropriate guidelines/recommendations for follow-up care (e.g., surveillance), a list of signs and symptoms of recurrence, long-term, and late effects, and psychosocial needs. In addition, it should include instructions for referral or re-entry into the cancer system if there is suspicion of recurrence or second cancers, and the contact information of the treatment team who prepared the individualized plan of care and the provider who will be responsible for ongoing follow-up care (see Appendix A for the full list of recommended information on management of care post-treatment). The specialist team responsible for the follow-up care planning should develop the initial individualized plan of care. The provider responsible for ongoing follow-up care will update this component of the follow-up care plan as the needs of the survivor change.
5. The survivor should have a most responsible provider (MRP) for ongoing follow-up care. The name and contact information of the MRP should be documented in the follow-up care plan. The MRP may be a primary care provider or a specialist. This decision should be made through a dialogue between primary care provider and the

specialist team responsible for follow-up care planning. Which provider to assume the MRP role should be decided based on the following criteria:

- a) Severity and risk of treatment complications, long-term and late effects;
 - b) Need for specialized procedures that can only be provided by specialist teams; and,
 - c) Risk of recurrence and secondary malignancies.
6. All care teams involved in the survivor's follow-up care should receive a copy of the follow-up care plan.
 7. The survivor should receive a copy of the follow-up care plan and review it with the MRP and other members of the care team to ensure that the survivor understands the care plan and its goals.

Surveillance

Surveillance is an important part of follow-up care. It includes monitoring for cancer recurrence or second cancers and assessing medical and psychosocial consequences of cancer. Surveillance should be organized and carried out in accordance with existing evidence-based clinical guidance.

A number of studies have indicated that primary care providers can provide effective surveillance for cancer survivors. Studies in breast,^{19,20} colorectal,²¹ and prostate²² cancers showed that when surveillance activities were shifted from specialists to primary care, the clinical (e.g., incidence and rate of recurrence and mortality, time to detection of recurrence) and psychosocial outcomes (e.g., depression, anxiety), and quality of life of survivors were maintained. Survivors also continue to receive surveillance tests that are aligned with recommended guidelines while being followed by their primary care providers,^{4,23} especially when the providers have received explicit follow-up guidance.²³ However, one of the challenges of fully adopting the primary care-led follow-up model of care is anxiety that primary care providers have related to the ease of re-entering the cancer system. To address this challenge, many RCPs in Ontario have introduced streamlined processes that allow primary care providers to quickly refer survivors back to specialists when necessary.³ Overall, this suggests that primary care providers can effectively manage surveillance activities for cancer survivors when appropriate supports are available.

8. The MRP for follow-up care should be responsible for ordering and coordinating surveillance tests for the survivor, including those who are receiving adjuvant hormonal therapies. The surveillance tests should be ordered well in advance to ensure that they are performed in accordance with the interval as recommended by evidence-based clinical guidance.
 - 8.1. If a surveillance test requires specialized procedures, the MRP should be responsible for coordinating them. If the MRP is a specialist (see Recommendation #5), they should carry out these surveillance activities.
9. If the MRP is a primary care provider, they should have timely access to specialist consultation in cases of uncertainty related to suspicion of cancer recurrence, metastasis, or second cancers.

10. A streamlined process should be available for the MRP to arrange for re-entry of the survivor into the cancer system in case of suspicion.
11. The MRP for follow-up care should offer in-person or secure telehealth options (e.g., phone call, videoconference, online patient health information applications), when appropriate, to share surveillance test results with the survivor.
12. The MRP for follow-up care should regularly assess any medical and psychosocial late and long-term effects and arrange for appropriate services. The MRP should also assess caregiver distress and, if needed, coordinate supports for caregivers.

Management of Consequences of Cancer

Consequences of cancer and its treatments include side effects, late and long-term effects. These include, but are not limited to, treatment toxicity, physical needs (e.g., nutritional requirements, lymphedema, dysphagia, pain, fatigue), and psychosocial issues (e.g., distress, anxiety, depression, sexual health, fear of recurrence, concerns related to employment and work re-entry, finances, and disability). These consequences may be temporary or chronic, or they may appear long after treatment was completed. Supportive care is needed to address social, psychological, emotional, spiritual, quality-of-life, and functional aspects of cancer to ensure high quality follow-up care.⁷

Primary care providers have reported willingness to provide supportive care for cancer survivors, if clinical guidance, education/training, support from and communication with specialists are available.^{24,25} Moreover, primary care providers are well-positioned to provide supportive care due to their frequent and regular contact with survivors.^{26,27}

Survivors themselves also play an important role in the management of consequences of cancer.²⁸ Studies have shown that when survivors play an active role in their own care and are engaged in self-management, their physical and psychological symptoms improve and they are more likely to adopt a healthy lifestyle.^{29,30,31,32}

13. Primary care providers should manage side effects, long-term and late effects experienced by the survivor and provide supportive care and self-management support, when appropriate.
 - 13.1. Specialist teams should provide timely consultation to primary care providers in cases of uncertainty on how to manage these consequences.
 - 13.2. Primary care provider should make appropriate referrals to specialists when the survivor requires specialist care (e.g., escalation of long-term and late effects and/or when specialized interventions or procedures are required).
14. Various delivery strategies should be considered when providing supportive care and information to the survivor. These strategies may include, but are not limited to, consultation by phone, referral to credible online and/or community resources (e.g., psychosocial oncology programs at cancer centres, community or online-based cancer support programs), and group-based educational sessions.
15. The survivor should have access to structured self-management programs and high-quality resources that can inform and educate them on how to manage their own physical and psychosocial symptoms (e.g., fatigue, pain). Self-management strategies

should be discussed with the survivor prior to completion of the treatment and during their follow-up visits.

Prevention and Health Promotion

Prevention and health promotion include activities that reduce the risk of late effects, recurrence, and new cancers (e.g., screening for new cancers) and improve the overall health of individuals (e.g., lifestyle counseling, smoking cessation, and immunization). There is consensus amongst survivors, primary care, and specialists that primary care should assume responsibility for general preventive health care and management of non-cancer-related health issues.³³ These activities are already performed by primary care as part of the day-to-day health management for all individuals, including cancer survivors.³⁴ Evidence suggests that primary care is effective in promoting healthy lifestyle³⁵ (e.g., smoking cessation,^{36,37} reduction of alcohol consumption).³⁸ Therefore, primary care is well-suited to lead prevention and health promotion activities for cancer survivors.

16. Regardless of who the MRP is (i.e., primary care provider or a specialist), primary care provider should be responsible for activities related to health promotion and prevention of disease. Primary care provider should work with the survivor to adopt healthy lifestyle activities that are consistent with survivor's cultural values and practices.

IMPLEMENTATION CONSIDERATIONS

The Working Group has identified a number of general considerations and process improvement opportunities that could help support the implementation of these recommendations.

Information Systems

- Clearly defined communication channels should be established between specialist teams and primary care providers when consultation or re-referral is needed. Various telecommunication solutions (e.g., eConsults, integrated electronic health records, hotline for rapid access to specialist team) should be considered to enable effective and timely communication between providers.
- The follow-up care plan should be prepared and delivered in a format that can be uploaded directly into primary care provider's electronic medical record system, where possible, to improve its use by primary care providers.
- Mechanisms should be in place to identify survivors and ensure that they receive necessary care by the most appropriate provider. An example is the use of a 'flag' in the hospital information system that signals a patient has completed their active treatment and is ready for routine follow-up care.
- Consideration should be given to leveraging the organized processes and infrastructure (e.g., communication channels) in existing provincial programs (e.g., Ontario Breast Screening Program) to ensure that eligible survivors receive appropriate surveillance tests in a timely manner.

- Cancer Care Ontario should consider capturing surveillance tests for survivors in the Screening Activity Report in order to monitor the concordance of surveillance activities with clinical guidance.

Access to Services

- Primary care providers have expressed concerns that they cannot order (e.g., when the primary care provider is an NP) and/or do not have timely access to diagnostic/surveillance tests (e.g., computerized tomography (CT) scan and colonoscopy). Efforts should be made to ensure that the orders for these tests are appropriately prioritized, and that the results are received by primary care providers in a timely manner. The use of an automated booking system for ordering routine tests should be considered.
- Availability of specialized psychosocial oncology providers and symptom management services vary across the province. Efforts should be made to ensure that awareness of and access to existing services is improved, and additional capacity is built to address unmet needs across the province.
- Healthcare providers should consider referring survivors to or adapting from existing evidence-based chronic disease management programs (e.g., Better Choices, Better Health[®]) to support individuals in self-managing their conditions.
- Not having a primary care provider is a major barrier to implementing these recommendations. RCPs should consider working with existing programs and services (e.g., Health Care Connect³⁹) and survivors to identify a primary care provider as needed.

Training and Education

- To increase primary care providers' ability and levels of comfort to offer follow-up care to survivors, existing continuing professional development programs on survivorship should be promoted. Online modules should be considered as they are more accessible to these providers.
- Curricula for trainees (e.g., physicians, nurses) should reflect this paradigm shift in follow-up care for survivors.

Communication

- During treatment planning, cancer centres should consider using standard communication to inform survivors and primary care providers about possible scenarios of follow-up care.
- Standard templates should be used to create the treatment summary and the individualized plan of care for follow-up. In addition, as many data elements (e.g., demographic, treatment information) as possible should be auto-populated from hospital information systems into the template to reduce burden on specialist teams when preparing these documents.

Funding

- Funding mechanisms should support the implementation of the recommended model of follow-up care. An Ontario Health Insurance Plan (OHIP) billing code specific to follow-up care for in-person and telephone/telehealth/virtual visits should be introduced. In addition, the recommended follow-up model of care should be reflected in the relevant Quality Based Procedures (e.g., systemic, radiation treatment).

NEXT STEPS

These recommendations will act as a guiding document as Cancer Care Ontario works with various stakeholders to implement changes across the province over the next few years. Given the breadth and the scope of the recommendations, a phased approach will be used for their implementation. Specifically, some recommendations will be implemented in the short term, while others may require more significant organizational changes and additional supports at the primary care, hospital, regional, and system levels.

- Initial implementation efforts will be focused on the breast and colorectal disease site groups at the RCC level. Over time, the intention is to expand to other disease site groups and other facilities in the RCPs.
- Cancer Care Ontario will work with the RCCs to facilitate the prioritization of recommendations that will be implemented in their local context and to determine how to support the implementation of the recommendations at a provincial level.
- Simultaneously, Cancer Care Ontario will work with primary care stakeholders to better understand and support the planning and implementation of the recommendations at the community level.
- Throughout the phased implementation process, Cancer Care Ontario will continue to work with key stakeholders to pursue system-level changes such as:
 - Making recommendations for changes to OHIP billing codes;
 - Developing tools and resources to supplement and support the implementation of the recommendations; and,
 - Building a robust provincial measurement strategy to enable data-driven improvements to follow-up care delivery in Ontario. This will include developing indicators to understand patterns of follow-up care (including intensity and setting of this care) to monitor concordance with guideline-recommended follow-up care, and to measure the impact on patients, providers, and the healthcare system.

GLOSSARY

Term	Definition
Late effects	Side effects of cancer treatment that appear months or years after treatment has ended. These can include physical and mental issues and second cancers. ⁷
Long-term effects	Any side effects or complications from treatment that begin during treatment and continue beyond the end of treatment. Also known as persistent effects. ⁷
Most responsible provider	The provider (or care team) “who has overall responsibility for directing and coordinating the care and management of an individual patient at a specific point in time”. ⁴⁰
Recurrence	Cancer that has returned after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body. ⁷
Re-referral	The process in which a primary care provider refers a survivor back to the same specialist who has previously provided care.
Supportive care	A specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life, and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer. ⁴¹
Self-management	Self-management in cancer is what a person does, in collaboration with their health care team to manage the symptoms, medical regimens, treatment side-effects, physical changes, psychosocial consequences, and lifestyle changes following a cancer diagnosis and/or treatment. It includes self-management activities and behaviours aimed to prevent or reduce health risks and optimize health and quality of life. ^{42,43,44}
Self-management support	Self-management support involves a collaborative relationship between patients and healthcare providers to identify the need for education and supportive interventions. The identification of patient needs includes: regular assessment of progress and problems, problem-solving support, goal setting and action planning. The aim of self-management support is to enhance patient skills and confidence in managing their health and well-being. Self-management support is underpinned by effective communication skills of health care providers and is augmented by patient education resources and tools that reinforce learning and behaviours. ^{42,43,44}
Survivorship	Phase of the cancer continuum following diagnosis and treatment, prior to recurrence of subsequent cancers or death. ⁷

Term	Definition
Telehealth	The delivery of services by healthcare organizations using information and communications technology solutions when the clinician and patient are not in the same location. ⁴⁵

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APPENDIX A: LIST OF RECOMMENDED DATA ELEMENTS FOR POST-TREATMENT FOLLOW-UP CARE PLANS

Purpose: To improve and establish consistent knowledge exchange and communication practices between healthcare providers and patients at the end of treatment, the following table outlines the recommended set of clinical information required by primary care providers, at minimum, to be able to deliver high-quality follow-up care for cancer survivors who are transitioned back to primary care. These essential data elements were established using a multi-pronged approach which included a jurisdictional scan; phased engagements with Primary Care Physicians from across Ontario through focus groups and a modified-Delphi consensus process with Cancer Care Ontario’s 14 Regional Primary Care Leads; and, input from Cancer Care Ontario’s Patient and Family Advisory Council. Principles adopted to guide this multi-pronged approach aimed for the final essential data elements to be brief, concise, informative, timely, standardized, and available in electronic format.

Component	Essential Minimum Clinical Information ^a
Treatment Summary	Stage
Treatment Summary	Location
Treatment Summary	Type of Cancer
Treatment Summary	Cancer diagnosis date and age at diagnosis
Treatment Summary	Past surgical oncology treatments and date(s) of treatment(s)
Treatment Summary	Past non-surgical oncology treatment(s) (e.g., treatment used, location on body and number of cycles)
Treatment Summary	Names of cancer team (e.g. Radiation Oncologist, Surgeon, NP, Navigator)
Treatment Summary	Previously experienced treatment side effects/interactions
Treatment Summary	Transfer of responsibility verbiage and identification of ongoing most responsible provider
Treatment Summary	Reconciled medications list
Individualized Plan of Care	Follow-up care guidelines
Individualized Plan of Care	Contacts of whom primary care physician/patient can reach for questions (e.g., Oncologist, Navigator, Cancer Centre etc.)
Individualized Plan of Care	Common treatment side effects/interactions

^a Additional clinical information may be included to supplement the identified minimum clinical information at the discretion of the provider based on individual patient needs and local / regional context.

Component	Essential Minimum Clinical Information ^a
Individualized Plan of Care	Suspected recurrence referral instructions
Individualized Plan of Care	A list of common signs and symptoms of recurrence
Individualized Plan of Care	Last investigations (i.e., results, modality, date)
Individualized Plan of Care	Notes section (e.g., treatment summary from oncologist, surgery notes, patient notes etc.)
Individualized Plan of Care	Information regarding genetic counseling received and/or genetic testing results
Individualized Plan of Care	A list of patient's psychosocial needs and concerns
Individualized Plan of Care	Link to relevant CCO clinical resources

Through the consensus approach used, additional data elements that were considered included:

- Contact information for local support groups and organizations
- A list of multidisciplinary services provided to the Patient by the Cancer Centre
- Employment, insurance and economic issues
- Medical history (i.e., pre-existing co-morbidities: anemia, COPD, hypertension, diabetes, etc.)
- Family history of cancer
- Allergies
- Patient's secondary contact
- Screening requirements for other cancers
- Symptom management questionnaire for patients
- Patient lifestyle practices and issues (e.g., smoker)
- Health promotion resources